

## AGE RELATIONS AND CARE

AGE RELATIONS AND CARE: OLDER PEOPLE'S EXPERIENCES OF SELF-  
CARE, FAMILY/FRIEND CAREGIVING, AND FORMAL HOME CARE

by  
Rachel Barken, B.A. (Hons.), M.A.

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AUTHOR: Rachel Barken, B.A. (Hons.), M.A. (Dalhousie University)

SUPERVISOR: Dr. Margaret Denton

COMMITTEE MEMBERS: Dr. Lori Campbell  
Dr. Amanda Grenier

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## Abstract

This thesis examines the implications of age relations for older people's negotiations of formal home care, family/friend caregiving, and self-care. Age relations constitute social processes, cultural discourses, and everyday practices that produce and sustain relations of inequality between and among people of different ages. Despite the overwhelming focus on care in the sociology of aging and in political discussions of aging societies, scholars have not clearly articulated how age relations shape, and are shaped by, experiences of later life care. Moreover, despite evidence that older people receive care from both formal care providers and family/friend caregivers—and that they continue to practise self-care when they receive care from others—we know little about the ways older care recipients negotiate the intersections that exist between these systems of care. Using data from a grounded theory study that involved qualitative interviews with 34 people aged 65 to 100 receiving home care in Ontario, this thesis considers how older people negotiate the intersections of formal home care, family/friend caregiving, and self-care, and how age relations can be used to understand experiences of later life care.

Findings suggest that older care recipients attempt to *strike a balance* between self-care, formal home care, and family/friend caregiving, to access care that reflects their needs, preferences, and timelines. In doing so, they negotiate the tensions and contradictions that exist between the realities of impairment, illness, and care needs in later life; and the desire to remain self-sufficient and avoid “burdening” others with care needs. These findings provide insight into the everyday practices through which older people construct age relations in the context of care: when participants negotiate care

arrangements, I suggest that they both reproduce and challenge the social processes and cultural discourses that are at the basis of age relations. Access to social and/or financial resources, however, had consequences for participants' negotiations of care and of age relations.

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## Chapter 1: Introduction

This thesis examines the implications of age relations for older people's negotiations of formal home care, family/friend caregiving, and self-care. Age relations constitute an array of social processes, cultural discourses, and everyday practices that produce and sustain relations of inequality between and among people of different ages. Based on a grounded theory study that involved qualitative interviews with 34 people aged 65 to 100 who were receiving home care in Ontario, this thesis explores older people's negotiations of care and experiences of age relations.

The needs and interests of an aging society garner widespread attention in political, popular, and academic debates. The overwhelming majority of these debates focus on a single subject: *care*. Concerns abound regarding the social, political, and individual changes necessary to provide care for a growing population of older people who experience physical and cognitive decline. Implicit in discussions of eldercare are questions of dependency, power, and the use and control of resources. These questions reflect broader changes regarding responsibilities of the state, the market, families, and individuals in aging, post-industrial societies (Fine, 2007).

Since the 1970s and 1980s, (mainly feminist) sociologists and gerontologists have engaged in theoretical debates and have developed a vast literature on the meaning, practice, and social distribution of care. Broadly, theorists recognize that care is an act of labour and of love (Graham, 1983) with physical, affective, and organizational dimensions (James, 1992). This literature makes visible the marginalization of people involved in care relationships and aims to gain wider recognition for care work. Feminist

theorists have constructed care as complex, skilled work that crosses public and private boundaries (Baines, Evans, & Neysmith, 1998; Phillips & Martin Matthews, 2008; Ward-Griffin & Marshall, 2003).

Despite the overwhelming focus on care in the sociology of aging and the fact that care is a primary concern in political discussions of aging societies, scholars have not clearly articulated how *age relations* frame approaches to care in the domains of theory, policy, and practice. A lack of explicit attention to age relations, I argue, limits our understanding of the experiences, opportunities, and constraints that older people face when they are in need of care. Age is relational because one's membership in an age group is defined in relation to other age groups, and because membership in these groups forms the basis for access to, or exclusion from, various rights and privileges. Yet, inequalities that are based on age intersect with other power relations associated with gender, class, and race/ethnicity (Calasanti, 2003; Calasanti & Slevin, 2001, 2006; McMullin, 2000, 2009). Individuals of the same age will therefore face different opportunities and constraints depending on their personal experience and social location.

The following question guides this thesis: *How can age relations be used to understand experiences of later life care?* Definitions and meanings of “old age” are socially and culturally produced (Gullette, 2004; Pecchioni, Ota, & Sparks, 2004), as the life course is structured according to age or stage-based periods (Grenier, 2012). “Later life,” however, is typically thought to begin at 65 and is often associated with exclusion from various rights and privileges. To address the implications of age relations for experiences of later life care, I examine older people's negotiations of formal home care,

family/friend caregiving, and self-care. In the home setting family/friend caregivers, and sometimes formal, paid care providers (such as home care workers, nurses, and therapists), support older people who require assistance with daily routines and activities. Previous research has established that intersections exist between formal home care and family/friend caregiving; for example as family members become increasingly responsible for care activities that were previously the responsibility of formal care providers (Ward-Griffin & Marshall, 2003). The intersections between systems of care become even more complex when we account for self-care practices—understood as the things that older care recipients do to maintain their own health, well-being, and living environment (Ball et al., 2004; Penning, 2002). There is little research, however, on the ways older people negotiate the intersections that exist between formal home care, family/friend caregiving, and self-care; and on the implications of age relations for older people's negotiations of care.

### ***Importance of study and research questions***

A qualitative, interpretive study that explores the significance of age relations for older people's negotiations of care has theoretical and practical importance. Theoretically, it gives insight into the ways older people experience and respond to age relations in their daily experiences and interactions. Although many studies explore older care recipients' experiences and mutual involvement in care relationships, they tend to take chronological age for granted as a physiological characteristic or as the basis for eligibility and access to services (e.g., Coeling, Biordi, & Theis, 2003; Holmberg, Valmari, & Lundgren, 2012; Roe, Whattam, Young, & Dimond, 2001). We know little about the implications of age

relations—as social relations of power, privilege, and disadvantage that are produced and sustained through an array of social processes, cultural discourses, and everyday practices—for experiences of later life care. A critical focus on age relations leads us to explore relations of inequality and difference between and among people of different ages, and helps to conceptualize care recipients’ diverse, complex experiences.

While this study extends knowledge on relations of power, privilege, and disadvantage in contexts of care, it also addresses a practical gap in the literature regarding older people’s negotiations of self-care, formal home care, and family/friend caregiving. A substantial body of literature examines the contributions of formal care providers and family caregivers, with the aim of improving practice or revealing gender inequalities in care work (Aronson, Denton, & Zeytinoglu, 2004; Campbell & Martin-Matthews, 2003; Keefe, 2011; Peckham, Williams, & Neysmith, 2014; Rosenthal, Martin-Matthews, & Keefe, 2007; Ward-Griffin & Marshall, 2003). Some studies also examine older people’s experiences of receiving formal home care (Aronson, 2002; Martin-Matthews, 2007) or care from family members (Barry, 1995; Coeling et al., 2003; McGraw & Walker, 2004), as well as the impacts of formal and family care on self-care practices (Cox & Dooley, 1996; Penning & Chappell, 1990; Penning, 2002). Yet, there are gaps in extant literature regarding older people’s positioning at the intersections of formal home care, family/friend caregiving, and self-care; and regarding how age relations shape (and are shaped by) negotiations of care. Here, “negotiations” refer to the purposeful actions and interactions that occur among individuals who are involved in care



relationships, with consequences for care arrangements (Kemp, Ball & Perkins, 2013; Strauss, 1978). The findings presented in this thesis address these gaps, and give a better understanding of the everyday realities of the older people around whom systems of care are organized. Most broadly, this thesis considers the following questions:

- 1) How do older people who are receiving care negotiate the intersections that exist between formal home care and family/friend caregiving?
- 2) How do practices of self-care intersect with formal home care and family/friend caregiving?
- 3) How can age relations be used to understand experiences of later life care?

### ***Defining “later life”***

This thesis focuses on older people and their experiences of age relations. Despite great variations in experiences of aging, the age of 65 is the dominant marker of old age in public and policy domains. In Canada, 65 is currently the dominant age of retirement (Wister & McPherson, 2014), and it is the age of eligibility for certain healthcare benefits (Government of Ontario, 2015). The age of 65 therefore confers a change in social status, based on assumptions that individuals over this age may no longer be able to participate in the labour force, and may need specific forms of health and social care (Grenier, 2012).

Although the age of 65 typically signals a transition to later life, defining “old age” is problematic because aging is a social, cultural, and relational process (Grenier, 2012; Gullette, 2004; Pecchioni et al., 2004). Experiences of aging are also framed by opportunities and constraints over the life course, as age intersects with other social locations of inequality (Ferraro & Shippee, 2009; McMullin, 2009). Depending on their social and cultural milieu, life course experiences, and health status, for example, one

individual who is 58 may define himself or herself as “old,” while another person who is 89 may resist the label of “old.” Although experiences of aging are diverse, I focus on the experiences of people who are 65 and older and who are defined within policy frameworks as “older people,” to ground this thesis in debates and discussions on “later life” (see Grenier, 2012; Hendricks, 2004). Given the variation that exists among older people, I argue that it is especially important to explore the interactional bases of age relations—to move away from assumptions that chronological age confers a definite change in abilities and needs, and toward an appreciation of the social processes, cultural discourses, and everyday practices that shape experiences of aging.

### ***The context of care at home in Canada***

While I focus on the experiences of people who are 65 and older, I also concentrate on experiences of receiving care *at home* to situate this research in discussions and debates on home and community care, and on family care relationships in later life. To contextualize this study, it is necessary to briefly review two relevant philosophies that guide home care policies and practices in Ontario. First, an emphasis on home and community care has emerged within the philosophy of “aging in place” that underlies debates and discussions on later life care (Wiles, Leibing, Guberman, Reeve, & Allen, 2012). Second, strategies of neo-liberal governance guide the structure and delivery of home and community care in Ontario (and elsewhere), as care is provided through mixed-market model of service delivery (Armstrong & Armstrong, 2003; Aronson et al., 2004; Martin-Matthews, Sims-Gould, & Tong, 2013; Neysmith, 2000).

Home and community care can be understood as one aspect of the broader philosophy of “aging in place” that has gained prominence in guiding discussions of aging societies. The concept of aging in place emphasizes older people’s capacity to live in their homes and neighbourhoods, with health and social supports, for as long as they wish and are able to (Carstairs & Keon, 2009; UNFPA & HelpAge International, 2012). While “aging in place” (and providing care at home rather than in hospitals or long-term care residences) is considered a more cost-effective use of health care resources (Keefe, 2011), it is also thought to reflect the preferences of many older people themselves. Although some older people may feel insecure or vulnerable in their homes (Cristoforetti, Gennai, & Rodeschini, 2011), or dislike their home environments and prefer to move elsewhere (Hillcoat-Nallétamby & Ogg, 2014), many indicate that they prefer to remain in their homes as long as possible (Mahmood & Martin-Matthews, 2008; Wiles et al., 2012). Research suggests that many older people view the home as a locus of security, privacy, and autonomy (Angus, Kontos, Dyck, McKeever, & Poland, 2005; Mahmood & Martin-Matthews, 2008; Wiles et al., 2012).

Home care is a key part of global and Canadian “aging in place” initiatives. Home care services provide support for older people who need help with personal care, homemaking, and some medical care to live at home. In many advanced countries, including Canada, between half and three-quarters of long term-care is delivered in the home (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011). The Canadian Home Care Association (2013) broadly defines home care as:

an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative

intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for family caregivers (xi).

The formal home care workforce includes health professionals such as nurses, therapists and social workers, but home care workers (also called personal/home support workers, social and health care assistants, or health aides) constitute the majority. They provide just over a third of formal home care to older people in Canada (Canadian Home Care Association, 2013). Home care workers provide assistance with daily activities such as bathing, grooming, and household tasks, and they increasingly perform more medically complex tasks that are delegated to them from nurses and therapists (Barken, Denton, Brookman, Plenderleith, & Zeytinoglu, 2015; Denton, Zeytinoglu, Brookman, Plenderleith, & Barken, 2014).

A neo-liberal ethos guides the structure and delivery of home and community care services in Ontario and elsewhere (Armstrong, 2010; Neysmith, 2000).<sup>1</sup> Neo-liberal governance is premised on a shift in responsibility for health and welfare services from the state to individuals (Breheny & Stephens, 2012; Rose, 2000). States do not provide services directly, but rather “govern at a distance” to reduce social spending on a variety of services, including health and social care. States encourage personal and familial responsibility for health and well-being, as well as the development of private and market-oriented organizations that are controlled through “techniques of accountability

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<sup>1</sup> There are similar market models of home care in other parts of Canada (Grenier & Guberman, 2009; Sharman, McLaren, Cohen, & Ostry, 2008) and throughout developed countries (Brennan, Cass, Himmelweit, & Szebehely, 2012; Lewis & West, 2014; Puthenparambil, Kröger, & Van Aerschot, 2015).

such as centrally set but locally managed budgets, and the practices of evaluation and auditing” (Rose, 2000, 324).

Reflecting this neo-liberal ethos, in Ontario publicly funded home care services are delivered through fourteen Community Care Access Centres that are located throughout the province. These centres do not provide services directly but rather are responsible for managing long-term performance-based contracts that are contracted out to service providers (Ontario Association of Community Care Access Centres, 2014). Those in need of care undergo an assessment by case coordinators to determine their eligibility for services (Ontario Association of Community Care Access Centres, 2014; Peckham et al., 2014).

In addition to publicly funded services, a burgeoning private home care industry exists in Ontario. Here individuals with the financial means to pay for care, private insurance plans, and some government programs such as respite programs cover the costs of home care (Ontario Home Care Association, 2013). According to the Ontario Home Care Association (2013), approximately 150,000 people in Ontario purchase 20 million visits or hours of home care privately every year, while an estimated 653,730 people received 34.5 million visits or hours of publicly funded home care in 2012 and 2013. Those who have the financial means to pay for care privately—either as an alternative or to supplement publicly funded care—need not undergo assessments to determine eligibility, but rather may choose the amount and type of services they receive.

Scholars have critiqued the market model of home care in Ontario and elsewhere: they find that it diminishes the quality and quantity of care and fails to deliver the

supports that people need. In a competitive environment and with increasing demand for services, for example, home care agencies often cut back the breadth of services as well as the time allotted to each client to reduce costs (Aronson et al., 2004; Martin-Matthews et al., 2013). Clients receive essential medical care, but the social aspects of home care, including long-term personal care and support in daily activities, are often neglected—and this has been found to lead to the social exclusion of older people in need of care (Aronson & Neysmith, 2001; Aronson, 2002; Grenier & Guberman, 2009). Moreover variation across service providers as well as inequities in funding levels can lead to inconsistencies in the nature and quality of care (Martin-Matthews et al., 2013; Ontario Association of Community Care Access Centres, 2014).

Home care services are a significant part of the long-term health care system, but family members and friends, typically referred to and relied upon as “informal” caregivers (e.g., Chappell & Hollander, 2013; Peckham et al., 2014; Penning, 2002) give the majority of support to older people in Canada (Hollander, Liu, & Chappell, 2009; Keefe, 2011).<sup>2</sup> In fact, estimates suggest that family/friend caregivers provide between 70 and 80% of care in home and community settings (Hébert et al., 2001; Lafrenière, Carrière, Martel, & Bélanger, 2003). Reflecting the neo-liberal ethos of individual and family responsibility, the stated goal of formal home care is to complement—but not to replace—the care that family and friends provide (Canadian Home Care Association,

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<sup>2</sup> Some family/friend caregivers reject the term “informal” because they feel that it has negative connotations (Brookman, Holyoke, Toscan, Bender, & Tapping, 2011). It can imply that caregiving is “casual or intermittent” while in reality it is often “intense and long term” (Lero, Keating, Fast, Joseph, & Cook, 2007, 2). Recognizing this, I simply use the term “family/friend care” instead of “informal care.”

2013; Funk, 2013; Peckham et al., 2014). Family members are often depicted as “partners in care” (Martin-Matthews et al., 2013; Ward-Griffin & McKeever, 2000) and home care organizations may provide support and education for family caregivers (e.g., Brookman, Holyoke, Toscan, Bender, & Tapping, 2011).

Keefe (2011) provides the following definition of caregivers: “A “caregiver” is a member of the immediate or extended family, a friend or a neighbour who provides support, care and assistance, without pay, to an adult or child who is in need of support due to a disability, mental or chronic illness, life-threatening illness or temporary difficulty” (4). Family/friend caregivers may be responsible for direct, hands-on caregiving and also for “managing care” or assisting formal care providers (Rosenthal et al., 2007; Sims-Gould & Martin-Matthews, 2010b). This work involves stresses and challenges, but caregivers may also find it to be rewarding and personally satisfying (Chappell & Funk, 2011; Connidis, 2010). While women give the majority of care to older people, researchers have acknowledged that men, as husbands and sons, also play a significant role in caring for older people (Campbell & Carroll, 2007; Campbell & Martin-Matthews, 2003).

Canadian data indicate that 12% of the population aged 65 and over received some form of care at home for a long-term health condition in 2012 (Sinha & Bleakney, 2014). People in this age group constituted about 40% of all care recipients in Canada, with those aged 75 and over disproportionately more likely to receive home care (Sinha & Bleakney, 2014). Among these individuals there is significant overlap between formal and family/friend care. Of the one million older people in Canada who received some

kind of care at home in 2009, almost a third of them received *both* formal and family/friend care (Hoover & Rotermann, 2012). Another estimate suggests that families and friends support 98% of older people who receive home care in Canada (Canadian Institutes for Health Information, 2010). Despite receiving significant support from others, however, older care recipients also continue to care for themselves—that is, they practice what is referred to as “self-care.” To practice self-care, older care recipients may direct and maintain their own health through preventive behaviour and response to illness (Penning & Chappell, 1990; Penning & Keating, 2000; Penning, 2002), and they may maintain responsibility for activities of daily living (Ball et al., 2004).

### ***Organization of thesis***

Given that formal care providers, family members and friends, and care recipients are all involved in care arrangements, it is necessary to consider how older people negotiate the intersections that exist between systems of care. Moreover, it is necessary to consider how age relations can be used to understand later life care, to give insight into the age-based relations of power, privilege, and disadvantage that are relevant to the experiences and opportunities of older people who are in need of care. In Chapter Two, I focus specifically on the concept of age relations to ground this thesis in a theoretical framework. I trace the theoretical foundations and assumptions that underlie the concept of age relations, and I give some examples that demonstrate the practical applications of age relations (Brooke & Taylor, 2005; Calasanti & Slevin, 2006; McMullin & Marshall, 2001; McMullin & Berger, 2006; Utrata, 2011; Zajicek, Calasanti, Ginther, & Summers, 2006). I then argue that theorizing age relations can enrich and extend knowledge on the



relations of power, dependency, and control that emerge in contexts of care, and that have implications for the experiences of older care recipients. In Chapter Three, I review relevant sociological and gerontological literature on care to situate this study in a substantive context. I highlight gaps in the literature on (1) older people's negotiations of formal home care and family/friend caregiving; (2) older people's practices of self-care, and the ways these intersect with formal and family/friend care; and (3) the implications of age relations for negotiations of care. In Chapter Four, I discuss the interpretive grounded theory methodology that guided the research design, data collection, and analytic procedures used for this study (Charmaz, 2006; Corbin & Strauss, 2008). Using interpretive grounded theory, I conducted semi-structured interviews with 34 people aged 65 to 100 who were receiving home care.

In Chapter Five, I draw on my analysis of interview findings to explore older care recipients' negotiations of formal home care, family/friend caregiving, and self-care. In Chapter Six, I explain how this study contributes to extant research on the intersections of formal home care, family/friend caregiving, and self-care. I also explore how care recipients construct age relations, or "do age" in the context of care. Finally, in Chapter Seven, I summarize the main contributions of this study. I address its limitations, and present questions to be explored in future research.

## **Chapter Two: Theoretical framework**

### ***Conceptualizing age relations: A roadmap of social processes, cultural discourses, and everyday practices***

#### ***Introduction***

Despite the overwhelming focus on care in the sociology of aging and in political discussions of aging societies, the literature that exists on experiences of receiving care in later life tends to not explicitly name age relations, nor does it consider how age relations shape (and are shaped by) the interactions and experiences of individuals who are receiving care in later life. This tendency to not explicitly name and address age relations is perhaps unintentional, but I suggest that it limits our understanding of the age-based relations of power, privilege, and disadvantage that are relevant to experiences of later life care. To move forward sociological understandings of care and of age relations, this thesis examines the implications of age relations for the experiences of older people as they negotiate the intersections of formal home care, family/friend caregiving, and self-care. Broadly, age relations constitute social processes, cultural discourses, and everyday practices that produce and sustain relations of inequality and difference between and among people of different ages. While the concept of age relations contributes to theoretical understandings of inequality and difference, it is also relevant to policy and practice contexts. For example, chronological age often marks eligibility for services such as pension benefits, and therefore shapes the resources and opportunities that are available to individuals on the basis of age. Age relations may also shape assumptions and expectations about the behaviour that is considered appropriate for people of different ages, and frame people's actions and interactions at different points in the life course.

In this chapter I trace the theoretical foundations, underlying assumptions, and some substantive applications of the concept of age relations, in order to ground this research in a theoretical framework. After a conceptual definition of age relations, I review its foundations in the age stratification (aging and society) perspective and in feminist perspectives on intersectionality. I explain how the concept of age relations fuses age stratification and intersectionality theories to consider the inequalities in power, privilege, and disadvantage that exist between and among people of different ages, as age relations intersect with gender, class, and race/ethnicity relations. I then discuss three theoretical assumptions that underlie the concept of age relations. First, socio-structural relations of inequality associated with age as well as with class, gender, and race/ethnicity emerge through one's positioning in relation to the social processes of production, reproduction, and distribution. These relations of inequality intersect to frame the advantages and disadvantages that people experience throughout their lives. Second, cultural discourses produce and sustain assumptions and expectations about age (such as those that are contained in the models of the third and fourth ages), and in turn shape relations of power and difference between and among people of different ages. Third, people exhibit agency through action and interaction, in the context of established social structures. In everyday practices (i.e., actions and interactions), individuals may both conform to and act against social structures and cultural discourses—in doing so they construct age relations, or “do age.”

Following this theoretical explanation of age relations, I review the work of scholars who have theorized age relations in the substantive areas of family caregiving

and of employment experiences in later life. While this research focuses primarily on the disadvantages and constraints that people face in later life, I argue that more research is needed to understand people's agency vis-à-vis age relations—that is, to understand how individuals experience and respond to age relations in their everyday practices (i.e., actions and interactions).

### ***Age relations***

Scholars including Calasanti (Calasanti, 2003; Calasanti & Slevin, 2001, 2006), McMullin (2000, 2009) and Krekula (2009) conceptualize age relations as relations of inequality between and among people of different ages that (a) are embedded in socio-structural and cultural arrangements; (b) intersect with other social relations based on gender, class, and race/ethnicity; and (c) are socially constructed as people “do age” in everyday actions and interactions, within socio-structural contexts. Age is relational because one's membership in an age group is defined in relation to other age groups. Moreover, age relations are characterized by power because membership in age groups forms the basis for access to, or exclusion from, various rights and privileges—although this access or exclusion occurs as age intersects with other relations of inequality associated with gender, class, and race/ethnicity (Calasanti, 2003; McMullin, 2009). These age relations operate in multiple policy and practice contexts, and shape the opportunities and resources that are available to people of different ages. For example, people *under* a given age are typically excluded from voting rights, while people *over* a given age are often granted access to pension benefits, depending on their work histories.

Age relations are a key principle of social organization, but scholars have devoted little attention to them relative to other relations of inequality that are focal points in sociology such as gender, class, and race/ethnicity (e.g., Choo & Ferree, 2010; Denis, 2008; Dill & Zambrana, 2009). To be sure, critical gerontologists, particularly those who adopt feminist and political economy perspectives, may implicitly address age relations (e.g., Estes, 2001; Grenier, 2012). In much of the literature in the sociology of aging, however, age relations are rarely explicitly *named* and *theorized* as social relations of inequality that have implications for experiences and opportunities over the life course (for exceptions see Calasanti, 2003; Calasanti & Slevin, 2001, 2006; McMullin, 2000, 2009). It is possible that age relations tend to be masked by other social locations, given that age intersects in complex ways with gender, class, and race/ethnicity. The relative invisibility of age relations is problematic, however, because it may limit sociologists' capacity to understand the array of social relations that affect people of all ages and at different points in their lives. As Calasanti (2003) writes, just as an "add women and stir" approach is inadequate for analyzing gender, it is insufficient to attempt to understand later life using "theories developed on the basis of younger groups' experiences" (199).

The concept of age relations is founded on the idea that age needs to be theorized as a social location in and of itself, as well as within the context of other interlocking systems of inequality. To theorize age relations, it is necessary to critically examine the relations of power and dependency that exist between and among people of different ages, as well as assumptions and expectations regarding the positions and activities that are considered appropriate for people of different ages. In what follows, I trace the theoretical

foundations and assumptions that underlie the concept of age relations. In doing so I ground this discussion of age relations in a sociological framework that accounts for relations of power, inequality, and difference that emerge at the socio-structural, cultural, and interactional levels.

### ***Theoretical foundations***

The main premise of age relations is that an array of practices, processes, and discourses produce and sustain relations of inequality and difference between and among people of different ages. This conceptual understanding is rooted in two theoretical perspectives: the age stratification (aging and society) paradigm that has emerged from social gerontology, and perspectives on intersectionality that initially emerged from anti-racist feminist theory. At its foundation, age stratification explains that societies are organized on the basis of age (Riley, 1987; Riley, Foner, & Riley Jr., 1999; Riley & Riley Jr., 2000). A limitation of age stratification, however, is that it tends to overlook questions of power and diversity, including the differences that exist between people of the same age (Dannefer, Uhlenberg, Foner, & Abeles, 2005; McMullin, 2000). Intersectionality theory addresses this limitation: it posits that the social relations of gender, class, race/ethnicity, (and age) do not exist separately from one another but rather intersect in complex ways to frame the opportunities and constraints that individuals face in different situations and at different points in their lives (Calasanti & Slevin, 2001; Collins, 1998; Dill & Zambrana, 2009).

#### *Age stratification (aging and society)*

The concept of age relations considers age as structured social relations that are embedded in social organizations, institutions, and systems. Social relations that are based on age shape access to opportunities, resources, and programs; influence interactions between people of different ages; and change over time. Gerontologists working from a variety of perspectives, and notably political economists, adopt this understanding of age (e.g., Estes, 2001). Yet, age stratification theory, more recently referred to as the aging and society paradigm, provides the initial foundations for conceptions of age as a dimension of social relations (Riley, 1987; Riley et al., 1999; Riley & Riley Jr., 2000). As such, age stratification forms the theoretical basis for discussions and debates of age as a principle of social organization.

Age stratification theory is premised on the idea that society is structured and stratified according to age. Age groups, or strata, represent different chronological ages and life course stages. Within social organizations, institutions, and systems, individuals are afforded specific roles and opportunities—and excluded from others—according to the age group or strata to which they belong. In other words age-based criteria, expectations, and norms shape people's movement in out and out of social institutions; the roles people perform in institutions; and access to resources such as money, prestige, or power (Riley et al., 1999). At a base level, age stratification theory explains that the most prevalent age strata are young, middle, and old age. These three age strata are differentially associated with access to and participation in the “three boxes” of education for the young, work and family in mid-life, and retirement or leisure in later life (Riley et al., 1999).

Matilda White Riley and her colleagues initially developed age stratification theory in the late 1960s and early 1970s, when they appraised the social and behavioural sciences research that existed on aging (Dannefer et al., 2005; see also Riley & Foner, 1968; Riley, Riley Jr., & Johnson, 1969, 1972). Riley had worked closely with Talcott Parsons, and his functionalist sociology provided a basis for the original formulations of age stratification theory. In brief, structural functionalism rests on the idea that society is a cohesive system where norms, traditions, and institutions (e.g., family, education, and work) function interdependently to ensure overall social stability and harmony (Parsons, 1968 [1937]). Drawing on functionalist theory, a key premise of age stratification is that “age-graded roles are part of the relatively stable apparatus of social structure” (Dannefer et al., 2005, S297). From this perspective chronological age is not just a property of individuals. Rather, age-based roles are a feature of the overall social system, and individuals are connected to the social system on the basis of age. These roles are sustained through social processes and institutions—as Dannefer et al. (2005) explain in their summary of Riley’s work, age-based roles “have a place of normative acceptance and functional compatibility within the social system and thereby give legitimacy to and are legitimated by ongoing social dynamics” (S297).

While age stratification is originally rooted in functionalist theory, it presents a more critical view of the relationship between individuals and society than that which initially emerged from functionalism (Dannefer et al., 2005). Moving beyond the traditional functionalist view of social roles as a feature of stability and harmony, Riley recognized that tensions and conflict could arise as individuals occupy and pass through



age-based roles. Age stratification may be problematic when individuals are denied resources or opportunities on the basis of age, such as when older people are excluded from paid work even if they need or want to continue working. The tensions and conflict that can result from age stratification—as well as the potential for change to existing age-based roles—became evident as Riley further developed the aging and society paradigm (Riley et al., 1999) and the concept of age integration (Riley & Riley Jr., 2000).

As age stratification theory evolved into the aging and society paradigm, Riley further conceptualized *process* and *change* associated with aging (Riley, 1987; Riley et al., 1999). Although age stratification theory originally emphasized the age-based roles that are a feature of social organization and that shape individual trajectories, the aging and society paradigm recognized that changes to social structures arise through individual and collective actions (Dannefer et al., 2005). Riley used the concept of *cohort flow* to articulate the dynamic relationship between individual aging processes and social structures (Riley, 1987). Drawing on the definition of cohorts put forward by Ryder (1965), Riley conceptualized cohorts as groups of people who are born at about the same time and pass through age strata in the same historical moment (Riley, 1987; Riley et al., 1999). She explained that successive cohorts have distinct experiences, norms, and values, and that these influence the social function and meaning of each age strata they enter. For example the roles, resources, and opportunities associated with adolescence today are much different than they were one hundred years ago. Adolescent cohorts themselves have influenced the meaning of this life stage as they have passed through it.

Each cohort will experience adolescence at a specific time in history, and therefore their experiences are distinct from other cohorts.

While the relationship between individuals and society is dynamic, Riley recognized that the two rarely evolve at the same time. There is often a lack of congruence between the experiences of individuals as they age and the social structures that shape age-based roles and opportunities. Riley introduced the concept of “asynchrony” or “structural lag” to articulate the social problems and strains that may arise when there is a mismatch between individual and structural change. Here changes in individual lives are often considered to precede structural change (Riley, 1987; Riley et al., 1999). Perhaps the best-known example of structural lag that is explicated in Riley’s work is “the failure of social structures to accommodate the increase in the number and kinds of older people in the population” (Dannefer et al., 2005, S300; see also Riley, Kahn, & Foner, 1994). Increased longevity throughout the twentieth and twenty-first century signals a change in individual lives. Social structures lag behind, however, when they fail to provide appropriate roles, opportunities, and services for the larger proportion of older people in society, including access to meaningful work and to health and social care services.

In recognition of the tensions and conflict that can arise from age stratification (such as structural lag), Riley’s later work on age integration articulated the potential for transformations to age-graded systems and structures (Riley & Riley Jr., 2000). Here Riley drew attention to social changes that might disrupt prevalent age strata and lead to new conceptualizations of the roles, resources, and opportunities that are available to

individuals of different ages. With the concept of age integration, Riley envisioned a society with more flexible life course pathways as well as greater interaction between younger and older people. Riley and Riley Jr. (2000) noted some shifts toward age integration in modern societies; for example education is no longer considered to be solely for young people but rather is regarded as a “lifelong” pursuit (Riley & Riley Jr., 2000, 268). Riley felt that age integration such as this could potentially diminish age-based conflict and tension, and contribute to a greater sense of intergenerational solidarity (Riley & Riley Jr., 2000). She recognized, however, that despite some trends toward age integration, institutional and social domains are still highly stratified on the basis of age (Riley & Riley Jr., 2000; see also Bytheway, 2005; McHugh, 2003). For example, age is often an eligibility criterion for social services and access to programs such as pension benefits. The concept of age stratification therefore usefully draws attention to the opportunities and resources that are available to individuals, as well as the constraints that they might face, on the basis of age.

The aging and society (age stratification) paradigm has made very significant contributions to sociological insights on aging. Importantly, the aging and society paradigm has conceptualized the institutionalized impacts of age structures as a key principle of social organization, as well as the ways these age structures may evolve over time through the confluence of structural, historical, and individual change. It has therefore presented a base level understanding of the relations of inequality that may exist between individuals of different ages (McMullin, 2000). There are, however, some valid critiques of this perspective. Critics point out that the aging and society paradigm, in

keeping with its functionalist roots, has problematically overlooked the impacts of power dynamics on aging processes at the structural and individual level (Marshall, 1995, cited in Bengtson, Burgess, & Parrott, 1997). For example, the aging and society paradigm pays little attention to the specific processes through which social changes occur, including “the ways in which social structures may be controlled by an elite few” (Bengtson et al., 1997, S82). This lack of attention to power dynamics is particularly evident in the disregard of the intersections of age with other social relations of inequality including gender, class, and race/ethnicity (McMullin, 2000). Otherwise put, the aging and society paradigm primarily emphasizes differences *between* cohorts, age groups, or strata, while overlooking questions of diversity *among* members of a given age group or cohort (Dannefer et al., 2005). In many ways, the concept of age relations addresses these limitations of the aging and society paradigm. To consider intra-cohort or intra-group differences—including relations of power and inequality *between and among* people of different ages—the concept of age relations draws on feminist theories of intersectionality (Calasanti & Slevin, 2006; McMullin, 2000, 2009).

### *Intersectionality*

The concept of age relations considers how age intersects with other social relations including gender, race/ethnicity, and class to create differences in individuals’ and groups’ experiences of aging. Here, Calasanti and Slevin (2001, 2006), notably, have drawn on and extended feminist intersectionality theory to conceptualize age relations. Intersectionality theory posits that gender, class, and race/ethnicity are interlocking power dynamics that frame experiences and opportunities over the life course (Choo & Ferree,

2010; Denis, 2008; Yuval-Davis, 2006). While each of these social relations may lead to specific privileges or disadvantages, intersectionality is premised on the idea that instances of marginalization are mutually constructed in unique ways as multiple relations of power and inequality intersect with one another (Denis, 2008; Hancock, 2007).

Analyses of sexism, for example, are considered to be incomplete unless one considers how women of colour experience sexism differently from white women, and additionally, how middle and upper class women experience sexism differently from lower-class women.

To some degree, intersectionality scholars note that *age* is one among many intersecting social relations (e.g., Denis, 2008; Yuval-Davis, 2006). Yet, intersectional analyses focus primarily on the intersections of gender, race/ethnicity, and class (e.g., Acker, 2006; Dill & Zambrana, 2009). As Calasanti and Slevin (2006) argue, age is often overlooked or treated as an “et cetera” on a list of oppressions” in research on intersectionality (1). The concept of age relations therefore explicitly considers how age intersects with other social relations of power and inequality. In doing so, the concept of age relations addresses some of the limitations of existing research on intersectionality (Calasanti & Slevin, 2001; Zajicek et al., 2006).

Intersectionality theory initially emerged from the Black feminist movement in the 1980s. Crenshaw introduced the term “intersectionality” in a discussion of employment among black women in the United States (Crenshaw, 1989; see also Yuval-Davis, 2006). Crenshaw and other feminists of colour critiqued the singular definition of “woman” in earlier feminist theories. In this singular definition the experiences of a minority of

relatively privileged women—white, abled-bodied, usually middle-class, and heterosexual women—were taken as the norm and then generalized to all other women (Baca Zinn & Thornton Dill, 2005; Brah & Phoenix, 2004; Denis, 2008). For example predominant feminist theories attended to gender inequalities (e.g., Gilligan, 1984; Smith, 1987), but feminist and anti-racist movements existed quite separately from each other and often had conflicting aims (Crenshaw, 1991). Women of colour felt that they were excluded from the feminist movement, and developed intersectionality to include multiple perspectives and experiences of marginalization in feminist analyses. While intersectionality theory originally focused on the oppression of women of colour, it has expanded to consider complex relations of inequality and difference more broadly, including the relations of oppression *and* privilege that affect all people (Yuval-Davis, 2006).

The development of intersectionality within feminist theory signalled a shift away from understandings of gender, race, and class as separate social relations, and toward an analysis of their intersections in specific historical and socio-cultural contexts. At the basis of this approach is the idea that social relations of power and inequality are not additive but rather are interdependent and mutually constructed (Collins, 1998; Hancock, 2007). In additive approaches multiple forms of marginalization such as racism, sexism, and classism are considered to add up into an overarching “triple oppression” (Yuval-Davis, 2006, 195). Intersectionality scholars reject the notion of triple oppression and argue instead that each social relation has a distinct reality or “ontological basis” (Yuval-Davis, 2006, 195). Given the complexity and specific nature of social relations of power

and inequality, intersectionality scholars consider how they mutually construct or affect one another in diverse, context-specific ways (Choo & Ferree, 2010; Yuval-Davis, 2006). Gender and race relations, for example, each emerge in specific historical, socio-cultural, and interactional contexts, and therefore cannot be considered to have parallel outcomes. In turn, experiences of disadvantage (and of privilege) are qualitatively different depending on one's position relative to intersecting, mutually constructed social relations and depending on other contextual features including time and place (Denis, 2008).

While intersectionality theory considers multiple dimensions and levels of analysis (Choo & Ferree, 2010) scholars share an intention to make visible the power dynamics that serve to marginalize certain individuals and groups (often minority women), and to bring about social changes that reduce and ultimately eliminate instances of oppression or marginalization. It has therefore expanded and added important insight to feminist theorizing. Scholars posit, moreover, that intersectional analyses may extend beyond race, class, and gender to address the array of identities, experiences, and categories that inform social relations in specific historical contexts (Brah & Phoenix, 2004; Crenshaw, 1991; Denis, 2008; Yuval-Davis, 2006). While the challenge of integrating a potentially unlimited number of categories in a given analysis is a concern, intersectionality scholars acknowledge that some social relations will likely be more important than others, in given contexts that involve specific individuals (Dill & Zambrana, 2009; Yuval-Davis, 2006). Nevertheless, a limitation of intersectional analyses is that they often overlook age, while they focus primarily on the intersections of gender, race/ethnicity, and class (Calasanti & Slevin, 2001; Zajicek et al., 2006). As

Calasanti and Slevin (2001) explain, “U.S. feminist scholarship has emerged not only from a race- and class- specific standpoint but also from an age-specific perspective, such that the prominence of younger women in feminist theorizing has resulted in the omission of old age and age relations within feminist scholarship” (cited in Zajicek et al., 2006, 177). Just as women of colour argued that early feminist theorizing reflected the biases of white women, proponents of age relations posit that the omission of age reflects the biases of younger and middle-aged researchers (Calasanti, 2003).

