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Informing care: Mapping the social organization of families' information work in an aging in place climate

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Abstract

Within an institutional ethnography method of inquiry, this dissertation makes visible the information work that permeates the care work of families of people living with dementia who are also aging at home. An institutional ethnography privileges people's everyday work and acknowledges that local contexts are influenced by translocal, ruling relations. To map out the social organization of family caregivers' information work, this dissertation details four separate, yet interrelated studies. The first study comprises two sets of interviews: one with 13 family caregivers of older adults to understand their experiences of the information work they do and a second with five paid dementia care staff to identify the decisions and work processes that impact families' information work. In the second study, I use Arksey and O'Malley's six stage scoping review framework to understand how academic research frames family caregivers' information work. I then structure the third study as a methodological critique as I deconstruct the scoping review framework and consider the implications of conducting a scoping review within an institutional ethnography conceptual framework. In the fourth chapter, I use Bacchi's "What's the Problem Represented to Be?" analytical tool to structure the reading of aging in place policies to examine the degree to which these policies acknowledge the work families do in the home to support an older adult to age at home. Results from the studies reveal a disjuncture between the ways that families experience information in their everyday lives and the ways that information is understood in the remaining articles. Information is mobilized by academic researchers and aging in place policies as an intervention or tool to enable caregivers to support older adults to age in place for as long as possible. Aging in place is ultimately conceived of as an ideological code that socially organizes and structures a particular way of understanding information, one that centers on informing *to* care. Whereas families view information as inextricably linked to their care work, policies and articles frame information as separate and outside of care.

Keywords

Aging in place, care work, dementia, family caregiving, information work, interviews, institutional ethnography, policy analysis, scoping review

Authorship Statement

The four articles that make up the body of this thesis are each intended for individual publication.

Chapter Three (On the fluidity of information: Negotiating tensions in everyday information work in paid and unpaid dementia care) will be submitted to *Journal of Documentation.* Chapter Four ("Add info and stir": An institutional ethnographic scoping review of family caregivers' information work) is published in *Ageing & Society.* Chapter Five (Disrupting knowledge synthesis methods using institutional ethnography: Reflections on the scoping review as a critical knowledge synthesis tool) will be submitted to *Social Problems.* Chapter Six (A logic of choice: Problematizing the documentary reality of Canadian aging in place policies) is in press in *Journal of Aging Studies*.

Acknowledgments

I am writing these acknowledgements from the University of Alberta Hospital, sitting bedside to my grandmother, Ione, next to my grandfather, Bob. Just a month after my defense, I now find myself in a rather curious and surreal position, now living and experiencing the very topic I unraveled and studied in this thesis. The borderless enormity of family caregivers' information work is more salient than ever.

It takes a mighty village to create a dissertation. This dissertation is a reflection of the interactions, lessons learned, stumbles, victories, and chats I've had along the way.

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Preface

When people recognize that care is a complex process with many components, it becomes possible to avoid either despairing about care or romanticizing it. Care is more likely to be filled with inner contradictions, conflict, and frustration than it is to resemble the idealized interactions of mother and child or teacher and student or nurse and patient.

Holstein & Mitzen, 2001, p. 64

Aging in the 21st century is a story of success, but it is also a story with subplots of concern and peril. One of the best tools people can use when facing concerns and perils is information.

The Merck Manual of Health & Aging, 2005, p. 1

Chapter 1

1 Introduction

During my Master of Library and Information Studies (MLIS) at the University of Alberta, I conducted a pilot study with five family caregivers of older adults. I wanted to better understand how these caregivers first assessed the quality and reliability of and then integrated online health information to support and guide their care work. I remember being struck by the frustrations they experienced while trying to locate and make sense of the information they needed. As I prepared for this pilot project, I was puzzled by a seeming disconnect between government policies that positioned information as central to meeting caregivers' needs and yet the mounting numbers of research articles that continued to relay caregivers' frustrations with scattered, unhelpful information. These early readings that guided my pilot study piqued my curiosity in exploring the complex and complicated relationship between information and care. My doctoral work builds on this pilot study, unwrapping and questioning this relationship in further depth and breadth.

This dissertation details a contemporary, Canadian-centric study that focuses on the information work that permeates the care work of families who are caring for someone who is living with dementia and who is also aging at home. More specifically, within an institutional ethnography method of inquiry, this dissertation aims to make visible the social organization of family caregivers' information work. To do so, I undertook a series of interrelated studies to make visible the nature of families' information work as well as the overarching structures that influence families' experiences of their information work.

1.1 The structure of this dissertation

I begin this introductory chapter by contextualizing the Canadian, historical, and disciplinary landscape for this research and follow this with a review of the relevant literature. In Chapter Two, I describe the tenets of institutional ethnography, the method

of inquiry that shaped the creation, analysis, and writing of my dissertation. Chapters Three to Six subsequently detail the four different studies that comprise my dissertation; each chapter represents a different influence on family caregivers' experiences of their everyday information work. As a result, each chapter is a contained unit, employing a different method and drawing unique conclusions in response to the methods and analytical lenses applied.

In Chapter Three, I outline the results from two sets of interviews. In the first set, family caregivers of older adults living with dementia articulated their everyday information work. In the second set, I interviewed paid dementia care staff to understand how their work might influence the ways that the families they interact with use and make sense of information. Descriptions and experiences of the work knowledges collected throughout Chapter Three's interviews are but the beginning of this institutional ethnography thesis. While Chapter Three describes the everyday, local experiences of information work, Chapters Four, Five, and Six are ordered in such a way as to progressively travel from family caregivers' local settings outwards, searching for and making known the networked linkages of organization and coordination, processes of administration and governance that are external to caregivers, but that still shape their local experiences. In Chapter Four, I employ a scoping review to understand how academic research and writing comes to construct and perpetuate a particular way of studying family caregivers' information work. Based on this scoping review, I structure Chapter Five as a methodological critique as I deconstruct the nature of the scoping review and consider the implications of examining a scoping review within an institutional ethnography conceptual framework. Moving from academic articles as texts, Chapter Six takes up policies as texts, examining the degree to which aging in place policies acknowledge the work families do to support an older adult to age at home. In the concluding chapter, I discuss and reflect on the implications for families' information work based on the combined findings from each of the preceding chapters.