To correct the neglect of age in many feminist intersectional analyses, a small number of critical and feminist gerontologists explicitly name age relations, and consider how they intersect with other social locations to frame the opportunities and constraints that people face throughout their lives, and notably in later life (e.g., McMullin, 2000; McMullin & Berger, 2006; Zajicek et al., 2006). To address age relations it is necessary, for example, to adopt the standpoint of diverse older people to consider complexities in their lived experiences (King, 2006). Addressing age relations rests, moreover, on the understanding that age is a key aspect of social institutions, organizations, and structures—as described in the aging and society paradigm. The concept of age relations therefore fuses the understanding of age as an aspect of social organization, as presented in the aging and society paradigm, with the understanding of diversity and complexity in experiences of disadvantage (and of privilege) that is illuminated in intersectionality theory. The concept of age relations considers age as a dimension of power that intersects with gender, race/ethnicity, and class, among other forms of difference, to shape the roles,



resources, and opportunities that are differentially distributed *between and among* people of different ages.

Although the concept of age relations is rooted in the age stratification and intersectionality frameworks, perhaps a limitation of both of these perspectives is that they emphasize the structural relations that shape individual trajectories—while overlooking questions of culture, meaning, and interaction. To conceptualize how age relations are produced and sustained at multiple, interrelated levels, it is useful to consider the insights on aging, power, and difference that have emerged from socio-structural (McMullin, 2000, 2009), cultural (Gullette, 2004; Katz, 2005; Twigg & Martin, 2015) and constructionist (J. Coupland, 2009; Gubrium & Holstein, 1999; Jaffe & Miller, 1994) perspectives in gerontology. In what follows, I draw on the work of critical and social gerontologists to explain how age relations are produced and sustained through (1) social processes of production, reproduction and distribution; (2) cultural discourses that are conveyed through text, language, and meaning; and (3) everyday practices of action and interaction. Considering these three interrelated levels of analysis is necessary to conceptualize the significance of age relations for the opportunities and constraints that individuals face at different points in their lives, and for the expectations and assumptions about appropriate behaviour and activities for people of different ages.<sup>3</sup>

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<sup>3</sup> To develop a comprehensive understanding of age relations, it is instructive to consider how scholars have conceptualized gender and gender relations. In Risman's (1998) conceptualization of gender as structure, she considers the links between the institutional level of the organization and distribution of resources, the interactional level of cultural expectations, and the individual level of socialization and identities (cited in McMullin,

***Theoretical assumptions: Social processes, cultural discourses, and everyday practices***

In this section, I articulate three theoretical assumptions that underlie the concept of age relations, to explain the relationship between the socio-structural, cultural, and individual processes that produce and sustain age relations. First, relations of power and inequality that are based on age emerge through one's positioning in relation to the processes of production, reproduction, and distribution, and subsequently frame the opportunities and constraints that individuals face throughout their lives. Second, age relations are culturally specific, and are constructed and reconstructed through cultural discourses including texts, language, and meaning. Cultural discourses shape assumptions and expectations about appropriate identities and activities in later life, such as those that are conveyed through the models of the third and fourth ages. Third, while social processes and cultural discourses have a structuring effect, people exhibit agency; that is, they act and interact meaningfully within socio-structural and cultural contexts to “do” or “accomplish” age. This consideration of agency is particularly important because it provides the means through which individuals may reproduce—or potentially challenge or resist—the social structures and cultural discourses that shape relations of power and inequality between and among people of different ages, as well as assumptions and expectations about age.

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2009, 54). Certainly an understanding of age relations requires similar attention to the multiple levels of analysis at which age relations come to operate, including the socio-structural, cultural, and individual levels.

*Social processes of production, reproduction, and distribution*

The concept of age relations is premised on the assumption that socio-structural arrangements lead to inequalities in power, privilege, and disadvantage between and among people of different ages. How do these social relations of inequality operate? Feminist scholars explain that socio-structural arrangements of power constitute “institutionalized patterns of unequal control over and distribution of a society’s valued goods and resources such as land, property, money, employment, education, health-care, and housing” (Dill & Zambrana, 2009, 2). These socio-structural inequalities in power, privilege, and disadvantage emerge through one’s positioning in relation to social processes of production, reproduction, and distribution (McMullin, 2000, 2009). Drawing on and extending the Marxist theory of productive social relations, McMullin (2009) explains that through production raw materials become useful and valuable resources; through distribution these resources are exchanged among people; and through reproduction people engage in work that supports human life on a daily and intergenerational basis.

McMullin’s (2009) conceptualization of inequality draws on the work of other scholars who similarly theorize the social processes of production, reproduction, and distribution (Allahar, 1995; Acker, 1988; Laslett & Brenner, 1987; all cited in McMullin, 2009). McMullin’s work is particularly useful to the discussion at hand, however, because she considers *age* within a set of intersecting social relations. In McMullin’s (2000, 2009) formulation, age intersects with class, gender, ethnic, and race relations to affect one’s differential positioning in relation to the processes of production, distribution, and

reproduction. This positioning may result in opportunities and privileges on the one hand, or constraints, barriers, exploitation, and oppression on the other hand. The consequent inequalities in power, privilege, and constraint are *relational*. This means that “the welfare of one group of people depends upon the deprivation of another,” as disadvantaged groups are excluded from access to “to resources, rewards, and privileges” (McMullin, 2009, 102). Relations of inequality have a structuring effect and are a foundation of social organization, but one’s positioning within intersecting sets of social relations does not wholly determine individuals’ experiences. McMullin (2009) conceptualizes class, age, gender, and race/ethnicity relations as a “cage” in which people act and interact. As will become clear later in this chapter, individuals may both conform to and resist social relations of power, privilege, and disadvantage (McMullin, 2009).

Understanding that power is differentially distributed between and among people of different ages provides a basis for conceptualizing the opportunities and privileges and constraints and barriers that people face at different points in their lives and in relation to people of different ages. For example, it provides insight into the relations of power, privilege, and disadvantage that exist between older people who are retired, and younger people who participate in the paid workforce. Retired people may be afforded less power and privilege because they are no longer directly involved in the processes of production, reproduction, and distribution. In the classic argument made by political economists of aging, the institutionalization of retirement in modern industrial societies has systematically removed workers from the labour force at a given age; most commonly 65. The institutionalization of retirement has lead to a “structured dependency” among older

people because they are excluded from productive social relations (Myles, 1989; Townsend, 1981).

Moving beyond the focus on “structured dependency” scholars acknowledge that a retired person’s position in relation to social processes depends on their past work experiences. Pensions, for example, are a form of distribution that create indirect links between retired workers and the processes of production (McMullin, 2009). Older people with stable pensions may have more status and power than, for example, younger people who are engaged in precarious work. Some older people, particularly those in privileged social locations, may also be empowered as they consume the material goods and lifestyles of the anti-aging and leisure industries and therefore gain entry into more highly valued activities and identities (Katz, 2005; King & Calasanti, 2006). Moreover, while age has implications for one’s positioning in relation to the social processes of production, distribution, and reproduction, age relations intersect with class, gender, and race/ethnicity relations (McMullin, 2009), in addition to less recognized social relations related to sexuality and able-bodiedness (Oleson, 2011), to create differences in the opportunities and challenges that members of a given age group face.

While age relations are best understood as they intersect with gender, class, and race/ethnicity, an important difference between age relations and other social relations of inequality is that *all* people grow older. One’s gender, race, or ethnicity (usually) remains constant throughout one’s life. Some people may transcend class positions: a working class person may become middle-class or vice-versa, although it is often challenging to do so (Calasanti, 2003). By contrast all people who live long enough will experience “old

age” in the chronological sense. Yet, as individuals age they will bring with them the relations of advantage and disadvantage that they have experienced throughout their lives (Ferraro & Shippee, 2009; McMullin, 2000). This leads to differences, for example, in the experiences of diverse groups of older women and men (Krekula, 2007; C. Russell, 2007), and among members of racialized groups (Jackson, Govia, & Sellers, 2011). In addition to this, age relations are culturally and historically specific. Cultural discourses shape the social status and power that is attributed to people of different ages as well as values and beliefs about the behaviour and activities that are considered appropriate at different points in the life course.

#### *Cultural discourses*

While the social processes of production, reproduction, and distribution structure the inequalities that exist between and among people of different ages, age relations are also produced and sustained through cultural discourses (Gullette, 2004; Katz, 2005; Pecchioni et al., 2004; Twigg & Martin, 2015). What do we mean by culture? According to cultural studies scholars, culture consists broadly of the words, meanings, symbols, and interpretations of reality that permeate everyday life (Hall, Hobson, Lowe, & Willis, 1980; Seidman, 2004). In this sense, culture does not refer simply to “highbrow” art forms such as literature, theatre, or music. Rather, culture infiltrates all aspects of society and is transmitted through forms of *discourse*, including “the language we use, our ideologies and religious faiths, or the texts and representations we produce” (Seidman, 2004, 136). This can include (but is not limited to) widespread media forms such as “mass circulation magazines, newspapers, books, movies, television, and popular music”

(Seidman, 2004, 136). The media transmits certain beliefs and values through, for example, representations of women and men, and of younger and older people. These messages are far from neutral: they “[communicate] ways of defining, classifying, and judging individuals and groups” (Seidman, 2004, 137).

Cultural discourses (i.e., words, images, and meanings) play a key role in constituting what it means to grow old; the behaviour that is expected of people of different ages; and the identities and opportunities that are available to individuals at different points in the life course (Twigg & Martin, 2015). As such, cultural discourses are a key part of age relations: they contain beliefs and values about aging, and may produce and sustain relations of inequality between and among younger and older people. In this regard, critical perspectives on the “third and fourth ages” are useful for explaining how cultural discourses produce and sustain assumptions and expectations about aging, as well as inequalities in power and status that exist between and among people of different ages. The models of the third and fourth ages shape the opportunities and identities that are available to older people depending on social locations of privilege and disadvantage, and according to health status or level of impairment (see Gilleard & Higgs, 2010; Grenier, 2012; Twigg, 2004; S. Williams, Higgs, & Katz, 2012).

The third age represents a position of status, privilege, and power in later life. It is characterized as a period of personal fulfillment, opportunity, and freedom available to older adults who are financially secure, in good health, and have few or no work responsibilities (Laslett, 1989). While the boundaries between the third and fourth ages tend to be symbolic rather than chronological, the third age typically refers to “younger”

older people, between the ages of 50 and 74 (Twigg, 2004, 64). In mainstream cultural discourses, “third agers” are depicted as “productive,” “successful,” or “active” individuals who take personal responsibility for their health and well-being (Katz, 2000; Rozanova, 2010). These individuals are thought to engage in specific lifestyles that are based on the consumption of products and lifestyles, including cosmetics, pharmaceuticals, vacations, and gym and club membership. Such consumption is a means through which individuals may maintain the ideals of youthfulness that dominate mass culture (Gullette, 2004; Twigg, 2004).

In alignment with “contemporary social and cultural practices” in late modern or postmodern Western societies, the third age is constructed as a life stage in which individuals may exercise agency and free choice, be self-expressive, and find pleasure and enjoyment in life (Gilleard & Higgs, 2010). As such, the assumptions and expectations about later life that are conveyed through cultural discourses of the third age may afford older people access to status and power. Yet, reflecting a broader neo-liberal ethos of individual responsibility, the health and well-being that is characteristic of the third age is considered to result from individual good choices over the life course, rather than from socio-structural relations of privilege and disadvantage (Breheny & Stephens, 2010; Rubinstein & de Medeiros, 2015). The lifestyles and consumption that are characteristic of the third age may therefore only be available to older people in privileged social locations, who have access to money and social resources that enable them to maintain good health and to be “active and “productive” in later life.



In contrast to the third age, the fourth age represents a *loss* of power and status in later life. The fourth age, typically occupied by people aged 75 and over, is characterized by frailty, decline, and dependence (Grenier, 2012; Lloyd, Calnan, Cameron, Seymour, & Smith, 2014; Twigg, 2004). It is culturally constructed as a “terminal destination” that exists outside the boundaries of the third age (Gilleard & Higgs, 2010, 123). As such, some scholars consider the fourth age to be “stripped of social and cultural capital” that has come to be associated with the third age, including the capacity to exercise autonomy and to find fulfillment in later life (Gilleard & Higgs, 2010, 123). Older people in need of long-term home care due to challenges with mobility and carrying out activities of daily living are often considered to be in the “fourth age” of the life course. These older care recipients’ needs tend to be viewed as “bodily deficits” that require public expenditures (Twigg, 2004, 64).

Other scholars have connected the negative connotations of decline, dependence, and care needs in the fourth age to the efforts of younger, able-bodied people to distance themselves from that which they perceive as threatening (Grenier, 2012; Lloyd, 2004). As such, older people in need of care are “socially and culturally ‘othered’ — both from society and within groups of older people” as they represent and embody cultural fears about dependency, decline, and death (Grenier, 2012, 174). Where individuals are considered to be personally responsible and in control of health and well-being, moreover, the dependencies that are characteristic of the fourth age may be seen as individual failures. Cultural representations of the fourth age therefore shape assumptions and expectations about older people with health conditions, impairments, and care needs.

These individuals are positioned primarily as powerless or dependent, and are afforded little social status.

Cultural representations of the third and fourth ages produce and sustain assumptions and expectations about aging, as well as inequalities in power and status between *and* among people of different ages; depending, for example, on health status or level of impairment (Grenier, 2012). Yet, while individuals make sense of their own experiences of aging through these cultural discourses (Gullette, 2004), they are not simply passive consumers of culture. They interpret and respond to cultural discourses in diverse ways; sometimes conforming to them while at other times challenging or resisting them (J. Coupland, 2009; N. Coupland, 2004; Seidman, 2004). For example, different cultural messages about aging are available to women and to men (Woodward, 2006), and people may respond to cultural messages differently depending on their social location and personal experiences (N. Coupland, 2004). Given that individuals exercise agency vis-à-vis cultural discourses—as well as in the face of socio-structural relations of inequality—an understanding of age relations must account for the ways in which individuals produce and sustain—and perhaps challenge—age relations through everyday practices of action and interaction.

#### *Everyday practices of action and interaction*

Social processes and cultural discourses shape the relations of power and inequality that exist between and among people of different ages, as well as the opportunities and constraints that individuals face depending on their age. Yet, the concept of age relations is premised on the foundation that social and cultural forces do

not wholly shape age. Similar to the ways people “do gender” (West & Zimmerman, 1987), people construct and attribute meaning to age through actions and interactions in socio-structural and cultural contexts. As individuals experience and respond to age relations, they exhibit agency: they “exert some control over the social relations” that structure advantages and disadvantages over the life course (Sewell 1992, cited in McMullin, 2009, 132).<sup>4</sup> Through agency individuals may both conform to—and resist—the deeply embedded social structures and cultural discourses that shape relations of power, privilege, and disadvantage between and among people of different ages.

How do we best account for agency, and individuals’ experiences and responses to age relations? Constructionist perspectives provide the means to examine individuals’ actions, interactions, and interpretations of meaning (Blumer, 1969; Corbin & Strauss, 2008). Constructionist researchers consider individuals as reflexive agents who engage in processes of interpretation and interaction to actively create and maintain the meaning of aging for themselves and for others (Gubrium & Holstein, 1999; Jaffe & Miller, 1994). Constructionist analyses of aging consider “how the social categories and forms of age enter into everyday life, how they are managed, and how they are socially organized” (Gubrium & Holstein, 1999, 287). From this perspective, aging—and age relations—are understood as “something that we achieve in the minutiae of our social lives, in social encounters of diverse sorts and even in individual acts of expression in speech and writing (J. Coupland, 2009, 851).

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<sup>4</sup> This represents a broad understanding of agency, but see Grenier & Phillipson (2013) for a discussion of diverse approaches to agency, including the ways in which agency may need to be redefined to account for the physical and cognitive impairments that are characteristic of the “fourth age.”

While constructionist perspectives recognize that structural and cultural contexts frame individual behaviour and action, they investigate individuals' standpoints and lived experiences of a situation (i.e., older people's experiences of aging) to give insight into the subjective understanding and meaning attributed to the social world. A guiding assumption is that experiences cannot be understood "by mechanically assigning subjects to groups" according to class, gender, race/ethnicity, or age (Sankar & Gubrium, 1994, viiii). These categories are important, but interpretive researchers provide a deeper understanding of the ways people experience membership in a given group, and how individuals relate to one another on the basis of age. Constructionist perspectives therefore provide the means to conceptualize how, through everyday practices, individuals make sense of the "sociocultural norms, expectations, demands, constraints and opportunities" that are associated with age relations (J. Coupland, 2009, 851). For example, rather than assume that the cultural discourses of the third and fourth ages influence all individuals in the same way, constructionist perspectives may help to understand how people experience and respond to these cultural discourses in diverse ways, in their everyday lives.

Constructionist perspectives can give insight into the ways individuals produce, sustain, and potentially challenge assumptions and expectations about aging, as well as the relations of inequality and difference that exist between and among individuals depending on their age. In Krekula's (2009) discussion of age codings, for example, she describes how people "do age" when they associate certain places, practices, and activities with people of different ages (9). Krekula (2009) explains that when people talk

“about not being able to do things because of one’s age” they position older people in relation to younger people, and reinforce the social and cultural beliefs that certain activities are more or less appropriate for people of different ages (12). Talking about “not being able to do things because of one’s age” may exclude older people from certain activities, and therefore support a view of older people as powerless or dependent on others. Individuals, however, may assert their continued involvement in various practices and places to challenge such age-based assumptions. For example, a man in his nineties who displays continued sexual activity is perhaps challenging the view that sexuality is solely the domain of younger people (see Loe, 2011, 146).

Jolanki, Jylha, and Hervonen (2000) provide a further example of the everyday practices through which individuals may experience and respond to age relations, in the micro-context of action and interaction. They find that older people use two competing interpretative repertoires—the choice repertoire and the necessity repertoire—to both reproduce and challenge assumptions and expectations about later life. With the necessity repertoire, individuals uphold the view “that old age consists necessarily and unavoidably of deterioration . . . illnesses and frailty are seen not only as inevitable signs of old age, but also as very the (*sic*) essence of old age to which there is no alternative” (Jolanki et al., 2000, 363). With the choice repertoire, by contrast, individuals express “that old age can be defined in various different ways and that one can choose from among a range of definitions the one that best fits in with the situation” (Jolanki et al., 363). In cases where participants contest negative images of later life—for example when they see old age as time of emancipation—they are embracing the choice repertoire and

are “trying to establish new meanings and definitions for old age and for older people” (Jolanki et al., 2000, 370). Through everyday talk, therefore, older people may “do age” in diverse ways.

The theoretical assumptions reviewed above give insight into the ways age relations are produced, sustained (and potentially challenged) at the structural, cultural, and individual levels. Clearly, age relations are complex social phenomena that have implications for the opportunities and resources available to individuals, the disadvantages and constraints that individuals may face, and the behaviour and activities that are considered appropriate for individuals at different points in their lives. Age relations, moreover, intersect with gender, class, and race/ethnicity, among other forms of difference, to shape diverse experiences of power, privilege, and disadvantage in later life. In the following section, I will draw on research conducted in some substantive areas of the sociology of aging to further demonstrate the practical applications of age relations. I focus in particular on the work of scholars who have theorized age relations in the areas of family caregiving and employment in later life.

### ***Practical applications of age relations***

Scholars have demonstrated the practical applications of theorizing age relations in some substantive areas of the sociology of aging. In doing so, they have provided important insight into the relations of power, privilege, and disadvantage that exist between and among people of different ages. Outlining the scope of research on age relations is challenging, however, because so many researchers discuss issues related to later life, such as diversity in later life and people’s experiences vis-à-vis broader

assumptions and expectations about aging, without explicitly naming age relations (see for example Estes, 2001; Grenier, 2012). This makes it especially difficult to provide a clear trajectory or comprehensive portrait of extant research on age relations. To make my task manageable and concise, I give examples from two areas where scholars have explicitly *named* age relations and have conducted research that demonstrates the practical applications of theorizing age relations: (1) family care work (Calasanti, 2006; Utrata, 2011; Zajicek et al., 2006) and (2) experiences and opportunities in paid work settings (Brooke & Taylor, 2005; McMullin & Marshall, 2001; McMullin & Berger, 2006). While not meant to be comprehensive, this review is intended to give insight into some of the practical applications of theorizing age relations.

It is important to note that extant research that names and articulates the practical application of age relations tends to focus primarily on the *disadvantages* that older people face relative to middle-aged and younger adults. As I have established, age relations intersect with other relations of inequality to frame diverse opportunities, privileges, and constraints at different points in the life course. Yet, *ageism* tends to be a primary focus in extant research that demonstrates the practical applications of age relations.

#### *Age relations and family care work*

Some scholars have demonstrated the practical applications of age relations in research on family care work (Calasanti, 2006; Calasanti, 2010; King & Calasanti, 2013; Utrata, 2011; Zajicek et al., 2006). Research in this area is somewhat limited in scope because it does not address the full range of family care relationships and how age

relations might affect them.<sup>5</sup> Yet scholars have focused explicitly on age relations—as they intersect with gender, race, and class relations—in the areas of childcare and spousal care. This research shows that caregiving responsibilities are unequally distributed and unequally valued among people of different ages. In particular, it focuses on the “invisibility” of older people’s care work, and on the disadvantages that older people often face relative to younger, working generations who perform care work.

With regard to childcare, researchers have focussed primarily on the ways in which responsibilities for childcare tend to disadvantage older women relative to younger women who work in the paid labour market. Utrata (2011) and Zajicek et al. (2006) suggest that expectations that grandmothers will care for grandchildren, coupled with some older women’s economic dependence, can reinforce privileges for younger adults while disadvantaging older women (Utrata, 2011; Zajicek et al., 2006). In Russia, grandparents care for nearly half of children for before they reach school age (Utrata, 2010). In Utrata’s (2011) study of caregiving grandmothers and single working mothers in Russia, younger women were often privileged because older women’s care work enabled them to engage in paid labour and to pursue individual goals. Zajicek et al. (2006) similarly find that Mexican American grandmothers are heavily involved in family caregiving due to expectations that grandmothers’ unpaid labour will enable younger

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<sup>5</sup> For example, a rich body of literature explores gender among sons and daughters who care for older parents (Campbell & Carroll, 2007; Campbell & Martin-Matthews, 2003; Matthews & Thompson, 2002). While age relations are certainly at play in these circumstances, this research tends not to name and explicitly theorize age relations. It is therefore excluded from the discussion presented in this chapter, which focuses on research where scholars have explicitly named and articulated the implications of age relations, in order to give insight into the practical applications of theorizing age relations.



generations to work for pay. Among Mexican American families, almost two thirds of grandparents who live with and care for grandchildren are women (Simmons & Dye, 2003, cited in Zajicek et al., 2006). By virtue of their age, gender, and status as an ethno-cultural minority, the Mexican American women in Zajicek et al.'s (2006) study were often economically disadvantaged and were unable to make meaningful choices regarding care work in later life. Grandmothers may be willing to care for grandchildren and may enjoy doing so, and their work may be "valued as an expression of love" (Zajicek et al., 2006, 191). Responsibility for family caregiving, however, can disadvantage older women because of widespread expectations that they will provide this care and because they are often financially dependent on family members.

Despite the constraints that some older women face when they care for grandchildren, they may "draw on newer discourses of femininity that value leisure and development of the self" to resist expectations related to family caregiving (Utrata, 2011, 620). These acts of resistance show how individuals may "do age" in ways that challenge assumptions and expectations about age. Yet, social locations of disadvantage may make it difficult for individuals to challenge or resist age relations. In Utrata's (2011) study many grandmothers of working-class backgrounds had few opportunities or financial resources in later life and felt increasingly dependent on adult children, given a lack of state supports for older people. These constraints made it difficult for older women to resist family care work, or to pursue interests of their own. For these older women, expectations related to caregiving tended to limit the opportunities available to them (representing an age-based disadvantage for older women), at the same time as they

provided opportunities to younger women who worked for pay and pursued individual goals (representing an age-based advantage).

Calasanti (2006, 2010) and King and Calasanti (2013) have also articulated the practical applications of age relations in research on spousal care work. They argue that the care work performed by older people tends to be invisible, and that this disadvantages older caregivers relative to younger generations who are engaged in care work (Calasanti, 2006). Yet, Calasanti (2006) and King and Calasanti (2013) note that older women and men face *different* advantages and disadvantages as spousal caregivers. In doing so they illustrate how age and gender relations intersect to structure differences in the opportunities and constraints that older women and men face as spousal caregivers.

Calasanti (2006) argues that both older men and women experience great challenges as caregivers in later life due to the emotional and physical demands of caregiving and the societal devaluation of older care recipients. Caregiving can be challenging at any age, but middle-aged caregivers tend to receive much more attention and support for their work. For example, feminist analyses of caregiving focus primarily on the “burdens” of caregiving among younger and middle-aged women (Calasanti, 2006). Academic and policy discussions, moreover, often focus on the challenges that middle-aged, working generations face when they attempt to balance employment and care for children and aging parents (Evandrou & Glaser, 2008; Rosenthal, 2000). By contrast, spousal caregiving among older people is often rendered invisible or is considered to be a normal aspect of marital relations (Calasanti 2006). Thus, spousal

caregiving can be a site in which older women and men experience some age-based disadvantages, relative to middle-aged adults who are caregivers.

Although older people may experience some disadvantages as caregivers, gender relations may lead to some differences in the experiences of older women and men who care for spouses (Calasanti, 2006; King & Calasanti, 2013). Men may experience some advantages relative to women because some of the skills and resources that they are more likely to acquire throughout their working lives can be of benefit in caregiving situations. Research suggests that older men's caregiving style is often less emotionally involved and more task-oriented. Older men apply skills and resources learned in paid work to caregiving situations; often adopting a 'take-charge,' task-oriented, problem-management approach (Calasanti, 2006, 2010). Here men may "benefit, in some ways, from the social distance that they maintain from routines of caring and emotional intimacy" (King & Calasanti, 2013, 706).

In contrast to men, older women caregivers often "expect that they will care effortlessly for spouses physically and emotionally" (Calasanti, 2010, 726). Others are less likely to offer support to female caregivers, and women are less likely to ask for help, because caregiving is thought to come "naturally" to women—but not to men (Calasanti, 2010; see also Connidis, 2010). While men's care work tends to be celebrated, women's is often considered a duty (Calasanti, 2006; 2010). Add to this that older men are often more likely than women to ask for and accept help from others when they are overwhelmed by caregiving. Thus, although older people's spousal care work is largely invisible (representing an age-based disadvantage), older women often receive even less

support and recognition when they are spousal caregivers than men do. Calasanti's research therefore suggests that age and gender relations may intersect in ways that afford some privileges to older male caregivers, while disadvantaging older female caregivers (Calasanti, 2006, 2010; King & Calasanti, 2013).

As the research presented above demonstrates, age relations intersect with gender, and sometimes class and race/ethnicity relations, to create differences in the advantages and disadvantages that individuals face when they are engaged in family care work. In general, this research suggests that age relations structure caregiving arrangements in ways that tend to disadvantage older people relative to younger generations who are engaged in care work. Expectations that grandmothers will care for grandchildren can sometimes limit older women's opportunities, while their unpaid labour advantages younger generations who work for pay (Utrata, 2011; Zajicek et al., 2006). Older women and men alike are heavily involved in spousal care and might experience some disadvantages given the invisibility of spousal caregiving relative to middle-aged adults' care work. Yet, men's more privileged occupational roles, as well as the tendency to celebrate their work as caregivers, can advantage older men relative to older women. The research reviewed above therefore suggests that age relations structure family caregiving arrangements in ways that may lead to a loss of power or privilege for some older people.

#### *Age relations and paid work*

Scholars have also named and demonstrated the practical applications of age relations in studies that examine older people's experiences of employment. Here, scholars have provided insight into the ways age relations shape the opportunities and

constraints that individuals face in the context of paid work (Brooke & Taylor, 2005; McMullin & Marshall, 2001; McMullin & Berger, 2006). This research does acknowledge that older workers face certain advantages, relative to younger workers. Yet, similar to research on family care work, this research focuses primarily on the *disadvantages* that older people face—and on the ways age and gender relations intersect to constrain the opportunities available to older women, in particular (McMullin & Berger, 2006).

Studies that consider the implications of age relations for older people's experiences in labour markets note that older workers may sometimes have more power and status relative to younger workers, particularly in cases where they may draw on experience gained through lengthy work histories. McMullin and Marshall's (2001) analysis of age relations among workers in the garment industry for example, finds that "older workers are thought to have more experience, be more responsible, and make fewer mistakes in their work than younger workers" (McMullin & Marshall, 2001, 121). Similarly, Brooke and Taylor's (2005) research in various public and private sector industries finds that older workers' higher levels of experience is often considered to be positive, and is associated with "the abilities to work 'smartly' and avoid mistakes, to monitor the quality of production, and to stabilise work groups" (424). Older workers might use their experience and skills to help younger workers (McMullin & Marshall, 2001), which can perhaps lead to cooperation and collaboration between people of different ages (Brooke & Taylor, 2005). Work experience can also be an asset in employment searches, although this is more often the case for men with consistent

employment histories than it is for women, who tend to have less stable work histories due to caregiving responsibilities (McMullin & Berger, 2006).

Although older workers may sometimes have some advantages in paid work settings due to the experience that they have acquired throughout their working lives, researchers find that these advantages are often eclipsed by the loss of power that older workers often face—with fewer opportunities and resources available to them in labour markets. McMullin and Marshall (2001), for example, find that older workers are disadvantaged in work contexts that are focused on cutting costs and increasing productivity. They found that older workers were more likely to face threats to their employment than younger workers because they were more often unionized and thus “[commanded] higher wages than younger, nonunionized employees” (McMullin & Marshall, 2001, 120). Despite their higher levels of experience, managers often used assumptions about age—such as “real or supposed age-related declines in dexterity and physical ability” as a rationale for removing older people from the labour force (McMullin & Marshall, 2001, 121). While managers appeared to be primarily concerned with cost reduction and were not explicitly ageist, they still reinforced age relations in ways that disadvantaged older employees relative to their younger counterparts (McMullin & Marshall, 2001, 121).

In their study of the garment industry, McMullin and Marshall (2001) also articulate the intersections of age and class relations: garment workers hold little power—in the context of capitalist relations of production—because they are members of the working-class. Yet, class relations intersect with age relations to shape differences in the

opportunities available to younger and older workers. McMullin and Marshall (2001) therefore see age as “a potential basis of division and conflict among the working class” (121). While class-based relations of inequality might oppress members of the working-class, individuals within this class group face different advantages and disadvantages depending on their age (McMullin, 2009).

Others researchers have similarly considered how assumptions about older people’s ability to learn new skills structure the opportunities available to older workers in various public and private sector industries. Brooke and Taylor (2005) find that these assumptions constrain older people’s capacity to advance their careers, and can therefore disadvantage older people at the same time as they privilege younger workers:

the redeployment of older workers to positions using new technologies was impeded by a perception that younger workers were more able to make skills transitions . . . this led to relatively limited opportunities for skills development among older workers – the perception became a self-fulfilling prophecy . . . younger workers were promoted to supervisory positions over older workers who were nevertheless seen as more experienced (Brooke & Taylor, 2005, 421-422).

Distinctions that are made between workers on the basis of age may shape interactions and relationships in paid work settings. Brooke and Taylor (2005) found that the promotion of younger workers more frequently than older workers—even when the latter were seen as more qualified—led to tensions and conflict between workers of different ages (Brooke & Taylor, 2005). For example, older workers resented the influx of younger managers. In the opinion of older workers, many of these younger supervisors did not have sufficient experience or skill to hold supervisory positions (Brooke & Taylor, 2005). In this example, age relations structure opportunities in the labour market, as well as the

relationships that emerge among workers of different ages in their everyday work settings.

Age relations may also frame the opportunities available to older people who are looking for employment. McMullin and Berger (2006) found that older people often experienced challenges when they attempted to find work because employers consider them “to old to be hired:”

According to many of our informants, prospective employers would refer to older applicants using phrases such as “over-qualified” or “too experienced” . . . In other cases, respondents were told that someone more “junior” was hired or that the organization was too “fast-paced” for them” (McMullin & Berger, 2006, 212).

Although assumptions about age tend to disadvantage older people in their job searches, age and gender relations often intersect to create differences in the types of challenges that older women and men face. McMullin and Berger (2006) found that older men were more likely to be considered overqualified, and that their lengthy paid work experience was sometimes viewed as an asset. Older male job candidates expressed “that being able to discuss their varied experience with potential employers was a technique that actively countered ageism in an interview setting” (McMullin & Berger, 2006, 215). Women, by contrast, were often less able to draw on past work experiences and were often considered to be less qualified (McMullin & Berger, 2006). Older women and men tend to have different levels of work experience: men are more likely to be consistently employed throughout their lives, whereas women—who often experience disrupted work patterns throughout their lives due to caregiving responsibilities and higher rates of unemployment, and who tend to work for lower pay—may be less able to draw on past



work experiences in their job searches. The skills associated with caregiving and with domestic work tend to hold little value in the paid labour market, and this leads to fewer opportunities for older women who have engaged in unpaid care work for much of their lives, and who are looking for paid employment later in life.

Discrimination regarding physical appearance also disproportionately affects older women in job searches. While older men may be considered to be distinguished in appearance, older women face specific pressures to meet cultural ideals of beauty that are based on youthfulness (Hurd Clarke, 2011). Here older women are “devalued not only in relation to men but also in relation to their younger counterparts” (McMullin & Berger, 2006, 220). In McMullin and Berger’s study almost all of the women, but only a couple of men, attempted to change their physical appearance to appear younger, for example by dying their hair. Age and gender relations, as they shape ideals for physical appearance, may therefore intersect to reduce the opportunities available to older women in employment searches relative to older men *and* younger women.

The studies presented above suggest that relations of power, inequality, and difference that are associated with age frame older people’s experiences in paid work settings. In these examples, age relations often operate in ways that privilege younger workers at the expense of older workers. Older women in particular—who are judged more harshly for looking “old,” who typically make less money than men, and whose work histories are often disrupted by caregiving—tend to experience more disadvantages than older men. Here research that demonstrates the practical applications of age relations suggests that labour market practices tend to produce and sustain the opportunities

available to younger and middle-aged people, as well as the disadvantages that older people (especially women) face.

In brief, studies on family caregiving arrangements and on employment experiences in later life illustrate how scholars have named and articulated the practical applications of age relations in some key areas of research in the sociology of aging. These studies show that relations of power and inequality between and among people of different ages significantly shape everyday experiences in the domains of family care work and paid work. Age relations structure experiences in these domains such that older people often face disadvantages, and these disadvantages often intersect with other relations of inequality based on gender, class, and race/ethnicity.

### ***Summary***

In this chapter, I have provided a conceptual understanding of age relations in order to ground this thesis in a theoretical framework. I have reviewed the theoretical foundations and assumptions that underlie the concept of age relations, and I have explained how age relations are produced and sustained through social structures, cultural discourses, and everyday practices of action and interaction. I have also reviewed the work of some scholars who have explicitly applied the concept of age relations to the substantive contexts of family care work and employment.

Extant research that explicitly names and theorizes age relations has made some important contributions to understanding the disadvantages that older people may face vis-à-vis younger generations, I suggest, however, that more research is required to account for the ways in which structural, cultural, and interactional processes play out at

the level of personal experience. It is necessary to consider more closely, for example, how individuals might reinforce—or potentially challenge or resist—the processes, practices, and discourses that are associated with age in their everyday experiences.

Exploring experiences of receiving care in later life provides an ideal opportunity to theorize the interactional bases of age relations. By virtue of their age and marginalized status as “dependents,” one would expect that older people who are receiving care, who are often considered to occupy the “fourth age,” might experience some age-based disadvantages. Yet, these disadvantages likely vary as care needs depend on one’s health status or level of impairment, and as age relations intersect with other social relations of inequality. Listening directly to older care recipients’ voices can likely give important insight into age-based relations of privilege and exclusion. As Collins (1990) explains, “those who are marginalized by power relations are often the best source of information concerning such relations” (cited in Calasanti, 2003, 209). Theorizing age relations with regard to experiences of receiving care and practising self-care can therefore shed light on a private, everyday setting in which age relations—including relations of power, dependency, and control between and among people of different ages—are worked out. In the following chapter I review and identify gaps in sociological and gerontological literature on care, to provide the substantive context for my study on older people’s negotiations of care and experiences of age relations.

### **Chapter Three: Literature review**

#### ***Situating older people's experiences of care: Reviewing the literature and identifying gaps***

##### ***Introduction***

This thesis considers how age relations shape, and are shaped by, older people's experiences of receiving care. In the previous chapter I traced the foundations, underlying assumptions, and some practical applications of the concept of age relations to provide a theoretical grounding for my study. In this chapter, I review and identify gaps in relevant sociological and gerontological perspectives on care, to situate this study within a substantive body of literature. To begin, I briefly review the context of research on family caregiving and paid care work, focussing specifically on the work of Canadian scholars. I then review feminist perspectives on care work. While these perspectives are not the focus of this thesis, they have informed some of the questions asked and approaches taken in research on *receiving* care in later life. More specifically, I explain that some of the literature on receiving care in later life has emerged as a critical response to the focus on caregiver stress and burden, and the invisibility of care recipients in earlier feminist literature. Critics argue that some of this literature tends to position people with long-term care needs as dependent or burdensome "others," and may inadvertently create boundaries that exclude or render care recipients invisible (Barry, 1995; Fine & Glendinning, 2005). Some feminist research might overlook care recipients' mutual involvement in care arrangements, and contribute to a one-directional view of care relationships (Dannefer, Stein, Siders, & Patterson, 2008; Fine & Glendinning, 2005).