While this is the order in which I have presented the chapters in this dissertation, it is not the order in which I conducted my research. I started my thesis research with the scoping review (Chapter Four). This was not only a pragmatic maneuver, as I was able to advance

my thesis work while waiting for ethics approval and participant recruitment for the studies outlined in Chapter Three, but this order directly reflects why I started this research. I prepared for this thesis work, as is expected, by reading broadly – in gerontology, sociology, nursing, public health, and the health sciences, among others. As my reading about families' care work proceeded, I noticed that the articles I read often kept track of the different care-related tasks that families do, including the type of task, the amount of time spent on each task, and which family member was most likely to complete different types of tasks. These tasks were, however, primarily instrumental or visible in nature, such as feeding, dressing, or keeping track of appointments or finances. Missing in these articles was an indication that information underlies and informs each of these tasks. Family caregivers gather, share, and keep track of information to complete or negotiate different care tasks. My background and training in the Library and Information Sciences and the initial findings from my MLIS pilot study were in conflict with these readings. The invisibility of families' information work in my readings was both puzzling and frustrating and ultimately prompted my desire to more systematically study the ways in which research frames family caregivers' information work.

1.2 Contextualizing the research

This section contextualizes the experiences of family caregivers of community-dwelling older adults who are aging in place, providing a historical trajectory of the gendered nature of caregiving and an overview of health information production and consumption.

1.2.1 An aging Canadian population

Population aging and projections of a country's age structure center around three main components: levels of fertility, mortality, and migration (Chappell, McDonald, & Stones, 2008). In Canada, these three components have contributed to "the almost uninterrupted aging of all provincial and territorial populations over the last 40 years" (Statistics Canada, 2007a). This aging trend is expected to accelerate throughout Canada as an increasing number of baby boomers (problematically referred to as the "silver tsunami") enter their older adult years. The aging of our population will be "one of the most

significant social forces shaping our society over the next 20 to 30 years" (Institute of Aging, 2007, p. 3), as the 2016 census recorded the number of Canadians over the age of 65 at 16.9% of the population, up from 13.0% in 2001 (Statistics Canada, 2017). Older adults constitute the fastest growing population group in Canada (Statistics Canada, 2010). Proportionally, the acceleration of aging is especially prominent amongst the oldest-old (those over 80 years of age): by 2056, 1 in 10 Canadians will be over the age of 80 (as compared to 1 in 30 in 2005) (Statistics Canada, 2007b). As of July 2015, for the first time in Canadian history, the number of older adults over the age of 65 outnumbered the number of children under the age of 15 (Statistics Canada, 2015) and by 2036, nearly one in four Canadians will be over the age of 65 (Statistics Canada, 2014). As the first members of Canada's baby boomer generation turned 65 in 2011, increasing attention has turned to the accelerated growth of our nation's aging population. Given its size, this cohort will increasingly highlight the complexities surrounding an aging population and will catalyze the development of "unique policies and practices before this generation moves into their 70s and 80s" (McPherson & Wister, 2008, p. 33), and, assumedly, for the caregivers who are and will be caring for this population.

The National Framework on Aging was created by The Federal/Provincial/Territorial Ministers Responsible for Seniors and serves as a reference point for the development of many Canadian policies and programs created in response to Canada's aging population. The main vision of this Framework states that "Canada, a society for all ages, promotes the well-being and contribution of older people in all aspects of life" (Health Canada, 1998, p. 6). This vision is supported through five overarching principles: participation, independence, dignity, fairness and security, which parallel the United Nations' 1991 Principles for Older Persons. From this Framework, three pillars of action were constructed: health, wellness, and security; continuous learning, work and participation in society; and supporting and caring in the community. This study contributes towards the continued development of this third pillar.

Older Canadians wield influence on all aspects of economic and social life (Phillipson, 2016). Within twinned workings of austerity measures ("period of fiscal discipline in which governments make significant cuts to public expenditure as a means of reducing

public debt" [Cooper & Whyte, 2017, p. 2]) and a neoliberal framework ("post-Cold War, post-welfare state model of social order that celebrates unhindered markets as the most effective means of achieving economic growth and public welfare" [Maskovsky & Kingfisher, 2001, p. 105]), conversations about aging populations tend to emphasize the costs and the burden that this population bears. Ferge's "individualization of the social" (1997) begins to explain how these twinned processes have brought about a new approach to aging populations. Aging is portrayed as a global concern, but there is a simultaneous trend to individualize the many supposed risks and problems attached to later life. This individualization of the social is reinforced by the individualized consumer-based lifestyle narrative, with an increasing onus of healthism - of personal responsibility for one's health and wellbeing (Crawford, 1980). The seductive logic of a neoliberal mindset, including individualism, privatization, and decentralization (McGregor, 2001), have resulted in declining forms of social protection and community programs for older adults, with a consequent increase in reliance on family and kin for care and support. As a result of these contexts that shape and are shaped by an aging population, I align the overall argumentation of my thesis with Estes' political economy of aging (1979; 2001; 2014). This approach conceptualizes aging and the many policies and institutions that are related to aging in terms of social, economic, and political power, with older adults' needs ultimately treated as a commodity from which the medical-industrial complex benefits.

1.2.2 Sixty-five: What's in a number?

The identification and conceptualization of "older adult" are traditionally tied to the age at which an individual enters into retirement. For the purposes of this dissertation, I used 65 as an age marker to define the older adult population, given its normative and colloquial implementations and its ubiquitous use in studies and in the majority of the literature surveyed. This is also in alignment with the age categories used in the most recent (2016) Canadian census, in which those 65 years of age and older are "seniors" (Statistics Canada, 2017).

Although 65 is broadly accepted in Canada as an age marker for the "senior" population, this value is not universally accepted, nor is it uncontested. In light of the "thirty year

gain in longevity since the beginning of the twentieth century" (Ristau, 2010, p. 39), 65 may no longer be universally considered as being elderly or old, and it is increasingly difficult to come to an agreed definition of what is old, senior, or elderly. This is compounded by the influx of baby boomers into the over sixty-five category, starting in 2011, which may provoke new conceptualizations of what being a senior means, not only for seniors themselves but for politicians, demographers, city planners, health care professionals, and social institutions.

The characteristics and wellbeing of seniors vary significantly among the three traditionally-divided age groups of older adults: 65 to 74, 75 to 84, and over 85 (Chappell, McDonald, & Stones, 2008). Given the heterogeneity in life circumstances amongst these three age groups, future definitions may opt to triangulate the definition of seniors, choosing separate qualifiers for each age range in order to capture and in recognition of the diversity in older adults. The presence of these three distinct older adult cohorts reveals certain limitations in the language used to describe individuals within the broad spectrum of 'senior'. Out-of-date and potentially restrictive terminologies such as senior citizen, elders, elderly, or retirees may need to be replaced with vocabularies that acknowledge and support the diversity within this age group (Ristau, 2010).

1.2.3 Contextualizing older adult care

Two common scales in assessing older adults' capabilities (and consequently, measuring what care might be needed or provided by paid and unpaid caregivers) are Katz's Activities of Daily Living (ADL) and Lawton and Brody's Instrumental Activities of Daily Living (IADL). Katz's Index of ADL represents six primary biological functions and assesses older adults' degree of independence in dressing, using the toilet, continence, feeding, bathing, and transfer (Katz, Ford, Moskowitz, Jaffe, & Cleveland, 1963). Later in 1969, Lawton and Brody extended this ADL index to asses more complex and demanding activities that may be indicative of an older adult's ability to live independently in the community: transportation, food preparation, housekeeping, shopping, and managing money. While these two tools measure physical impairments or disabilities and are helpful in creating a common language when talking about care needs,

they do not assess other factors that may predict an older adult's need or desire for care, including availability of social support from family and friends.

After years of lobbying by a number of women's groups, the 1996 Canadian census was the first to include a three-part question about the amount of time individuals spend on unpaid work (Luxton & Vosko, 1998), representing a turning point in the recognition of the unpaid work, including caregiving, done by many Canadians. Caregiving has become an expected part of the life course for many Canadian families and friends who are estimated to provide between 70 to 80 percent of care needed by older adults in the community (Keefe, 2011). The Family Caregiver Alliances defines family caregivers as "any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care" (2014). The 2012 General Social Survey reported 8.1 million Canadians (or 28%) provided care to a chronically ill, disabled, or aging family member or friend in the 12 months preceding the survey (Sinha, 2013). Age-related needs were identified as the single most common problem requiring help from caregivers. In 2007, one in five Canadians over forty-five reported assisting an older adult because of the older adult's long-term health condition (Cranswick & Dosman, 2008).

The locus of care for Canadian older adults is shifting, with the responsibility for ongoing management of care transferring from paid professionals to family members, and the site of care as the home rather than the clinic (Sadler & McKevitt, 2013). Indeed, it is now family caregivers, not the formal health care system, who provide the majority of care to older adults in Canada (Chappell, 2007). Such familial support systems reduce the demands and costs on formal health care and social systems, allowing older adults to age at home rather than living in an institutionalized setting (Sinha, 2013). As government agencies prioritize finding cost effective and efficient ways to provide care, inviting families (whether explicitly or implicitly) to take up older adult care work appears reasonable, creating the impression that a government's nonintervention in the home is justified and practical (Hooyman & Gonyea, 1995). The home, accompanied by a

nostalgic notion of the nuclear family, is idealized as the privileged site of care, for both mothers caring for children and family members caring for an aging adult.

This deliberate shift from caring for older adults in more costly hospitals and long-term care facilities to the home is accompanied by an increase in the normative emphasis on aging in place. Aging in place, continuing to live in the same or a familiar place or community for as long as possible, even if health changes occur, has and continues to be a policy ideal. Aging in place is often equated with aging at home, "positioned as positive in that it meets the presumed desire of the majority of ageing people to stay in the homes in which they have lived a sustained portion of the lives" (Johansson et al., 2013, p. 109). Aging in place is promoted as respecting older adults' wishes and is "presented as a necessary way of restraining the increase of expenses in a financing crisis of publicly funded care services related to the rising dependency ratio" (Vasara, 2015, p. 56). The home is portrayed as the idyllic environment to obtain care, where families can provide care that is portrayed as "kind, sensitive and attuned to individual needs and compatible with traditional values" (Garner, 1999, pp. 162) ultimately enabling government, policy makers, and other organizations that coordinate caregiving resources to withdraw programming and support structures. Of the nearly five million seniors recorded in the 2011 census, 92.1% lived in private households (Statistics Canada, 2013). Furthermore, according to the Canada Mortgage and Housing Corporation, approximately 85% of older Canadians would prefer to age in place, remaining in their homes for as long as possible (2015). The large number of older adults currently in their own home combined with their desire to likely stay in their homes (Institute for Life Course and Aging, 2007) will require innovative supports beyond relying on family and friends, particularly with an increasing number of caregivers reporting distress and burnout (Health Quality Ontario, 2015).

1.2.4 Contemporary issues in care: Dementia

Alzheimer's disease (AD), the most common cause of dementia (Wackerbarth & Johnson, 2002), is marked by losses and changes in memory, thinking, mood, and behaviours, as cognitive abilities progressively deteriorate (Alzheimer Society of Canada, 2010). Alzheimer's disease and other forms of dementia are the most significant cause of

disability among Canadians over the age of 65, affecting nearly 564,000 Canadians and costing Canadians $10.4 billion dollars annually to care for those living with dementia (Alzheimer Society of Canada, 2016). Furthermore, health care costs in the last five years of a person living with dementia's life are approximately 57% greater than health spending in the last five years of individuals living with other diseases (Kelley, McGarry, Gorges, & Skinner, 2015). With 25,000 new cases of dementia diagnosed each year, 937,000 Canadians are estimated to be living with this disease within the next 15 years (Alzheimer Society of Canada, 2016)

In the United States, family members are estimated to provide 80% of care needed by patients with AD (Etters, Goodall, & Harrison, 2008). One in five Canadians has experience caring for a person living with some type of dementia (Alzheimer Society of Canada, 2016). Caregivers of those with AD are more likely to be female and be married to the individual diagnosed with AD (Wimo, Jonsson, Bond, Prince, & Winblad, 2013). While families or friends caring for those living with dementia may face disproportional health-related costs, this cost may not take into account the multiple complex, ongoing health and social needs of the growing number of those living with dementia who may wish to or are forced to age in place (Morton-Chang, 2015). As many of those living with dementia, especially with lesser care needs, may "end up prematurely or inappropriately in residential long-term care (LTC), or waiting in a hospital bed for a place" (Morton-Chang, 2015, p. ii; Alzheimer Society of Canada, 2016), understanding how to best support the work that family or friend caregivers do to enable an older adult living with dementia to age in place is of crucial importance.