After I review feminist perspectives on caregiving, I consider research on the experiences of people who are *receiving* care in later life. Here, scholars have engaged in research with care recipients directly to counter the one-directional view of care relationships that has emerged in some feminist literature. In my literature review I focus specifically on experiences of receiving care in *later life* and *at home*—from both formal care providers and family/friends caregivers—to ground this thesis in current debates and discussions on home and community care. In brief, the research that exists on older people’s experiences of receiving care at home suggests that care recipients demonstrate reciprocity, develop relationships with care providers, and re-interpret independence and dependence in light of illnesses, impairments, and care needs. This literature also suggests that older people continue to practise self-care while they receive care from others—that is, older care recipients engage in practices that promote health, prevent illness, and maintain functional independence (Craft & Grasser, 1998; Ory, DeFries, & Duncker, 1998; Penning, 2002).

To conclude this chapter, I identify some gaps in extant research. Although literature on receiving care provides an understanding of care recipients’ mutual involvement in care relationships, scholars have not fully addressed older care recipients’ experiences at the intersections of the systems of formal home care, family/friend caregiving, and self-care. Moreover, despite the overwhelming emphasis on *later life* in the literature on care, more research is needed to articulate the implications of *age relations*—as relations of inequality between and among people of different ages—for older people’s experiences of receiving care. In this thesis, I seek to address these

limitations. I will examine how older care recipients negotiate the intersections of formal home care, family/friend caregiving, and self-care, and I will consider the implications of age relations for experiences of receiving care in later life.

### ***Context of research on caregiving***

Care has been a topical area of sociological inquiry since the 1970s and 1980s. Scholars, primarily writing from feminist perspectives, have developed rich theoretical and conceptual understandings of caregiving. Broadly, researchers recognize that care is an act of labour and of love (Graham, 1983) with physical, affective, and organizational dimensions (James, 1992). They distinguish between caring *for* others by providing physical and practical assistance, and caring *about*; an affective disposition that involves concern for others (Graham, 1983). Researchers consider both the unpaid care work performed by family and friends, and well as the contributions of paid care workers.

In Canada, researchers have extensively documented the care that family members and friends provide to older people (Campbell & Carroll, 2007; Campbell & Martin-Matthews, 2003; Chappell & Funk, 2011; Connidis & Kemp, 2008; Connidis, 2010; Keating, Otfinowski, Wenger, Fast, & Derksen., 2003; Keefe & Fancey, 2002; Keefe, 2011; Rosenthal et al., 2007; Sims-Gould & Martin-Matthews, 2010b). Researchers find both gender differences in patterns of family caregiving as well as differences according to the nature of the relationship, such as whether care is provided by a spouse or adult child. Women, as daughters and wives, typically provide more care to older family members (Chappell & Funk, 2011; Connidis, 2010; Keefe, 2011) and tend to be the focus of the majority of research on caregiving (e.g., Aronson, 1992; Keefe & Fancey, 2002;

McGraw & Walker, 2004). Yet, researchers have acknowledged that men, as husbands and sons, also give care to family members (Campbell & Carroll, 2007; Campbell & Martin-Matthews, 2003). Canadian statistics estimate that, of 2.7 million people aged 45 and older who provided care to an older person in 2007, 57% were women while 43% were men—although female caregivers typically provide more hours of care than male caregivers do (Cranswick & Dosman, 2008).

While both women and men are engaged in family caregiving, there are gender differences in the type of care that is provided. For example, sons who are caregivers are more likely to do typically “masculine” tasks like household maintenance and care management, while daughters are more likely to do typically “feminine” tasks such as personal care and domestic work (Campbell & Martin-Matthews, 2003; Connidis & Kemp, 2008; Cranswick & Dosman, 2008; Thompson, 2002). Gender differences in caregiving, however, tend to be less pronounced among older people who care for an intimate partner or spouse. Older men who are spousal caregivers tend to provide similar amount of personal care as older women do (Arber & Ginn, 1995; Calasanti, 2006). Family caregiving patterns may also be different among lesbian, gay, bisexual, and transgender people. For example “fictive kin” may take the place of traditional family caregivers such as spouses or children (Brotman, Ryan, & Cormier, 2003; Muraco & Fredriksen-Goldsen, 2011). That said, adult children do care for gay or lesbian parents, and when they do they may have to contend with issues of discrimination (Brotman et al., 2007; Connidis, 2010).

There are both advantages and disadvantages to family caregiving (Chappell & Funk, 2011). On the one hand, caregiving can be emotionally rewarding and can strengthen bonds between family members (see Connidis, 2010). Caregivers, however, may face some constraints and challenges because caregiving tends not to be recognized as a form of work and is relatively invisible in social policies (Keefe, 2011). Research suggests that caregiving tends to be more stressful for women than it is for men (Chappell & Funk, 2011). It is possible that men experience less stress because of their relative economic advantages and access to informal support; because their care work is celebrated whereas women's is considered a duty; or because being a good caregiver is less closely tied to men's identities (Calasanti, 2006, 2010; Connidis, 2010). Finally, while family members provide the large majority of care to older people, scholars express caution about the future supply of family caregivers—as shifting family structures (e.g., higher divorce rates, lower fertility); women's participation in paid labour; and people living at a distance from their family members are seen to impact on the supply of family caregivers (Keefe, 2011; Neal, Wagner, Bonn, & Niles-Yokum, 2008; Phillips & Bernard, 2008).

Complementing this research on family caregiving, a large body of research explores the contributions of formal care workers who provide support to older people (Armstrong, Armstrong, & Scott-Dixon, 2008; Aronson & Neysmith, 1996; Denton, Zeytinoglu, & Davies, 2002; Denton et al., 2014.; Lum, Sladek, Ying, & Holloway Payne, 2010; Meintel, Fortin, & Cognet, 2006; Sharman, McLaren, Cohen, & Ostry, 2008; Sims-Gould & Martin-Matthews, 2010a; Ward-Griffin & Marshall, 2003).



Research has documented the complex instrumental and emotional labour performed by care workers, as well as the skills that care workers bring to their work. For example, beyond performing mandated tasks laid out in a client's "care plan" home care workers spend much time directly interacting and negotiating care with clients, their family members, and other health care providers (Meintel et al., 2006; Sims-Gould & Martin-Matthews, 2010a). As such, care workers' skills include "sensitivity, social skills, ingenuity, patience, judgment, and ability to problem solve" (Sims-Gould & Martin-Matthews, 2010a, 106). In the current Canadian policy structure, however, care workers are increasingly gaining responsibility for more medically complex tasks (Barken et al., 2015; Denton et al., 2014).

While the above provides a snapshot of the context of research on caregiving in Canada, in what follows I review in more detail feminist perspectives on caregiving. It is necessary to review these perspectives because they provide a foundation for research on receiving care: scholars who consider the experiences of receiving care have critiqued, and sometimes extended, earlier research on caregiving.

### ***Feminist perspectives on caregiving***

Feminist scholars have developed rich theoretical and conceptual understandings of care work.<sup>6</sup> This research helps to explain why women tend to be over-represented among both paid and unpaid caregivers, and draws attention to the consequences of this care work for women's opportunities over the life course. Feminists argue that women's disproportionate involvement in family care and in paid care work results from patriarchal

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<sup>6</sup> For comprehensive reviews of theories on care, see England (2005) and Fine (2007).

conditions in capitalist societies, gender divisions of labour, and processes of socialization that maintain and reproduce masculine and feminine roles over the life course (Hooyman, Browne, Ray, & Richardson, 2002). Women typically learn how to care at a young age and often in their homes rather than in educational or work settings. Caring is therefore often considered to be an intrinsic feminine capacity and is disregarded as learned, skilled work (Armstrong, 2013; Glenn, 2010; Palmer & Eveline, 2012).

Variants exist in the feminist tradition, but scholars typically agree that it is necessary to provide a clear conceptual understanding of care, to recognize care as a moral or social practice, and to identify the virtues—such as responsiveness, responsibility, and attentiveness—that are involved in giving care (Cooper, 2007, 244). Building on this common ground, feminists have produced interrelated analyses of the ethical aspects of care, and of women's work as care providers. These perspectives make visible the moral, social, and political dimensions of care. They highlight the importance of conceptual understandings of care for the domains of policy and practice, as values and assumptions about caregiving come to shape the allocation of services and resources for people engaged in care relationships.

### *Ethics of care*

The ethics of care, a philosophical and theoretical framework, upholds care as an altruistic ideal associated with women's moral reasoning and as key aspect of human relationships (Fine, 2007; Milne & Larkin, 2015). Joan Tronto, a leading theorist in this area, explains that care is a process that involves four phases: caring about, caring for,

caregiving, and care-receiving (Tronto, 1993). These processes are associated with four moral elements: attentiveness, responsibility, competence, and responsiveness. Care is a concrete activity that involves caring *for* and *about* others as well as a moral orientation: “an ethics or a set of values that can guide human agency in a variety of social fields” (Sevenhuijsen, 2000, 6). While care is conceptualized as an important human practice at the level of individual relationships, ethics of care theorists move beyond the private sphere and envision care as a guiding feature of social, political, and public processes (Sevenhuijsen, 2000; Tronto, 1993).

Ethics of care theory recognizes the interconnectedness of all people involved in care relationships and the potential strength of social networks that sustain them (Fine & Glendinning, 2005; Gilligan, 1984; Kittay, 1999). Theorists working in this area critique the widespread dichotomous constructions of independence and dependence. Capitalist societies tend to prioritize the ability to act independently for economic gains, and at the same time position dependence as private or shameful (Fine & Glendinning, 2005; Kittay, 1999). The “productive” economic and social contributions of people (traditionally men) who are able-bodied and independent are highly valued, while the ‘non-productive’ activities of giving and receiving care tend to be devalued. Ethics of care theorists, by contrast, draw attention to the *interdependencies* that exist among all people, as they both give and receive care at different points in their lives (Sevenhuisjen, 2000).

Interdependence is understood “as the result of reciprocity between partners, exchanges between dependent actors over time, and the networking of these relations of dependence” (Fine & Glendinning, 2005, 61). Ethics of care theorists use the concept of

*interdependence* to articulate the links between caregiving, care needs, and the broader networks of care in which individuals are embedded (Fine & Glendinning, 2005; Sevenhuijsen, 2000). Ethics of care theorists suggest that the concept of interdependence should replace the independence/dependence dichotomy, and guide understandings of and responses to care needs.

Ethics of care theorists envision care “as an activity of relationships, of seeing and responding to need, taking care of the world by sustaining the web of connection so that no one is left alone” (Gilligan, 1984, 73). They emphasize the positive social aspects of care, but assert that it should not be taken for granted as women’s natural role that occurs in the private sphere of the home, or that is relegated to a peripheral position (Tronto, 2010). Since care is a fundamental aspect of the life course that unites all people an ethic of care is envisioned as a public virtue and as a key aspect of citizenship—not just a private practice—that should guide thought and action in public, political, and social spheres (Barnes, 2012; Sevenhuijsen, 2000). Theorists argue that such an understanding of care would make the needs of both caregivers and receivers central to political discussions and decision-making processes (Sevenhuijsen, 2000).

On a practical level Barnes (2012) and Lloyd (2010) have used ethics of care theory to critique the personalization agendas that guide the provision of home care services in the United Kingdom. Personalization schemes emphasize individuals’ role in managing or directing their own care and purportedly give greater choice and control to those who are receiving care. Drawing on ethics of care scholarship Lloyd (2010) argues that such personalization agendas—with their overriding emphasis on independence and

activity—may overlook both the relational aspects of care as well as the realities of dependence and vulnerability experienced by some people in need of care, including people nearing the end of life or living with cognitive impairments. The hazard of such policies, Barnes (2012) explains, is that they may sustain inequalities between people with care needs who are able and willing to actively direct their own care and those who are unable to do so. Ethics of theory, by contrast, may be used to develop policies that recognize the relational and social aspects of care and that ensure universal access to care for all people, regardless of ability to direct their own care (Barnes, 2012).

#### *Care as women's work*

Like ethics of care theorists, feminists who examine the labour of caring believe that it should be a public concern. They focus more heavily, however, on women's actual experiences of caregiving in political economic contexts, rather than on the ontological and moral aspects of care. Neysmith (2000), for example, argues that theoretical discussions on the ethics of care may seem disconnected from the experiences of people who are giving and receiving care in the context of welfare state restructuring. To advocate on behalf of care providers (and recipients) and to ensure that they receive adequate support, feminists who study women's care work direct attention to the political and practical aspects of care (Fine, 2007).

Although all people may be involved in networks of interdependence, women are largely responsible for caring for children and for older, sick, and disabled people, and this care work tends to be invisible and undervalued. Feminist scholars argue that women's disproportionate responsibility for family care work contributes to their poorer

economic, social, emotional, and physical well-being over the life course (Baines et al., 1998; Hooyman et al., 2002). Unpaid caregiving is seen to disadvantage women because it is emotionally stressful (Connidis, 2010; MacRae, 1998) and because it limits their abilities to advance careers and maintain financial independence (Baines et al., 1998; Hooyman et al., 2002; Keefe, 2011). Government policies exacerbate the stress women experience as caregivers when they emphasize community and family responsibility for care. Given assumptions that caring is women's natural capacity, "community care" often means that unpaid female family members take responsibility for the majority of care work (Baines et al., 1998; Guberman, 2004; Hooyman et al., 2002; Keefe, 2011; Purkis, Ceci, & Björnsdóttir, 2011).

Feminists began their research with considerations of the disadvantages that women face as family caregivers but extended this analysis to include paid and formal care; work which women primarily do (Graham, 1991; James, 1992; Ungerson, 1990). Paid care work holds little social status because it is often considered "just an extension of ordinary domestic labour" (Aronson & Neysmith, 1996, 61). Canadian researchers have extensively documented the exploitation of women's labour in health and social care (Armstrong et al., 2008; Armstrong & Armstrong, 2003; Aronson & Neysmith, 1996; Baines et al., 1998; Guberman, 2004). Poor employment conditions, including low pay, few or no benefits, few opportunities for training and development, instability, and unsafe working environments are common characteristics of care work (Aronson et al., 2004; Craven, Byrne, Sims-Gould, & Martin-Matthews, 2012; Hooyman et al., 2002). These working conditions may lead to economic insecurity and poor health outcomes (Denton,

Zeytinoglu, & Davies, 2002) and may therefore disadvantage care workers throughout their lives.

While women perform the majority of care work, care responsibilities are unequally distributed among different groups of women. With regards to unpaid care work, women in disadvantaged social locations, including women of colour and from lower socio-economic classes, often have little choice in whether or not to assume caregiving responsibilities because they may not be able to access or afford additional supports (Hooyman, et al., 2002). Paid care work is also racialized work: in Canada and in other developed countries, the large majority of care workers belong to minority groups and/or are recent immigrants who have been recruited from developing countries (Armstrong et al., 2008; Bourgeault, Atanackovic, Rashid, & Parpia, 2010; Glenn, 2010; Martin-Matthews, Sims-Gould, & Naslund, 2010; F. Williams, 2010). Add to this the widespread social and cultural beliefs that women from some ethnic groups that are over-represented among care workers, such as Filipino women, are “naturally” well suited to caregiving (Bourgeault et al., 2010). Issues of discrimination, as well as language and cultural barriers, may compound the poor working conditions that tend to be associated with care work (Bourgeault et al., 2010; Martin-Matthews et al., 2010; Meintel et al., 2006; Neysmith & Aronson, 1997). These challenges may serve to reinforce the disadvantages that care workers from racialized and ethnic minority groups face.

In sum, feminist theories call for a more equitable distribution of caring responsibilities and provide a framework for examining the meaning and practice of care. Importantly, ethics of care theorists’ understanding of human relationships accounts for

the interdependencies that exist among all people, as they give and receive care throughout their lives. Feminists who study women's caring labour give insight into the relations of inequality that hold women—especially poorer women, and those from racialized or ethnic minority groups—responsible for care work. This feminist literature makes important contributions to sociological understandings of care, but there are some limitations to it. In particular, critics have argued that much of the feminist literature on caregiving neglects the perspectives of those who are receiving care, including older people (Barry, 1995; Calasanti & Slevin, 2006) and disabled people (Morris, 1995, 2001). The feminist perspectives I have just described, for example, may reinforce the social exclusion of people who require support due to impairments or long-term health conditions. Critics suggest that ethics of care theory presents a one-directional image of the relationship between care providers and recipients, and therefore may silence those in need of care (Dannefer et al., 2008; Fine & Glendinning, 2005). Ethics of care theory recognizes that all people may be interdependent at different points in their lives, but the person being cared for in a given situation is typically considered to be *dependent*, with little voice or active involvement in the care relationship (Fine & Glendinning, 2005, 616). In a similar vein, some argue that research on caring labour, with its emphasis on the problems women face as caregivers, constructs care recipients as “aggregate bundles of needs” that place an undue burden on women family members and on marginalized care workers (Barry, 1995, 365).

Distinctions between care providers and recipients are also evident in some policy discussions. Here a fixed, one-directional view of the relationship between family



caregivers and recipients fails to account for the complex, interpersonal, and reciprocal nature of care (Henderson & Forbat, 2002; Lloyd, 2000). While policies might support caregivers' rights, they can be divisive when they pit caregivers against recipients and diminish the latter groups' interests and standpoints (Lloyd, 2000). As Fine and Glendinning (2005) argue, the domains of theory, research, and policy have tended "to separate and segregate the world of 'carers' from those for whom they 'care' " (601).

***Care recipients' voices: Older care recipients' involvement in care relationships***

Scholars have engaged in research with care recipients directly to counter the somewhat one-directional view of care relationships that has emerged in much of the literature on caregiving (e.g., Aronson, 2002; Barry, 1995; Byrne, Frazee, Sims-Gould, & Martin-Matthews, 2012; Hale, Barrett, & Gault, 2010; Martin-Matthews, 2007; Twigg, 2000). Importantly, this literature shows that care is not simply about care providers doing things *to* or *for* care recipients—rather, care relationships emerge as individuals respond to the care that both formal and family/friend caregivers provide. In what follows I identify some key ways that scholars have demonstrated care recipients' mutual involvement and contributions to care arrangements. Broadly, this research shows that care recipients engage in emotional, organizational, physical, and cognitive labour throughout the care process (Barry, 1995; Twigg, 2000). In this regard studies on older people's experiences of receiving both formal and kin care have considered how care recipients (a) engage in relations of reciprocity; (b) negotiate and develop relationships with care providers; (c) re-interpret the concepts of independence and dependence; and (d) practise self-care (i.e., care for themselves) while they receive care from others.

In the following discussion, I focus specifically on studies that consider older people's experiences of receiving care in *later life* and *at home*. This is certainly not the only context in which care relationships are relevant. For example, researchers have considered the experiences of younger disabled adults (Allen & Ciambrone, 2003; Morris, 1995), or of people who live and receive care in residential or assisted living facilities (Ball et al., 2004; Kemp et al., 2013; Kontos, 2004). Yet, care needs often increase in later life, and discussions on care often focus specifically on older people. Further, in the context of frameworks and strategies on "aging in place," policymakers as well as many older people themselves consider "the home" to be the ideal site of care (Keefe, 2011; Wiles et al., 2012). I therefore focus primarily on experiences of receiving care among *older* people and *at home* to situate this study in the context of the debates that currently guide policy and research. Moreover, because paid care workers and family/friend caregivers alike support older people at home (Hoover & Rotermann, 2012; Sims-Gould & Martin-Matthews, 2010b; Ward-Griffin & Marshall, 2003), I consider literature that examines older people's experiences of *both* formal home care and family/friend caregiving.

### *Reciprocating*

To challenge the view that care relationships simply involve care providers doing things *to* or *for* care recipients, scholars have engaged with care recipients directly to articulate their reciprocal involvement in care arrangements (Cox & Dooley, 1996; Dunér & Nordström, 2007; Forbat, 2005; Keefe & Fancey, 2002; Lewinter, 2003). Broadly, scholars have established that reciprocity emerges when there is balance of power or a

sense of interdependence between care providers and recipients, and when care arrangements support the autonomy and dignity of the person who is receiving care (de São José, Barros, Samitca, & Teixeira, 2015; Dunér & Nordström, 2007; Forbat, 2005). By contrast, older people may lose power in care relationships, such as those with their adult children, when their capacity to reciprocate declines (Connidis, 2010). Care recipients often consider reciprocity to be a positive aspect of care (de São José et al., 2015), and they may refer to principles of reciprocity to justify the receipt of help from others (Allen & Wiles, 2014).

Some older people in need of support may discuss reciprocity in terms of positive, mutually supportive family relationships that are developed over the life course (Connidis, 2010; Dunér & Nordström, 2007; Forbat, 2005; Keefe & Fancey, 2002; Lewinter, 2003). They may demonstrate “efforts to give or show appreciation and respect for their children who helped them” (Lewinter, 2003, 367). For example, they may attempt to avoid posing too many demands on adult children or interfering with their lives (Barry, 1995; Keefe & Fancey, 2002; Lewinter, 2003). Older care recipients may also give gifts or financial support to family members to express reciprocity (Allen & Wiles, 2014; Lewinter, 2003).

In addition to reciprocating with family members, Lewinter (2003) finds that older care recipients demonstrate reciprocity when they interact with home care workers. In her Danish study, home care workers were not technically allowed to accept gifts from their clients. Still, older home care recipients often shared a cup of coffee and sometimes a snack with home care workers to express hospitality and appreciation for the help care

workers provided. Reciprocating enabled older care recipients to demonstrate their active involvement in care relationships, and consequently a sense of control over the care arrangement (Lewinter, 2003).

### *Developing relationships*

To further demonstrate care recipients' mutual involvement in care arrangements, research shows how care recipients negotiate and develop relationships with both family caregivers and formal care providers (Barry, 1995; Coeling et al., 2003; Connidis, 2010; Mahmood & Martin-Matthews, 2008; McGarry, 2009; McGraw & Walker, 2004; McWilliam, Ward-Griffin, Sweetland, Sutherland, & O'Halloran, 2001; Roe et al., 2001). These studies show that care is a two-way—rather than unidirectional—process, as care relationships emerge through the interactions between care providers and recipients.

Connidis (2010) has explained how the relationships between older parents in need of care, and adult children who provided care, are characterized by *ambivalence*. The concept of ambivalence captures the contradictions and paradoxes that emerge as individuals exercise agency and negotiate relationships in the context of structured social relations (Connidis & McMullin, 2002; Connidis, 2010). Connidis (2010) finds that ambivalence emerges as care-receiving parents and caregiving children contend with norms of obligation, experiences of loss, and expectations of familial support. In a similar vein, McGraw and Walker (2004) find that care-receiving mothers construct relationships with caregiving daughters that range from symmetrically connected (emotionally close) to symmetrically constrained (tense and emotionally distant). In this study care-receiving mothers often attempted to minimize conflict with caregiving daughters, and to ensure

positive relationships with them (McGraw & Walker, 2004). The extent to which care recipients reject or accept help may also influence the relationships they develop with care providers. Coeling et al. (2003), for example, identify three archetypal dyadic relationships that exist between care recipients and family/friend caregivers: “complete and mutually accepted immersion of an identity into the care process by both parties, retention of personal identities while also accepting the caregiving or care-receiving roles, and rejection of the roles by one or both parties” (Coeling et al., 2003, 21).

Researchers have considered how care recipients develop relationships with paid care workers as well as family/friend caregivers (Mahmood & Martin-Matthews, 2008; McGarry, 2009). For evident reasons such as the formal care provider’s status as a paid worker and lack of familial history, the relationships that care recipients develop with formal care workers often take different forms than the relationships that exist between care recipients and family/friend caregivers. Here the context of the home space is significant to the relationships that emerge. Although later life care can alter family relationships (Barry, 1995; Funk, 2010; McGraw & Walker, 2004), it does align with the symbolic significance of the home as a place for intimate relationships. By contrast, formal care can be experienced as a disruption to the privacy of the home space (Angus et al., 2005; Holmberg et al., 2012; Mahmood & Martin-Matthews, 2008; Twigg, 2000). For example, formal home care means that residents must relinquish some control of the home to outsiders (Hale et al., 2010; Martin-Matthews, 2007), and they might consider home care to be disruptive or threatening because strangers (care workers) are entering their homes (Janlöv, Hallberg, & Petersson, 2005). Yet, care recipients might experience

a sense of autonomy when they construct relationships with formal home care providers. Depending on the policy structure of home care services (i.e., whether care recipients receive publicly funded home care or pay for care themselves), care recipients might have some control over which care providers enter their home and which spaces within the home they are able to access (Twigg, 1999).

In the intimate home space, care recipients might develop close and friendly relationships with care providers, or they might try to maintain professional relationships and therefore some distance between themselves and those who are caring for them (Mahmood & Martin-Matthews, 2008; McGarry, 2009). Mahmood and Martin-Matthews (2008) find that care recipients engage in relationships with home care workers and family caregivers alike to construct an “intermediate domain” at the nexus of public/work/professional and private/home/non-professional boundaries. These boundaries are not clearly defined, but rather exist on a continuum of integration and segregation. For example, some care recipients develop friendly relationships with formal care providers, yet speak up and assert their “space” when care workers do something that the care recipient considers to be inappropriate (Martin-Matthews & Sims-Gould, 2011, 117).

While relationships between paid care providers and older care recipients may exist in an “intermediate domain,” research does indicate that there are certain aspects of the care relationship that are particularly important to older care recipients. Byrne et al. (2012) find that older people receiving home care value care providers who know and treat them as individuals, and who are empathetic and understanding. Indeed the

development of trusting, supportive relationships between formal care providers and older care recipients—extending beyond the completion of specific tasks—has been identified as a key aspect of high quality care (Byrne et al., 2012; Holmberg et al., 2012; Turpin, McWilliam, & Ward-Griffin, 2012). Care recipients appreciate care workers who are reliable, flexible, patient, and have time to listen and to interact with them on a personal level (Aronson, 2004; Bourgeault et al., 2010; Byrne et al., 2012; Francis & Netten, 2004; Glass, Teaster, Roberto, & Brossoie, 2005; McGarry, 2009; Raynes, Coulthard, Glenister, & Temple, 2004).

Although care recipients are involved in developing care relationships, the extent to which they expect, want, or feel able to participate in care relationships may vary (McWilliam et al., 2001). Roe et al. (2001), for example, find that care recipients develop relationships with both formal and family care providers that are characterized by different styles of accepting help. These range from positive acceptance where older care recipients feel positive about needing and receiving help and are actively involved in decision making; to resigned acceptance where they feel they have little choice over the care they are receiving; to passive acceptance, where care recipients simply follow care providers' instructions and offer little input (Roe et al., 2001, 404). Poor health status and low levels of energy—and in the case of formal care, models that prioritize professional rather than client expertise—may constrain care recipients' mutual involvement in care arrangements (McWilliam et al., 2001). Byrne et al. (2012) explain that home care practices that overlook care recipients' involvement in care relationships may diminish care recipients' sense of personhood, insofar as they may fail to respect care recipients'

beliefs, values, and preferences for care. Despite these constraints, studies that consider how care recipients negotiate and develop care relationships show that care is a process that involves interaction among multiple individuals—rather than a set of tasks to be completed by one person, for another.

*Re-interpreting independence and dependence*

Studies that show how care recipients develop relations with care providers establish their mutual involvement in care relationships, and challenge one-directional conceptualizations of care. This is emphasized even further in studies that consider the diverse ways older people re-interpret the concepts of independence and dependence in light of illnesses, disabilities, and care needs (Ball et al., 2004; Crist, 2005; Hale et al., 2010; Hammarström & Torres, 2010; Holmberg et al., 2012; Plath, 2008). To be sure, needing care in later life might be an experience of discontinuity, dependence, and loss for some people (Connidis, 2010; Janlöv et al., 2005). In Janlöv et al.'s (2005) study, for example, older people who were entering the home care system often struggled with losses and their feelings about needing to ask for help. Yet, the meanings of independence and dependence are contested and complex (Bell & Menec, 2015; Hammarström & Torres, 2010; Plath, 2008). On the one hand, individual measures of independence may consider older people's capacity to perform instrumental activities of daily living (IADLs) and activities of daily living (ADL). This approach assumes that there is a clear relationship between functional impairment and dependence (Hammarström & Torres, 2010). On the other hand, independence and dependence may be conceptualized "as social constructions; i.e., as a product of social relations and a result of the interaction



between older people and their social environment” (Hammarström & Torres, 2010, 76; see also Plath, 2008). This latter constructionist approach conceptualizes independence and dependence on a continuum, rather than as polar opposites.

Using this constructionist approach, Hammarström and Torres (2010) question the assumption that “dependence is automatically brought to the fore once one becomes in need of help and care,” and consider “whether it is possible to think of oneself as independent if one receives help in everyday life” (76). They find that older people who are in need of care experience varying states of “being,” “feeling,” and “acting” dependent. All of the interview participants in their qualitative study received home care, and would be classified as dependent using individual measures such as IADL and ADL scores. Yet, the home care recipients re-interpreted independence and dependence in light of their care needs. Some participants, for example, viewed themselves as autonomous and self-reliant, even though they needed help from others (Hammarström & Torres, 2010, 82). Here, autonomy may be understood as the capacity to make meaningful decisions about one’s own life, even in situations where impairments place limits on physical (and perhaps cognitive) independence (Ball et al., 2004; Hammarström & Torres, 2010). Plath (2008) similarly finds that older care recipients defined independence “in terms of being able to access a range of resources, supports and social rewards in the community, so that social, emotional and physical needs could be met” (1354).

Hale et al. (2010) and Holmberg et al. (2012) both explain that care providers can support older people’s sense of independence and autonomy when they involve older people in care activities, and provide care that supports care recipients’ desired goals and

activities. Byrne et al. (2012) similarly note that collaboration and negotiation between paid care workers and care recipients, involving efforts on the part of care providers to help ““as much” or “as little” as needed,” and to work *with* care recipients, may support care recipients’ autonomy (388). In general, research suggests that older people find a balance between accepting help and maintaining autonomy or self-determination when they receive family care (Crist, 2005) and formal home care (Holmberg et al., 2012; Soodeen, Gregory, & Bond, 2007).

### *Practising self-care*

Practices of self-care give further insight into care recipients’ mutual involvement in care relationships, including the ways they make sense of their changing needs and abilities. While various definitions and applications of self-care exist, researchers broadly conceptualize self-care as the ways individuals direct and maintain their own health through preventive behaviour and response to illness (Dean, 1989; Morrongiello & Gottlieb, 2000). Research suggests that components of self-care among older people include detecting, diagnosing, and treating illness; seeking help to engage in behaviours or practices that contribute to health; and maintaining and promoting health and functional independence (Craft & Grasser, 1998; Ory et al., 1998). Related to the understanding of self-care as a means of promoting functional independence, some researchers include activities of daily living such as bathing and dressing, and instrumental activities of daily living such as cooking, cleaning, and medication management, in their conceptualizations of self-care (Ball et al., 2004).

Beyond the broad definitions provided above, the concept of self-care is somewhat elusive and has been defined and applied in diverse ways across settings and contexts. In what follows, I will explain some of the various ways that researchers have conceptualized the self-care practices of older people who are receiving care from others. In doing so I give an understanding of older people's self-care practices, as they occur in relation to formal and family/friend care.

Quantitative studies tend to use specific responses to survey questions to measure self-care practices among older people who are receiving care. For example, in addition to analyzing open-ended survey questions, Penning (2002) used the following indicators to assess older people's self-care practices:

Activities daily living [ADLs] including dressing, using the toilet, getting about the house, getting in and out of bed, and bathing); household management tasks (instrumental ADLs [IADLs], including shopping, meal preparation, light and heavy housework, using the telephone, and laundry), as well as various other activities (advanced activities of daily living [AADLs], including yard work, taking medication, taking care of money, and looking after long-term personal finances) (8-9).

Quantitative analyses have important implications for understanding the relationship between practising self-care and receiving care from others. Significantly, Penning's (2002) and Penning and Chappell's (1990) quantitative research finds that older people who have more chronic conditions and limitations to activities of daily living practise higher levels of self-care, but that the receipt of formal care does not have a significant impact on the level of self-care practised. These findings challenge two popular assumptions: First, the provision of formal care does not "undermine self-reliance and personal responsibilities for care" (Penning, 2002, 4). Second, self-care is not higher

among people who are able-bodied, and lower among people with impairments and illnesses, who are receiving family/friend or formal care.

While quantitative research gives important information about the amount and type of self-care that older people in need of care practise, qualitative studies attend to the meaning and value that older people attribute to self-care. Qualitative studies suggest that practising self-care is important to older care recipients because it enables them to maintain continuity with valued identities and roles and to be involved in care processes (Ball et al., 2004; Cox & Dooley, 1996). Through practices of self-care older people in need of care may demonstrate self-sufficiency, and represent and embody independence as a physical act. For example, while Ball et al. (2004) do not focus specifically on the home setting, their research provides an important understanding of self-care practices among older people who are receiving formal care in assisted living facilities. Ball et al. (2004) draw on Baltes and Baltes' (1990) "selective optimization with compensation" to describe the self-care practices of assisted living residents:

Some residents used selection, choosing to perform activities less often, such as bathing three times a week instead of daily. Optimization was a more common strategy. Residents optimized their abilities by spending more time performing activities, trying to improve function with physical and mental exercise, adhering to treatment regimens, and conserving energy by resting. Residents compensated for their impairments by substituting or changing the way they performed activities (e.g., taking a sponge bath instead of tub bath) and by using a variety of assistive devices. Although residents typically resisted help they felt unneeded, residents also recognized receiving help as a way to support their remaining self-care abilities (479).

Through self-care practices, residents adapted to their changing functional abilities, and demonstrated their continued involvement in care relationships. Self-care practices may

also be a response to receiving care from others: in Cox and Dooley's (1996) study older care recipients practised self-care to assist family caregivers, by "doing as much as possible for one's self, learning new ways of doing tasks required for daily living, and accepting paid or professional care" (143).

Research suggests that older people consider self-care to be an important means to "age successfully" and to rely less on formal health care systems (Bassett, Bourbonnais, & McDowell, 2007; Morrongiello & Gottlieb, 2000). Adopting a critical perspective of such self-care practices, Hurd Clarke and Bennett (2013) consider how neo-liberal discourses that emphasize a shift in caring responsibilities from the state to the individual shape older people's self-care practices. In neo-liberal contexts, the state may act as a "facilitator" of health when it encourages individuals to take personal responsibility for health. An example is when health care research and practices provide guidance for older people to engage in certain self-care practices, such as exercise, to avoid the "hazards" that have come to be associated with decline in later life (Higgs, Leontowitsch, Stevenson, & Jones, 2009, 689; see also Katz, 2000; S.Williams et al., 2012). In this neo-liberal context, older people with chronic health conditions and impairments may consider care of the self to be a moral responsibility (Hurd Clarke & Bennett, 2013).

While the above research gives an understanding of the levels of self-care that older care recipients practise as well as the meaning and value they attribute to self-care, it is challenging to conceptualize self-care comprehensively because some studies consider the things that older people do to care for themselves without actually calling these activities "self-care." For example, while Janlöv et al. (2005) do not use the term

“self-care,” they explain how some older people who need home care find “new ways of managing daily tasks and personal care to keep dependency at bay” (331). Similarly, Holmberg et al. (2012) find that older people who received visits from home care nurses participated in care tasks. When it was possible, participants “prepared themselves before the nurse’s arrival, which could involve having a shower, sitting in the chair where the treatment was to take place or taking out the equipment needed” (Holmberg et al., 2012, 708). This research suggests that older people in need of care do many things to care for themselves—regardless of whether or not these practices are referred to as “self-care.”

In summary, the literature I have just reviewed establishes that older care recipients are mutually involved in care relationships. Care recipients demonstrate reciprocity in care arrangements, develop relationships with formal care providers and family/friend caregivers, reinterpret independence and dependence, and practise self-care while they are receiving care from others. Care is not a one-directional process, but rather is mutually constructed by care recipients and providers alike—an insight that adds important nuance to sociological and feminist conceptualizations of care. Yet, as I will explain below, there are some gaps in the literature regarding (1) how older people negotiate the intersections of formal home care and family/friend caregiving; (2) how practices of self-care intersect with formal home care and family/friend caregiving; and (3) how age relations shape (and are shaped by) experiences and negotiations of care.

***Gaps in the literature: The intersections of formal home care, family/friend caregiving, and self-care***

As the literature reviewed above establishes, older people who receive care at home develop relationships with family members and friends, as well as with formal home care workers (e.g., Coeling et al., 2003; Mahmood & Martin-Matthews, 2008; McGarry, 2009; McGraw & Walker, 2004). Sociologists and gerontologists have long been concerned with the relationship that exists between formal home care and family/friend caregiving and have developed several models that address how the receipt of formal home care impacts on family/friend caregiving, and vice-versa (Cantor, 1979, 1991; Chappell & Blandford, 1991; Greene, 1983; Litwak, 1985; Kemp et al., 2013; Ward-Griffin & Marshall, 2003). Yet, these models rarely consider how *older care recipients themselves* negotiate the intersections of these systems of care (but see Allen & Ciambrone, 2003; Porter, 2005; Porter, Ganong, Drew, & Lanes, 2004). Further, while research establishes that older people continue to practise self-care while they receive care from others (Penning, 2002), we know very little about the ways self-care practices intersect with formal home care and family/friend caregiving. In the following section I will review extant models of the relationship between formal home care, family/friend caregiving, and self-care, and describe the very limited research that considers care recipients' positioning at the intersections of these systems of care. I will then suggest questions that could usefully address gaps in extant research, to give insight into older people's experiences at the intersections of formal home care, family/friend caregiving, and self-care.

*The relationship between formal home care and family/friend caregiving*

Scholars have developed several models to better understand the relationship between formal care and family/friend caregiving; these are outlined in Table 1. As Ward-Griffin and Marshall (2003) explain, some conventional models reflect the interests of service providers and aim to show how family members might effectively complement formal care to reduce health care costs (e.g., Chappell & Blandford, 1991; Greene, 1983). Other models are more critical and shed light on inequalities in care provision and on the invisibility of the care provided by (mostly female) family members (Kemp et al., 2013; Ward-Griffin & Marshall, 2003).