1.3 Review of the literature

This section highlights key areas of research that informed and influenced the creation of this dissertation. Two main bodies of literature are explored in-depth: caregiving and information. First, a discussion of caregiving definitions and identities will lead into an exploration of traditional and evolving conceptualizations of women's work. An understanding of historical and contemporary perspectives and theories on caregiving

helps to frame subsequent sections regarding caregivers' information practices and, ultimately, work. This section collectively reveals that the onus on caregivers to navigate and use information to guide their caregiving parallels a shift towards a neoliberal stance that caregiving is the family's (and often a woman's) personal responsibility (Federici, 2012).

1.3.1 Caregiving

1.3.1.1 Caregiving: Definitions and identities

Care work, "the work of looking after the physical, psychological, emotional, and developmental needs of one or more other people" (Standing, 2001, p. 17) is a complex practice. While an intimate experience, directly related to how we care and are cared for, this particular type of work is also a societal phenomenon, related to how society as a whole produces itself: "care is fundamental to the human condition and necessary both to survival and flourishing" (Barnes, 2012, p.1). Perhaps simply, this type of work rests on the notion that "people produce people" (Feder Kittay, Jennings, & Wasunna, 2005, p. 443). It therefore demands "love and labour, both identity and activity, with the nature of demands being shaped by the social relations of the wider society" (Graham, 1983, p. 14). This dual nature of care work arises from the ways in which care manifests itself: one can care *about* others and/or one can care *for* others. Caring *for* others focuses on the nature of the work, examining the visible activities or tasks associated with the activities of daily living, whereas caring *about* involves the emotional or mental work in caring for someone's wellbeing and is associated with the identity of the carer (Bruhn & Rebach, 2014; Neysmith, 1995).

Care work has been described as "survival" (Fisher & Tronto, 1990), "conscription" (Grant et al., 2004) and a "process" (Gordon et al., 1996). Many of the definitions surveyed give mention or an awareness of the crux of caregiving, that is, the aforementioned dual nature of care work: comprising both affect or concern and labour or tasks. Maintaining a balance between these two aspects of care is challenging. Holstein and Mitzen (2001) critique contemporary discussion of care, finding that it "overemphasizes the emotional and intellectual qualities and ignores its reference to

actual work, or overemphasizes care as work at the expense of understanding the deeper intellectual and emotional qualities" (p. 61). It is this intangible, affective component that is often ascribed to care work that makes its conceptualization as "work" particularly tenuous: "its affective dimension means that it does not fit neatly into the category of work, and dominant gender ideology constructs it as a 'labor of love'" (Barker, 2012, p. 574). Attempting to connect emotional work with traditional conceptualizations of work proves particularly difficult, as care work "cannot be adequately met by labor supplied only for money" (Folbre, 1995, p. 75), given the emotional work assumed to be involved. To acknowledge the emotional, personal, and nurturing aspects of caring, Hewitson's (2003) broader conceptualization of care work, "all aspects of such work – including the multitudinous ways in which effort is expended in emotional or nurturing activities, behavior, or thoughts" (p. 268) is used in this study.

Barker (2012) provides an overview of the factors that differentiate caring work from other sorts of work: "its association with women and the family, isolation of those who do this work, intimacy in the sense of caring for the emotional and physical needs of others and its affective nature" (p. 576). Similarly, Harrington Meyer (2000) attempts to describe the "elusive elements of caring work that make the difference between caring and doing a job" (p. 95) by outlining a series of dichotomies: talk versus tasks, love versus detachment, specialness versus fairness, patience versus schedules, family relations versus work relations, and relationship versus rules. Gordon et al. (1996) succinctly relay the potential in investigating the dichotomy of public and private spheres that maintain the discourse of care work as non-work: "only through disclosing and naming the practices that constitute human life can we create an expanded public discourse that integrates our private lives and our public policies and preoccupations" (p. xv). Information work is one such practice that constitutes human life as it enables wellbeing and care, but has yet to be disclosed and named, a gap this study sought to bridge.

While there is a general consensus as to the importance of care work and of the need to account for its value (Barker, 2012), a lingering question remains as to what sort of "work" care work is. This question is, however, crucial in deciphering the discourse of

unpaid caregiving as non-work. Attention must be brought to all facets of work that family caregivers perform, particularly given the tendency of governments and sociocultural norms to download care responsibilities to families (often women) under the guise that it is "natural", "desired", and "better" for older adults, their families, and their communities. One such facet of work that requires attention is information work. While this concept does not yet widely appear in caregiving or gerontological literature, my thesis work advocates for the inclusion of information work in conversations regarding the evolving conceptualizations of care work.