**Table 1: Models of the relationship between formal and family/friend caregiving**

Conventional models	Critical models
<i>Hierarchical compensatory</i> : preference for family care, ordered by primacy of relationship (Cantor, 1979, 1991).	<i>Socialist-feminist</i> : gender dynamics shape transfer of care tasks from formal to family care providers (Ward-Griffin & Marshall, 2003).
<i>Substitution</i> : formal care leads to decline in family care (Greene, 1983).	<i>Convoys of care</i> : various individuals (including care recipients) negotiate care relationships in socially structured contexts (Kemp et al., 2013).
<i>Task specificity</i> : formal and family/friend caregivers perform distinct tasks (Litwak, 1985).	
<i>Complementary</i> : Formal care supplements (but does not replace) family care (Chappell & Blandford, 1991).	

The four predominant ‘conventional’ models date back several decades, and examine the partnerships and division of labour between formal and family/friend care providers (Ward-Griffin & Marshall, 2003). The hierarchical compensatory model



(Cantor, 1979, 1991) suggests a preference for spousal care followed by care from children or other relatives, with formal care only replacing kin care when family or friends are unavailable. The substitution model (Greene, 1983) posits that formal care results in a decline in family/friend care. The task specificity model (Litwak, 1985) suggests that formal and family/friend care providers perform different tasks, and that the nature of the task determines the source of care. Finally, the complementary model (Chappell & Blandford, 1991) finds that formal care supplements—but does not replace—family/friend caregiving, and that it is typically used when care recipients' needs exceed the caring capacities of family or friends. While there is limited empirical support for the first three models (Ward-Griffin & Marshall, 2003), several studies support the complementary model (Chappell & Blandford, 1991; Davey & Patsios, 1999; Denton, 1997; Penning & Keating, 2000; Penning, 2002).

Critics argue that these 'conventional' models are out-dated and are limited because they consider formal and family/friend care as distinct, rather than intersecting, systems; assume the effectiveness of partnerships between formal care providers and family/friend caregivers; neglect the gendered dynamics of caregiving (Ward-Griffin & Marshall, 2003); and do not account for the full array of systems and individuals involved in care arrangements (Kemp et al., 2013). The emphasis on family care as preferable to formal care may also reflect the priorities of professionals and policymakers—who work in a context that tends to focus on cost reduction—rather than the interests of caregivers (Ward-Griffin & Marshall, 2003) or care recipients (Kemp et al., 2013).

In alignment with the criticisms raised above, two critical approaches have emerged more recently and consider the interpersonal dimensions of formal and family/friend care relationships in socio-structural contexts. First, Ward-Griffin and Marshall's (2003) socialist-feminist model views "female caregiving as highly skilled emotional, mental, and physical work that crosses "public and private" boundaries (204). Ward-Griffin and Marshall's (2003) framework recognizes the interlinkages between public and private spheres, the gender dynamics and power relations involved in care work, and the ways political, social, and economic circumstances, such as cutbacks to services in a market-modeled system, shape the distribution of care work (Ward-Griffin & Marshall, 2003; see also Neysmith, 1998, 2000). Importantly, this model captures the socio-structural contexts in which nurses and family caregivers negotiate relationships.

Empirical research that uses the socialist-feminist model finds that complex intersections exist between formal and family caregiving. Nurses and family caregivers often develop dynamic relationships that change over time, and nurses' tasks are often transferred to family caregivers (Ward-Griffin & Marshall, 2003; Ward-Griffin & McKeever, 2000). While Sims-Gould & Martin-Matthews (2010b) do not use the socialist-feminist model explicitly, they similarly consider how family caregivers "share the care" with formal care providers. Examples are when family caregivers prepare meals in advance of formal care providers' visits, or when formal care providers leave notes for family caregivers (Sims-Gould & Martin-Matthews, 2010b, 417).

The second critical model suggests that formal and family/friend care providers and care recipients are all involved in "convoys of care" (Kemp et al., 2013). This model

builds on Kahn and Antonucci's (1980) "convoy model of social relations," which suggests that convoys, or dynamic networks of personal relationships, are mechanisms for distributing and exchanging social support. A convoy of care includes all of the people, including formal and family/friend caregivers, who provide a care recipient with health care, socio-emotional support, monitoring, advocacy, and help with activities of daily living and instrumental activities of daily living. Convoy members can change over time and "may or may not have close personal connections to the recipient or to one another" (Kemp et al., 2013, 18). Structural and environmental characteristics of the care setting; power dynamics associated with gender, class, race/ethnicity, health, and age; and the personal characteristics of convoy members all influence the relationships among people who are involved in care activities. In the convoy of care model, individuals directly involved in care relationships, *including recipients*, are conceptualized as active participants who engage in negotiations in socio-structural contexts.

Despite these advances in critical understandings of the relationship between formal home care and family/friend caregiving, care recipients' voices are still largely neglected. As Ward-Griffin and Marshall (2003) acknowledge, their socialist-feminist model overlooks the ways care recipients influence caregiving relationships and transfers in care tasks. Like some other feminist models of caregiving, it tends to separate care providers from recipients, and perhaps inadvertently, may position older people who require care as passive, dependent consumers of care (Barry, 1995; Fine & Glendinning, 2005; Lloyd, 2000). Kemp et al.'s (2013) convoy of care model, more promisingly, conceptualizes care recipients as engaged and involved in care arrangements. This model

provides a framework for considering the socio-cultural and structural contexts that frame the intersections between systems of care, as well as individuals' interactions as they engage in care relationships. To date, however the convoy of care model is primarily theoretical, and has been applied to research on assisted living in the United States—a context that differs substantially from that of home care in Canada (Kemp et al., 2013; Perkins et al., 2013). Kemp et al. (2013) acknowledge that more research is necessary to discern the properties and outcomes of convoys of care in different settings, including the home and community care setting.

Although the majority of research on the relationship between formal and family/friend care tends to focus on care providers rather than care recipients, there are a few notable exceptions that begin to give insight into care recipients' negotiations at the intersections of these systems of care (Allen & Ciambrone, 2003; Porter, 2005; Porter et al., 2004). Broadly, this research suggests that the constructs of “formal” and “informal” (i.e., family/friend) care are artificial, and may not reflect care recipients' actual experiences. Notable here is Porter and colleagues' phenomenological study, which investigated older widows' classifications of help from various sources (Porter, 2005; Porter et al. 2004). Rejecting the “formal/informal” dichotomy, Porter et al. (2004) suggest a new typology based on qualitative interviews with older widows who received care in their homes: the regular helper, the can-will doer, the on-call helper, and the mainstay.

While Allen and Ciambrone's (2003) critique of the task specificity model (Litwak, 1985) does not focus specifically on older people, it also gives insight into care

recipients' negotiations of formal home care and family/friend caregiving. Based on research with care recipients themselves, Allen and Ciambrone (2003) find that formal care providers sometimes take responsibility for needs that are typically met by family members or friends such as emotional support, while family members sometimes take on traditionally "formal" roles, such as that of case manager. These findings counter the task specificity model, and specifically the assertion that there is a clear division of labour between formal and family/friend care.

Beyond this limited research, however, we know very little about the strategies or processes through which older care recipients negotiate the intersections of formal home care and family/friend caregiving. For example, do older care recipients conceive of formal home care and family/friend caregiving as distinct or intersecting systems? Why and how do they negotiate the relationship between formal home care and family/friend caregiving? Since older care recipients are located at the intersections of formal home care and family/friend care, it is surprising that scholars do not consider more fully how care recipients negotiate between these systems of care.

*The relationship between practising self-care and receiving care*

The fact that older people who receive care also do many things to care for themselves further complicates the relationship between formal and family/friend care. Yet, while research establishes that older care recipients continue to practise what is known as "self-care" (Ball et al., 2004; Cox & Dooley, 1996; Penning, 2002), there is very little knowledge of the intersections that exist between older care recipients' self-care practices and the formal home care and family/friend caregiving that they receive.

Studies that consider the relationship between receiving care and practising self-care tend to be one-directional because they focus primarily on the conditions that influence self-care practices. For example Kemp et al.'s (2013) "convoy of care" model identifies various factors that influence the self-care practices of residents in assisted living, including "facility staffing levels, staff training, and adherence to care schedules and standards, family support, and residents' ability to perform and manage care tasks, as well as their attitudes and values and financial resources" (22). Similarly Penning (2002) primarily considers the impacts of formal care on self-care practices. Little research, however, explores how care recipients' self-care practices shape, and are shaped by, the intersecting systems of formal home care and family/friend caregiving. To be sure, some research—although it does not explicitly name "self-care"—does consider the activities that older care recipients do to demonstrate their involvement in care relationships (Holmberg et al., 2012; Janlöv et al., 2005), and could potentially give insight into the ways self-care practices might shape the receipt of care from others. Still, however, it is necessary to consider how older care recipients' self-care practices intersect with formal home care and family/friend caregiving. For example, do care recipients consider their self-care practices to be separate from formal home care and family/friend caregiving, or do they consider their self-care practices to be embedded in these other systems of care? Finally, what do these self-care practices mean to care recipients, in the context of intersecting systems of care?

*Age relations and receiving care*

In addition to practical gaps in the literature on care recipients' negotiations at the intersections of family/friend caregiving, formal home care, and self-care, there is a broader theoretical limitation: we know very little about the implications of age relations for experiences and negotiations of care. Many studies on receiving care in later life, such as those noted in this literature review, take chronological age for granted as a physiological characteristic, or as the basis for eligibility and access to services (e.g., Coeling et al., 2003; Holmberg et al., 2012; Roe et al., 2001). Some studies do briefly consider the links older people make between needing care and subjective perceptions of old age (Allen & Wiles, 2014; Hammarström & Torres, 2010; Janlöv et al., 2005). For example, Allen and Wiles (2014) find that older people consider care needs to be an expected part of aging, and also equate the receipt of care with being old—that is, they assume that needs for support characterize a person as “old,” regardless of chronological age. Yet, within the literature on receiving care in later life, scholars rarely explicitly name age relations—as social relations of power, privilege, and disadvantage—that have implications for meanings and experiences of later life care, and they rarely articulate how individuals experience and respond to age relations in the context of care. The lack of explicit attention to age relations in the literature on home and community care is surprising because so much of the research focuses on later life; a life stage that tends to be associated with exclusion from various rights and privileges (Calasanti, 2003; McMullin, 2009). Situations of care involve relations of power, dependency, and control between and among people of different ages. Thus, care arrangements are likely sites

where individuals experience and respond to age relations—as they are produced and sustained through social processes, cultural discourses, and everyday practices.

### ***Research questions***

To address the gaps in extant research noted above, this thesis considers the following questions:

- 1) *How do older people who are receiving care negotiate between formal home care and family/friend caregiving?* How does an investigation of older people's experiences of receiving care impact our understanding of the intersections of formal home care and family/friend caregiving?
- 2) *How do older people who are receiving care from others practise self-care? How do practices of self-care intersect with formal home care and family/friend caregiving?* How does an investigation of older people's self-care practices impact our understanding of the intersections between systems of care?
- 3) *How can the concept of age relations be used to understand older people's experiences of care? How do older people experience and respond to age relations when they are practising self-care, and receiving formal home care and family/friend caregiving?*

### ***Summary***

To situate this thesis in a substantive context, this chapter has reviewed and identified sociological and gerontological perspectives on caregiving and on receiving care. An extensive body of literature exists on care and caregiving, and much of this literature is based on feminist perspectives on care. These feminist perspectives have, importantly, advanced research on the conditions and contexts of caregiving, but critics have argued that the focus on caregiver stress and burden tends to obscure the voices of older people and people with disabilities who are in need of care (Barry, 1995; Calasanti & Slevin, 2006; Morris, 1995, 2001). Researchers have therefore engaged with care recipients directly to give older care recipients a voice, and to challenge the somewhat



one-directional views of care relationships that emerged from some earlier feminist literature. Notably, research finds that care recipients are reciprocally involved in care arrangements; develop and negotiate relationships with care providers; re-interpret independence and dependence in light of care needs; and finally practise self-care at the same time as they receive care from others. This research highlights care recipients' agency and mutual involvement in care relationships, and therefore adds important insight into sociological and feminist literature on care.

Although previous literature engages with older care recipients directly and accounts for their involvement in care arrangements, I have identified some gaps in extant research. Practically, we know little about care recipients' positioning and strategies of negotiation at the intersections of formal home care, family/friend caregiving, and self-care. For example, considerations of how older people develop relationships with family caregivers are useful, but could be enriched through an analysis of the ways care recipients negotiate between these family caregiving arrangements and the receipt of formal home care. Likewise, knowledge of the relationship between self-care and receiving care could be enriched through a more comprehensive analysis of the multi-directional intersections that exist between self-care, formal home care, and family/friend caregiving—rather than simply considering the factors that impact on older people's self-care practices.

Theoretically, although so much literature on receiving care focuses on older people in particular, scholars who write about home and community care rarely explicitly name age relations, or articulate their implications for experiences of receiving care. I

suggest that this tendency to only consider age relations implicitly—or in some cases, to overlook them entirely—limits both theoretical and practical understandings of later life care and of age relations. A lack of explicit attention to age relations limits our ability to fully appreciate how relations of power, privilege, and disadvantage between and among people of different ages are implicated in experiences and negotiations of later life care. In this thesis, I draw on interviews with 34 older people receiving care at home to build on and expand the research presented in this literature review. In the following chapter I will describe the interpretive grounded theory methodology that I used to gather and analyze data for this study.

## **Chapter Four: Methodology**

### ***An interpretive grounded theory study of older people's experiences of self-care, family/friend caregiving, and formal home care***

#### ***Introduction***

This thesis examines older people's negotiations of formal home care, family/friend caregiving, and self-care, in the context of age relations. I used an interpretive grounded theory methodology to gather and analyze data for this study. This was an ideal methodological framework because it enabled me to gather data on participants' actions and interactions, and to consider how broader social conditions and contexts framed their experiences.

In this chapter, I outline the methodological framework and research design that I used for this study. To begin, I explain the main premises of grounded theory (Glaser & Strauss, 1967), with a focus specifically on the interpretive variants of grounded theory that informed my research design (Charmaz, 2006; Corbin & Strauss, 2008). Following this I outline the *intensive interviewing* technique that I used to gather data (Charmaz, 2006), and I discuss the logistics of the study including ethics, recruitment, eligibility, and the interview process. I provide a profile of interview participants, and address my efforts to achieve theoretical saturation. I then consider my positioning as a researcher—including my past experiences, reflections on fieldwork, and power imbalances that arose during interviews—to provide a reflexive account of the research process. Finally, I outline the procedures that I followed to analyze findings (including open, axial, and selective coding), and the measures I took to ensure the validity of my analysis. As I argue throughout this chapter, interpretive grounded theory enabled me to develop rich

conceptual understandings of participants' experiences of care and negotiations of age relations.

### ***Interpretive grounded theory***

Grounded theory is a methodological framework that provides guidelines for developing formal theories based on a systematic analysis of empirical data. Glaser and Strauss originally developed this methodology in their classic text, *The Discovery of Grounded Theory* (1967). Glaser and Strauss (1967) presented grounded theory as an inductive methodology, in contrast to the deductive approaches that were common in sociology in the mid-twentieth century. With deductive approaches, researchers are concerned with testing pre-conceived theories. Grounded theorists, by contrast, use empirical data to generate theoretical concepts that 'fit' (are applicable to) and 'work' (are relevant to) the empirical settings under investigation (Glaser & Strauss, 1967).

Grounded theory is rooted in two theoretical traditions in the social sciences. Based on his training at the University of Chicago, Strauss drew on pragmatist philosophy and interactionist sociology to develop grounded theory. Glaser was trained at Columbia University, and he integrated multivariate analysis into grounded theory (LaRossa, 2005). Since its inception, however, multiple versions, understandings, and uses of grounded theory have emerged (Oleson, 2007). On the one hand objectivist versions of grounded theory, following Glaser's positivist leanings, view data as "real in and of themselves" and seek to develop deterministic predictions and explanations of a universal reality (e.g., Glaser, 1978, cited in Charmaz, 2006, 131). On the other hand, more recent interpretive and constructivist versions of grounded theory, rooted in pragmatist philosophy and

interactionist sociology, emphasize understanding rather than explanation; view data as situated, social constructions that emerge throughout the research process; and acknowledge the existence of multiple realities (Charmaz, 2006; Corbin & Strauss, 2008).

My use of grounded theory aligns much more closely with interpretive and constructivist approaches, and with the interactionist tradition in sociology. To provide a theoretical grounding for my approach, I will briefly outline the assumptions of pragmatist and interactionist theory. Pragmatist philosophers, notably Mead and Dewey, argued that people are self-conscious, interactive beings and that theories and methods in the social sciences should attend to the empirical realities of human behaviour (Pawluch & Neiterman, 2010). At the University of Chicago, Blumer (1969) drew on pragmatist philosophy to develop symbolic interactionism, a sociological theory and method that aims to make sense of individuals' actions, interactions, and interpretations of meaning. The main premise of symbolic interactionism is that individuals assign meaning to other people, to themselves, and to objects through micro-processes of action and interaction. From this perspective, social interaction is only possible because groups of people negotiate the meaning of gestures and language. When people interact with others they collectively make sense of, and may change, the world around them (Blumer, 1969). At the same time, people act and interact within the context of existing social conditions. Symbolic interactionism therefore provides a theoretical basis for linking social interaction at the individual level, with the conditions and structures that exist at the broader societal level. Corbin and Strauss (2008) usefully explain the underlying tenets of interactionism as follows:

Important to us are the great varieties of human action, interaction, and emotional responses that people have to the events and problems they encounter. The nature of human responses creates conditions that impact upon, restrict, limit, and contribute toward restructuring the variety of action/interaction that can be noted in societies. In turn, humans also shape their institutions; they create and change the world around them through action/interaction (6).

Drawing on interactionist sociology, constructivist and interpretive grounded theorists “study *how*—and sometimes why—participants construct meanings and actions in specific situations” (Charmaz, 2006, 130, emphasis in original). Here interpretive grounded theorists emphasize social context:

We realize that, to understand experience, that experience must be located within and can’t be divorced from the larger events in a social, political, cultural, racial, gender-related, informational, and technological framework and therefore these are essential aspects of our analyses (Corbin & Strauss, 2008, 8).

Methodological approaches may evolve over time, and interpretive or constructivist grounded theory builds on and differs from Glaser and Strauss’s (1967) original formulation of grounded theory in two important ways. First, grounded theorists originally accepted the objective “truth” or “reality” of the researcher’s findings. By contrast, the constructivist viewpoint is that research itself is a process of social construction, thus “concepts and theories are *constructed* by researchers out of stories that are constructed by research participants who are trying to make sense out of their experiences and/or lives, both to the researcher and to themselves” (Corbin & Strauss, 2008, 10). Through this process data are *co-created* by researchers and participants, in social contexts. This means that our understanding of reality is interpretive rather than objective (Oleson, 2007). Second, while Glaser and Strauss (1967) emphasized that

grounded theorists should develop formal theories of social processes, interpretive methodologists recognize that this approach may be used to develop thick descriptions or conceptual understandings, and need not necessarily result in the production of a formal theory (Corbin & Strauss, 2008).

Following the premises of interpretive grounded theory, I acknowledge that the findings presented in this thesis are constructed through my interactions with participants and my interpretation of data, and that context is very significant for older people's negotiations and experiences of care. I use grounded theory to develop substantive concepts that provide an interpretive understanding (albeit partial) of the experiences of older care recipients as they receive formal home care and family/friend caregiving, and as they practise self-care. I also aim to connect the micro conditions of participants' everyday experiences of care with "the macro or larger socio, political, and historical conditions that led to the more "immediate" set of conditions" (Corbin & Strauss, 2008, 230). Here I argue that *age relations* constitute a set of relevant—and often overlooked—social conditions, that are produced and sustained through social processes, cultural discourses, and everyday practices, and that can be used to understand the experiences of older care recipients. When I analyzed data, therefore, I treated age relations as a sensitizing concept (LaRossa, 2005) that had consequences for older care recipients' experiences and interpretations of meaning as they negotiate the intersections of self-care, family/friend caregiving, and formal home care.

In this thesis, I follow in the footsteps of other researchers who have used grounded theory to articulate people's everyday experiences of aging or age relations. For

example Utrata (2011), as previously mentioned, has used grounded theory to understand how single working mothers and caregiving grandmothers construct age and gender relations; Berger (Berger, 2009; McMullin & Berger, 2006) has used grounded theory to describe how older workers experience and manage age discrimination; and Hurd Clarke (Hurd Clarke, 2002; Hurd, 2000) has used grounded theory in her analysis of older women's experiences of body image and embodiment. This rich research has generated important insight into experiences of aging, and it has compelled me to use grounded theory to study older people's negotiations of care and of age relations. Having outlined the underlying assumptions and main tenets of grounded theory, I will now discuss the process that I followed to collect and analyze data for my study.

### ***Research design***

#### *Intensive interviews*

I used *intensive interviews* to gather data; a technique often used in grounded theory because it “permits an in-depth exploration of a particular topic or experience” from the perspectives of research participants (Charmaz, 2006, 25). Here interviews are understood as contextual and negotiated processes, in which researchers and participants reconstruct their subjective worlds (Charmaz, 2006). As Holstein and Gubrium (1995) similarly explain in their discussion of *active interviewing*, interviews are not just “a pipeline for transmitting knowledge,” but involve “meaning making practices on the part of both interviewers and respondents” (4).

In intensive interviewing, the researcher's role is “to listen, to observe with sensitivity, and to encourage the person to respond” (Charmaz, 2006, 25-26). Using a



semi-structured interview guide, I elicited participants' experiences of care through broad, open-ended questions on participants' self-care practices, needs for support, use of home care, relationships with family/friend caregivers, and feelings about aging (see Appendix A). I used a series of questions to guide the interviews but the structure was loose and conversational; enabling participants to share any information that they felt was relevant (Holstein & Gubrium, 1995). Participants often discussed their experiences of care within a broader life context; relating it to what else it enabled them to accomplish, their relationships with family and friends more generally, and their experiences of growing older. Throughout interviews I used probes to inquire further about specific viewpoints, practices, and experiences (i.e., asking participants to describe in more detail the dimensions, contexts, and meanings of responses). To obtain a demographic profile of participants I also asked questions about participants' age, place of birth, employment and education history, and marital status (see Table 2).

The interviews focused on participants' experiences and negotiations of care. Yet, "formal home care," "family/friend caregiving," and "self-care" can mean different things to different people. Throughout the interviews, I strove to treat participants as experts in their own experiences, and to privilege participants' understandings of care arrangements. It was necessary to clearly define "formal home care" to set eligibility criteria and to include in my sample people who were receiving some form of care at home on a long-term basis. In my interview questions, however, I avoided using terms such as "caregiving" and "self-care," and simply asked participants to tell me about the kinds of help they received from formal home care providers and from family or friends, and the

kinds of things they did to care for themselves. Where appropriate I probed further; for example I asked participants how they got along with the people who helped them; if there was ever overlap between what different people helped with; if there were things they wished they were getting more help with; and if there were specific reasons why they engaged in certain self-care practices. In line with a grounded theory approach, these questions and probes enabled me to ground my analysis and findings in participants' everyday experiences and realities.

### *Ethics*

Before I began recruiting interviews participants, I obtained ethics approval from the McMaster Research Ethics Board (see Appendix B). To recruit participants, I originally intended to send requests through e-mail list serves, post notices in community centres, and distribute brochures via home care case managers, to invite eligible participants to contact me. I recruited very few participants using these methods. After approximately two months, only one participant had responded to an e-mail request, and none had responded to flyers or brochures that were posted in community centres or distributed via case managers.

To recruit more participants, I obtained two ethics amendments (see Appendix B). The first amendment enabled me to present my research at places where potential participants gather, such as seniors' social and support groups. At these events I invited interested participants to leave their contact information on a sign-up sheet. I then telephoned participants at a later date to schedule an interview. The second ethics amendment enabled a research associate working at one home care agency to telephone

clients, inform them of my study, and ask their permission for the research associate to pass their contact information to me. I then telephoned these clients to give more information about the study and to schedule an interview with those who were interested. I obtained ethics approval from the Toronto Central Community Care Access Centre, in addition to McMaster University, for this method of recruitment.

Prior to each interview participants read and signed an informed consent form, and I clarified any concerns that they had about the research process (see Appendix C). I informed participants that taking part in an interview would have no effect on the home care services they received, that I would keep all information confidential, and that I would use pseudonyms and remove any identifying information to protect their identity after the interview was complete. I stored all of the participants' information on a password-protected personal computer, and I kept signed consent forms in a secure room in my home.

### *Eligibility*

The participants that I recruited for interviews were 65 and older, lived in the Greater Toronto and Hamilton Area, and received formal home care services for on-going support with daily activities such as bathing, dressing, housework, or medical care. This included nursing care, personal care, or help with household tasks provided by a home care agency (not a housekeeper hired solely for cleaning help). While transportation and meal delivery services, such as Meals on Wheels, are certainly important to many older people living in their own homes, I excluded people who were receiving *only* these services because I was most interested in the relationships and interactions that develop

over time as older people negotiate care arrangements in their homes. That said, many participants in my study used transportation and meal delivery services in addition to personal or nursing care.

This study focused on the experiences of individuals who are living with chronic health conditions and impairments in later life, and tend to fall into the social category of the “fourth age.” Therefore, I excluded people who were receiving formal care on a short-term basis (less than two months) for acute conditions. I also excluded people with dementia or cognitive limitations due to ethical concerns with regards to their ability to understand the interview process and provide informed consent. With these broad criteria in place, I aimed to gather a sample of older care recipients with diversity in terms of gender, class, race/ethnicity, sexuality, living environment, and health status or level of physical impairment.

### *Recruitment*

There are several challenges associated with recruiting older people who are receiving home care. It may be difficult to recruit older care recipients in public spaces because many of them may spend much of their time at home. Add to this that some older care recipients may be unable or unwilling to participate in an interview due to poor health, or may already have many health-related appointments and multiple care providers entering their home—leaving them with little time or energy to meet with a researcher. To gain a sufficient sample of participants it was necessary to recruit through various means, including: presenting at seniors’ groups and day programs; a research associate contacting clients directly; seniors’ ministries at religious institutions contacting

members; home care case managers and supervisors distributing brochures; posting flyers in seniors' housing and community centres; distributing information to potential participants at a caregiver exhibition; Meals on Wheels drivers distributing brochures; sending an e-mail through an LGBT seniors' mailing list; and word of mouth (see Table 2 for a break-down of participants recruited by each of these methods, and Appendix D for recruitment instruments). Using such varied recruitment strategies was valuable because it enabled me to gather participants with diverse experiences of care, living situations, and health conditions or impairments.

**Table 2: Recruitment methods**

<b>Recruitment method</b>	<b>Number of participants recruited</b>
Seniors' social and support groups (attended 5)	12
Telephone calls to clients from a home care agency research associate	7
Brochures and flyers distributed by home care case managers and supervisors	4
Seniors' ministries at religious institutions	3
Caregiver exhibition	3
Flyers posted in community centres	1
Brochures distributed by Meals on Wheels drivers	2
Senior LGBT e-mail list serve	1
Word-of-mouth	1
Total	34

*Summary of interview process*

Grounded theorists often conduct between 20 and 60 interviews to achieve sufficient variation in responses (Creswell, 2013), and following this recommendation I interviewed 34 participants. Interviews took place in participants' homes, with the exception of two that I conducted by telephone at participants' requests. Interviewing

people in their homes gave important context for data because it enabled me to directly observe the spaces where participants negotiate care relationships.

I conducted most interviews with individual care recipients. Family members or care workers were sometimes in the home and occasionally entered the room during interviews, but they typically respected our privacy as we conducted the interview. In one case a married couple participated in an interview together. While Joe, the husband, was technically allotted home care, his wife Fannie also used and benefitted from these services. Therefore, I considered both Joe and Fannie to be “care recipients.” In three cases family members participated in the interview and assisted with providing answers at participants’ request. I included data from family members in my interview analysis, but identified these participants as family members rather than care recipients. Where I felt that data from a family member accurately reflected the participant’s viewpoint, based on my interpretation of the interview as a whole, I used it as point of entry into the care recipient’s experience.

I conducted two interviews that I chose to exclude from data analysis. Both participants were referred to me from a seniors’ ministry at a church and agreed to participate in interviews when I telephoned them. In one case, it became very clear throughout the interview that the participant did not understand the questions being asked or the purpose of my being there. I suspect that she had dementia and may not have understood the informed consent process. In the other case, after the interview began I learned that the participant had received short-term home care in the past but was no

longer receiving these services, and therefore was ineligible for the study. I ended both of these interviews early and destroyed the data collected.

The 34 interviews that form the basis for this study lasted between 21 minutes and two hours, with the average length being 56 minutes. With participants' consent, each interview was audio-recorded and professionally transcribed. Immediately following each interview, I copied recordings to my password-protected computer and then deleted them from the audio-recorder. I shared the interviews with a professional transcriptionist, but she had no access to participants' personal information.

#### *Profile of participants*

Of the 34 participants included in my sample (see Table 3), 26 (76.4%) were women and eight (23.5%) were men. Participants ranged in age from 65 to 100, with the average age being 81. All participants were White. While 21 (61.8%) were born in Canada, 11 (33.3%) had migrated from various parts of Europe and two (5.8%) had moved to Canada from the United States. All participants lived in the Greater Toronto and Hamilton Area. Living environments varied: 19 (55.8%) of participants lived in houses or condominiums that they owned; five (14.7%) lived in subsidized seniors' housing; four (11.8%) lived in privately rented apartments; and another four (11.8%) lived in assisted living or retirement communities. Finally one participant lived in subsidized public housing, and one other lived in an attendant care building for people with disabilities.

Participants had varying levels of support from family and friends. The majority of participants, 21 (61.8%) were widowed, divorced, or never married and lived alone,

while seven (20.6%) lived with spouses or partners, and four (11.8%) lived with adult children. One participant lived with a niece, and one other with a live-in home care worker. Some participants discussed very positive relationships and received consistent, high levels of support from family and friends, while others had very few family members or friends who helped them, and sometimes had experienced conflicting or abusive relationships with family. Varied living environments and care relationships gave important insight into diverse contexts, arrangements, and negotiations of care.

Participants in this study were from diverse class backgrounds. While 20 (58.8%) had some university or college education, six (17.6%) had graduated from high school, and eight (23.5%) had never completed high school (see Table 2).<sup>7</sup> Living environments varied: 19 (55.8%) of participants lived in houses or condominiums that they owned; five (14.7%) lived in subsidized seniors' housing; four (11.8%) lived in privately rented apartments; and another four (11.8%) lived in assisted living or retirement communities. Finally one participant lived in subsidized public housing, and one other lived in an attendant care building for people with disabilities.

Participants' health problems or impairments were complex and diverse. Three quarters of participants ( $n=26$ ) had developed increased needs for care or health problems in later life. Heart conditions, chronic pain, arthritis, and diabetes were some of the more common health problems among participants. One quarter of participants ( $n=8$ ), however, had long-term disabilities and chronic health conditions that began earlier in life (roughly

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<sup>7</sup> Of the eight participants who had never graduated from high school, three of them experienced disruptions to their education due to war—pointing to the importance of considering how historical contexts shape life course experiences, including educational attainment and subsequent opportunities.



before the age of 60), ranging from cerebral palsy to Parkinson's disease to HIV. In later life, these participants had increasing care needs because these conditions were worsening and sometimes intersecting with other health problems, leading to co-morbidity.

While all participants had some health problems or impairments, their use of formal home care varied: some used it for household tasks such as cleaning and cooking, while others needed help with personal tasks like bathing and dressing. Others still received home nursing care for wound care, injections, or administering suppositories. Participants received formal care from various sources: the majority of participants ( $n=30$ ; 88.2%) had undergone assessments by Community Care Access Centre case coordinators and were deemed eligible for publicly funded home care services. Of these 30 participants, five paid for some home care privately, in addition to receiving publicly funded home care. Three participants (8.8%) used only formal home care for which they paid privately.

**Table 3: Demographic profile of participants**

Pseudonym	Gender	Age	Marital Status	Country of origin	Education	Work history	Living situation	Type of formal care (public/private)	Main source of family/friend caregiving
Alice	F	92	Widowed	Canada	College	Secretary, stay-at-home mother	Alone in apartment	Public	Son, granddaughter, some friends occasionally
Andy	M	75	Married	Holland	University	Engineer	With wife in condominium	Public	Wife
Angela	F	65	Single, never married	Canada	University	Nurse	Alone in apartment in retirement community	Public	None
Anne	F	100	Widowed	United States	Some university	Philanthropist	Alone in condominium	Private	Friend's daughter occasionally
Beth	F	82	Widowed	Canada	College	Nurse	Alone in apartment	Public	Nieces, sister-in-law, friends occasionally
Carol	F	98	Widowed	England	High school	Stay-at-home mother, volunteer	Alone in apartment in retirement community	Public	Daughter
Celia	F	71	Widowed	Italy	Some high school	Factory work, retail	Alone in house	Public	Sister, neighbours, daughter and son

Pseudonym	Gender	Age	Marital Status	Country of origin	Education	Work history	Living situation	Type of formal care (public/private)	Main source of family/friend caregiving
David	M	82	Widowed	Scotland	Some college	Communication technician	Alone in house	Public	Daughters
Diana	F	79	Single, never married	Canada	University	Financial industry	Alone in apartment	Public	Friend
Donald	M	70	Single, never married	Canada	Some high school	Unemployed due to disability, some work in office	Alone in apartment in subsidized seniors' housing	Public	Family occasionally
Doris	F	78	Divorced and widowed	Canada	Elementary school	Factory work, housekeeper, server	Alone in apartment in subsidized seniors' housing	Public	Daughter occasionally
Earl	M	92	Widowed, now lives with partner	Hungary	Some college	Draftsman	With partner in condominium	Public	Intimate partner, daughter, son.
Ellen	F	89	Married	Canada	High school	Beautician, dance instructor	With husband in house	Public	Husband, daughter occasionally
Fannie	F	83	Married	Hungary	Some high school	Stay-at-home mother	With husband in condominium	Public and subsidized private	Daughter and son occasionally
Hannah	F	90	Single, never married	Germany	High school	Government administration	Alone in house	Public	Neighbour occasionally
Ingrid	F	91	Widowed	Estonia	Some high school	Custodian	With daughter in condominium	Public and private	Daughter
Joe	M	89	Married	Czech Republic	Some high school	Store owner	With wife in condominium	Public and subsidized private	Wife; daughter and son occasionally
Josie	F	82	Widowed	United States	College	Secretary	Alone in apartment in subsidized seniors' housing	Public	Daughter
Judy	F	75	Divorced	Canada	Some elementary school	Did not specify; some unemployment	With son in apartment in subsidized seniors' housing	Public	Son
Pseudonym	Gender	Age	Marital Status	Country of origin	Education	Work history	Living situation	Type of formal care (public/private)	Main source of family/friend caregiving
Kate	F	77	Divorced	England	University	Social worker	With daughter and granddaughter in house	Subsidized private	Daughter
Lise	F	81	Widowed	Germany	College	Factory work, accountant	Alone in apartment in retirement community	Public	Daughter and son-in-law
Louisa	F	74	Divorced	Canada	Some university	Financial analyst	With son in apartment	Public	Son
Maggie	F	89	Widowed	Canada	College	Secretary, housekeeper	Alone in house	Public	Daughters and sons-in-law
Marion	F	89	Widowed	Canada	University	Doctor	Alone in condominium	Private	Sister, daughters and son
Martha	F	67	Divorced and widowed	Canada	Some high school	Stay-at-home mother, call centre	Alone in apartment in subsidized	Public	Daughter

housing									
Pseudonym	Gender	Age	Marital Status	Country of origin	Education	Work history	Living situation	Type of formal care (public/private)	Main source of family/friend caregiving
Norah	F	68	Single, never married	Canada	College	Early childhood educator	Alone in apartment in attendant care building	Public	Friends
Phillip	M	84	Married	Canada	High school	Owner of construction company	With wife in condominium	Public and private	Daughter
Ray	M	66	Common-law partner	Canada	University	Interior decorator, music producer, disc jockey	With partner in house	Public	Intimate partner
Robert	M	89	Married (wife lives in long-term care)	Canada	High school	Steel mill worker	With niece in house	Public	Niece
Rosa	F	93	Widowed	Canada	Elementary school	Factory work, retail	Alone in apartment in retirement home	Public	Daughter
Ruth	F	73	Single, never married	Canada	University	Teacher, president of computer company	Alone in condominium	Public	Friends
Sarah	F	68	Divorced	Canada	University	Dental hygienist	Alone in condominium	Public	Son and daughter-in-law
Suzanne	F	80	Divorced	Canada	University	Actress, activist	With live-in care worker in house	Public and private	None
Yolande	F	72	Divorced	Canada	Some university	Truck driver, singer, waitress, owned convenience store	Alone in apartment in subsidized seniors' housing	Public	None

### *Saturation*

Following the tenets of grounded theory I strove to complete a sufficient number of interviews to achieve theoretical saturation, which refers to the point at which additional data cease to provide new insights into emerging concepts and themes (Charmaz, 2006; Corbin & Strauss, 2008). I conducted analysis on an ongoing basis throughout data collection, and this enabled me to identify variations in the themes as I was developing them. I then tried to seek research participants whose experiences might

present further variations in these themes, and ultimately lead to theoretical saturation. For example, I noted that participants with the most severe or debilitating health problems had different experiences of care than those who seemed to be coping relatively well with physical impairments and health conditions. To gather more data on the experiences of people with particularly severe health problems, I distributed flyers and brochures at seniors' assisted living and retirement buildings (places where people with especially severe health conditions or disabilities might live). My efforts to achieve theoretical saturation were somewhat constrained, however, by my ability to access particular types of participants and their ability or willingness to take part in interviews. Participating might be especially difficult, for example, for people who are very sick. Add to this that individuals with cognitive impairments were ineligible for my study, which places limits on variation in the types of health problems that participants in my sample reported.

### *Reflexivity*

Interpretive grounded theorists recognize that researchers are not neutral and objective observers—rather, they are present and embedded in their studies, and both influence and are influenced by the research process (Corbin & Strauss, 2008; Oleson, 2007). Interpretive methodologists therefore encourage researchers to be *reflexive* to provide a better understanding of the processes through which findings are constructed. Reflexivity can involve “(1) full explanation of how analytic and practical issues were handled; (2) examination of the researcher’s own background and its influences on the research; and (3) reflections on the researcher’s own emotions, worries, and feelings” (Oleson, 2007, 423). In this section I will outline some key issues related to reflexivity in

my study, including my decision to study home care; the ways I experienced and negotiated power differentials during interviews; and my own reactions and emotions throughout the research process.