1.3.1.2 Care work as women's work

With definitions of caregiving outlined, this section explores caregiving as a traditionally gendered construct. Historical and contemporary divisions of labour, dividing market (the public sphere, governed by men) from home (the private sphere, managed by women), have swayed and shaped women's work and identities. Persisting invisibility and undervaluing of women's unpaid domestic work can be attributed to two historical developments: the rise of familism and the ubiquity of the cult of domesticity propaganda of the later 18th and early 19th century. Both developments benefitted men as they entered the marketplace while women (and their caregiving) were sequestered to the private (domestic) sphere, affirming their invisible duty to caring in the home (Gordon, Benner, & Noddings, 1996; Hooyman & Gonyea, 1995). As a rise in capitalistic practices and thought created a sharp division between the public world of men, "centered in the waged labor market" (Hooyman & Gonyea, 1995, p. 28) and the locus of women's domestic work, firmly centered within the private domain of the home, familism, or the "family ethic" was touted as an ideal. Familism, calling for "traditional family values [in an] effort to restore and regulate patriarchal modes of family life" (Hooyman & Gonyea, 1995, p. 111), reinforced a woman's place in the domestic sphere as natural and essential for the maintenance of men in the paid (public) workforce. Care work continues to underpin and support the economy, particularly with government and policy structures and decisions perpetuated by neoliberalism and austerity measures, yet this work (and, accordingly, the women performing this work) are devalued, viewed as peripheral to and excluded from the marketplace, particularly "in a society that defines work primarily in

terms of measurable output and wages" (Hooyman & Gonyea, 1995, p. 116). Sokoloff (1988) declares the cult of domesticity, that is, this exclusion of women from social (outside the home) production and the subsequent transformation of women's labour from public contributions for the community to a private service for their husbands, "the world historic defeat of the female sex" (p. 123) as it gave rise to a universal and accepted oppression of women by men.

Glazer (1993) reflects on the "puzzling persistence of women's unpaid domestic labor … despite the industrialization or commercialization of much household production" (p. xi), which may be explained in part by the economic and power relationships encapsulated in the gendered division of care work (Baines, Evans, & Neysmith, 1998). The persistence of women's unpaid domestic work can be attributed, in part, to the decommodification of women's work in the home: "markets paradoxically require altruistic, collective behaviour on the part of women in the household in order to enable men to act individualistically in the market" (Grant et al., 2004, p. 13). Caregiving is a task sequestered to the home, viewed as a duty that should be wholly the family's (and more specifically, of the matriarch): "the central underpinning of work economy has been business' reliance on the presence of women at home so that men can enter the workplace unencumbered by family responsibilities that might restrict their time or distract their attention from the job" (Hooyman & Gonyea, 1995, p. 291). Nona Glazer (1993) has written a great deal on feminist economics as it relates to women's paid and unpaid work and succinctly observes that "as household members, women have responsibilities assigned to them by custom, law, and circumstances and justified by ideologies" (p. 15). Women are often portrayed as the sole providers of the physical and emotional needs of the family, and therefore, of society (Bunting, 1992). The societal and cultural contexts that shape and constrain care work are also outlined by Baines et al. (1998), "the use of the term caring signals not only the reality that this work is frequently invisible and usually undervalued but that it also takes place in the context of relationships in which the norms of obligation, responsibility and feelings of affection and resentment intertwine" (p. 4, 5).

Second wave feminism of the 1970s encouraged women to question objective and universal knowledge based on white, male experiences as a means to "understand the character of household caring, to explore its traditional norms, and to reconsider the social structures that limit its functions" (Fisher & Tronto, 1990, p. 51). While attempting to frame caregiving as a societal and not individual responsibility, the focus of this framing was very much on questioning and reinterpreting pre-assigned roles, such as wife or mother[1], including the care work required to raise and provide for children and to maintain the home. Informal (or familial) caregiving is rarely conceived or construed as "work", given that work "is taken to mean paid labor, thereby excluding much of the labor women perform" (Calasanti & Zajicek, 1993, p. 122). The implementation and use of the term "care work", used both in the literature of this era as well as throughout this thesis, is in recognition of and is purposefully used to emphasize that "care is a labor; it is work even when it goes unremunerated" (Feder Kittay, Jennings, & Wasunna, 2005, p. 444).

Historically, "academic feminism has paid scant attention to ageism, to age relationships, or to old age itself" (Freixas, Luque, & Reina, 2012, p. 45). Abel (1991), as cited in Hooyman and Gonyea (1995), is critical of feminists for their "lavished attention on motherhood but their slighting of other forms of caregiving" (p. 122). Building on Hochschild's (1989) mothering-focused notion of the "second shift", given that current and projected demographics make it increasingly likely that women will be caring for an older family member at some point in their lives, this "second wave of nurturing" (Sheehy, 1995) demands further research and attention. In response, this thesis brings attention to older adult care work, an increasingly common form of care work that takes place in the home. Like childcare work, older adult care work is also a gendered form of work. Canadian women are more likely to spend more time caring for seniors than men; 49% of women spend more than ten hours per week caring for an older adult as compared to 25% of men (Milan, Keown, & Robles Urquijo, 2011). These figures align with

[1] I recognize that these arguments predominantly align with a SNAF (Standard North American Family) family schema, one that is both raced and classed.

Stark's (2005) assertion that "care for the elderly is deeply gendered, both in terms of the care that aging women and men receive and regarding those who perform care work and their working conditions" (p. 7).

1.3.1.3 Caregiving as a choice

Whereas the idealization of women as "natural" caregivers strategically perpetuates the ideology that women are "the sole providers for the emotional and physical care needs of the family and, by extension, of society" (Bunting, 1992, p. 56), Hooyman and Gonyea (1995) state that the "choice about whether to assume the caregiver role is essential" (p. 259). Harrington Meyer (2000) explains that this notion of choice is, however, an illusion: "individual choices regarding care work are highly restricted by a persistent ideology about the gendered nature of care work, conflicting demands and expectations regarding paid and unpaid work, the paucity of affordable market-based options, and the instability of social supports implemented via welfare states" (p. 2). The illusion of choosing whether or not to provide care may be a struggle experienced by a family caregiver, unaware as to the source or nature of this externally originated, yet internally experienced, tension. This tension surrounding a caregiver's capacity to choose whether or not to provide care work is related to the proclivity for care work to be "readily perceived as an embedded part of women's identity … forged under terms and conditions that were not of their choice" (Baines et al., 1998, p. 9). These authors go on to indicate that when care work is conflated with a woman's identity (which has deep-rooted historical and sociocultural origins as elaborated in previous sections), this may set the stage "for an extremely negative image of women who do not fit this script by never opting for or by actually rejecting care work" (1998, p. 9).

Community care is another area in which family caregivers' semblance of choice is a façade. Upholding the ideals of familism and a neoliberal mindset of individualization (McGregor, 2001), aging in place is heavily promoted by different social and government structures as an idyllic care choice, for both caregiver and receiver(s) (Vasara, 2015). Larsson, Silverstein, and Thorslund (2005) perpetuate this illusion of choice, reporting that "in-home support is a crucial element in fulfilling the residential choice of frail older people (and their families) to age in place, while meeting society's obligation to cost-

effectively provide long-term care services to those in need" (p. 630-631). Aging in place discourse idealizes the home and surrounding community, accompanied by a nostalgic notion of the nuclear family, as the privileged site of care. By portraying the home as the environment best suited to provide and receive care that is "kind, sensitive and attuned to individual needs and compatible with traditional values" (Garner, 1999, pp. 162), government agencies and other support services are able to withdraw programming and support structures, placing this work on family members, friends, and older adults themselves. Ultimately, then, the trend of aging in place "has removed power of choice from the care receiver and caregiver, imposing dependency on both of them" (Garner, 1999, p. 163).

1.3.1.4 Contending with caregiving's dichotomies

Authors of scholarly literature use a number of dichotomies to categorize care work, perpetuating traditional dualisms and tensions surrounding care as women's work, including paid/unpaid, public/private, love/labour, and formal/informal. The ideology of separate spheres, that is, keeping the home and the market as separate entities, has created the "duality of the loving home and the impersonal public domain" (Hooyman & Gonyea, 1995, p. 33), spurred by ideologies of familism and individualism. Not only do these dichotomies prompt polarization and conflict, but by lumping family caregivers into only one of two broad categories, it becomes increasingly difficult to uncover the rich personal and unique characteristics and contexts present within each caregiver (and how these contribute towards different ways of experiencing care work). In explaining the existence and persistence of these dualisms, Glazer (1993) explains that "this approach is deeply rooted in Western social thinking, in the dialectic and in a binary approach to the social world … [one that] blinds us to overlaps and permeable boundaries" (p. 30). Care work is a complex concept, composed not only of dualisms, but of contradictory notions, including the very construction of caregiving as a "structural necessity yet an arena of social exclusion" (Barker, 2012, p. 582) that continues to rest, in large part, on women's work.

To bring awareness, recognition and value to the care work performed in the domestic sphere, feminist theories of caring continue to contend with and contest these

dichotomies. Viewing care work as a process, as suggested by Fisher and Tronto (1990), may reveal that "in reality, caring crosscuts the antitheses between public and private, rights and duties, love and labor" (p. 56). Hooyman and Gonyea (1995) similarly acknowledge that family caregiving "transcends traditional boundaries between public and private domains, between work and leisure and between productive and reproductive relationships" (p. 124), and argue for a more aggressive and proactive stance by claiming the popularized feminist notion of the "personal is political", thus "identifying and rejecting the public versus private dichotomy by which women are excluded from public participation" (p. 33). Joan Tronto (1987) echoes the need for a rejection of the public/private split, given its "implicit devaluation of the female" (p. 654). To ward off isolation that may accompany dualisms or categorization, Neysmith (1995) calls on researchers to "extract [their] thinking from the dualisms of formal versus informal care … allowing [them] to focus on how [they] are defining the needs of elderly persons and the implications of these interpretations for the content and organization of caring labour" (p. 110).

My thesis work acknowledges and explores the contradictions that surround care work, allowing for the acceptance of the complex interconnections between the public and private spheres, ultimately enhancing conceptualizations of both information work and care work. The aforementioned ideals to "crosscut", "transcend" or to "extract" highlight the importance of going beyond the dichotomies that stifle the understanding and valuing of care work. While a goal of a feminist framework is to break down the dichotomies of public/private, informal/formal, etc., this framework must first challenge the underlying social, market, and cultural forces by "[resolving] the implicit contradiction between feminist demands for independence and equality for women and the sharing and interdependence that occurs across the life span" (Hooyman & Gonyea, 1995, p. 34). My application of IE as a means to trace the broad, institutional forces that invisibly shape and guide family caregivers' actions at a local, everyday level is in an attempt to begin to transcend these dichotomies.

1.3.2 Information

Moving progressively narrower in scope, in the following four sections I first broadly examine health information and influences on its consumption and then move to an exploration of caregivers' information practices. I then conclude this section with an overview of the conceptualizations of information work to date.

1.3.2.1 Health information

Trends in the consumption and production of health information from an increasing number of sources arise from changing policies that reflect an "increasing emphasis on the role of individual citizens in maintaining and managing their own health" (Harris, 2009, p. 72). Transferals of responsibilities between formal and informal structures are observed in governments' delivery of digital health information to patients and families, seen as a strategic and cost-saving way of extending and strengthening the provision of health services (Simpson, Hall, & Leggett, 2009; Nettleton & Burrows, 2003). Government-disseminated health information (particularly in online formats) relies on the construct of an informed and empowered patient, that is, "an empowered individual who actively seeks out and makes effective use of health information" (Simpson, Hall, & Leggett, 2009, p. 35). The cost-saving benefits that are touted through this information provision to families, caregivers, and patients rest on a potentially tenuous assumption regarding an individual's ability and willingness to engage with information.

This shift of responsibility of care work from public institutions to the individual, the family, and/or the community is also seen in the shift of responsibility in using information that can support and guide care work. Health care providers and governmental structures assume that informed and empowered patients and their families will take a greater personal responsibility for their health, reducing reliance on formal (and often costly) health structures and systems. Increased health information provision to end users (caregivers, older adults, etc.), reinforces the erroneous assumption "that the availability of information automatically leads to understanding" (Simpson, Hall, & Leggett, 2009, p. 39). This plays into Nettleton and Burrows' commentary that current governmental policies towards the digitization of the welfare state assume that "the

'information rich' will achieve better welfare outcomes than the 'information poor'" (2003, p. 169). This assumption is highly individualistic, reflecting overall trends in health care and in older adult care, and assumes that a great deal of unpaid work will be undertaken by caregivers, patients, and community members to ensure that the information that is provided can be located, understood, and put to use. Indeed, responsibility for one's health (or responsibility for an aging family member's health) rests on the speculative supposition that "if people are provided with 'good' information, they will be 'empowered' to make 'good' choices" (Harris, Wathen, & Wyatt, 2010, p. 212).