“Personal struggles and experiences offer an important touchstone for academic theorizing” (Twigg, 2004, 62). My decision to study home care is based in part on personal experience. My father passed away in 2006 after living with multiple sclerosis for seven years. Throughout the course of his illness (and my adolescence), home care workers were consistently present in my family’s home. Through first-hand experience, I observed the kinds of relationships that developed between my father and home care workers, as well as between home care workers and family caregivers (primarily my mother) and other family members (myself and my siblings). My reflections on my own experience, nine years later, would then influence my awareness of the issues that emerge as care workers enter the home space, as well as the potential benefits, conflicts and challenges that can arise between and among systems of care.

In addition to these experiences of home care within my family, I have also gained knowledge of some of the circumstances surrounding care arrangements through my volunteer work as a visiting companion with a seniors’ support agency. In this position I visited “Elizabeth,” a woman in her late nineties, on a weekly basis for two years. Elizabeth lived with her daughter and son-in-law and also received home care several times a week for help with personal care and housework. During our visits, Elizabeth would sometimes discuss her relationships with home care workers, and very frequently, her relationship with her daughter, a primary family caregiver. My time spent with

Elizabeth sensitized me to some of the issues that emerge between older people receiving home care, their home care workers, and family caregivers.

While I did not share my personal experiences with participants, the knowledge and perspectives that I gained when I observed my father's experiences and through my friendship with Elizabeth likely shaped my approach to the research and my interactions with participants in both positive and negative ways. On the one hand I believe that my personal experience was a benefit because it enabled me to ask appropriate questions with sensitivity and to engage in a rich and nuanced analysis of data. On the other hand, it is possible that I may have taken for granted and glossed over issues that seemed commonplace to me, but may have stood out to someone with less personal knowledge of home care.

"Relative differences in power and status" are implicated in the relationship between researchers and participants (Charmaz, 2006, 27). In my research, participants were in a relatively vulnerable position because of their chronic health conditions and impairments while I, as a young, able-bodied researcher entering their homes, was in a position of relative power. Power differentials also arose due to class positions: I am a well educated, middle-class White woman, while some of my research participants were from lower-class backgrounds and had little education. It is possible that some participants may have felt somewhat intimidated during the research due to these class differences and their limited knowledge of academic research. Other participants, however, were very comfortable taking part in the interview because they were well educated and familiar with the nature of research, and some (from varied class

backgrounds) had participated in research studies before. To mediate imbalances in power with all participants, and to ensure that participants did not feel as though they were talking to someone who held authority, I clearly positioned myself as a student. I strove to make it clear to participants that they were experts in their own experiences, and that *I* was learning *from them* throughout the interview. The interview enabled participants to share their stories, and some commented that the interview provided an important opportunity for social interaction.

My interactions with participants became complicated in the small number of cases where participants mistook me for a care provider and asked my advice; for example, on what kinds of exercises they should be doing or how to access more home care services. Such “researcher role conflict” is common in research with people who are receiving home care (Locher, Bronstein, Robinson, Williams, & Ritchie, 2006, 160). When this occurred I explained to participants that I was a student researcher and did not have knowledge on specific health practices, nor the capacity to provide them with more services. Where appropriate I provided participants with an information sheet with contacts for seeking home care and community services and others supports (see Appendix E).

Issues of power also arose in the three interviews where family members participated in the interview along with the participant. At times, family members seemed to speak on participants’ behalf, which could perhaps diminish the care recipients’ voice and sense of authority. To mediate this I engaged directly with the care recipient and directed questions toward them. Nevertheless, I do believe that it is important to include

data from family members in my analysis and findings. For reasons ranging from emotional distress to language barriers, these participants were not comfortable participating in an interview alone. Interviewing these participants *with* their family members enabled me to give a voice, albeit mediated, to those who would otherwise be left out of the research.

Intensive interviewing can be emotionally demanding, and our emotions no doubt impact on our experiences during research. In some cases conducting interviews was emotionally upsetting for me and for the participants as they shared difficult life experiences, including histories of abuse, deaths of family members, current challenges, and worries about the future. While I could not offer solutions to these struggles, I listened sympathetically and supportively, which I hope put participants at ease when they shared their experiences. In other cases, it was truly heartening to hear about the long lives well lived, strong family connections, happiness in the past and present, and optimism about the future.

To reflect on my reactions and emotions, I kept notes in the form of an interview log throughout data collection. Here I recorded notes on the context of the interview, any challenges or positive experiences I had during the interviews, and the ways in which I felt my presence shaped the interview process. I also noted the assumptions I would sometimes make after entering a participant's home—for example, I sometimes assumed that participants of lower-class backgrounds, who sometimes lived in what I considered to be unpleasant environments, might be less articulate in discussing their care arrangements. My class-based assumptions often turned out to be untrue. Recording them



enabled me to reflect on and correct personal biases, to ensure that they did not impinge on future interviews or on my analysis of data.

Establishing rapport and a sense of trust is necessary to gather rich data on participants' personal experiences. As Charmaz (2006) writes, "strong bonds build trust and foster open conversations with research participants about areas ordinarily left unspoken" (112-113). While participants generally openly and willingly shared their experience with me, I often found that it was easier to establish rapport and develop a sense of trust with those I had met in person—for example, at a seniors' group—prior to conducting the interview. Building trust was sometimes more challenging when I had not met participants before the interview, simply because we had not yet had the opportunity to develop a relationship. In these cases I found that it was helpful to have a brief, informal conversation with participants before I gave them the informed consent form. This enabled us to develop a greater sense of comfort as we conducted the interview.

### ***Data analysis***

#### ***Coding procedures***

Grounded theorists suggest guidelines for analysis that are especially useful because they are specific enough to provide the researcher with procedures to systematically and comprehensively analyze data, yet are flexible enough to enable the researcher to work through the data in ways that fit with specific research contexts. For example, grounded theorists recognize that different phases of coding may happen iteratively and dynamically, rather than one after the other (Charmaz, 2006; LaRossa, 2005). Following the principles of interpretive grounded theory, I conducted a rigorous,

in-depth, analysis of interview transcripts that involved open, axial, and selective coding. Open coding involved breaking the data apart to identify concepts; axial coding involved relating concepts to one another, and selective coding involved identifying the themes that were most central to my interpretation of data (Corbin & Strauss, 2008). Throughout these coding stages I engaged in a constant comparative analysis, wrote memos, and made diagrams. This analysis occurred throughout data collection: I analyzed each interview as soon as possible after having conducted it, which enabled me to develop ideas and questions to be raised in subsequent interviews.

Data analysis occurred in four stages. First, after the interviews were professionally transcribed, I read over entire transcripts while listening to the audio recording of the interview to ensure quality and completeness. Where possible I filled in and corrected any words that the transcriptionist had missed. I also read over any fieldnotes that I wrote after the interview to contextualize the transcript in relation to my experiences of the interview.

Second, using NVivo 10— a qualitative analysis software package to facilitate data storage and retrieval—I conducted open coding; described as “breaking data apart and delineating concepts to stand for blocks of raw data” (Corbin & Strauss, 2008, 195). I read each transcript very closely and developed a coding scheme based on the relevant categories and concepts that I identified in the interviews. I modified and expanded the coding scheme throughout open coding to reflect emerging ideas and variation in findings, sometimes adding codes, and sometimes collapsing two or more codes into one. I created broad codes (e.g., “family support”) and sub-codes (e.g., “amount of family

support,” “complaints about family support,” etc.) to capture the dimensions and properties of concepts and categories. My coding scheme was comprehensive such that *all* parts of the interview were assigned to at least one, and sometimes several, codes (see Appendix F for open coding scheme). Throughout this process I engaged in a comparative analysis to compare incidents coded in the same way for similarities and differences (Corbin & Strauss, 2008). For example, under the code “feelings of control over home care,” I compared incidents that gave insight into the ways different participants felt or acted “in control” of the home care they were receiving.

Third, I conducted axial coding to build “process” into the analysis; focusing on the contexts and contingencies of incidents within each code and on the relationship between codes. For example, did feelings of control over home care differ between participants who were paying privately for home care, in comparison to those who were receiving publicly funded home care? Axial coding also involved “crosscutting or relating concepts to each other” (Corbin & Strauss, 2008, 195). Here I focused specifically on certain categories that were becoming relevant—such as feelings of control over home care—and considered the contexts, contingencies, causes, and consequences of that category. To do this I developed a spreadsheet in Microsoft Excel, where I copied key sections of interview transcripts and recorded notes on the context next to them—“the *when, where, why*, and so on” (LaRossa, 2005, 847, emphasis in original). I focused explicitly on open coding first and then moved on to axial coding, but the two phases were somewhat iterative: if I developed ideas regarding process or context while

conducting open coding, I would record them to keep in mind while I later focused explicitly on axial coding.

Finally, during selective coding, I developed the main themes around which to construct my interpretation of participants' negotiations of formal and family/friend care—themes that were well connected to other findings and that got to the heart of participants' negotiation strategies. As I coded the data, I treated age relations as a sensitizing concept (LaRossa, 2005) that drew my awareness to relations of power, privilege, and disadvantage between and among people of different ages, and to the ways participants experienced and gave meaning to aging and growing older.

Throughout the coding process I wrote memos to track ideas with regard to the properties, dimensions, and variations in emerging concepts and to reflect on my interpretations of the data. Using NVivo 10 was particularly useful for doing this because I could easily connect memos with relevant codes. I also developed diagrams to depict the relationships between concepts and the contexts in which they emerged (see Figure 1, Chapter Five). I shared emerging ideas and diagrams with my supervisor, Dr. Margaret Denton, at monthly meetings throughout the data collection and analysis process. This was especially useful for talking out and gaining feedback on emerging ideas. I also read and re-read entire transcripts at various points as I coded the data to make sure that my interpretations truly reflected participants' viewpoints and experiences as a whole.

### *Validation*

Given that interpretive research is a social construction and is subject to multiple interpretations, it is impossible to conclude whether the analysis is entirely valid (i.e.,

“right” or “wrong”). Qualitative methodologists, however, suggest some guidelines for ensuring the accuracy of findings. Notably, Creswell (2013) outlines the following eight validation strategies: prolonged engagement and persistent observation; triangulation; peer review or debriefing; negative case analysis; clarifying researcher bias; member checking; rich, thick description; and external audits (250-251). Creswell (2013) suggests that researchers engage in at least two of these strategies to ensure the accuracy of findings. In this study, I have engaged in three validation strategies to ensure that my analysis is a fair and comprehensive representation of participants’ perspectives.

First, I engaged in *negative case analysis*, “[refining] working hypotheses as the inquiry advances” to consider cases that did not fit within broader themes that were emerging from the data (Creswell, 2013, 251). To ensure the overall validity of my study I accounted for negative cases throughout data collection and analysis, and refined emerging ideas accordingly. To give a realistic interpretation of participants’ experiences, I have carefully considered negative cases, and not focused solely on those cases that fit within more predominant themes. For example, some participants with especially severe health conditions were “negative cases” because their experiences were different than those of other participants. As I will explain further in the findings chapter, these participants did not seem to engage in as purposeful negotiations of care as some other participants. I included these cases in my explanation of themes to ensure that the findings presented are comprehensive.

Second, I have attempted to *clarify researcher bias* in the discussion of reflexivity presented above, where I discuss my past experiences and assumptions that may impact

on my interactions with participants and my analysis of data. Throughout this methodology chapter more generally I clearly outline the decisions I made throughout the research process. With this information, readers can consider how my social positioning might have impacted the research and influenced the findings presented (Creswell, 2013).

Third, in the following chapter, I provide *rich, thick descriptions* of research findings. I describe in detail participants' backgrounds and living circumstances, and the context surrounding quotes, to enable readers to better understand how I am making sense of participants' experiences. With this information, readers can better understand participants' realities, and may come to their own conclusions about the validity of the data and its transferability to other settings (Erlandson et al., 1993, cited in Creswell, 2013).

### ***Summary***

In this chapter, I have outlined the interpretive grounded theory methodology that guided the research design and method of analysis for this thesis. Interpretive grounded theory was an apt framework for gathering rich data on participants' negotiations of formal home care, family/friend caregiving, and self-care. While grounded theory begins at the micro-level of analysis, interpretive methodologists emphasize that it is necessary to consider social conditions and contexts, in relation to participants' experiences, actions, and interactions. Therefore, grounded theory was especially useful for considering the implications of age relations, as a "sensitizing concept," for participants' experiences and interpretations of care. In the following chapters, I will articulate the findings and theoretical insights that emerged from this grounded theory study.

## **Chapter 5: Findings**

### ***A balancing act: Older care recipients' negotiations of self-care, formal home care, and family/friend caregiving***

#### ***Introduction***

This thesis explores the implications of age relations for older people's negotiations of self-care, formal home care, and family/friend caregiving. As I established in Chapter Three (literature review), gaps in sociological and gerontological research leave us with a limited understanding of care recipients' positioning at the intersections of these systems of care. Research that explores the relationship between formal home care and family/friend caregiving focuses primarily on care providers' perspectives, and tends to overlook care recipients' everyday experiences and negotiations of care (Cantor, 1979, 1991; Chappell & Blandford, 1991; Greene, 1983; Litwak, 1985; Ward-Griffin & Marshall, 2003). There is therefore a gap in knowledge on the relationship between formal and family/friend care, *as it is experienced from the perspectives of older care recipients*. Moreover, studies on older care recipients' self-care practices tend to focus on the factors that influence self-care (Kemp et al., 2013; Penning, 2002), and in some cases, on self-care as a means through which care recipients involve themselves in care activities (Ball et al., 2004; Cox & Dooley, 1996). Yet, we know little about the ways older care recipients themselves—who are located *at the intersections* of formal home care, family/friend caregiving, and self-care—negotiate the relationships between these systems of care. These gaps in extant research leave us with a limited understanding of the relationship between different systems of care, and of the everyday realities of the older people around whom systems of care are organized.

To address these gaps, in this chapter I draw on findings from a grounded theory study that involved 34 qualitative interviews to articulate how older care recipients negotiate the intersections of self-care, formal home care, and family/friend caregiving. I address the following questions:

- *How do older people who are receiving care negotiate between formal home care and family/friend caregiving?* How does an investigation of older people's experiences of receiving care impact our understanding of the intersections of formal home care and family/friend caregiving?
- How do older people who are receiving care from others practise self-care? *How do practices of self-care intersect with formal home care and family/friend caregiving?* How does an investigation of older people's self-care practices impact our understanding of the intersections between systems of care?

In this chapter, I focus explicitly on participants' *negotiations* of care. Drawing on an interactionist perspective (Strauss, 1978), the concept of negotiation draws attention to the ways that individuals, who occupy different roles and positions within care relationships, interact with each other over time in ways that have consequences for care arrangements. Negotiations may be explicit, for example when care recipients ask for specific kinds of assistance. They may also be implicit, such as when individuals act (or do not act) in ways that communicate expectations or desires for support from others (Connidis & Kemp, 2008; Finch & Mason, 1993; Finch, 1989; Kemp et al., 2013). While my findings focus specifically on care recipients' perspectives, I consider their actions and interactions to be negotiations, both implicit and explicit, of their relationships with care providers. In turn, these negotiations have consequences for participants' care arrangements, including the intersections that exist between the systems of self-care, family/friend caregiving, and formal home care.



Most broadly, findings suggest that participants' concerns about burdening others with care needs, and maintaining a sense of independence, translate into practical strategies of negotiating the intersections of formal home care, family/friend caregiving, and self-care. As such, participants' negotiations of care represent their efforts to reconcile the tensions that exist between the realities of impairment, illness, and needs for care in later life, with the desire to remain self-sufficient and avoid imposing what they considered to be undue demands on others. To reconcile these tensions, I suggest that participants' negotiations of care involved efforts to *strike a balance* between (a) the formal home care they received and their relations of support with family members and friends, and (b) their capacity to care for themselves (i.e., practise self-care) and the care they received from others (see Figure 1).

I suggest that participants' negotiations of care exist along a continuum and range from situations where they were able to *strike a balance* between systems of care that reflected their needs, preferences, and timelines; to situations where *imbalances in care* left participants with unmet needs. To varying degrees, the majority of participants ( $n=30$ ; 88.2%) expressed some sense of balance between systems of care. To be sure, their care arrangements involved some challenges, such as when participants did not get along with formal care workers. In many cases, however, financial means and/or strong relations of support with family and friends facilitated participants' negotiations of care. With these resources participants often felt that they could access much needed support, while still maintaining a sense of "independence" and not imposing what they considered to be undue burdens on others.

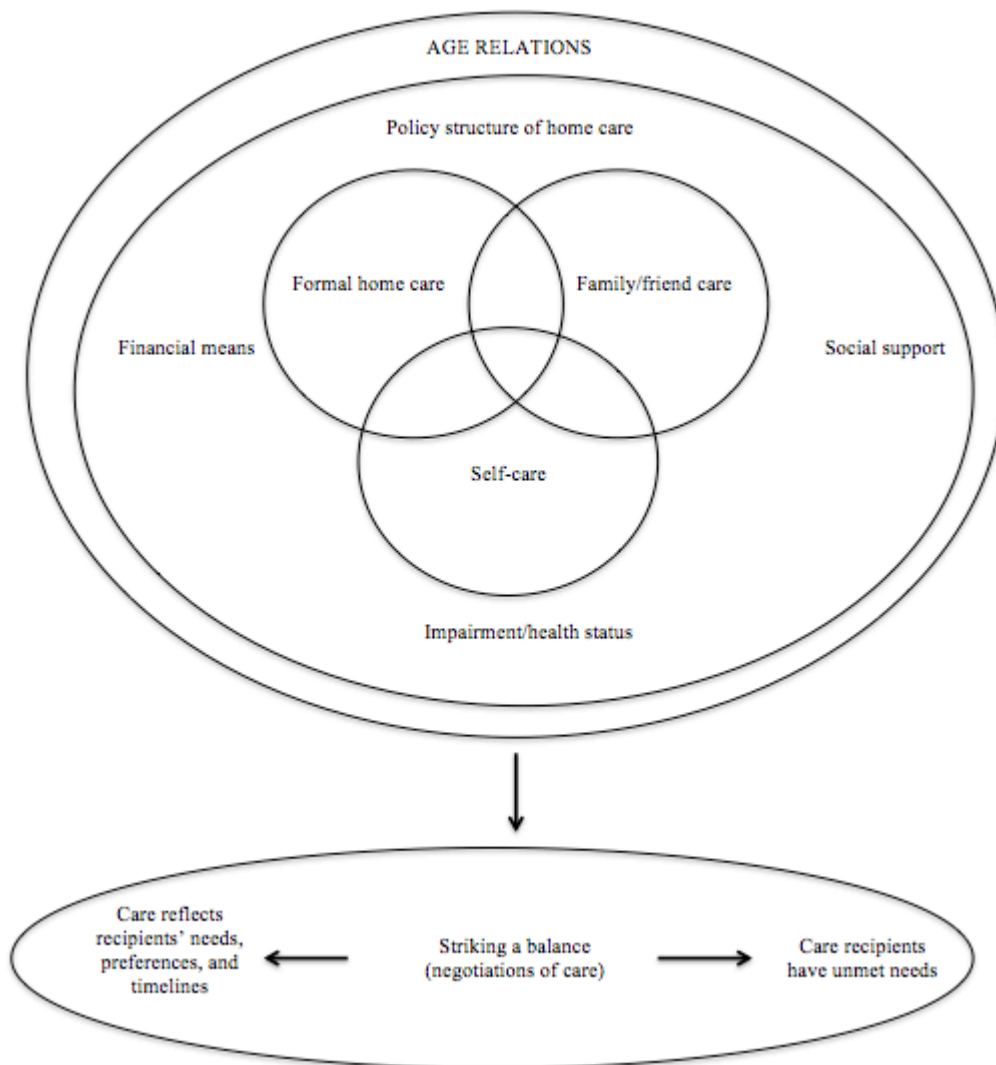
At the other end of the continuum, however, a smaller number of participants ( $n=4$ ; 11.8%) expressed a sense of powerlessness and vulnerability in their negotiations of care. This occurred when participants had needs that exceeded the care they were allotted through the publicly funded home care system, often coupled with few financial means and little to no support from family and friends. These participants experienced challenges in their efforts to strike a balance between systems of care that reflected their needs, preferences, and timelines, and often had unmet needs.

In Figure 1, I use concentric circles to depict the intersections of self-care, formal home care, and family/friend caregiving. Participants' negotiations of care were framed by their access to financial resources and social support, their level of impairment or health status, and the policy structure that shaped the availability of home care services. At the bottom of Figure 1, I depict the potential outcomes of participants' efforts to strike a balance (i.e., negotiations) between systems of care. These outcomes ranged from situations where the balance between systems of care reflected participants' needs, preferences, and timelines, to situations where imbalances in care left participants with unmet needs. More broadly, as I will explain in Chapter Six, *age relations* had implications for participants' negotiations of care.

This chapter is divided into three sections. The first section explains the strategies that participants often used to strike a balance between the formal care they received, and their relations of support with family members and friends. The second section integrates participants' self-care practices, and explains how participants often struck a balance between the care they received from others and their capacity and desire to care for

themselves. Finally, the third section explains the challenges that some participants faced in their negotiations of care; resulting in “imbalances in care.” These participants either struggled to care for themselves, or turned to family to “fill in gaps” when home care services were insufficient.

**Figure 1: The intersections of formal home care, family/friend caregiving, and self-care** (adapted from Kemp et al.'s (2013) convoy of care model).



### ***1. Balancing formal home care and family/friend caregiving***

To gather an understanding of care recipients' positioning at the intersections of formal home care and family/friend caregiving, I asked participants to describe their relations of support with the people who helped them. Participants discussed the tasks that both formal home care providers and family members or friends assisted with, their relationships and interactions with care providers, their feelings of satisfaction or complaints about the care they received, and their preferences for care. Although participants received varying types and levels of both formal home care and family/friend care, their negotiations of these systems of care were shaped first and foremost by their concerns about "burdening" family and friends with their care needs—especially, though not exclusively, younger working generations. Given these concerns participants attempted to ensure that they received sufficient care, while not imposing what they considered to be too many demands on kin. Many participants engaged in one of the following strategies to "strike a balance" between formal home care and relations of support with family and friends: turning to formal home care as first choice, coordinating formal and family/friend care, engaging in relations of reciprocity, or accepting formal and family/friend care. To varying degrees, participants drew on financial and/or social resources as they made choices regarding their relations of support with formal care providers and with kin. In doing so, participants demonstrated some sense of control and autonomy in their negotiations of care.

*Concerns about being a "burden"*

Although I did not ask participants specifically about the demands that their care needs placed on others, they frequently discussed how they did not want to impose on family members—especially adult children—who were busy with their own lives. These concerns were often framed in terms of the responsibilities that adult children faced as they balanced careers, childcare, and sometimes health problems of their own (see also Peters, Hooker, & Zvonkovic, 2006). The following quotes illustrate participants' deep-seated concerns about burdening family members with their care needs:

I don't want to go with my children. It's not because my children aren't nice; no, no, I don't want to be . . . I don't want to bother . . . they have their own life, their own family (Celia, 71).

So I wouldn't say . . . I wouldn't say it would be nice if we saw each other a little more, you know, so you're saying, like, what I would like but I wouldn't say a word (Josie, 82).

But she is also working and she found out she has a blister in the brain, too. So, she's not . . . so I don't want to aggravate her . . . No, they are good but you are...you know, elderly people have to realize, you can only so much ask the children (Lise, 81).

My nieces live far away; one is in Mississauga, one is in King City and one is in Markham and my sister-in-law is in Markham . . . But I sometimes wish they lived closer and could do a little more shopping for me. I don't like to call them where, you know; they're so far away and . . . but I . . . I survive. I have enough (Beth, 82).

The majority of participants (27; 79.4%) were widowed, divorced, or never married, and lived alone. They discussed family support primarily in terms of their relationships with children, and the ten participants who both lived alone and were childless discussed the support that they received from friends, or sometimes siblings and nieces and nephews. It is important to note that some—but not all—of the seven participants who lived with intimate partners did not express such strong concerns about burdening family members.

For example Ellen, who relied heavily on her husband for support, did not discuss her care needs as posing an undue burden on him. Rather she expressed a sense of interdependence between what she could do for herself and what her husband helped with (see also Calasanti, 2006; Connidis, 2010):

What we do when we go shopping, I have James take me into the kitchen and I take the groceries out of the bag and I put it on the table and then I fold the bags and then when my bibs get washed, I get them to bring them up and I fold them; try to use my hands to do things but I can't cook (Ellen, 89).

Ray, who was visually impaired, similarly discussed the partnership that existed between himself and his same-sex partner:

Saul's not terribly mechanically inclined. I am but the lack of sight . . . so we actually work together. I'll give you an example. The gate latch. Trying to put screws in the gate latch. Well, I can work a screwdriver and I can hold the latch but do you think I can get the screw on the screwdriver? (Ray, 66).

Other participants who lived with spouses or intimate partners, however, did not necessarily discuss these care relationships as “partnerships.” Phillip's wife, for example, had severe dementia, and while he received some formal care, he was also a caregiver to his wife. Earl lived with an intimate partner whom he had met in later life, and due to the nature of this “new” relationship, he did not want to impose too many demands on her. I will further elaborate on these and other cases below to show how the nature and structure of family relationships shape participants' negotiations of care. For the majority of participants, however, a primary concern was the demands that their care needs placed on either their adult children or on other kin.

*Turning to formal home care as a “first choice:” Maintaining established family relationships*

As participants expressed concerns about the demands that their care needs placed on others, some considered formal home care to be a “first choice” and preferred to use home care rather than ask family or friends for help. These participants often enjoyed close and supportive relationships with family members, but negotiated their care arrangements to ensure that their care needs did not impose what they considered to be an undue burden on kin. In other words, participants did not want established family relationships to spill over into the work of caregiving (see also Kemp & Denton, 2003; Peters et al., 2006). “Turning to formal home care as first choice” was therefore a way for participants to reconcile their concerns about being a potential “burden” with the realities of their needs for support in later life, and to strike a balance between systems of care that reflected their needs and preferences. Here, participants were relatively privileged in their negotiations of care: some had the financial means to pay privately for home care services as an alternative or to complement publicly funded home care, while others had successfully navigated a complex public care system to access sufficient care.

Joe and his wife Fannie,<sup>8</sup> for example, clearly asserted that they preferred to receive formal care, and food from Meals on Wheels, rather than ask their children to help with cooking and cleaning. Joe and Fannie’s adult children lived nearby and the couple enjoyed regular visits with them. Yet, when asked if there were things they liked, or things they would like to change about their relationships with their children, Joe and Fannie replied:

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<sup>8</sup> Although Fannie was not technically allotted home care, the supports Joe received were just as necessary for her because arthritis limited her ability to clean their condominium and to cook.

No, listen, I would like to if they [family] will come, like, not only once a week. It would be nice, you know. But, they have their own life, you know, they have their own family and they have to work and they have their own problems, you know, so you don't want to give them more like we have to (Joe, 89).

And, with the kids, I mean, if I would tell them that, "Please cook us meals," they would, but it's not as same we love them, okay, and they love us and I don't think it's reasonable to ask them to do that, okay? (Fannie, 83).

Joe and Fannie's home care services extended beyond the services allotted through Ontario's public health care system, but they did not pay for supplementary services, such as Meals on Wheels, themselves: Joe and Fannie were Holocaust survivors who came to Canada from Eastern Europe after World War II, and the costs for Joe's home care were covered by compensation claims from the German government.<sup>9</sup> Still, Joe and Fannie had some complaints about the home care services they received. For example, they were happy that they could access kosher meals, but they were often unsatisfied with the quality of food. Although home care was sometimes less than ideal, Joe and Fannie were adamant that they preferred to receive home care to meet their needs for help with cleaning, preparing meals, and running errands, and did not want to ask their children for additional support.

It is possible to pay privately for home care, as an alternative or to complement the services that are provided through Ontario's publicly funded home care system.

Financial means, therefore, may enable individuals to make choices regarding the type

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<sup>9</sup> The Claims Conference (Conference on Jewish Material Claims Against Germany) negotiates with the German government to fund a variety of health and social care services for Holocaust survivors. Services include home care, case management, emergency assistance, kosher meal delivery, transportation for medical appointments and grocery shopping. In Canada, these services are provided through specific home care agencies (Claims Conference, 2012).



and amount of care they receive, and to avoid asking family members for support. For example, Suzanne drew on her considerable financial means—acquired from her wealthy family, and throughout the course of a prestigious career—and hired a live-in companion to help with various tasks that ranged from bathing and dressing to cleaning her home, to walking her two dogs, to driving her to appointments and events. Although Suzanne (twice divorced) enjoyed occasional visits with her children and grandchildren, she clearly asserted her preference to pay for someone to provide care. She felt that it was unfair and unrealistic—for both older people and for their adult children—to expect families to take on caring responsibilities. Yet, Suzanne recognized that most people did not have the financial means to pay privately for care, and had few options but to turn to family for later life care:

You see I'm really one of the very few fortunate people. I have a person that lives here with me. And so I have all the help I need to get from A to B . . . you know, this thing of the family's looking after their parents, most of them aren't . . . well, not most of them; many of them are not in the same city. And they may not have room. And also the worst part is that the parent often, I would say, doesn't want to go. I mean I've . . . I just think that would be a nightmare to be made to go and live with the children, and think you'd have any independence at all. It's just . . . I'd rather live in a room this size for the rest of my life than have to . . . the noise and the . . . their house. I don't want to be in on that. I don't want to have a big, noisy dinner with them. Now other people are thrilled. But it's something that should be much more in the hands of the sick person than in the hands of the family. And because often people treat elderly people very, very badly and very rudely, especially when they're all of a sudden in their house (Suzanne, 80).

Financial means might enable some participants to avoid asking family members for assistance. In other cases, changing family relationships in later life shaped care recipients' negotiations of care, as they used formal home care as an alternative to asking family for help. An example here is Earl, who had paralysis and had relied on his wife,

Sophia, for help with dressing and administering a suppository until her death five years earlier. More recently Earl had developed a relationship with another woman, Judith, who had moved into his condominium. Yet, he did not want to turn to Judith for care in the same way as he had relied on Sophia, and instead received formal home care on a daily basis. When asked what kinds of help he received, Earl replied:

Well, Sophia used to do my shoes. Yeah, she used to administer the suppository too. But when she died, you know, I had to have somebody [a care worker]. And now Judith . . . well, she's an old lady just like my wife. I lived with my wife sixty-seven years, and she died, and that was five years ago. But she's [Judith] an older girl, and she's not in the family way (Earl, 92).

When Earl used home care as an alternative to asking Judith for help, he was navigating the complexities that arise as individuals contend with changing care needs in later life and as they develop new intimate relationships. Earl accepted and expected Sophia, his lifelong partner, to give care and viewed this care a normal aspect of spousal relations. Yet, Earl had shifted his expectations of support from Judith, with whom he developed an intimate relationship in later life. Earl did not want Judith to help him in the same ways as Sophia had, in part because of her age and in part because he felt that she lacked the same caring disposition, as he expressed when he stated that Judith “is not in the family way.” As an alternative, Earl turned to formal support for his personal care needs.

In the examples presented above, participants often viewed close and supportive relationships with family members as important. Yet, they did not want children or intimate partners to take responsibility for household tasks or personal care. These participants turned to formal home care as a “first choice” to reconcile their concerns

about imposing too many demands on family members, with the realities of their care needs in later life. In doing so, they were sometimes able to mitigate any disruptions to established family relations that care needs might present. Some participants, like Suzanne, were relatively privileged because they could pay privately for this help and therefore had much more control and choice regarding the kinds of help they received and who provided it. Other participants used publicly funded home care, because they either did not need or could not afford additional home care services—or in the example of Joe and Fannie, received additional services as the result of compensation claims in the current policy structure. Particularly in the eight cases where participants paid privately for home care services, however, they considered support from family members to be a choice, rather than a necessity. As such, these participants maintained a sense of control and autonomy in their negotiations of care and in their relationships with family members. By consequence, the “balance” of formal home care and family/friend support tended to reflect their needs and preferences. As the following section will show, some participants also expressed considerable autonomy and control as they coordinated large networks of formal home care and family/friend care.

#### *Coordinating formal home care and family/friend care*

Although some participants turned to formal home care as a “first choice,” others coordinated complex, intersecting networks of formal home care and support from family members and friends. Although participants received considerable amounts of support from various sources, they coordinated their care networks to ensure that their care needs did not impose what they considered to be an undue burden on any one person. As these

participants coordinated care, they were often able to strike a balance between formal home care and family/friend caregiving that reflected their needs, preferences, and timelines. Once again, participants often drew on financial and social resources as they made choices about when, where, and from whom they received care.

Ruth was positioned at the centre of a large and complex network of care, and actively coordinated relations of support with formal care providers and with friends. For example, while Ruth was technically allotted publicly funded home care for bathing, she directed her own care: because she could bathe alone, Ruth arranged for the home care worker to use the time allotted for bathing to help with household tasks, such as cooking and cleaning, that were very difficult for Ruth to do alone since she had lost her vision. Ruth was well educated and heavily involved in various community groups, and as she negotiated her care arrangements, she drew on her in-depth knowledge of the services and supports that are available to older and disabled people in need of care. She also relied on a wide circle of very supportive friends for help with transportation, shopping, and chores. In addition to this, Ruth had the financial means—acquired throughout the course of her career as a business professional—to pay someone to clean her condominium. Family support was limited: Ruth, a lesbian, did not have a serious partner and had never had children. While she enjoyed close relationships with her sisters, they lived far away and were unable to provide instrumental care on a regular basis. Yet, Ruth felt she could always turn to her friends for help and to her sisters for emotional support. As the following quote demonstrates, she expressed a sense of autonomy and control as she negotiated formal home care and relations of support with friends and family members:

They [home care worker] can do some shopping for you . . . It's very rare that I ask her to do that but today I forgot to ask anyone [friends] to pick it up . . . she would have run out and done it. She does whatever...whatever I need and . . . even my cleaning lady who I . . . of course, I pay . . . she knows that I have a thing about my place looking really good (Ruth, 73).

While Ruth accepted help from others, “coordinating care” enabled her to ensure that she did not ask too much of any one person: she could turn to either friends or formal care for assistance when needs arose, and struck a balance between these systems of care that reflected her needs and preferences.

While Philip similarly coordinated a complex, intersecting network of formal and family care, his positioning as both a “care recipient” and a “caregiver” shaped his negotiations of care in unique ways. Phillip received several hours of home care a week for housework and for foot care related to complications from arthritis. He was also a caregiver for his wife, Kathryn, who had severe dementia and was unable to speak or walk. Both publicly funded and privately paid home care were an almost constant presence in the couple's home, and Phillip organized who would do what and when. In addition to this, Phillip and Kathryn's daughter, who was trained as nurse, provided regular support. Phillip described the close relationships he had with formal care providers, and the convergence of family and formal care, when he explained how he, Kathryn, his daughter, and home care workers spent time together:

My nurse daughter is a fabulous help to us. She gives one day a week; every Thursday, she gives her day to come here and she's a very practical girl, being a nurse. She sees things to do, she helps us every Thursday and usually we go out and have lunch with two of the girls [home care workers] and Kathryn on that day, as well (Phillip, 84).

To negotiate this complex, intersecting network of care, Phillip saw himself as a “manager” and drew on the skills—as well as the financial means—that he had developed throughout his career as the owner of a construction company:<sup>10</sup>

I was a builder all my life, forty-one years, I told you; so my whole life has been managing . . . managing . . . and now, with all that management experience, I’m managing a flock of girls; I’ve got about seven girls and I’m managing everything and it’s my nature (Phillip, 84).

Like Ruth, Phillip expressed considerable choice and autonomy as he negotiated formal home care and family care. He was able to rely heavily on formal home care, some of which he purchased privately. While Phillip very much appreciated the support that his daughter provided on a regular basis, he did not feel that he was imposing too many demands on her. Rather, he felt that various individuals—including his daughter and both publicly and privately paid care providers—worked well together to ensure that he and Kathryn received the support they needed to continue to live together at home. These systems of care intersected in complex ways: Phillip’s daughter used her professional nursing skills to provide family care, and Philip regarded the privately paid home care workers—“the girls”—like family. He took them out to lunch with the rest of the family, and his and Kathryn’s home was decorated with many pictures of the couple spending time with their home care workers. When Phillip drew on support from various individuals—who often complemented each other to form one overarching network of care—he struck a balance between his and Kathryn’s needs for support, and the demands

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<sup>10</sup>The gender relations that shape Phillip’s negotiations of care are evident in this example. His managerial approach is consistent with other research on older husbands’ care work (King & Calasanti, 2013; R. Russell, 2007). Older men often draw on skills gained in paid work settings when they care for spouses, and Phillip clearly connected his paid work experience to his role as a caregiver and as a care recipient.

that caregiving might place on family members. Through his negotiations of care, and as he paid for substantial home care services, Phillip was able to reduce the potential “burdens” that his and Kathryn’s care needs placed on others.

Celia similarly coordinated support from various individuals for assistance with different tasks, to ensure that her care needs did not overwhelm any one individual. For example, neighbours (whom she paid) helped with yard work, and Celia’s sister helped with transportation and errands. Celia’s care needs were increasing, as her arthritis worsened. Yet, her negotiations of formal home care and support from family members exemplify her efforts to reconcile her needs for care with her concerns about placing too many demands on family members’ and friends’ time and energy:

*I:* Mm Hmm. Are there any kinds of help you wish you were getting more of that you’re not?

*Celia:* Yeah, the same that I said before, the home care.

*I:* Mm Hmm. To have more help.

*Celia:* Yeah, the home care . . . that’s what I’ve been thinking about, see, I’ve been worrying, because at the moment, like I said, I don’t really know how things are going to turn out to but I . . . for the moment, in my mind, I’ve been thinking about I need an extra day from the home care.

*I:* Right. Yeah. What about from your family or your friends, is there anything else you wish they would do to . . . to help?

*Celia:* No. No, no, they’re, you know, if they come just to see me, like, especially my daughter, like, she has small children, if they come for an hour, two hours, I prefer to go there. The way her house is, it’s better the children they stay around there.

*I:* Right. Yeah, they have more space (Celia, 71).

Later in the interview, Celia described the support that her sister provided with transportation:

*Celia:* My sister’s the one who comes more often now. See, she was the one help me more.

*I:* Does she live nearby?

*Celia:* Oh, she lives, like, right downtown at Bloor, between Yonge and Church.