This downloading of responsibility for using health information from health care professionals and government bodies to patients parallels the downloading of responsibility for care and housing of the elderly, from institutions to families and older adults themselves. Henderson and Petersen confirm this shift, finding that "the notion that the state should care for the health of its citizens, long seen as a fundamental principle of welfare states, is increasingly replaced by the expectation that citizens should play a more active role in caring for themselves as 'clients' or 'consumers'" (2002, p. 1). This active client is described as an empowered health care consumer with the presumed basis of empowerment being information (Harris, 2009). Barnes and Henwood (2015) discuss the *informatization of care*, in which care is being marginalized by this empowerment bestowed upon information. This emphasis on the expectation of autonomous use of information by carers as a means to meet the complex needs of the older adult is contrasted by a significant number of studies "indicating that extensive unmet caregiver information needs persist" (Washington, Meadows, Elliott, & Koopman, 2011, p. 39), indicative that further research in this area is still needed.

Nettleton and Burrows have argued that health and medical information "[have] escaped and [are] thus no longer something that can be accessed and, more importantly perhaps, produced and regulated by medical experts" (2003, p. 178). A key component of this inability to contain health information stems from the increasing social nature of health information and the increasing number of sources (in print, websites, social media sites, etc.) that now produce and disseminate health information (Henwood, Green, & Balka,

2009). Evolving producer-consumer boundaries and relationships allow more traditional consumers of information (patients, family members, caregivers) to join health care providers and researchers as producers of information. Health information, however, has been noted as expanding in volume and increasing in complexity; the process of using, interpreting and assessing the authority of health information is consequently becoming more difficult and intense (Harris, 2009), particularly with the increase of online health sources. “Most often, individuals seek health-related information, at any given time, from a combination of personal (e.g., self, friends, family) and impersonal (e.g., book, Internet) sources” (Lambert & Loiselle, 2007, p. 1013). With access to a wealth of health information, choosing between a variety of health information sources (in person, in print, or online), an increasing responsibility is being passed “to individuals, with their effectiveness determined by their ability to gather, then intelligently act on, health information” (Johnson & Case, 2012, p. 5). The four studies that comprise this dissertation were designed to investigate the work family caregivers do, specifically with regards to the work needed to harness and access this “escaped” health information that is needed to guide their care work.

1.3.2.2 Information mediaries

Information mediaries are increasingly appearing in the literature, in recognition that people turn to one other in helping to meet each other’s information needs. Catalysts for caregiver-focused research include an “increased demand for the role of familial caregivers regarding health situations” (Coward & Fisher, 2010, p. 4) as observed in a study by Fox and Jones (2009), who found that half of all online health inquiries are on behalf of someone other than the person typing in the search terms. Information mediaries are “those who seek information in a non-professional or informal capacity on behalf (or because) of others without necessarily being asked to do so, or engaging in follow-up” (Abrahamson & Fisher, 2007) and have been described using a variety of terms, including “gatekeepers, proxies, encounterers, information-acquirers-and-sharers, information stars, and natural helpers” (Coward & Fisher, 2010, p. 1). Latour (2005) illuminates the distinction between intermediaries and mediaries: the former are conduits for information, applying no input or outside meaning while the latter, the focus of this

thesis, “transform, translate, distort and modify the meaning of the elements they are supposed to carry” (p. 39). “The information-seeking work involved in taking responsibility for one’s … family members’ health involves much more than simply looking for and locating data relevant to a specific condition … it means sifting through, interpreting and dealing with the implications of the information one finds” (Harris, 2009, p. 78). This sifting through and dealing with the implications of the information found is evidence of family caregivers’ information mediation. Caregivers gather, filter, and translate information for the older adult in their care, making judgments regarding the degree of usefulness and pertinence of the information found.

This research is the first to conceptualize information mediation as work and sought to further investigate this role of searching on behalf of another, particularly in a culture of transferring health management from professionals to families and individuals. My thesis work also sought to cast a critical lens on the concept of information mediaries, a point of view that does not yet appear in the literature. Questioning the phenomenon of information mediaries, examining who benefits from this information partnership while highlighting the presence of work in this mediation facilitates a richer and more complex understanding of family caregivers’ information work.

1.3.2.3 Caregivers’ information practices

Information is, evidently, a key resource that enables a caregiver to be involved in the health and wellbeing of the older adult in their care. The role of information and the way by which information is used to shift the responsibility of care towards families and friends is evident in the United Kingdom government’s National Strategy for Carers: “the government believes that information is central to meeting carers’ needs. Without it they do not have the means to make choices or have control over their own lives” (Department of Health, 1999, p. 43). When transferals of care work between institutions, families, and older adults occur, “people who need information must learn to find it in new ways … [with] a risk that people who cannot find the new information or understand the changing rules will have their important needs go unmet” (Stark, 2005, p. 25). For older adults who may be uncertain where to locate necessary information or which information to access to manage their health and wellbeing, the gradual transfer of responsibility from

government structures to individuals in managing health information places increasing demands on family and friend caregivers.

"Appropriate and timely information is an essential element in a positive caregiving experience" (Dunbrack, 2005, p. 1). A cross-country survey of Canadian family caregivers revealed a commonality of information needs, including a need for information regarding: pain management, navigating a complex health care system with a variety of uncoordinated services, bereavement support, respite, practical caregiving information, what to expect as the illness progresses, dealing with various members and actors of the professional and volunteer care team, legal and financial questions, emotional and spiritual support, and complementary and alternative therapies (Dunbrack, 2005).