*I:* Okay.

*Celia:* Yeah. So, if I need her she will . . . she will come. If we go see someplace, some relatives or the other place, even to go to a funeral, they will take me. Her and her husband, they will . . . they come here and they will get me and they take me there (Celia, 71).

The examples presented above show how participants often demonstrated considerable choice and control as they coordinated care from complex, intersecting networks of formal home care and family/friend caregiving. This often enabled them to access care that met their needs, preferences, and timelines. The capacity to demonstrate choice and autonomy in negotiations of care, however, may only be more readily available to individuals in relatively privileged social locations: when participants coordinated care, they drew on social advantages related to their knowledge of community resources, strong and supportive relationships with family and friends, and sometimes financial resources that enabled them to pay for the kinds of care they wanted.

#### *Engaging in relations of reciprocity*

Complementing participants' negotiations of formal home care and family/friend care, (i.e., turning to family as first choice or coordinating care), participants sometimes explained how they engaged in relations of reciprocity, or "gave back" to care providers, to ensure that they were not imposing undue demands on others. Paying family members and friends for assistance, and providing emotional support to formal care providers, was important to participants because it enabled them to maintain a sense of control and autonomy as they sought out much-needed help. Moreover, acts of reciprocity enabled participants to reconcile their concerns about imposing too many demands on others, with



the realities of their care needs in later life (see also Allen & Wiles, 2014; Lewinter, 2003).

Maggie, for example, felt relatively satisfied with the balance of formal home care and family/friend caregiving, and part of her satisfaction stemmed from the fact that she was able to engage in relations of reciprocity with both formal care providers and with family members who provided support. For example, Maggie paid her son-in-law to drive her places. This enabled her to accept help without feeling guilty about asking too much of her son-in-law, and to retain some control over when she received assistance with transportation:

And my son-in-law is excellent and I just give him a cheque the first of every month because then I don't feel so embarrassed. He's embarrassed taking the cheque but "No, this is the way we're going to do it" so . . . I would much rather give him something per month and then say "Oh, I really need to go to Wal-Mart. Would you just drive me up there? And we have that errand done, and I don't have to be concerned about it. And he's very willing to do it. So, it works well. (Maggie, 89)

Maggie also expressed a sense of reciprocity, in terms of emotional support, regarding the formal home care that she received. This care was not simply about Maggie receiving instrumental support from someone else. She enjoyed an amicable relationship with her home care worker, as the two women shared information about their personal lives:

She's [home care worker] just exceptional because she'll come in and "Well, how are you today?" And I say "I'm okay. How are you?" "Well, I'm okay too, but now let's think about it. Do you really feel pretty good today?" And kind of gets you talking and then she'll tell me something about her little boy or whatever. We just have a little friendly chat while she does the . . . while I get in the tub and . . . It's just a lovely start to the day because then your mind is thinking about other things . . . (Maggie, 89).

Mutual concern and caring characterized Maggie's relationship with her home care workers. As such, "receiving care" was a fulfilling and positive experience for Maggie.

In Ingrid's case, cultural and language barriers marked the relations of reciprocity that she developed with her daughter. Ingrid had migrated to Canada from Estonia when her children were young and now lived with her daughter Heidi, who also participated in the interview and sometimes acted as an interpreter for her mother. Due to Ingrid's limited knowledge of English, Heidi was heavily involved in organizing and managing formal home care. Ingrid felt that it was very important to reciprocate; for example, she did as much housework and cleaning as possible, and left more of her savings to Heidi than to her son, who only visited on occasion and provided neither instrumental nor emotional support. Despite Heidi's objections, giving money was an important way for Ingrid to justify the support her daughter provided—and to not feel as though she was imposing too many demands on her:

*Heidi:* She manages her own money; keeps track of that and . . .

*I:* Right. Yeah.

*Ingrid:* So far.

*I:* All those things, yeah.

*Heidi:* I don't...I don't interfere except every once in a while she decides she's going to dump some in my account and I object.

*Ingrid:* I don't have to tell her because I . . .

*Heidi:* Well, she doesn't tell me. She does it behind my back and I go to the bank and find out. I'll say, "What's this? It's the wrong amount." "Oh. Well I put it into your account."

*Ingrid:* Well I think it's only fair because she's been taking care of me and the other son I have, they care less (Ingrid, 91, and daughter Heidi).

These acts of reciprocity presented above afforded participants a sense of control and autonomy as they negotiated care (see also Lewinter, 2003). Paying family for assistance with transportation, for example, enabled some participants to run errands on

their own timelines, without feeling guilty about asking for help. Demonstrating concern for formal care providers, moreover, enabled participants to establish a mutual relationship of support and care with those who helped them in their homes. Reciprocity enabled participants to take personal responsibility for their care needs, and to access much needed support without feeling as though they were imposing undue demands on others. Financial means, once again, impacted on care recipients' capacity to reciprocate—as they often discussed reciprocity in terms of paying others for their support.

*Accepting formal and family/friend care*

While participants often exerted a fair degree of control and autonomy in their negotiations of care, it is important to note that there were some situations where participants received high levels of support from others, and yet were perhaps less purposefully or actively involved in their negotiations of care. These participants expressed a sense of balance with some aspects of their care arrangements. For example they often felt as though family care and formal home care complemented each other. Yet, when these participants had complaints about some aspects of the care they received, they did not necessarily feel that it was in their means to make changes to their care arrangements. In these cases it seems as though debilitating health conditions, and a sense that one has little control regarding one's health and one's capacity to access support, precluded participants from engaging in purposeful or active negotiations of care.

In Ellen's case, especially severe health conditions, and perhaps the fact that her husband was a primary caregiver,<sup>11</sup> marked her negotiations of care in unique ways. Ellen had ongoing health problems and had spent much time in the hospital since she had contracted botulism four years earlier. Ellen felt dizzy and nauseated every day and could no longer walk or use her hands due to paralysis. Ellen lived with her husband, Jack, who provided much care, and she also received a couple of hours of publicly funded home care daily. While formal home care often complemented the support that Jack provided, Ellen did not actively attempt to strike a balance between systems of care. Ellen described the supports she received as follows:

*Ellen:* 'Cause I can't comb my hair.

*I:* Mm Hmm. So does the home care worker help with those kinds of things?

*Ellen:* Yes. Yeah and James can comb it.

*I:* Mm Hmm. Mm Hmm. That's great. Is there any other kind of overlap between, say, what the home care worker helps you with and what Jack helps you with? Do they ever do the same things, or . . . ?

*Ellen:* Well . . . well, when she comes back in the afternoon . . . and she comes from four to six . . . usually we have dinner around, oh, five-thirty or quarter to six and she stays and does the dishes for us but she usually gets me undressed and puts my pyjamas on so Jack doesn't have to do that. I come out and have my dinner and then I'm all ready to go to bed. So she does that (Ellen, 89).

In Ellen's example, it seems as though concerns about being a burden, and purposeful negotiations of care, were perhaps secondary to the realities of the severe pain and physical discomfort that she experienced on a near-constant basis.

In Judy's case, a combination of mental and physical health problems perhaps placed some limits on her capacity to "actively" strike a balance between systems of care.

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<sup>11</sup> Care tends to be considered as normal aspect of marital relationships, and is less likely to be regarded as "caregiving" (Calasanti, 2006).

As Judy coped with severe depression and multiple physical health problems, she quite gladly accepted the support she received from formal care providers and from her son. Similar to Ellen, formal home care and family/friend caregiving sometimes complemented each other. For example, formal care workers were not allowed to cook, and because Judy found it difficult to cook alone, she appreciated that her son could assist with cooking:

*Judy:* Wednesday is peri-care but now they've decided instead of doing peri-care, they're going to bathe me. And then Thursday, they do my laundry and then Friday is another bath day. Saturday and Sunday they come in for maybe five, ten minutes to make me a sandwich and then they're gone.

*I:* Right. Okay. Yeah.

*Judy:* But then, like I said, my son's been staying with me and he's been very, very helpful to me. He's been cooking my supper for me and if he's here for lunch, we have lunch together (Judy, 75).

When participants “accepted care,” they tended to express less control and autonomy in their negotiations of care. A balance still sometimes existed between systems of care—particularly in cases where participants received high levels of support from family members in addition to formal home care. Yet, participants did not necessarily feel that they could change their care arrangements when some aspects of care were less than ideal, and simply accepted the services that were provided. As Doris stated, for example:

*Doris:* Well, the showering's the only thing that gets me. I've been just getting in the shower maybe once or twice a week.

*I:* Right.

*Doris:* I . . . I felt bad at first but then I realized when my Mum was in the home, she . . . she only got a shower once a week, or a bath (78).

The experiences of participants who “accepted care,” tend to fit in the middle of a continuum that ranges from situations where participants were able to strike a balance

between systems of care that reflected their needs and preferences, to situations where imbalances in care left participants with unmet needs. In these cases, some aspects of the balance of care reflected participants' needs and preferences. In other ways, participants expressed a need for more or different kinds of support, but they had little sense of control and autonomy as they negotiated their care arrangements.

As the findings presented above suggest, participants engaged in various strategies to strike a balance between formal home care and family/friend care that reflected their needs, preferences, and timelines. In doing so they attempted to reconcile their care needs in later life, with their concerns about placing what they considered to be too many demands on kin. Yet, participants' negotiations of care also involved "self-care" practices—that is, as participants negotiated their relations of support with family and friends, they also did many things to care for themselves. To give a more comprehensive understanding of the intersections that exist between systems of care, in the following section I discuss how participants attempted to "strike a balance" between their self-care practices, and their relations of support with formal care providers, family, and friends.

## ***2. Balancing self-care with care from others***

To gather an understanding of the subjective meaning that participants attributed to self-care practices, I asked them to describe the things they did to care for themselves. In other words, rather than begin with a pre-determined definition of self-care and ask participants, for example, if they engaged in a specific self-care practice such as exercise, in what follows I conceptualize self-care as the activities that participants raised in response to the question "in your daily life, are there things you do to take care of

yourself?” As such, these findings give insight into the ways older people in need of care understand and interpret self-care.

Participants’ responses illustrate self-care practices that range from engaging in diet and exercise routines, to cleaning and managing one’s home, to maintaining responsibility for personal care such as bathing and dressing. Participants’ capacity to engage in specific self-care practices varied according to health status or level of impairment, but they overwhelmingly emphasized that it was important to them to care for themselves as much as possible, and to resist accepting what they considered to be “too much” help from others—that is, when they felt that accepting help for certain care activities would signify a lack of personal responsibility for care, or would signal a transition toward further decline and dependency.

Although participants tended to see themselves as “independent,” they had increasing needs for support in later life. When it was necessary, participants sought out and accepted support and guidance that enabled them to continue to practise self-care in ways that were personally meaningful, and that enabled them to maintain a sense of control and autonomy in their negotiations of care. Here accepting help did not necessarily conflict with participants’ sense of self-sufficiency—rather, they felt that they could continue to be independent with the support of others (see also Ball et al., 2004; Hale et al., 2010; Hammarström & Torres, 2010). For example, support from family members and friends and from formal home care providers enabled participants to maintain diet and exercise routines, to engage in activities to prevent health conditions from worsening, and to play an active role in housework. Moreover, participants often

discussed how others had advised them on self-care practices. In this regard broader messages about health in later life, as well as advice from health care professionals, impacted on participants' self-care practices.

When participants sought out accepted support for self-care practices, they were often able to strike a balance between the things they could do to care for themselves, and the support they received from others. Once again, financial and social resources sometimes enabled participants to access the support for self-care they needed and wanted—and to maintain a sense of “independence,” despite needing help from others due to various health conditions and impairments.

#### *Minimizing reliance*

Throughout interviews, participants did not only discuss their dependence on others—or the things they could not do—but rather emphasized the things that they did to care for themselves and to minimize their reliance, to whatever degree possible, on family members, friends, and formal care providers (see also Ball et al., 2004). For example, participants followed diet and exercise routines to maintain their own health and to (hopefully) stave off current and future dependencies, resisted accepting too much help with housework, and modified activities such as bathing so that they could continue to do them alone. Participants attempted to maintain personal responsibility for health and well-being, and to do so they diligently followed the advice that health professionals gave them, as well as broader messages about “good health” in later life. Yet, these self-care practices were also personally meaningful to participants: they often expressed a sense of



pride and satisfaction as they played a role in maintaining their own health and well-being.

Despite receiving care for a variety of health conditions and impairments, participants often still asserted themselves as healthy people who were doing what was within their means to prevent health conditions from worsening—and care needs from increasing—as they grew older.

For example, although Donald received home care several times a week for help with bathing, cleaning, and occasionally grocery shopping, he followed self-care routines to maintain his own health. Donald had a lifelong disability, cerebral palsy, and was experiencing more complications from it as he aged. Despite needs for help, Donald explained what he did to care for himself as follows:

I do wall push up and chair sit-ups and things like that . . . I eat pretty good. I eat a lot of high fibre foods, like, my cereals, my porridge . . . and I'll try my darnedest to stay healthy believe you me (Donald, 70).

While Donald recognized that his capacity to care for himself was changing in later life, he felt that his self-care practices would enable him to stave off further “decline” associated with age. Through taking personal responsibility for health and well-being, he hoped to avoid having to move to a nursing home in the future:

As you get older, you can't help yourself but what can you do? You . . . I know, eventually, that I'm going to have to go in a [nursing] home eventually but I'm going to have to . . . I'm going to have to really, really try to stay out of there and I think this [diet, exercise] is how you do that (Donald, 70).

Hannah drew on health care professionals' advice as she followed exercise routines to reduce complications from diabetes. Hannah took pride in her diligence with exercise routines, and felt that self-care had enabled her to remain living in her own two-story

home and to avoid accepting too much formal assistance. During our interview Hannah physically demonstrated her exercise routine:

*Hannah:* I had diabetes; they say you have to take care of your feet and all these things.

*I:* Mm Hmm.

*Hannah:* I started to clean them, I had to start . . . and I started gymnastics.

*I:* Oh.

*Hannah:* And if I wouldn't have done that, I would not be able to climb out and into the bath all by myself. If I . . . you know, sometimes, you do something you're on your knees, don't get up . . . well, I just have to twist this way or that way to find the chair and go up alone and it's very easy or . . . put it this way, here, I mean, I had done this now for years.

*I:* Mm Hmm.

*Hannah:* See this here?

*I:* Mm Hmm.

*Hannah:* You go twenty times, you go down here . . . [*Hannah bends down and touches her toes, which she can do easily*]

*I:* Oh, wow.

*Hannah:* . . . you rub this, you rub that, you swing . . .

*I:* You're so flexible.

*Hannah:* And this is something . . . I definitely have to say that it's why I am the way I am. Then here . . . well, in the summertime, I walk up there and . . . and the steps, you know. There's another thing, I have to be very, very slow; I get slower. But, that's gymnastics (Hannah, 90).

Beyond specific diet and exercise routines, some participants simply tried to “do as much as possible” in activities of daily living rather than accept help from others. For example, when I asked Lise about the kinds of help she received from home care workers and family members, she focused first and foremost on her resistance to others' help—because her doctor had advised her to continue to do as much for herself as possible, and because she felt she had an “independent nature:”

*Lise:* Yeah, they [home care workers] . . . they will do the wash and sometime they do in . . . they clean it and want to put it in, then later on, they had to come back. I said, “It's waste of time.”

*I:* Right.

*Lise*: I can take it out; that's not the problem. And like, Saturday, I had the wash so I just load in and, you know, they have a lot of work to do.

*I*: Mm Hmm.

*Lise*: My doctor says I should do as much as possible.

...

*I*: Are there other kinds of things you wish your family would help with more?

*Lise*: No, actually not because I think . . . I can support myself. And I'm very proud of myself. I'm like my mother; I have the same nature like my mother . . . very independent (*Lise*, 81).

Some participants also explained how they modified their ways of doing things so that they could continue to do them alone (see also Ball et al., 2004; Baltes & Baltes, 1990). This enabled them to maintain a sense of personal responsibility for daily activities in later life, even as their abilities and needs changed. For example, Kate strongly expressed that she did not want to accept more help with activities like bathing, even though osteoporosis and stenosis made it increasingly difficult for her to get in and out of the bath alone. Kate felt that accepting more help with bathing would signal an unwelcome transition toward further decline and dependence. Kate therefore modified her personal care routines, taking a shower instead of a bath, to care for herself and to minimize her reliance on others:

*Kate*: I have . . . I'm beginning to have a bit of difficulty getting in and out of the bath but I can still manage it and I don't want anybody here.

*I*: Mm Hmm.

*Kate*: I . . . I sort of don't like the idea of someone coming in giving me a bath or anything . . . or getting into . . . I just have to use the shower; I can't get into the bath; I use the shower and I don't really fancy having someone . . . coming and doing that, I mean, I . . . I suppose eventually it might come but hope . . . I'm kind of in the position that I hope . . . I hope like I die before I get worse. You know what I mean? (*Kate*, 77).

Participants' efforts to minimize reliance on others shaped their perceptions of the intersections of self-care, formal home care, and family/friend caregiving. Participants did

not want formal home care providers, family members, or friends to “take over” the tasks they felt they could do independently. In some cases, participants even resisted help that was provided when they felt that could (or should) do things for themselves. Although participants needed support from others, they felt that engaging in self-care would enable them to avoid further transitions toward decline and dependency. As such, participants attempted to maintain some boundaries between their self-care practices and the help that they accepted from others. In doing so they maintained a sense of self-sufficiency or independence, even as they were positioned as “care recipients” in later life.

*Seeking out and accepting support and guidance on self-care*

Despite their efforts to minimize reliance on others, participants were in fact receiving formal home care—and often support from family members and friends—for assistance with a variety of activities. How do we make sense of this seeming contradiction between asserting oneself as self-sufficient, and yet accepting help from others? Findings suggest that when participants faced challenges or limits in their efforts to practise self-care alone, they often sought out or accepted support and guidance that enabled them to continue to care for themselves in ways that were personally meaningful, and also that enabled them to maintain a sense of personal responsibility for their own health and well-being. Here, participants were often able to strike a balance between their self-care practices and the care they received from others that reflected their needs and preferences. To varying degrees, for example, participants made choices about the type and amount of support they received for self-care practices, and in some cases about who provided this support. When participants sought out support and guidance on

self-care practices, however, access to financial and social resources was often an asset. In some cases, the money to purchase care privately, or to access additional forms of support, enabled participants them to make choices regarding the kinds of support they received for self-care practices.

To strike a balance between systems of care, participants often sought out support so that they could continue to practise self-care in ways that had been important to them throughout their lives. Eating healthfully was particularly important to Carol, for example, who felt that the healthy diet she had followed throughout her life, which consisted of very little processed food, contributed to her longevity and relative good health. Following a healthy, gluten-free diet was especially important to Carol because she had Celiac disease and a very sensitive stomach. Although she received daily home care as well as regular support from her daughter, Carol felt that it was important to maintain some personal responsibility for her diet. To do so, she remained centrally involved in preparing her own meals. Although meal preparation was a “task” home care workers were assigned to do, Carol worked alongside home care workers to prepare food; setting out ingredients in advance of their visits:

And, I . . . for my breakfast, I have rice and a chopped banana in it and almond milk, special milk. Yeah, and so, when they [home care workers] come at noon, I usually have a bowl of soup out for them and make a sandwich . . . oh . . . no, I put the ingredients for them to make the sandwich (Carol, 98).

Carol also received help from her daughter, Maureen. This family support intersected with formal home care in ways that supported Carol’s capacity to maintain

control over her diet. For example, Maureen bought the gluten-free groceries that home care workers would then help Carol prepare:

*Carol:* But she [Maureen] does all my shopping and I . . . she goes to Costco and they have a most delicious chicken. It's very tasty and she gets me a chicken . . . a whole chicken. Well that makes five meals.

*I:* Yeah, that lasts. That's great.

*Carol:* And the girls [home care workers] will cut it up for me; they cut it up and she's [Maureen's] going to British Columbia next week. This weekend, she's going and she's told . . . but I've got loads of food so there's nothing I need (Carol, 98).

Marion paid privately for home care, and had considerable control when she made choices regarding the tasks that care workers assisted with, and when. She drew on this support to engage in the self-care practices that had been prescribed to her as she recovered from a broken hip. Marion wanted to walk regularly, because she felt that it would speed her recovery and would help to prevent future falls. Yet, therapists had instructed Marion to be careful to not fall again. Marion therefore had her formal care workers accompany her on short walks every day:

I had lots of visits with healthcare providers or workers and one of them was . . . had to do with physical care of myself so they were very keen that I have this thing and that I wasn't taking any chances with repeating any falls or anything . . . I go for walks on the sidewalk and I go for . . . there's a nice corridor on the front of this building, and walking up and down there. And . . . and I . . . I always go with somebody, with a caregiver. So that's . . . that's a help and that way, she can test how I'm doing (Marion, 89).

While Carol and Marion sought out and accepted support for self-care practices, they upheld their personal responsibility for health and well-being. They drew on financial means, and networks of formal and family care, to access support for self-care practices (e.g., paying for home care privately, purchasing more expensive gluten-free foods, or accepting help from both care workers and family members). With these

resources available to them, Marion and Carol were well positioned to make meaningful choices regarding their self-care practices, and to maintain a sense of control and autonomy in care arrangements.

The examples of Carol and Marion show how some participants wanted to be “in charge” as care providers assisted with self-care practices. In other cases participants accepted advice and guidance on self-care from formal care providers that enabled them to care for themselves. With this advice, participants once again assumed a sense of personal responsibility for their own health and well-being—and yet were often able to strike a balance between systems of care that reflected their needs and preferences. Martha, for example, explained how a home care nurse taught her how to raise her legs to reduce the swelling that was a symptom of cellulitis:

*Martha:* He [nurse] does marvellous care for my legs, as you see, I have to have them bandaged all the time.

*I:* Okay.

*Martha:* And his suggestion is I keep them up as much as possible.

*I:* Mm Hmm.

*Martha:* Which has worked wonders, because when I wasn't keeping them up before I was able to get this chair, my feet were like this [big] size (Martha, 67).

Martha, who had never completed high school and had lived on a low income throughout her life, had very little knowledge about health promotion or illness prevention practices. Thus, she highly valued receiving advice on self-care practices from a nurse, with whom she enjoyed a close and trusting relationship.<sup>12</sup> When asked about the things she did to

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<sup>12</sup> Martha felt that home care services did not necessarily meet *all* of her needs for support with self-care—for example, she would have appreciated a care worker to accompany her on short walks in the hallway of her apartment building, but such support was not provided through the public home care system.

care for herself, Martha also discussed how support from family members enabled her to continue to engage in activities of daily living. Once a month Martha's step-daughter-in-law purchased a large grocery order, and her daughter thoroughly cleaned her apartment. With this support in place, Martha was able to do the lighter cleaning and prepare meals.

Martha explained:

*Martha:* And I try and keep the house as clean as I can but it's pretty hard washing the floors so my step daughter-in-law comes in once a month and does the floors really good for me so that all I have to do is just take the mop over them. I . . . my daughter, ninety percent of the time, does the groceries because they're too awkward to handle. If she can't do them, then I usually go down here to Queen Street to . . . it's called . . . it used to be IGA . . . and they deliver.

*I:* You make all your own meals?

*Martha:* Yes. I do a . . . I . . . when I do my grocery list at the end of the month, if my daughter's going to do my shop, I do it in meals (Martha, 67).

Family caregiving supported Martha's capacity to continue to engage in daily chores, and formal home care enabled her to practise self-care in ways that reduced the symptoms of cellulitis. In Martha's experience, self-care intersected with formal home care and family care in ways that shaped her daily experiences; making it somewhat easier for her to cope with challenges of multiple, debilitating chronic health conditions.

David similarly acceptance guidance on self-care practices from a nurse, as well as instrumental support from his daughters. Like Martha, David felt that both formal home and family caregiving supported his capacity to care for himself. David wanted to maintain his health as much as possible, and he explained how he had more energy since a home care nurse advised him to eat more protein with his breakfast:

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There was one nurse told me . . . She says “There’s no protein in that. You’ve got to have protein.” I said well I don’t want a heavy breakfast. She said “Well, do you like peanut butter?” I said “Sure.” She said “Well, have that. Put that in your cereal.” I said “Peanut butter in porridge?” She says “Yeah, it’s great.” She says “Try it.” So, I did. I was amazed. Oh gosh. Makes a difference (David, 82).

In addition to accepting advice on self-care practices related to his diet from a home care nurse, David also expressed a sense of balance between his capacity to run errands and buy groceries alone, and the support that his daughters provided. David was able to continue to go out and do some shopping alone. He sometimes felt lonely at home, and therefore enjoyed being able to get out the house to run errands. At the same time, David appreciated that his daughters bought the heavier groceries, so that he did have to worry about overexerting himself at the grocery store:

My daughters will call me generally from work before they come home and see if I need anything, and if I do, they’ll get it. About once . . . about once a week I’ll make the effort to go out shopping. I’m fine as long as I have a good tall buggy with me to . . . a shopping cart to lean on. But I couldn’t . . . I can’t walk and carry. I use a walking cane and so I can only carry stuff in one hand. But then with this aneurysm I’m not supposed to lift anything heavy, so anything like a case of water or anything like that have my daughters pick up for me, you know? [mhm] They don’t mind (David, 82).

Although participants did not want formal home care providers, family members, or friends to “take over” the tasks they felt they could do independently, the examples presented above illustrate the high value that they placed on support and guidance from others. In doing so, they struck a balance between their self-care practices and the support they received from others. Participants received support from both family members and formal care providers, and these systems of care sometimes intersected to support their self-care

practices. For example, both home care workers and family members supported Carol as she followed a healthy diet. This support enabled participants to continue to care for themselves in ways that were personally meaningful, and to maintain a sense of control or autonomy in care relationships. Through their negotiations of care, therefore, participants reconciled their desire to remain self-sufficient and “independent” with the needs for support that they were experiencing as a result of health conditions and impairments in later life. In these examples, participants were often in relatively advantaged social locations: they lived in comfortable environments, and in some cases had the financial means to purchase care privately to supplement or as an alternative to publicly funded home care. Even in examples where participants had limited financial means—such as Martha—strong networks of family support, as well as sufficient access to home care, enabled them to practise self-care in ways that were personally meaningful.

### ***3. Imbalances in care***

Positioned at the intersections of self-care, formal home care, and family/friend caregiving, participants often attempted to strike a balance between systems of care that reflected their needs, preferences, and timelines. In a smaller number of cases ( $n=4$ ; 11.8%), however, participants expressed a sense of powerlessness and constraint in their negotiations of care. These participants had needs that exceeded the publicly funded home care services they were allotted, yet had few economic and/or social means to access additional support. As such, it was more difficult for these participants to strike a balance between systems of care that reflected their needs, preferences, and timelines. To cope with unmet needs, these participants sometimes expressed considerable guilt as they

turned to family to “fill in gaps.” They also sometimes struggled to do things for themselves (i.e., practise self-care) when both home care services and support from family and friends were insufficient. As these participants contended with mental and physical health conditions, restricted access to publicly funded home care services, and small networks of support from family and friends, it was often difficult for them to make meaningful choices regarding their care arrangements.

*Turning to family to fill in gaps*

When some participants had needs that exceeded the publicly funded home care services they were allotted, they felt that they had no choice but to turn to family to “fill in gaps” in care provision. These participants had close relationships with their family members and appreciated their support. Yet, they expressed a sense of guilt or ambivalence about relying on them for significant help, and would have preferred to receive more formal home care. Rosa, for example, explained how she relied heavily on her daughter Megan to help organize formal care and to fill in gaps where home care services were inadequate:

*Rosa:* I don’t know how Megan's managed it all.

*I:* What sorts of . . . what sorts of things does Megan help you with?

*Rosa:* Well, Megan does all of it; she does all my shopping; she does all my medication and she’s always busy bringing me pads and diapers and toilet paper and Kleenex and she does it . . . all she can do . . . she’s very worn out . . . She can be angry, too, but I don’t blame her. If I had all her stuff that she lugs here to . . . for me . . . the toilet paper . . . all the stuff. She says she’s a bag lady (Rosa, 93).

Rosa felt guilty about the demands that her care needs placed on Megan, but felt that she had no other choice due to the limited availability—and sometimes the poor quality—of the publicly funded home care she received. When asked if she needed more

help with anything, for example, Rosa replied, “you know...if I say anything my daughter will kill me . . . it’s the cleaning.” Rosa felt that she could not ask for more help because Megan was already doing so much, and that she could not voice complaints about home care services because she would sound too demanding. Rosa faced challenges as she negotiated relations of support with formal care providers and family caregivers because of her various physical and mental health problems, with which she struggled on a daily basis, and because of limited social support—unlike some other participants who had large, complex networks of support, Rosa’s daughter was the only family member who helped her regularly. Moreover, Rosa did not have the financial means to pay privately for more help.

Like Rosa, Louisa experienced challenges due to the limited availability of home care and turned to family to fill in gaps in organizing formal care. Louisa expressed struggles with inadequate and fragmented care and discussed the conflicting and unsupportive relationships she had with both home care workers and with her case coordinator. For example, Louisa described how she received care from a roster of home care workers and felt that some of them did not follow proper standards for hygiene when they helped her to bathe or prepare meals. She also had experiences where care providers came to her home with bad colds, and thus put Louisa’s health at risk. Louisa felt that her case coordinator paid little attention to these complaints and failed to ensure that she received adequate care.

Given the many problems that Louisa experienced as she attempted to obtain consistent, high quality care, she found it incredibly stressful to navigate the formal care

system. Louisa therefore turned to her son, Jesse, for advocacy and to organize and manage formal care. Louisa lived with Jesse, who also participated in the interview, and at times spoke on Louisa's behalf when she found it too emotionally upsetting to discuss her experiences. Jesse's ability to help his mother with physical tasks was limited because he had muscular dystrophy, and Louisa did not have other family or friends that helped her. Yet, Jesse played a significant role in managing care (see also Rosenthal et al., 2007), and expressed that her mother would not be able to cope without his help. Due to insufficient home care, Jesse took on some of the roles that might otherwise be the responsibility of a case coordinator. As Jesse stated:

So, it's a very fragmented system and I think, like, when you were asking about how sort of involved I am, I truly think that if I were not here and if I were not advocating for my mom, my mom . . . I . . . I think she would just crumble because . . . it's so emotionally upsetting . . . to have all of these issues happen all the time and to constantly be advocating. And I think in some ways, like I think if she was living, like, on her own, . . . I just don't think she would be able to cope and yet, at the same time, too, home care is supposed to be helpful and make things easier, yet it's not (Jesse, son of Louisa, 74).

Rosa and Louisa experienced inconsistencies and inadequacies in publicly funded home care. Rather than strike a balance between formal and family/friend care that reflected their needs and preferences, they turned to a sole family member to "fill in gaps" where home care services were insufficient. Rosa's and Louisa's adult children took on significant responsibilities for care—not because these participants preferred to receive support from their children, but simply because no other options were available to them: publicly funded home care services were insufficient, and these participants had neither the financial means, nor the social networks to access care elsewhere. Rosa and Louisa

therefore felt constrained in their capacity to make meaningful choices in their negotiations of formal home care and family caregiving.

*Practising self-care due to unmet needs*

Some participants also discussed their self-care practices as “struggles” that occurred when they had needs that exceeded both the formal home care they were allotted as well as the caring capacities of their families and friends. When asked about the things she did to care for herself, for example, Angela explained the things she did to “get by” with everyday activities: Angela needed to bathe at specific times so that she could attend her frequent medical appointments. Yet, home care did not always come at the right time. As an alternative, Angela found a new way of bathing that she could manage alone: she took a sponge bath. Modifying activities to maintain a sense of independence was a meaningful self-care practice to some participants, such as Kate, described earlier.

Angela, by contrast, engaged in this “self-care” practice because she had no other options:

Yeah, well if you have to go down to the hospital every day, you want to be clean first. I want to be clean. More than one [shower] every two weeks like I’ve had lately. I’m so tired of sponge bathing; I could kill it. But then you’ve agreed not to have a shower unless there’s somebody in the apartment . . . I sponge bathe every day but it’s still a pain in the b-hind. It takes a lot longer (Angela, 65).

Angela would have preferred more help with bathing at the time of her choosing, rather than have to resort to sponge baths. Moreover, Angela did not feel that she could turn to family or friends for assistance: her relationships with family were marked by a troubled childhood, with a history of family alcoholism and physical abuse. Given her difficult upbringing, Angela had chosen never to marry or have children of her own. She had some close friends, but they had their own problems and were unable to provide support. Add

to this that Angela lived on a fixed income, and therefore simply did not have the means to pay for more formal home care privately. Angela had recently moved to an apartment in seniors' housing, yet felt as though she had been cheated out of services:

Well, I'm geared income, so . . . I don't have any extra income. It goes to rent. So, I wouldn't have any extra, and they tried . . . That was one of the stresses when I moved here, is they got me into the program, and then a week later after they get me into the program, then they came in and told that I have to pay seventeen dollars an hour. Well, I can't afford seventeen dollars an hour for nursing care. And that was about ten days after they had started the program in here. And they knew darn well they were going to say that . . . And I don't have . . . My one girlfriend just moved to Florida this weekend, and another girlfriend, her husband just tried to commit suicide so . . . they are busy (Angela, 65).

Yolande similarly discussed the struggles and the sense of powerlessness that she experienced as she attempted to care for herself, in the face of limited home care and family support. Yolande described how she struggled to clean her own apartment and to run errands, and how her practices of "self-care" actually exacerbated the chronic pain that she experienced:

*Yolande:* Every two weeks, they [home care workers] come in for twenty minutes.

They wash my floors and they clean the bathroom and if there's a few dishes, they'll do the dishes and that's it.

*I:* Okay.

*Yolande:* I don't get anything else. I've asked for more help but . . . see, I don't know if you'll notice on the floor, there's a lot of marks.

*I:* Hmm.

*Yolande:* That was all black marks and I had . . . I had to get down on my backside and scrub them because they won't do that. Yeah. She [case coordinator] said you'll get . . . she said I'd get an hour every two weeks but they're in and out of here like nothing. Because I . . . I keep things clean; I don't like dirt.

*I:* Sure, yeah.

*Yolande:* . . . and I keep clean as much as I can and usually, after I've done what I did here, I'd be in bed for three days (Yolande, 72).

Yolande also explained how she managed, with difficulty, to buy her own groceries. Unlike David, who could turn to his daughters for assistance with grocery shopping when necessary, Yolande lacked family support— although she had raised five children alone after leaving an abusive husband, only three of her children were still alive, and none provided regular support. Thus, Yolande felt she had no choice but to buy groceries alone:

Well, the shopping; I shouldn't really be doing it. I shouldn't be picking and lifting things. But I do it. What else? Well, I do . . . I do most things . . . I do the harder things that [home care] won't do. But, again, I have to be capable at the time. I have to be in less pain and have the energy because by four o'clock, I'm ready to sleep (Yolande, 72).

Like Angela, Yolande would have readily accepted more help. Yet, Yolande expressed that she had no other choice but to clean her own apartment and run errands: her efforts to access more care were unsuccessful, she lived on a fixed income and could not pay for additional help herself, and she had no family members or friends who provided regular support.

The cases presented above illustrate the powerlessness and vulnerability that some individuals face in their negotiations of care; particularly when they lacked financial means and support from family and friends. These participants had few choices available to them in their negotiations of care, and it was therefore difficult for them to strike a balance between systems of care that reflected their needs, preferences, and timelines.

### ***Summary***

In this chapter, I have drawn on data from qualitative interviews with 34 older care recipients to describe how they negotiate the intersections of formal home care,



family/friend caregiving, and self-care. Using an interpretive framework to give insight into the everyday realities of older care recipients, I suggest that participants' negotiations of care can best be understood as a *balancing act*. Participants attempted to strike a balance between the formal home care they received and their relations of support with family members and friends, and between their self-care practices and the care they received from others. Findings suggest participants' concerns about burdening others, and maintaining a sense of "independence" even in the face of chronic conditions and impairments in later life, translate into practical strategies of negotiating care arrangements. In turn, these negotiations have consequences for the intersections that exist between systems of care.

I have conceptualized participants' negotiations of care along a continuum, that ranges from situations where participants were able to strike a balance between systems of care that reflected their needs, preferences, and timelines; to situations where *imbalances in care* left participants with unmet needs (see Figure 1). Participants expressed varying degrees of control and autonomy in their negotiations of care, and sometimes had complaints about certain aspects of the support they received. Yet, the majority of participants ( $n=30$ ; 88.2%) typically expressed some sense of balance between formal home care, family/friend caregiving, and self-care.

In a smaller number of cases ( $n=4$ ; 11.8%), participants expressed a sense of "imbalance" in their negotiations of care. In these cases participants had needs that exceeded the publicly funded home care services they were allotted. At the same time, little access to financial or social resources made it difficult for them to access additional

support. As such, they expressed guilt about relying on family for help, or struggled to care for themselves and to “get by” with daily activities. These participants’ negotiations of care tended to be characterized by a sense of powerlessness and vulnerability.

In the next chapter, I will draw on previous research and explain how these findings contribute to knowledge on the intersections of formal home care, family/friend caregiving, and self-care. Specifically, I suggest how these findings can be conceptualized using Kemp et al.’s (2013) convoy of care model, and can extend some aspects of this model. I will then draw on findings to illustrate how *age relations* can be used to understand experiences of later life care. To demonstrate the practical applications of age relations in the context of care, I will explain how older care recipients experience and respond to age relations, or “do age,” as they are positioned at the intersections of self-care, formal home care, and family/friend caregiving.

## **Chapter 6: Discussion**

### ***Implications of findings for “convoys of care,” and for theorizing age relations***

#### ***Introduction***

In the previous chapter, I conceptualized older people’s negotiations of formal home care, family/friend caregiving, and self-care as a balancing act. Participants attempted to strike a balance between (1) their capacity to care for themselves and the care they received from others, and between (2) the formal home care they received and their relations of support with family members and friends. I suggested that participants’ negotiations of care exist along a continuum; ranging from situations where they were able to strike a balance between systems of care that reflected their needs, preferences, and timelines, to situations where imbalances in care left participants with unmet needs (see Figure 1). When participants negotiated their care arrangements, I suggest that they attempted to reconcile the tensions that exist between the realities of impairment, illness, and needs for care on the one hand, and on the other hand the desire to remain self-sufficient and to avoid “burdening” others with their care needs.

In this chapter, I will discuss these findings in relation to extant literature that explores older people’s negotiations of formal home care and family/friend caregiving (and to a lesser extent, self-care). Some other studies suggest that the boundaries between formal and family care are artificial, as older care recipients do not clearly distinguish between these systems of care (Allen & Ciambrone; Porter et al., 2004). Adding complexity to these findings, however, my findings suggest that older care recipients are aware of the potential limits of family and kin care and engage in practical strategies to negotiate the intersections that exist between them.

These findings, I suggest, can be best conceptualized using Kemp et al.'s (2013) convoy of care model and can extend some aspects of it. The convoy of care model integrates formal care, family/friend caregiving, and self-care, and considers the broader contexts that shape the intersections between these systems of care. Drawing on the convoy of care model, I discuss how the policies that guide the structure and delivery of home and community care services in Ontario impact on older care recipients' negotiations of formal home care, family/friend caregiving, and self-care. To be sure, the impacts of policies on care recipients' experiences have been considered elsewhere (e.g., Aronson, 2002; Aronson & Neysmith, 1997; Grenier & Guberman, 2009). I suggest, however, that the convoy of care model is particularly useful for considering how socio-structural contexts frame negotiations of care, and in turn have implications for the relationships that exist between and among individuals involved in care relationships (i.e., "convoys"). Drawing on my findings I also suggest that a critical understanding of 'self-care'—as a personal responsibility in neo-liberal contexts—could add an important layer of theoretical depth to the convoy of care model. Such an understanding of self-care provides insight into the meaning and value that care recipients attribute to self-care, which in turn has implications for the nature and structure of convoys of care.

While these findings help to develop a substantive understanding of the intersections of self-care, formal home care, and family/friend caregiving from the perspectives of care recipients, they also give insight into a broader social phenomena that informs convoys of care and yet is underexplored within extant literature on care: the implications of *age*—as a set of social relations that are produced, sustained, and perhaps

challenged through social processes, cultural discourses, and everyday practices—for experiences of receiving care in later life. In this chapter, I revisit the findings presented in Chapter Five to address the following questions:

- How can the concept of age relations be used to understand older people's negotiations of formal home care, family/friend caregiving, and self-care?
- How do older people experience and construct age relations while they receive care from others, and practise self-care?

Exploring how individuals construct age relations as they receive care in later life and as they practise self-care is important, I suggest, because it sheds light on an everyday setting in which relations of power, dependency, and control between and among people of different ages are worked out. In brief, I suggest that participants both reproduce and challenge the social processes and cultural discourses that are at the basis of age relations when they negotiate the intersections of self-care, formal home care, and family/friend caregiving. In some cases, however, participants also experience age-based disadvantages in their negotiations of care. At a practical level, these experiences and responses to age relations then have consequences for older people's care arrangements or "convoys of care." At a theoretical level, participants' experiences and responses to age relations give insight into the interactional processes through which social structures and cultural discourses are both sustained and contested, and to the intersecting inequalities that frame experiences of care in later life.

### ***Contributions of findings to previous research***

In Chapter Five, I suggested that participants attempted to strike a balance between the systems of formal home care, family/friend care, and self-care to reconcile

their concerns about being self-sufficient and imposing too many demands on others with the realities of their care needs in later life. I suggest that these findings add complexity to the small number of studies that focus specifically on care recipients' negotiations of formal and family/friend care (Allen & Ciambrone, 2003; Porter, 2005; Porter et al., 2004). These other studies suggest that dichotomous constructions of "formal" and "informal" care, depending on whether or not the care provider is paid, may not reflect the realities of people who are receiving care. Previous research suggests that older care recipients might not clearly differentiate between these systems of care (Porter et al., 2004), and that formal care providers might take on tasks normally performed by family members and vice-versa (Allen & Ciambrone, 2003). Some of my findings are consistent with these others studies: they suggest that complex intersections do indeed exist between systems of care and that participants engage support from various sources, beyond the specific tasks that are commonly associated with either formal or family care. On the one hand, for example, some participants developed "family-like" relationships with formal care providers, such as when Phillip treated home care workers like daughters. On the other hand, participants' family members sometimes took on the roles that are typically the responsibility of formal care providers, such as when Louisa's son acted as a case coordinator.

Despite some consistencies with other studies, some of my findings contrast with previous research that explores older people's responses to formal and family/friend care. Porter et al.'s (2004) study of older widows' classifications of help from various sources suggests that dichotomies between formal home care and family/friend caregiving do not

reflect the realities of older care recipients' lives. The systems of "formal" and "informal" care may indeed be regarded as social constructions. In contrast to Porter et al.'s (2004) findings, however, participants in this study considered self-care, formal home care, and family/friend care to be distinct systems, and often engaged in specific strategies of negotiation as they were positioned at the intersections of these systems of care.<sup>13</sup> I suggest that participants' negotiations of can best be understood using Kemp et al.'s (2013) convoy of care model, and can perhaps extend the understanding of "self-care" that is presented in this model.

The convoy of care model was developed through empirical research on the care arrangements of assisted living residents in the United States (Kemp et al., 2013; Perkins et al., 2013). It considers care recipients, as well as formal and family/friend caregivers, to be active participants who engage in negotiations in socio-structural contexts. The convoy of care model provides a framework to conceptualize the relationships that exist between and among various individuals involved in care arrangements, and to consider how multi-level factors that exist at the "societal, community, facility and individual levels" shape negotiations of care (Kemp et al., 2013, 17). It may be contrasted with "conventional" models of the relationship between formal and family care, such as the

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<sup>13</sup> The discrepancy between my findings and those of Porter's is likely related to the fact that actually *receiving* formal home care was not an eligibility criterion in her research (Porter, 2005; Porter et al., 2004). Participants simply classified the various people who helped them, regardless of compensation, according to the types of help they provided. By contrast, all participants in my study used either publicly funded or privately paid formal home care. I asked participants directly about their experiences with formal home care, and also about their self-care practices and relations of support with family members and friends.

hierarchical compensatory, substitution, task specificity, and complementary models. These conventional models often fail to account for the processes of negotiation that occur at the intersections of systems of care, and tend to overlook the broader socio-structural and cultural contexts that shape care arrangements (Kemp et al., 2013; Ward-Griffin & Marshall, 2003).

Factors that influence the negotiations of convoy members (e.g., care recipients and providers) include broader values about personal and familial responsibility for later life care, policies that guide the delivery of home and long-term care services, and socio-structural relations of inequality associated with age, class, gender, or race/ethnicity (Kemp et al., 2013). In what follows I will show how this study's findings add empirical support to the convoy of care model, and can extend some aspects of it. I will articulate how the neo-liberal rationales that underlie home care policies, as well as assumptions and expectations about "self-care" in later life, had implications for participants' negotiations of care.

The convoy of care model suggests that "broader social, economic, and political forces . . . shape the labor market, the balance between formal and informal care, social policy . . . ultimately affecting who gives and receives care and under what conditions" (Kemp et al., 2013, 20). My findings illustrate how the mixed-market model of home care in Ontario impacts on older care recipients' access to formal home care and family/friend caregiving, and practices of self-care. As explained in Chapter One, older people who are in need of home care in Ontario may undergo an assessment to gain access to publicly funded home care services (Ontario Association of Community Care Access Centres,



2014; Peckham et al., 2014). These services, however, tend to be restricted in a context of neo-liberal reforms and cost cutting; where responsibilities for later life care are increasingly transferred from the state to families and individuals (Funk, 2013; Martin-Matthews et al., 2013; Neysmith, 2000; Ward-Griffin & Marshall, 2003). As other scholars have acknowledged, this transfer in care work under neo-liberal reforms reflects ideologies of familism—namely, the gendered beliefs that family members (most often women) are available and willing to take on primary responsibility for later life care (Baines et al., 1998; Ward-Griffin & Marshall, 2003).

Contrasting with the policy emphasis on family responsibility for care, participants often expressed a preference for formal care for long-term and personal care; a finding that is consistent with other studies on older people's preferences for care in Canada (Kemp & Denton, 2003). While many participants enjoyed close and supportive relationships with kin, they did not necessarily want them to become heavily involved in caregiving. To varying degrees, participants had internalized the stigma and shame that tends to be associated with dependency in later life (see Calasanti & Slevin, 2001).

Participants' care convoys, including who was involved in giving care, can be understood at least in part as an outcome of their efforts to reconcile the tensions that exist between policy assumptions about family responsibility for later life care, and their deep concerns about the demands that their care needs may place on others. When participants had needs that exceeded the services that were available through the publicly funded home care system, for example, some felt as though they had no choice but to rely heavily on family and friends for support. In other cases, care recipients and families with

the financial means paid for home care services that were available through a burgeoning private home care industry. In other cases still, individuals coordinated their care networks, and engaged in relations of reciprocity, to avoid imposing what they considered to be undue demands on any one person. Regardless of the particular strategy of negotiation, these findings highlight how policy structures have impacts on the nature and structure of older people's care convoys, including the relations that exist between and among individuals involved in care relationships.

Kemp et al. (2013) consider self-care to be an aspect of convoys of care, and importantly, the convoy model can be used to conceptualize the intersections between self-care practices and support from others. Yet, this model has not necessarily integrated the links between self-care practices at the individual level and broader socio-cultural contexts. Within the convoy model self-care practices tend to be taken for granted as a set of activities, with less attention paid to the social and cultural meaning of self-care. For example, how do social and cultural expectations about self-care in later life impact on older care recipients' negotiations of care, and how does this influence the outcomes of care convoys? To extend the convoy model of care, my findings provide insight into how expectations about personal responsibility for health and well-being shape participants' negotiations of care—including their relationships and expectations for support from both formal care providers and family/friend caregivers.

A critical perspective on self-care considers how individuals are increasingly positioned as “active consumer[s] of health care” in late modern, neo-liberal societies (Hurd Clarke & Bennett, 2013, 211). In this context, individuals—rather than the state—

are typically considered to be responsible for health and well-being (Higgs et al., 2009; Hurd Clarke & Bennett, 2013; Lupton, 1995). This neo-liberal ethos guides policies and practices in various domains, including those related to older people's health and self-care. For example, health care research and practices provide guidance for older people to engage in certain forms self-care, such as exercise, to avoid the "hazards" of mental and physical decline in later life (Higgs et al., 2009, 689, see also Katz, 2000; S. Williams et al., 2012).

Reflecting neo-liberal discourses, the older care recipients in my study assumed a high degree of personal responsibility for health and well-being. Health care professionals had advised many participants on specific self-care practices, and participants often considered self-care, such as diet and exercise regimes, to be a means of staving off age-related declines and future dependencies. In turn, the meaning and value that participants attributed to self-care had consequences for the relationships between and among individuals involved in care convoys. Often, these relationships were premised on efforts (on the part of both care recipients and providers) to preserve care recipients' sense of self-sufficiency or independence to whatever degree possible. Even when participants sought out and accepted others' support, they still wanted to do as much as possible to care for themselves. Such an understanding of self-care—as an individual responsibility in neo-liberal contexts—could therefore add an important layer of theoretical depth to the convoy of care model. Participants practised self-care in specific social and cultural contexts, and this had implications for the nature and structure of participants' convoys of care.

Finally, one of the purposes of the convoy model of care is to show how particular aspects of convoys of care may lead to specific outcomes. For example, some convoys of care might enable individuals to “age in place,” while others might precipitate a move to another environment to receive care (Kemp et al., 2013). My findings highlight the salience of social and financial resources for participants’ convoys of care. On the one hand, participants with strong networks of support from family and friends and/or with the financial means to pay for additional home care or other forms of support (e.g., paying family members for assistance, paying for cleaning help) often had greater control and autonomy in their negotiations of care. This often enabled them to “strike a balance” between systems of care that reflected their needs, preferences, and timelines. On the other hand, a small number of participants with few financial means and with small (or non-existent) networks of kin support experienced a sense of powerlessness and constraint in their negotiations of care, leading to “imbalances in care.” These different negotiations of care, framed by access to financial and/or social resources, had consequences for the nature and structure of participants’ care arrangements, or convoys of care.

In brief, the convoy of care model can be used to conceptualize how socio-structural contexts shape the negotiations that exist among members of convoys, including care recipients. Moreover, my findings suggest that a critical understanding of “self-care” as an individual responsibility could add an important layer of theoretical depth to the convoy of care model: it helps to understand the negotiations that occur as individuals balance their capacity to care for themselves with the support they receive

from others. The convoy of care model also recognizes that intersecting inequalities and relations of power, privilege, and disadvantage associated with gender, class, race/ethnicity, age, health, and sexuality frame negotiations of care (Kemp et al., 2013). While my findings cannot give insight into the significance of each of these social relations for participants' convoys of care, they do have implications for understanding the implications of *age relations* for older people's negotiations of care. Because age relations are a significant—yet underexplored—aspect of older people's negotiations of care, I will explain how participants experienced, reproduced, and challenged age relations as they received care from others and as they practised self-care. In doing so I give insight into the implications of age relations for the outcomes of participants' "convoys of care"—and into the complexities that exist between conformation and resistance to social structures and cultural discourses associated with age.

***Age relations and receiving care: The significance of social processes, cultural discourses, and everyday practices***

In what follows, I revisit the findings presented in Chapter Five to illustrate how participants both reproduced and challenged age relations, and sometimes experienced age-based disadvantages, in their negotiations of care. In other words, I consider how older people construct age relations, or "do age," as they negotiate the intersections of self-care, formal home care, and family/friend caregiving. Such an exploration gives insight into the interactional bases of age relations, and enriches understandings of the interconnected social processes, cultural discourses, and everyday practices through which age relations are produced, sustained, and perhaps challenged. To begin, I review

the conceptual understanding of age relations that was presented in Chapter Two (theoretical framework) to describe the aspects of age relations that are salient to the opportunities and constraints that older people face when they are receiving care from others.

Recall that age relations constitute an array of (1) social processes, (2) cultural discourses, and (3) everyday practices that produce and sustain relations of power and inequality between and among people of different ages (Calasanti, 2003; Calasanti & Slevin, 2001, 2006; Krekula, 2009; McMullin, 2000, 2009). As outlined in Chapter Two, social locations associated with age—and also with gender, class, and race/ethnicity—shape one's positioning in relation to the social processes of production, reproduction, and distribution, and consequently one's access to power and status in society (McMullin, 2009). The older care recipients in my study no longer worked for pay and were therefore no longer directly involved in the processes of production and distribution. To varying degrees the chronic illnesses and impairments that they experienced in later life limited their capacity to engage in relations of reproduction, for example to care for others. On a surface level, therefore, older care recipients were in positions of relative powerlessness due to their positioning in relation to the social processes of production, reproduction, and distribution.

Although being a care recipient tends to be associated with relative powerlessness, age intersects with other social locations such as gender, class, and race/ethnicity to shape differences in the opportunities and constraints available to older people in need of care. Given that inequalities accumulate over the life course (Ferraro & Shippee, 2009), older

care recipients' access to power and status was shaped by their positioning in relation to social processes of production, distribution, and reproduction throughout their lives and not just in later life (McMullin, 2009). In general, however, a consideration of the social processes that produce and sustain age relations would suggest that older people in need of care experience a loss of power due to their dependency on others. These older care recipients tend to be regarded as “as consuming resources while dependent on others for the production of those resources” (Stone, 2003, 61).

In addition to the social processes that shape inequalities at a structural level, age relations are produced and sustained through cultural discourses that are conveyed through texts, language, and images (Gullette, 2004; Twigg & Martin, 2015). Cultural discourses shape assumptions and expectations about aging including the opportunities that are available to individuals at different points in their lives and the relations that exist between and among people of different ages. As explained in Chapter Two, Western culture tends to celebrate youth while diminishing the status and power associated with old age. For example the bodily and health changes that occur in later life are typically conceived of as “decline,” (Gullette, 2004), and to “age successfully,” means to *avoid* these changes (Angus & Reeve, 2006; Calasanti, 2003). Care needs tend to signify a transition from the “third age” of activity, to the “fourth age” that is characterized by dependence (Grenier, 2012; Lloyd et al., 2014) and a “failure” to meet the mandates of successful aging (Calasanti, 2003; Calasanti & Slevin, 2001).

In alignment with neo-liberal discourses and political rationales that hold individuals personally responsible for health and well-being in later life (Breheny &

Stephens, 2012; Katz, 2000; Rose, 2000), individuals who are in need of care tend to be perceived of as burdensome “others” (Fine & Glendinning, 2005; Weicht, 2013). They are often considered primarily, if not solely, as service users with few opportunities to occupy other roles or make meaningful social contributions (Grenier, 2012). Although participants in this study had diverse experiences, the realities of chronic illness and impairment meant that they were positioned outside of the ideals of good health and productivity that are celebrated in cultural discourses of aging and are based on activity, such as that of “successful aging” (see Katz, 2000).

While age relations are produced and sustained through social processes and cultural discourses, they emerge through the dynamic interplay of structure and agency: through everyday practices of “doing age,” individuals both reproduce—and challenge—dominant and deeply embedded social structures (McMullin, 2009) and cultural discourses (J. Coupland, 2009). Through their negotiations of care, for example, individuals may reproduce assumptions and expectations about the behaviour that is considered appropriate for people of different ages. At the same time, they may act in ways that challenge the ways in which privileges, opportunities, and constraints are distributed among people of different ages, as well as deeply held beliefs and values about the behaviour and activities that are considered appropriate for individuals at different points in their lives.

### ***Everyday practices of age relations***

Participants’ actions and interactions, as they negotiated the intersections of self-care, family/friend caregiving, and formal home care, represent complex and sometimes



contested experiences and responses to age relations. As such, findings give insight into older people's *agency* as they "do age" in the face of social processes and cultural discourses that tend to depict older people in need of care as relatively powerless. I suggest that participants in this study both reproduced and challenged age relations in their everyday negotiations of care—and in some cases, experienced age-based disadvantages. On the one hand, participants conformed to the cultural ideals of independence, and in some ways *reproduced* the view—deeply embedded in cultural discourses associated with age—that older people who rely (perhaps too heavily) on others for care are "burdensome" or "dependent." On the other hand, participants attempted to strike a balance between systems of care that aligned with their needs, preferences, and timelines. In doing so, they challenged the view that older people in need of care are powerless. In some cases, however, participants with limited financial means, and with little or no kin support, experienced some disadvantages that were associated with age and impairment—in the context of available home and community services. These participants experienced a sense of powerlessness and vulnerability in later life. Findings therefore illustrate the complexities that exist between conformation and resistance to social structures and cultural discourses that are associated with age, as well as the intersecting inequalities that frame experiences of care in later life.

#### *Reproducing age relations*

As explained in Chapter Five, interview findings suggest that participants' negotiations of care were framed, first and foremost, by their desires to remain self-sufficient or "independent" and to avoid burdening others with their care needs.

Participants negotiated their care arrangements to show that they, personally, were not imposing undue demands on others. To do this, participants sometimes (1) practised self-care to minimize their reliance on others; and (2) turned to formal care rather than family/friend care when care needs arose. Through such negotiations of care, I suggest that participants were experiencing and responding to age relations—or “doing age”—in ways that upheld differences among older people according to health status or level of impairment. Such differences are embedded in the cultural discourses of the third and fourth ages (Grenier, 2012), and admonish older people to remain self-reliant in later life (Breheny & Stephens, 2012; Katz, 2000; Kemp & Denton, 2003; Rubinstein & de Medeiros, 2015).

To minimize their reliance on family members and friends as well as on formal home care, participants engaged in such self-care practices as exercising and eating healthfully to keep their care needs from increasing, and doing as much housework as possible—even while receiving help for these activities—to avoid appearing “too dependent.” Participants highly valued healthy lifestyles and attempted to stave off age-related decline and avoid future dependencies. Consider, for example, the self-care practices of Lise, whom we met in Chapter Five. Although Lise received help from others, she emphasized first and foremost her “independent nature” and expressed that it was very important for her to stay active and to do as much housework as possible, in following the advice of her doctor. In addition to maintaining her physical health Lise did cognitive exercises, such as arithmetic, to keep her mind alert and to minimize the risks of dementia. Lise’s self-care practices may be understood in a context where concerns about

aging extend from bodily to cognitive decline, including profound fears about developing dementia (S. Williams et al., 2012).

Lise's example suggests how participants reproduced age relations when they negotiated the relationship between self-care practices and care from others. The age relations that are embedded in cultural discourses suggest that staying physically active and mentally alert is a route to a good old age (Katz, 2000; S. Williams et al., 2012). These discourses are communicated to individuals through messages regarding self-care as means of health maintenance and illness prevention (Higgs et al., 2009; Lupton, 1995). As previously mentioned, in neo-liberal contexts individuals are increasingly held responsible for the self-care practices that are suggested by health care professionals, in order to stave off physical and mental decline in later life (Katz, 2000). When the older care recipients in this study practised self-care to minimize their reliance on others, they took personal responsibility for fulfilling the valued roles and ideals that are associated with self-care, productivity, and independence in later life—and attempted to distance themselves from the decline and dependence that is characteristic of the “fourth age.”

Given their concerns about burdening others with care needs, participants' negotiations of formal home care and family/friend care sometimes involved efforts to turn to formal care as a “first choice:” some participants paid for additional formal home care as a supplement or alternative to family care, and others avoided turning to family for additional help even when home care services were less than ideal. Consider, for example, how Joe and Fannie, a married couple, negotiated formal home care and family/friend caregiving. Joe and Fannie strongly expressed that they did not want to rely

on their children for help with housework and errands, even though their children lived nearby and they enjoyed regular visits with them. Like many other participants, Joe and Fannie felt that it was unfair for older people in need of care to ask too much of their adult children, who were busy raising their own families and building their careers (see also Kemp & Denton, 2003; Peters et al., 2006). Joe and Fannie used formal home care for help with housework, transportation, and errands, and also turned to Meals on Wheels when it became difficult for them to cook.

Turning to formal home care as a first choice, to reduce demands on family members, enabled participants like Joe and Fannie to retain an identity as “independent” even as they experienced increased needs for care (see also Breheny & Stephens, 2012). Participants felt that it was their personal responsibility to reduce the demands that their care needs placed on others. While participants were trying to distance themselves from views of older people in need of care as burdensome, they were reproducing the view, deeply embedded in age relations, that older people who do ask family members for too much help *are* in fact burdensome. At a practical level these ways of “doing age” had consequences for the relationships that existed between individuals involved in convoys of care. For example, participants did not want formal care providers or family/friend caregivers to “take over” the tasks they felt they could do independently, and they did not want needs for care to disrupt established family relationships.

While participants’ experiences and responses to age relations have implications for the nature and structure of convoys of care, they also show how dominant expectations about independence are reproduced through everyday actions and

interactions, in ways that sustain distinctions between older people according to health status or level of impairment. When participants attempted to avoid imposing too many demands on others and when they attempted to maintain a high degree of personal responsibility for self-care, they were implicitly sustaining the distinctions and resulting inequalities between older people who are “independent” and those who are “dependent.” While independence is celebrated as a cultural ideal and is a means of achieving successful aging, dependence tends to be stigmatized and is often regarded as shameful. In attempting to distance themselves from dependence, participants were sustaining cultural distinctions that lead to the marginalization and exclusion of people who have needs for care in later life *and* who are perhaps unable or unwilling to care for themselves. Through their negotiations of care, therefore, participants had internalized and were reproducing dominant assumptions about aging with impairments or chronic health conditions.

#### *Challenging age relations*

Although older care recipients reproduced some aspects of age relations, in other ways they *challenged* age relations when they negotiated the intersections of self-care, formal home care, and family/friend caregiving. At the same time as participants upheld that they were self-sufficient, they emphasized the importance of social support in later life. They did not feel that requiring support necessarily negated their sense of independence, and expressed a sense of interdependence between themselves and those who provide care for them. Through their negotiations of care, participants attempted to access care that contributed to their well-being, and that enabled them to maintain a sense

of autonomy as they received care from others. As such, they challenged the view—embedded in the social processes and cultural discourses that underlie age relations—that being a “care recipient” in later life signals an experience of decline, loss, and powerlessness. Participants challenged age relations when they sought and out accepted support on self-care practices, coordinated care from a variety of sources, and engaged in relations of reciprocity to ensure that they received adequate support in later life.

When participants faced limits to their capacity to practise self-care independently, they often sought out support and guidance that enabled them to continue to practise self-care in ways that were personally meaningful. Participants turned to formal home care providers, as well as family members and friends, for assistance and support with a variety of self-care practices. For example, participants sometimes arranged for care workers and family members to help them prepare meals that aligned with personal beliefs about a healthy diet, or had care workers support them while they walked. These negotiations of care enabled them to remain active and to leave their home space without having to worry about safety, and to engage in daily practices that were personally meaningful.

Consider Carol, for example, who expressed how important it was for her to follow a strict, healthy diet. Carol received formal home care for assistance with food preparation and her daughter helped with grocery shopping. These relations of support, however, did not signal a transition toward “dependence” or “decline.” To the contrary they represented a form of interdependence and enabled Carol to stay instrumentally involved in self-care practices related to eating. While Carol expressed an in-depth

knowledge of self-care practices and wanted to instruct care providers on how to support her, other participants highly valued advice on self-care. Martha, for example, greatly appreciated that her home care nurse had taught her how to raise her legs to reduce the severe swelling that she experienced as a symptom of cellulitis. Guidance and advice from a home care nurse enabled Martha to practise self-care in ways that she felt were important to her daily well-being.

The examples of Carol and Martha illustrate some of the contested ways of “doing age” that emerged as participants negotiated the relationship between self-care and care from others. As established participants assumed a sense of personal responsibility for health and well-being, reflecting cultural discourses of age relations that present health and well-being as the hallmarks of “active” or “successful” aging (Gilleard & Higgs, 2010; S. Williams et al., 2012). Yet, participants negotiated their care arrangements in ways that challenged the view of self-care as *entirely* an individual responsibility. For example, both formal home care and family care enabled Carol to maintain continuity with self-care practices that had been important throughout her life. For Martha, support and guidance on self-care actually presented an opportunity for growth and learning in later life. As participants negotiated their self-care practices they expressed a sense of interdependence between their capacity to care for themselves and the support they received from others.

To strike a balance between formal home care and family/friend caregiving, some participants actively coordinated their relations of support with family members, friends, and formal care providers, and engaged in relations of reciprocity with those who

supported them. Ruth, for example, was positioned at the centre of a large and complex network (or “convoy”) of formal home care and kin support, and made decisions about who would help her with which activities and when. Ruth exhibited a considerable degree of control as she attempted to balance formal home care and relations of support with family and friends. Ruth was aware, for instance, that she could turn to various individuals (both formal care workers and friends) to assist with grocery shopping. While Ruth did not want to impose an undue burden on others, she embraced care as a positive thing and felt that it contributed to her well-being as she contended with chronic health conditions and impairments.

As another example, Maggie conceptualized care from family and from formal home care workers in the context of close and supportive relationships developed over time. While Maggie felt well supported, she still exhibited reciprocity in her negotiations of care and this afforded her a sense of autonomy and control. Paying her son-in-law for assistance with transportation, for example, meant that Maggie could run errands at the time of her choosing without feeling guilty about turning to her son-in-law for help. This enabled Maggie to challenge the stigma and shame that tends to be associated with aging and impairment (see Calasanti & Slevin, 2001).

When participants accepted support from others and at the same time retained a sense of autonomy in care relationships, their actions had practical consequences for the relationships among people involved in “convoys of care.” For example, when participants negotiated formal home care and family/friend caregiving they made some choices about who would help them with which care activities, and when. Consistent with



other literature, examples where participants attempted to reciprocate or to give back to care providers (either financially, or in terms of emotional support) suggest that care relations involve a sense of interdependence and a sharing of power and control (de São José et al., 2015; Forbat, 2005).

In addition to enriching understandings of the relationships between members of convoys of care, the experiences and responses to age relations described above represent a challenge to the age-based relations of power and inequality that are conceptualized at the socio-structural and cultural level. Illnesses and impairments certainly may place older care recipients in a position of vulnerability. Yet, many participants in this study challenged the view that older people—and particularly older people in need of care—hold less power than those who are younger and able-bodied. Through their everyday negotiations of care, participants were challenging the stigma that is often associated with needing care in later life and the distinctions between people who are “aging successfully” and those who experience illnesses, impairments, and increased needs for care. Through their small acts of resistance to dominant assumptions about older people with care needs, participants’ everyday practices may be used to develop alternative ways of conceptualizing older people as interdependently and reciprocally involved in care relationships.

#### *Experiencing age-based disadvantages*

Although participants often expressed a considerable degree of control and autonomy when they negotiated their care arrangements, there were some less frequent cases ( $n=4$ ) where participants’ experiences were marked by a sense of powerlessness and

constraint—leading to “imbalances in care.” These participants had unmet needs. They either struggled to care for themselves, or turned to family to fill in gaps when formal home care services were insufficient. Angela, for example, felt that she was unable to access much needed care and to strike a balance between systems of care that reflected her needs, preferences, and timelines. She practised self-care to “get by” because the publicly funded home care services that were available to her were insufficient, and because she had few family or friends to provide assistance. As another example, consider Rosa’s negotiations of care. While Rosa turned to her daughter when home care services were inadequate, she expressed a sense of guilt about doing this. Yet, Rosa was reticent to voice complaints about home care to her daughter for fear that she would sound too demanding or unappreciative and therefore “put up” with the services that were provided.

Participants like Angela and Rosa were neither able to reproduce cultural ideals of independence in later life, nor were they able to express power and control in their negotiations of care—and perhaps challenge discourses of decline or dependency. Although choice and preference are presented as advantages of market-modeled care (Aronson & Neysmith, 1997), these participants’ experiences show how “choices” in negotiations of care can be restricted for those with few financial means, and—given assumptions of familial support—for those with more limited support from family or friends. This had consequences for the relationships that existed among individuals involved in care convoys: these participants felt as though they held little power relative to those caring for them

The experiences of participants who experienced age-based disadvantages give insight into the ways intersecting relations of inequality shape access to and experiences of receiving care in later life. Age relations alone do not shape opportunities and experiences in later life; rather experiences of aging emerge from the complex intersections between age, class, gender, and race/ethnicity relations, among other forms of difference. In the examples presented above the sense of powerlessness and vulnerability that some participants experienced may be best understood at the intersections of age and impairment, for those with limited financial means and social support. In the context of restricted access to home and community services, it was particularly difficult for participants on low incomes, or with small or non-existent networks of family support, to access the kinds of care they needed or wanted. By contrast some participants in more advantaged social locations were better positioned to access care that reflected their needs and preferences. These findings have implications for understanding the relations of inequality that exist *among* older people with chronic health conditions and impairments depending on their access to financial resources and social support.

### ***Summary***

In this chapter, I have discussed the main contributions of this study of negotiations of care and of age relations. I have suggested that socio-cultural discourses of personal responsibility for health and well-being, which tend to present older people in need of care as “burdensome,” translate into practical strategies of negotiating the intersections of formal home care, family/friend caregiving, and self-care. I have

conceptualized these findings using Kemp et al.'s (2013) convoy of care model, which provides a framework for linking socio-structural factors and individual negotiations of care. I have suggested, however, that a critical understanding of “self-care” as an individual responsibility in neo-liberal contexts could add an important layer of theoretical depth to the convoy of care model.

Kemp et al. (2013) recognize that age relations are a feature of care convoys, but the implications of age relations for older people's negotiations of care tend to be underexplored. To add conceptual and theoretical depth to the convoy of care model—and to understandings of older care recipients' experiences—I have drawn on this study's findings to theorize the interactional bases of age relations. In other words, I have suggested that negotiations of care constitute everyday practices through which individuals both reproduce and challenge age relations. In some cases, however, participants experienced age-based disadvantages as they contended with impairments in later life, insufficient home care, and little social support. These disadvantages occurred in a context where access to publicly funded home care services tends to be limited. Diverse experiences and responses to age relations have implications for older people's “convoys of care,” including the type and amount of support that formal care providers and family/friend caregivers provide, and the relations of power that exist between people who are giving and receiving care. At the same time, these findings give insight into the interconnected social processes, cultural discourses, and everyday practices through which age relations are produced, sustained, and sometimes challenged, and to the intersecting inequalities that frame experiences of care in later life.

As I explained in Chapter Five, some participants “accepted” formal and family/friend care without necessarily engaging in such purposeful negotiations of care. In these cases, it seems as though severe mental and physical health conditions placed limited on participants’ negotiations of care. This stance of “accepting care” made it more difficult to discern participants’ experiences and responses to age relations. As I will explain in the following chapter, more research may be required to discern how some individuals who appear to be less purposeful in their negotiations of care experience and respond to age relations.

The discussion presented in this chapter draws specific attention to individuals’ agency in the face of social processes and cultural discourses that present older care recipients as primarily dependent, burdensome, or powerless. These findings therefore help to advance theorizing on the interactional bases of age relations, in the practical context of care relationships. In the following and concluding chapter, I will draw together the arguments presented throughout this thesis to demonstrate its overall significance. I will address the strengths and limitations of this research, and identify questions for future research.

## **Chapter 7: Conclusion**

### ***Introduction***

Using data from a grounded theory study, this thesis has explored how 34 people aged 65 to 100 negotiate care and experience age relations. I have addressed how older people negotiate the intersections that exist between formal home care, family/friend caregiving, and self-care. I have also explored the age-based relations of power, privilege, and disadvantage that are relevant to contexts of care, and that shape (and are shaped by) the everyday realities of older care recipients. In this concluding chapter I will summarize and highlight the main contributions of this research. I will then discuss the value of the interpretive grounded theory methodology that I used to gather and analyze findings, and address the policy and practice implications of this research. Finally I will address the limitations of this study and identify questions that could be addressed in future research, to further advance understandings of older people's negotiations of care and experiences of age relations.

### ***Summary of findings and contributions***

#### ***The intersections of formal home care, family/friend caregiving, and self-care***

The findings presented in this thesis give insight into the everyday realities of older care recipients, as they are located at the intersections of the systems of self-care, formal home care, and family/friend caregiving. In the broader context of “aging in place,” long-term care policies in Ontario and across Canada increasingly consider the home to be the ideal site of care (Carstairs & Keon, 2009; UNFPA & HelpAge International, 2012). Evidence also suggests that many older people prefer to receive care in their own homes, rather than in hospitals or long-term care facilities (Mahmood &

Martin-Matthews, 2008; Wiles et al., 2012). Moreover, the neo-liberal philosophy that guides the structure and delivery of home and community services in Ontario (and in other parts of Canada and comparable countries), shifts caring responsibilities away from the state and toward the market, families, and individuals (Armstrong, 2010; Neysmith, 2000).

In this context, there are complex intersections between (a) the formal home care that individuals may access through a publicly funded system or purchase privately; (b) the support that older people in need of care receive from family and friends, and (c) older people's self-care practices—understood as the things that people do to maintain their own health, well-being, and living environments. Researchers have devoted considerable attention to the relationships that exist between formal home care and family/friend caregiving (Cantor, 1979, 1991; Chappell & Blandford, 1991; Greene, 1983; Kemp et al., 2013; Litwak, 1985; Ward-Griffin & Marshall, 2003). This literature, however, rarely considers the viewpoints and practices of the older people around whom systems of care are organized. Moreover, while older care recipients continue to practise self-care (Ball et al., 2004; Penning, 2002), there is only limited knowledge of the intersections that exist between older people's self-care practices and the care they receive from others, including formal home care providers and family/friend caregivers.

To extend knowledge on older people's positioning at the intersections of formal home care, family/friend caregiving, and self-care, I have suggested that participants' negotiations of care can best be understood as a *balancing act*. Participants attempted to strike a balance between (1) the formal home care they received and their relations of

support with family members and friends, and (2) their self-care practices and the care they received from others. Through these negotiations of care, participants attempted to reconcile their desires to remain self-sufficient and avoid burdening others with the realities of impairment, illness, and care needs in later life. I have suggested that these negotiations of care exist along a continuum; ranging from situations where participants were able to strike a balance between systems of care that reflected their needs, preferences, and timelines, to situations where imbalances in care left participants with unmet needs. Access to financial and social resources, moreover, significantly impacted on participants' capacity to strike an effective balance between systems of care.

This study gives insight into the everyday realities of older people who are receiving care, and has some important implications for knowledge of the intersections that exist between formal home care, family/friend caregiving, and self-care. Some previous research has suggested that the constructions of “formal” and “informal” care are artificial, and do not reflect older care recipients' perceptions of care (Porter et al., 2004). The findings presented in this thesis, by contrast, suggest that these systems of care—while indeed social constructions—have a particular significance and meaning for older care recipients. The meaning of these systems emerges in the context of social policies that shape the resources available to older people in need of care, and socio-cultural expectations that frame beliefs and values about later life care. On the one hand, home and community care policies hold that families—rather than the state—should be primarily responsible for older people's care needs (Funk, 2013; Neysmith, 2000; Ward-Griffin & Marshall, 2003). On the other hand, older people in need of care are faced with



socio-cultural messages that encourage individuals to be self-sufficient in later life and to avoid “burdening” others with their care needs (Breheny & Stephens, 2012; Weicht, 2013), and that present “self-care” as individual responsibility (Higgs et al., 2009; Hurd Clarke & Bennett, 2013). Participants’ profound concerns about maintaining independence and reducing the burdens that their care needs placed on family members therefore conflicted with the policy emphasis on family care.

Participants’ responses to conflicting policy and socio-cultural messages about later life care translate into very concrete ways of negotiating the intersections of self-care, formal home care, and family/friend caregiving. Most notably, participants’ concerns about maintaining self-sufficiency and “independence” impacted on their negotiations of the relationship between self-care and care from others. While impairments and illnesses in later life placed some limits on care recipients’ capacity to practise self-care independently, they still wanted to maintain as much personal responsibility for health and well-being as possible, reflecting neo-liberal discourses that present self-care as a means of achieving good health in later life (Higgs et al., 2009; Hurd Clarke & Bennett, 2013). Yet, participants recognized the limits to their self-care practices, and accepted support and guidance that enabled them to continue to practise self-care in ways that were personally meaningful. In addition to this, participants’ concerns about burdening kin impacted on their negotiations of formal home care and family/friend caregiving. Although participants accepted care that contributed to their well-being they engaged in specific strategies of negotiation to ensure that they did not impose undue demands on family and friends. For example, some participants paid family

and friends for assistance, or coordinated help from various sources and individuals to ensure that their care needs did not overwhelm any one person.

Through these strategies of negotiation, many participants were often able to strike a balance between systems of care that reflected their needs, preferences and timelines ( $n=30$ ; 88.2%). In some less frequent cases, however ( $n=4$ ; 11.8%), participants expressed “imbalances in care.” In other words, there was a disjuncture between participants’ needs and preferences for care on the one hand, and the supports and resources that were available to them—from either kin, or from the formal home care system. These participants tended to have limited social and/or financial resources. In these cases participants often expressed unmet needs and a sense of powerlessness in their negotiations of care.

While various models have been developed to account for the complex relationships that exist between formal home care and family/friend caregiving, the findings presented in this thesis are perhaps most consistent with the convoy of care model recently proposed by Kemp et al. (2013). Rather than focus only on the relationship between formal care providers and family/friend caregivers, the convoy model considers the intersections that exist between and among various individuals involved in care relationships—including care recipients, as they practice self-care and negotiate formal and family/friend care.

Using the convoy of care model I have explained how the policy context of home and community care services in Ontario—with restricted access to home care and an emphasis on family responsibility for care—impacts on older people’s negotiations of

formal home care, family/friend caregiving, and self-care. Moreover, I have suggested that a critical understanding of “self-care,” as an individual responsibility in neo-liberal contexts, could add an important layer of theoretical depth to the convoy of care model. Reflecting a neo-liberal ethos, the older care recipients in this study often assumed a high degree of personal responsibility for self-care. Here, the intersections of self-care and care from others may be seen to reflect efforts, on the part of both care recipients and providers, to maintain care recipients’ sense of independence and self-sufficiency to whatever degree possible. In turn, these negotiations of care have implications for the nature and structure of participants’ convoys of care, including the relationships that exist between and among people involved in giving and receiving care.

The convoy of care model recognizes that social relations of inequality associated with gender, class, race/ethnicity, and age frame negotiations of care. While my findings cannot give insight into all of these aspects of convoys of care, they do help to articulate the implications of *age relations* for negotiations of care in later life. As I will explain next older care recipients’ negotiations of care represent experiences and responses to age relations. Subsequently, participants’ ways of “doing age” have consequences for the nature and structure of convoys of care.

*The implications of age relations for experiences of care*

To contribute to the convoy of care model—and to sociological understandings of age as a source of power, inequality, and difference—this thesis has attended to the interactional bases of age relations. This work, I suggest, adds important insight into sociological research on aging, care, and inequality. Sociologists have clearly named

gender, class, and race/ethnicity as social relations of inequality that impact on everyday actions and interactions, and that are constructed through social and cultural processes (e.g., Choo & Ferree, 2010; Denis, 2008; Dill & Zambrana, 2009). With some exceptions, however, age relations are rarely explicitly *named* as social relations of inequality (Calasanti & Slevin, 2001, 2006; McMullin & Berger, 2006; Utrata, 2011; Zajicek et al., 2006). As I have noted, some studies on older people's experiences of care do implicitly address age relations. Some researchers, for example, consider older care recipients' subjective perceptions of old age (Allen & Wiles, 2014; Hammarström & Torres, 2010; Janlöv et al., 2005). To the best of my knowledge, however, the literature that exists on experiences of receiving care in later life does not *explicitly* name age relations, nor does it consider how age relations shape, and are shaped by, the interactions and experiences of individuals who are receiving care in later life.

The relative "invisibility" of age relations is problematic, I suggest, because it presents a barrier to developing a sociologically robust understanding of the social processes, cultural discourses, and everyday practices that are based on age. These processes, discourses, and practices are implicated in experiences and negotiations of care. Exploring how individuals construct age relations as they receive care in later life, and as they practise self-care, can therefore shed light on an everyday setting in which relations of power, dependency, and control between and among people of different ages are worked out.

Due to their relative exclusion from the social processes of production, reproduction, and distribution, older care recipients are thought to have little access to

status and power, although one's access to power depends on intersecting inequalities that accumulate over the life course (Ferraro & Shippee, 2009; McMullin, 2009). Moreover, cultural discourses present independence and activity as the hallmarks of "success" in later life, and hold individuals personally responsible for health and well-being (Breheny & Stephens, 2012; Katz, 2000; S. Williams et al., 2012). Individuals who fail to meet these mandates are "socially and culturally 'othered,' " and later life care comes to represent the decline, loss, and dependency that is characteristic of the "fourth age" (Grenier, 2012, 194; see also Gilleard & Higgs, 2010; Lloyd et al., 2014).

While age relations are produced and sustained through social processes and cultural discourses, my findings give insight on the interactional bases of age relations—they suggest how older care recipients might both reproduce and challenge age relations as they negotiate the intersections of formal home care, family/friend caregiving, and self-care. Reflecting the ideals of personal responsibility for health and well-being in later life, participants practised self-care to minimize their reliance on others and to maintain an identity as independent. They also negotiated their care arrangements to reduce the "burdens" that their care needs placed on kin. In these ways, participants reproduced beliefs and values about aging that are upheld in cultural discourses, and that encourage individuals to avoid "decline" and "dependence" in later life. These cultural discourses also distinguish between older people according to health status or level of impairment, as upheld in the models of the third and fourth ages (Grenier, 2012). Participants' attempts to maintain independence and self-sufficiency and to reduce the burdens that their care needs placed on others may therefore represent their efforts to conform to the cultural

ideals of independence and of self-care (i.e., the “third age”), and to escape negativity and powerlessness that surrounds the “fourth age.” Through their negotiations of care, therefore, participants were sustaining distinctions among older people according to health status or impairment and capacity to care for oneself.

Although participants reproduced some aspects of age relations, their negotiations of care also represent some challenges to dominant expectations and assumptions of age. At the same time as participants maintained an identity as self-sufficient, they accepted that care from others could contribute to their well-being. They sought out support and guidance that enabled them to practise self-care in ways that were personally meaningful, and they negotiated family/friend caregiving and formal home care to access care that reflected their needs, preferences, and timelines. In doing, so, these older care recipients challenged the view, embedded in cultural discourses, that needs for care in later life signal a transition toward decline and dependence, or that independence necessarily means doing things alone. Participants expressed the importance of reciprocity and interdependence in later life and challenged the distinctions between independence and dependence that are at the basis of age relations. In doing so they challenged the view that older people with illnesses, impairments, and care needs hold little power relative to younger and able-bodied people.

In this study, access to financial and/or social resources afforded some participants a greater sense of power or control in their negotiations of care. Older care recipients’ positioning in relation to processes of production, distribution, and reproduction throughout their lives—and not just in later life—shaped their access to power and status

(McMullin, 2009). As such, more advantaged participants were sometimes either able to pay privately for home care services, or had access to other resources (e.g., could pay for cleaning, lived in comfortable environments, and had a good knowledge of how to navigate the home care system) that afforded them a considerable sense of power and control in their negotiations of care.

Older people who are in need *and* who have limited access to financial and/or social resources, however, may be excluded from sources of power or status in later life. These participants experienced age-based disadvantages as they contended with impairments and care needs in later life, limited financial means, and small (or non-existent) networks of family/friend support. In these cases, participants struggled to do things alone, or relied heavily on a family member—and expressed a sense of guilt or ambivalence about doing so. These participants held little power in their negotiations of care because they were often reticent to speak up—either to formal care providers, or to family members—for fear that they would sound too demanding and potentially lose the assistance that they currently received. As such, these participants’ negotiations of care were characterized by a sense of powerlessness or vulnerability. These findings highlight how intersecting relations of inequality—associated with age and with access to social and financial resources—shape the opportunities and experiences of older people who are in need of care.

This study has provided insight into how older people experience and construct age relations, or “do age,” in their negotiations of care. It has advanced theoretical knowledge on the ways in which individuals may both reproduce and challenge age

relations through everyday practices (i.e., actions and interactions) as they negotiate care arrangements. More practically, these findings have significance for understanding how relations of power, privilege, and disadvantage frame the resources and opportunities available to older care recipients, as they are located at the intersections of self-care, formal home care, and family/friend caregiving. In turn, these negotiations of care and of age relations have consequences for care recipients' "convoys of care," including the relationships and the distribution of power between and among people who are involved in giving and receiving care. To fully appreciate the implications of this study, however, it is necessary to address its methodological implications, its potential contributions to policy and practice, and questions that could be addressed in future research.

### ***Methodological implications***

I employed an interpretive grounded theory design to gather and analyze data for this study and to give insight into older people's experiences of age relations and negotiations of care (Charmaz, 2006; Corbin & Strauss, 2008). This involved *intensive interviews* with 34 older people who were receiving home care. These interviews privileged older care recipients' voices, and an interpretive analysis of interview data enabled me to develop concepts that reflect participants' everyday realities and understandings of the world around them. Following the tenets of interpretive or constructivist grounded theory, however, I acknowledge that the findings presented in this thesis do not represent a singular "truth" or "reality" (Charmaz, 2006; Corbin & Strauss, 2008). Rather, these findings represent my interpretation of the stories participants told about their lives. Findings were constructed in the context of the research interview—a



situation that likely involved power imbalances between myself as a researcher and interview participants, despite my best attempts to position participants as experts in their own experiences and to mitigate power imbalances. Interviews were subject to further re-interpretation throughout the process of coding data. Thus, rather than representing a singular “truth” this study gives an understanding, albeit partial, of older people’s negotiations of care and experiences of age relations. I have provided rich, thick descriptions of data to duly give voice to participants, and to give readers the opportunity to evaluate findings based on an in-depth knowledge of participants’ experiences and situations (Creswell, 2013).

Interpretive grounded theory is an ideal framework for gathering data on participants’ experiences and interpretations of meaning in micro-contexts of interaction. Moving beyond the micro-context, however, this methodology enables researchers to consider the interlinkages between everyday practices of action and interaction, and the broader social conditions that shape participants’ more immediate experiences. In my analysis of data, therefore, I began with participants’ everyday experiences and then treated age relations as a sensitizing concept to draw my awareness to the social conditions that have consequences for older care recipients’ experiences and interpretations of meaning (LaRossa, 2005). I used this approach to consider the implications of age relations—as they are produced and sustained through social processes, cultural discourses, and everyday practices—for older people’s negotiations of care. Interpretive grounded theory therefore enabled me to consider how individuals experience, reproduce, and challenge age relations in their everyday practices, in the

context of the intersecting systems of self-care, formal home care, and family/friend caregiving.

### ***Policy and practice implications***

In addition to enriching sociological literature on care and age relations, the findings presented in this thesis may also contribute to policies and practices that guide the organization and delivery of home care services in Ontario and elsewhere, in order to improve the experiences of older people receiving home care. At the policy level these findings may be used to critique the heavy reliance on family members as “partners in care” that underlies home care policies (Funk, 2011; Peckham et al. 2014; Ward-Griffin & McKeever, 2000). Other research has considered the challenges and constraints that family caregivers often face as they attempt to balance care for older relatives with paid work, childcare, and other responsibilities (Baines et al., 1998; Hooyman et al., 2002; Keefe, 2011). Extending this critique, my findings suggest that the heavy emphasis on family reliance for care may also be problematic for older people in need of care. While many older care recipients express profound concerns about burdening family members and do want their care needs to interfere with established family relations, some older people simply do not have family members who are available to provide care. Policies that assume family members’ involvement in care may result in challenges and constraints in particular for some older people with small or non-existent networks of family support, and who lack the financial resources to purchase additional care services privately. As such, this research provides evidence for the development of home care

policies that do not assume high levels of family support, but rather ensure consistent, continuous home care services for all people who are in need.

While findings have implications for the development of more appropriate policies, they may also be used to improve practices at the level of direct home care service delivery. Specifically, these findings have implications for the development of person-centered and relationship-centered care—approaches that increasingly guide the delivery of home care services in Ontario and across Canada (Brookman, Jakob, DeCicco, & Bender, 2011). Key aspects of person-centered include sharing power among individuals involved in care relationships; respecting and accommodating clients' needs, perspectives, and interests; and involving clients in decision-making. Relationship-centered care, moreover, hinges on strong, mutually beneficial relationships between and among clients, family members, and care providers (Beach et al., 2006; Brookman et al., 2011).

Research findings may contribute to practice guidelines that are person- and relationship-centered insofar as they recognize older people's voices regarding the intersections self-care, family/friend caregiving, and formal home care. For example, findings suggest that older care recipients benefit from care that enables them to engage in self-care practices that are personally meaningful. While home care practice often focuses on the tasks that care providers do *for* care recipients, creating guidelines for working *with* care recipients in ways that support their capacity and desire to care for themselves would represent an important step in the development of person-centered care (see also Byrne et al., 2012). Such an approach would require flexibility in service

delivery, in order to enable care providers to give the kinds of assistance that diverse older people need. The development of person- and relationship-centered approaches could help to recognize older people's contributions to care, and to foster strong relationships between care providers and recipients.

### ***Limitations and questions for future research***

This thesis provides important insight into the experiences of older care recipients as they negotiate care arrangements, and experience and respond to age relations. Yet, there are some limitations with regards to the diversity of my sample and questions that merit attention in future research. In this thesis I have focussed primarily on the implications of age relations for older people's negotiations of care. Findings do suggest that access to social and financial resources impacted participants' negotiations of care. More research is needed, however, to discern how the intersecting locations of age, class, gender, race/ethnicity, and sexuality impact on older people's negotiations of care.

It is notable, for example, that all of the participants who expressed a sense of powerlessness in their negotiations of care were women. Older women tend to have lower incomes than men (Denton & Boos, 2007; McDonald & Robb, 2004), and they are also more likely to live longer with chronic health conditions and disabilities. To appreciate the implications of gender relations for experiences of later life care, a future study could explore how gender and age relations intersect as older people negotiate their care arrangements.

Evidence from other research also suggests that diverse racial and ethnic groups have different values regarding later life care, and may face different challenges in

accessing care (Lloyd, 2004). This study included some limited ethnic and cultural diversity: some participants had migrated to Canada from various part of Europe, but all participants were White. The findings did not point to noticeable trends in participants' negotiations of care in relation to cultural or ethnic background. Future research with a diverse sample of participants could fruitfully address how race or ethnicity intersects with age relations (as well as other social locations) to frame older people's negotiations of care.

A future study could also focus on lesbian, gay, bisexual, transgender, or queer (LGBTQ) care recipients, to explore if and how their negotiations of care and of age relations may differ from heterosexual care recipients. Other research has suggested that LGBTQ people in need of care may have family relations and care arrangements that differ from those among older people who are heterosexual. Older LGBTQ people's care networks might more likely involve "fictive kin" in the place of traditional family caregivers such as spouses or children (Brotman et al., 2003; Muraco & Fredriksen-Goldsen, 2011). Two participants in this study identified as gay or lesbian, and consistent with this research, friends, or fictive kin, were significant within their networks care. Like other participants, however, these two participants still negotiated their care arrangements to retain a sense of independence and to ensure that their care needs did not impose an undue burden on any one friend or family member. More research among LGBTQ people could explore broader trends or differences in their negotiations of care and experiences of age relations.

Participants in this study faced diverse health conditions and levels of impairment, and this provided important insight into the ways people with different abilities and needs negotiate care arrangements and age relations. It is notable that some participants with particularly debilitating health conditions tended to be less “active” in their negotiations of care. In some cases, these participants accepted both formal home care and family/friend care without necessarily engaging in purposeful negotiations of care. While these participants were generally satisfied with the balance of formal and family/friend care that they received, they did not necessarily feel that it was within their means to change their care arrangements if services were insufficient. These participants’ experiences fit somewhere in the middle of a continuum that ranges from situations where participants strike a balance between systems of care that reflects their needs, preferences, and timelines, to situations where imbalances in care leave participants with unmet needs. It was more difficult, however, to discern how these participants were “doing age.”

It would be useful to recruit more participants with especially debilitating health conditions to provide greater insight into the experiences of people who are perhaps less purposeful in their negotiations of care. I faced barriers when I attempted to recruit more participants with severe health conditions, however, because they were perhaps less likely to be aware of the study through the recruitment methods that I used (e.g., flyers, presentations at seniors’ groups, etc.). It is also possible that they may have been unwilling or unable to participate in interviews due the challenges they faced on a daily basis.

To recruit more people with particularly debilitating health conditions—and to give insight into the ways diverse settings might influence the intersections of formal, family, and self-care, it could be useful to conduct research among residents in long-term care facilities. Some research suggests that families may be less involved in caring for older people in residential settings relative to the home (Colombo et al., 2011). More research on residential long-term care could give further insight into the intersections that exist between formal, family, and self-care care, as residents face multiple health conditions and impairments.

It could be useful to employ a longitudinal design to provide a more in-depth understanding of the impacts of health status or level of impairment on negotiations of care and of age relations. A longitudinal design could show how negotiations of care change over time, perhaps with changes in health status, shifts in the nature and structure of kin relationships, and potential changes to the policy context (see Kemp et al., 2013). Further, although people with dementia or cognitive limitations were excluded from this study due to ethical concerns regarding informed consent, it is important to understand how they experience age relations and negotiate care arrangements. People with dementia may be unable to participate in traditional interviews, but other qualitative methodologies, such as participant observation (see for example Kontos, 2004), could give important insight into their experiences and negotiations of formal home care, family/friend caregiving, and self-care.

Finally, I have focused explicitly on the implications of age relations for older people's experiences of care. Yet, age relations shape the opportunities and resources that

are available to individuals at different points in the life course, and not just in later life. A comparative analysis of older and younger people who are receiving care from others could therefore provide useful insight into the significance of age relations for experiences of care across the life course. Such research would be an important contribution to sociological understandings of age relations, and of the intersections of formal home care, family/friend caregiving, and self-care.

### ***Summary***

In sum, this thesis has provided insight into older people's negotiations of care and experiences of age relations. Drawing on findings from qualitative interviews with older care recipients, I have conceptualized older care recipients' negotiations of formal home care, family/friend care caregiving, and self-care as balancing act. Older care recipients attempted to strike a balance between self-care, formal home care, and family/friend caregiving. Through these negotiations of care, older care recipients experienced, reproduced, and challenged age relations. While access to financial and social resources often afforded participants greater autonomy and control in their negotiations of care, some participants experienced age-based disadvantages as they contended with care needs in later life, meagre financial resources, and small (or non-existent) networks of kin support. These negotiations occurred in the context of restricted access to home and community services, and as participants responded to socio-cultural expectations that position older people as personally responsible for health and well-being. These findings extend sociological understandings of the intersections that exist between different systems of care, and of the ways age relations can be used to



understand experiences of care in later life. They have implications for understanding the relations of power and inequality that exist between and among people of different ages, in the practical context of care relationships.

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### ***Appendix A: Interview guide***

*Introduction:* My name is Rachel and I'm a doing a PhD in Sociology. My research looks at how older adults get along with paid care workers (e.g. PSWs, nurses who work in the home) and family members or friends who also support you. I really appreciate you taking the time to speak with me. This interview will be open-ended (not just "yes or no" answers). I might sometimes ask you to elaborate on certain answers, and you are also free to share information that you feel is important even if I don't directly ask about it.

Please know that you don't have to answer any questions that make you uncomfortable and that we can stop the interview at any time. Please also know that I won't share any private information with anyone else. When I write my research, I will change your name.

- 1) First, can you tell me a little bit about yourself?  
When/where were you born?  
Where did you grow up?  
What is your family like?  
How far did you go in school?  
What kind of work have you done throughout your life?
- 2) Can you tell me about a typical day in your life?
- 3) In your daily life, are there things you do to take care of yourself?
- 4) What do others do for you in a typical day?
- 5) Can you tell me about the people who do these things for you?
- 6) Can you describe what these people (e.g. family members/friends and paid workers) do when they are helping you with a specific task (e.g., preparing meals, dressing, bathing, etc.)?
- 7) Can you tell me about times when people are helping you and things work well?
- 8) Can you tell me about times when you don't feel like you get the support you need?
- 9) Do you see your life differently now than in the past?
- 10) Is there anything else you'd like to share or anything we haven't talked about?
- 11) Is there any advice you would give to others who have similar experiences to you?


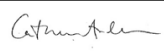


Thank you very much for your time.

**Appendix B: Ethics certificates**



MREB Clearance Certificate

[https://ethics.mcmaster.ca/mreb/print\\_approval\\_catherine.cfm?ID...](https://ethics.mcmaster.ca/mreb/print_approval_catherine.cfm?ID...)

 <p><b>McMaster University Research Ethics Board (MREB)</b>          c/o Research Office for Administrative Development and Support, MREB          Secretariat, GH-305, e-mail: <a href="mailto:ethicsoffice@mcmaster.ca">ethicsoffice@mcmaster.ca</a></p>		<p><b>CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH</b></p>	
Application Status: New <input checked="" type="checkbox"/> Addendum <input type="checkbox"/> Project Number: 2013 235			
<b>TITLE OF RESEARCH PROJECT:</b> Age relations care: Older adults' experiences self-, informal and formal care			
<b>Faculty Investigator(s)/ Supervisor(s)</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
M. Denton	Sociology	416-898-192	barkenre@mcmaster.ca
<b>Student Investigator(s)</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
R. Barken	Sociology	23923	mdenton@mcmaster.ca
The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB: <input type="checkbox"/> The application protocol is cleared as presented without questions or requests for modification. <input checked="" type="checkbox"/> The application protocol is cleared as revised without questions or requests for modification. <input type="checkbox"/> The application protocol is cleared subject to clarification and/or modification as appended or identified below:			
<b>COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.</b>			
Reporting Frequency: Annual: Dec-18-2014 Other:			
Date: Dec-18-2013 Vice Chair, C. Anderson: 			



MREB Clearance Certificate

[https://ethics.mcmaster.ca/mreb/print\\_approval\\_catherine.cfm?ID...](https://ethics.mcmaster.ca/mreb/print_approval_catherine.cfm?ID...)

 <p><b>McMaster University</b> Inspiring Innovation and Discovery</p>		<p><b>McMaster University Research Ethics Board (MREB)</b> c/o Research Office for Administrative Development and Support, MREB Secretariat, GH-305, e-mail: <a href="mailto:ethicsoffice@mcmaster.ca">ethicsoffice@mcmaster.ca</a></p> <p><b>CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH</b></p>	
<b>Application Status:</b> New <input type="checkbox"/> Addendum <input checked="" type="checkbox"/> <b>Project Number:</b> 2013 235			
<b>TITLE OF RESEARCH PROJECT:</b> Age relations care: Older adults' experiences self-, informal and formal care			
<b>Faculty Investigator(s)/ Supervisor(s)</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
M. Denton	Sociology	416-898-192	barkenre@mcmaster.ca
<b>Student Investigator(s)</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
R. Barken	Sociology	23923	mdenton@mcmaster.ca
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<b>COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.</b>			
Amendment#1, cleared March 3, 2014			
<b>Reporting Frequency:</b>		<b>Annual:</b> Dec-18-2014	<b>Other:</b>
<b>Date:</b> Dec-18-2013		<b>Vice Chair, C. Anderson:</b> 	

MREB Clearance Certificate

[https://ethics.mcmaster.ca/mreb/print\\_approval\\_catherine.cfm?ID=3206](https://ethics.mcmaster.ca/mreb/print_approval_catherine.cfm?ID=3206)

 <p><b>McMaster University Research Ethics Board (MREB)</b>          c/o Research Office for Administrative Development and Support, MREB          Secretariat, GH-305, e-mail: <a href="mailto:ethicsoffice@mcmaster.ca">ethicsoffice@mcmaster.ca</a></p>		<p><b>CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH</b></p>	
<b>Application Status:</b> New <input type="checkbox"/> Addendum <input checked="" type="checkbox"/> <b>Project Number:</b> 2013 235			
<b>TITLE OF RESEARCH PROJECT:</b> Age relations care: Older adults' experiences self-, informal and formal care			
<b>Faculty Investigator(s)/ Supervisor(s)</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
M. Denton	Sociology	416-898-192	barkenre@mcmaster.ca
<b>Student Investigator(s)</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
R. Barken	Sociology	23923	mdenton@mcmaster.ca
The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB: <input checked="" type="checkbox"/> The application protocol is cleared as presented without questions or requests for modification. <input type="checkbox"/> The application protocol is cleared as revised without questions or requests for modification. <input type="checkbox"/> The application protocol is cleared subject to clarification and/or modification as appended or identified below:			
<b>COMMENTS AND CONDITIONS:</b> Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.			
Amendment#2, cleared April 3, 2014			
<b>Reporting Frequency:</b>		<b>Annual:</b> Dec-18-2014	<b>Other:</b>
<b>Date:</b> Dec-18-2013		<b>Vice Chair, C. Anderson:</b> 	

*Appendix C: Letter of consent*



DATE:

**A study of older adults' experiences of care**  
**Student Investigator: Rachel Barken, MA, PhD Candidate**  
Department of Sociology  
McMaster University  
Hamilton, Ontario, Canada  
**416 898-1926**  
E-mail: [barkenre@mcmaster.ca](mailto:barkenre@mcmaster.ca)

**Faculty Supervisor: Dr. Margaret Denton,**  
Department of Sociology  
McMaster University  
Hamilton, Ontario, Canada  
**905 52509140 ext. 23293**  
E-mail: [mdenton@mcmaster.ca](mailto:mdenton@mcmaster.ca)

**Research Sponsor:** Social Sciences and Humanities Research Council

**What am I trying to discover?**

I am conducting interviews with older adults to learn about the ways they take care of themselves and the ways they experience support from paid care workers (such as personal support workers or nurses) and family members and friends in the home setting. I'm conducting this as part of my PhD research at McMaster University's Department of Sociology.

You are invited to take part in an interview to discuss your experiences of receiving care in your home.

**What will happen during the study?**

If you choose to participate in this study, you will be asked to take part in a one-on-one interview to discuss your experiences of receiving care. I expect the interview will take approximately one to two hours. With your permission, the interview will be audio-recorded. I may also take hand-written notes during the interview.

During the interview, you will be asked to discuss the ways you take care of yourself, how get along with paid care providers (such as personal support workers and nurses) and family members or friends who help you, and how you feel about the help you are receiving from others. I will also ask you some questions about your age and family background.

**Here are some sample questions:**

- In your daily life, are there things you do to take care of yourself?
- What do others do for you in a typical day?
- Can you tell me about times when people are helping you and things work well?

**Are there any risks to doing this study?**

It is expected that there will be minimal risks to participating in the interview. However, I recognize that you might find it stressful to discuss your experiences of receiving care because it is a private and sensitive topic. You do not need to answer questions that make you feel uncomfortable or that you do not want to answer. You can stop the interview at any time.

**Are there any benefits to doing this study?**

The research will not benefit you directly. I hope to learn more about the relationships among older adults receiving care, paid care providers, and family/friend caregivers. I hope that what is learned as a result of this study will help us to organize services and supports that better meet the needs of older adults receiving care at home.

**Who will know what I said or did in the study?**

Every effort will be made to protect your confidentiality and privacy. I will not use your name or any information that would allow you to be identified. I will not share your name or contact information with anyone else and I will change your name to a pseudonym when I write my research paper. Any other identifying information you share with me will not be published or shared with anyone else. However, we are often identifiable through the stories we tell. Other people who know you may recognize you from your stories even if I use a pseudonym.

I do not work at [agency] and I am not connected with this organization in any other way. I will not share any information with staff at [agency], and I am not in any position to change the amount or type of services you receive from them. Therefore, the information you share with me will in no way affect the services you receive from [agency].

Although I will protect your privacy as outlined above, if the law requires it, I will call emergency services if you reveal that you are in immediate danger.

I'd like to interview you in privacy. It will be best if other people (such as family members or paid care providers) are not in the room while we are conducting the interview. If you'd prefer to have someone else present during the interview, please let me know. I can accommodate that.

If you give me permission to audio-record the interview, I will copy the interview in written form on my personal computer within one week after completing the interview. The audio recording will be deleted from my recorder. I will change your name to a pseudonym in the written version of the interview. My computer is protected by a password and no one but me has access to it.

I expect to complete this study within a year of this interview, but I will keep the written version of the interview indefinitely and potentially use the information in future research.

#### **What if I change my mind about being in the study?**

It is your choice to be part of the study or not. If you decide to be part of the study, you can stop the interview for whatever reason, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. After the interview you may choose to withdraw from the study at any point until August 2014, when I will complete all of the interviews for my research.

If you do not want to answer some of the questions you do not have to, but you can still be in the study.

#### **How do I find out what was learned in this study?**

I expect to have this study completed by approximately January 2015. If you would like a brief summary of the results, please let me know how you would like it sent to you.

#### **IF YOU WOULD LIKE TO PARTICIPATE, OR IF YOU HAVE QUESTIONS ABOUT THE STUDY:**

Please contact me:

**Rachel Barken**

Telephone: 416 898-1926

E-mail: [barkenre@mcmaster.ca](mailto:barkenre@mcmaster.ca)

Mailing address:

118 Montgomery Avenue, #310-E  
Toronto, Ontario  
M4R 1E3

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat  
Telephone: (905) 525-9140 ext. 23142  
c/o Research Office for Administrative Development and Support  
E-mail: [ethicsoffice@mcmaster.ca](mailto:ethicsoffice@mcmaster.ca)

### CONSENT

- I have read the information presented in the information letter about a study being conducted by **Rachel Barken**, of McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time or up until approximately **August 2014**.
- I have been given a copy of this form.
- I agree to participate in the study.

Signature: \_\_\_\_\_

Name of Participant (Printed) \_\_\_\_\_

1. I agree that the interview can be audio recorded.

... Yes.

... No.

2. ...Yes, I would like to receive a summary of the study's results.

Please send them to this email address

\_\_\_\_\_  
Or to this mailing address:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

... No, I do not want to receive a summary of the study's results.

***Appendix D: Recruitment instruments******Bulletin board notice***

## **Are you over 65 and using home care services?**

We are looking for volunteers to take part in a study of  
***older adults' experiences of using home care services and of  
 receiving support from family members/friends.***

Women and men over 65 who live at home and receive on-going support from home care providers (such as personal support workers or nurses) and help from family members or friends are eligible for this study.

You will be asked to participate in a one-hour interview at a time and location of your convenience.

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

**Rachel Barken**

Department of Sociology, McMaster University

**416 898-1926** or

Email: [barkenre@mcmaster.ca](mailto:barkenre@mcmaster.ca)

This study has been reviewed by, and received ethics clearance  
 by the McMaster Research Ethics Board.

Call Rachel Barken  
 416 898-1926  
 Or  
 Email:  
[barkenre@mcmaster.ca](mailto:barkenre@mcmaster.ca)

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Call Rachel Barken  
 416 898-1926  
 Or  
 Email:  
[barkenre@mcmaster.ca](mailto:barkenre@mcmaster.ca)



*Brochure***About the Researcher**

I am a doctoral student in Sociology at McMaster University. My research looks at aging, health, and care relationships. I am also an active volunteer with seniors support organizations in my community.

**Contact Information**

If you have any questions about this study or would like to participate, please contact Rachel Barken by telephone:

**416 898-1926**

Or by email at:

**barkenre@mcmaster.ca**

This study has been reviewed and cleared by the McMaster Research Ethics Board.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact the McMaster Research Ethics Board Secretariat.

Phone: (905) 525-9140 Ext. 23142  
Email: [ethicsoffice@mcmaster.ca](mailto:ethicsoffice@mcmaster.ca)  
Mail:

c/o Research Office for Administrative Development and Support  
McMaster University  
1280 Main St West  
Hamilton, ON L8S 4L8

My faculty supervisor, Dr. Margaret Denton, can be reached at (905) 525-9140 ext. 23293 or [mdenton@mcmaster.ca](mailto:mdenton@mcmaster.ca)

**McMaster University**

**McMaster University**

**A Study on Older  
Adults' Experiences  
of Care**



**Research Investigator  
Rachel Barken**

Doctoral Student  
Department of Sociology  
McMaster University  
Hamilton, ON

**About the Researcher**

I am a doctoral student in Sociology at McMaster University. My research looks at aging, health, and care relationships. I am also an active volunteer with seniors support organizations in my community.

**Contact Information**

If you have any questions about this study or would like to participate, please contact Rachel Barken by telephone:

**416 898-1926**

Or by email at:

**barkenre@mcmaster.ca**

This study has been reviewed and cleared by the McMaster Research Ethics Board.

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McMaster University  
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Hamilton, ON L8S 4L8

My faculty supervisor, Dr. Margaret Denton, can be reached at (905) 525-9140 ext. 23293 or [mdenton@mcmaster.ca](mailto:mdenton@mcmaster.ca)

**McMaster University**

**McMaster University**

**A Study on Older  
Adults' Experiences  
of Care**



**Research Investigator  
Rachel Barken**

Doctoral Student  
Department of Sociology  
McMaster University  
Hamilton, ON

*Appendix E: Resource sheet for participants*

If you find yourself in need of any additional help or support, you may find the following organizations useful:

Name	Contact Information.	Service area and hours.	Description
<b>Community Navigation Access Program (CNAP)</b>	1-877-540-6565 (toll free) <a href="http://4seniors.org/">http://4seniors.org/</a>	Services all areas. Mon-Friday, 9 am-5 pm.	<ul style="list-style-type: none"> <li>• Helps seniors and family members find and access support.</li> <li>• Contact with a professional social worker</li> <li>• Connects seniors with service providers in the community.</li> </ul>
<b>Senior Crisis Access Line</b>	416 619-5001 <a href="http://www.csmhas.com/Scal.html">http://www.csmhas.com/Scal.html</a>	Service area from Hwy. 401 to Lake Ontario, from Warden Ave. to Islington Ave.  Mon-Fri 10 am-9:30 pm Sat-Sun 10 am-6 pm	<ul style="list-style-type: none"> <li>• Help stabilizing age-related mental health and addiction crises</li> <li>• Risk and safety assessments,</li> <li>• Immediate referrals to community mobile crisis units.</li> <li>• Support for families and caregivers.</li> </ul>
<b>The Seniors Safety Line</b>	1 866 299-1011 (toll-free) <a href="http://www.onpea.org/">http://www.onpea.org/</a>	Services all areas. 7 days a week, 24 hours a day.	<ul style="list-style-type: none"> <li>• Confidential resource for seniors suffering abuse, including physical, mental, sexual, neglect, and financial.</li> <li>• Support offered in over 150 languages.</li> <li>• Operated in association with the Assaulted Women's Help Line.</li> </ul>
<b>Toronto Distress Centres</b>	416-408-HELP (4357), <a href="http://www.torontodistresscentre.com/">http://www.torontodistresscentre.com/</a>	Services all areas. 7 days a week, 24 hours a day.	<ul style="list-style-type: none"> <li>• Access to confidential support via telephone in crisis or distress situations.</li> </ul>
<b>Gerstein Centre Crisis Line</b>	416-929-5200 <a href="http://www.gersteincentre.org/">http://www.gersteincentre.org/</a>	Services all areas. 7 days a week, 24 hours a day.	<ul style="list-style-type: none"> <li>• Crisis intervention for mental health problems.</li> </ul>
<b>Crisis Outreach Service for Seniors (COSS)</b>	416 640-1459 <a href="http://www.copacommunity.ca/?q=Crisis-Outreach-Service-for-Seniors">http://www.copacommunity.ca/?q=Crisis-Outreach-Service-for-Seniors</a>	Service area from Bloor St./Danforth Ave to Lake Ontario, and from Jane St./Windermere Ave to Warden Ave.  7 days a week, 9 am to 5 pm.	<ul style="list-style-type: none"> <li>• Crisis intervention and outreach service for seniors.</li> <li>• Short-term response through in-person support when other services are unavailable.</li> <li>• Support for mental health and/or addiction crises.</li> <li>• Support for those struggling with isolation and/or homelessness.</li> </ul>

*Appendix F: Open coding scheme*

Aging	Advantages of aging	Things that are easier with age
		Things that make aging easier
	Aging and health	Aging and mental health
		Aging and physical health
	Disadvantages of aging	Things that are harder with age
		Things that make aging harder
	Future outlook	Dying
		Living
	Generational differences	
	Loneliness	
	Older people as a burden	
	Relationships in later life	
Cleaning help		
Family structure	Children	
	Cousins	
	Grandchildren and great-grandchildren	
	Nieces and nephews	
	Parents	
	Siblings	
	Spouse	
Family support	Administrative help	
	Amount of family support	
	Complaints about family	
	Emotional support	
	Feelings about family support	
	Financial support	
	Giving support to family	Accommodation support
		Caregiving
		Emotional support
		Gifts
		Money
		Sharing information
	Help with home modifications	
	Help with housework	

	Help with meals	
	Help with medications	
	Help with mobility	
	Help with organizing care	
	Help with personal care	
	Help with shopping	
	Help with technology	
	Telephone calls	
	Transportation	
	Visits with family	
Formal home care	Amount of formal home care	
	Complaints about services	
	In charge of relationship	
	Meals on Wheels and dining	
	Positive aspects of formal support	
	Receiving help since when	
	Relationships with home care workers	
	Service structure	
	Source	
	Tasks home care workers help with	
	Telephone calls	
	Therapy	
	Workers' race and ethnicity	
	Workers' training	
Friend help	Administrative help	
	Amount of friend help	
	Emotional support from friends	
	Food preparation	
	Giving support to friends	
	Help around home	
	Paying for friend help	
	Shopping	
	Technology	
	Transportation	
General feelings about help		
Giving up driving		
Health conditions	Things that are harder with	

	health conditions	
	Things that help with health conditions	
Health professionals visits		
Home	Activities at home	
	Challenges of home	
	Feelings about home	
	Home modifications	
	Pets	
	Use of space	
Hospital visits		
Neighbourhood		
Outings	Barriers to getting out	
	Being outside	
	Courses	
	Cultural events	
	Eating out	
	Exercise	
	Hair appointments	
	Religious groups	
	Seniors' groups	
	Shopping	
	Special events	
	Transportation	
	Visiting family and friends	
Overlap in care activities	Family/friend and self-care	
	Home care and cleaning	
	Home care and family	
	Home care and friends	
	Home care and self-care	
Participant characteristics	Age	
	Education	
	Hobbies	
	Income	
	Places lived	
	Religion	
	Sexual orientation	
	Social class	
	Volunteer work	
	Work	
Physical appearance	Clothing	
	Feelings about appearance	

Relationships with friends		
Self-care	Barriers to self-care	
	Bathing	
	Diet	
	Dressing	
	Driving	
	Exercise	
	Feeling about self-care	
	Housework	
	Keeping safe	
	Learning	
	Mobility aids	
	Paperwork	
	Preparing meals	
	Quitting smoking	
	Resting	
	Seeking alternative healthcare	
	Self-monitoring	
	Spending money	
	Taking medication	
	Toileting	
Things you can't do		