Some of the information complexities family caregivers have to contend with stem from their need to balance, mediate, and integrate information received from health care professionals, other individuals (family members, friends, etc.), as well as print and media sources (Washington, Meadows, Elliott, & Koopman, 2011; Hirakawa, Kuzuya, Enoki, & Uemura, 2011). Family caregivers have complex and evolving older adult-related information needs, yet a number of studies consistently report that these needs go unmet (Bee, Barnes, & Luker, 2008; Greenwood, Mackenzie, Cloud, & Wilson, 2009), particularly in "obtaining the information and education necessary to care for an older adult" (Washington et al., 2011, p. 37). Information mediaries in Abrahamson, Fisher, Turner, Durrance, and Combs Turner's (2008) study described the health information they found as being too technical, with too much jargon, resulting in a difficulty in determining the quality of health information. Similarly, Washington et al. (2011) found that family caregivers, serving as information mediaries for the older adult in their care, required information that is individualized, understandable, and designed to meet their unique needs. Also often cited is the need for health-related information that responds to family caregivers' information needs that change over time, corresponding to the older adult's health changes over time (Wackerbarth & Johnson, 2002). Repeated and ongoing evidence that caregivers encounter difficulties when seeking information about the older adult in their care warrants further investigations in this domain.

A review of the available literature examining family caregivers' information practices reveals an abundance of descriptive studies, underscoring Ginman's (2000) and Dervin's (2005) assertions that studies examining caregivers' use of information for their caregiving responsibilities require "more than surveys to quantify the types of information needed by patients and carers" (Harland & Bath, 2008, p. 467). An understanding of individuals' information practices, including individuals' impetuses for information seeking, how individuals use information, and where individuals locate information, these authors propose, are equally important. Consequently, my dissertation research supports Harland and Bath's (2008) argument that "information is dependent on the individual user and that 'best' information, as an objective reality, does not exist" (p. 468). In my thesis work, I conceived of participants as complex, heterogeneous information workers and therefore privileged their unique experiences and accounts of their work. This strategy speaks to the user-centered paradigm in Library and Information Science (LIS) research (Dervin & Nilan, 1986) and of an institutional ethnographic method of inquiry.

As Barnes, Henwood, and Smith (2016)'s study of the influence of caregiver-care receiver relationships on information use concludes, the provision of and access to information is not sufficient in and of itself: "information is not a panacea for uncertainty … more information might not necessarily lead to greater certainty or clarity" (p. 523). The focus on providing information to older adults and their families without any means of support or structure to understand, process or translate it, is evidence of the many facets of information work family caregivers do. Information that is "provided in a manner which is bereft of meaning, judgment, sense making, context and interpretation and instead dumped on consumers whether through the internet, television, or advertising can create considerable frustration and distress, and increase marginalization and disempowerment of these people" (Simpson, Hall, & Leggett, 2009, p. 39-40). Provision and availability of information alone does not necessarily generate value or assistance. Part of the information work required by caregivers includes provision of context, reflection and understanding to the information found or delivered, work that is often ignored or taken for granted.

Warner and Procaccino (2004) discuss the gendered nature of information use: “women have guarded the health of their families since the dawn of human time … as gatekeepers for health” (p. 709). Just as women are often regarded as “natural” caregivers, so too have they internalized and assumed a major responsibility for information work within the home on behalf of family and friends. Indeed, a common finding in research on consumer health information services is the predominance of female users (Marton, 2011). Harris (2009) is one of few scholars who illuminates the invisibility of information work and its gendered nature: “regardless of where it takes place, the health-informing support women provide to others is work, although it is a form of work that is seldom acknowledged” (p. 80). The site of care, often the home, is a contributing factor to this invisibility, “at home, information management, self-care, and health maintenance remain largely invisible and underarticulated” (Harris, 2009, p. 80). The site of information management (the home) and the fact that women typically self-identify as “health information managers” (Harris, 2009, p. 74) collectively contribute to the overall context and culture of invisibility that were made visible in my research by privileging the everyday and every night information work done by family caregivers.

This complexity and invisibility of information work on many counts and on different axes (the site, the skills, the individuals) may explain why the information needs of caregivers have repeatedly been reported as being poorly met. One final contributor to the invisibility of information work in library and information sciences is the focus on the family caregiver as an individual gatekeeper of information, a “lone ranger” information seeker (Urquhart & Yeoman, 2010, p. 127). Throughout this thesis, I challenge the neoliberal mindset of individualization (McGregor, 2001) by highlighting the interdependence and interconnectedness that are not only recognized by feminist perspectives (Garner, 1999) but that are reported in health information seeking studies of women (Genuis, 2012) and family caregivers (Barnes, Henwood, & Smith, 2016).

1.3.2.4 Information work

The first appearance of the term “information work” occurs in one of Corbin and Strauss’ earliest articles articulating their illness trajectory theory, “Managing chronic illness at home: Three lines of work” (1985) and is later expanded in their monograph, *Unending*

Work and Care: Managing Chronic Illness at Home (1988). This sociological concept focuses on the fluctuations of the trajectory of an illness as opposed to the medicalized focus of the illness itself. The trajectory refers "not only to the physiological unfolding of a disease but to the total organization of work done over that course, plus the impact on those involved with that work and its organization and then the consequences of that impact of the work itself" (p. 34) and also includes "the impact of the illness, the changes in the lives of the ill and their families that in turn affect their management of the illness itself" (p. 47). The acts of "undergoing and experiencing" (Corbin & Strauss, 1988, p. 34) are highlighted, as are the many forms of work that may arise and change as the course of a chronic illness can change. Affording individuals a sense of agency in their actions surrounding their chronic illness, information work is said to be one component of illness work, that is, the different actions an individual can take in shaping their illness trajectories. Corbin and Strauss outline different activities that encompass information work: "networking, scouting out, coaching and training, providing and clarifying instructions, distinguishing between needs and wants, searching for people, places, and necessary things" (1985, p. 244). While Corbin and Strauss do not explicitly define information work, they portrayed it as being central to clinical processes, "vital to the diagnostic process" (1988, p. 26), occurring between physicians and patients "when making arrangements for tests, explaining when, where, and how those tests are to be conducted, discussing what preparation is needed, and communicating during the actual test procedure" (1988, p. 26).

Within library and information science, Hogan and Palmer (2005), Souden (2008), Kaziunas, Ackerman, and Veinot (2013), and Büyüktür and Ackerman (2017), all draw from Corbin and Strauss' illness trajectory model (1985; 1988). These authors have each advanced the concept of information work in relation to a patient managing their chronic illnesses. Hogan and Palmer (2005), in a nation-wide survey of people living with HIV/AIDS, define information work as being "broader than information seeking but narrower than information behavior" and place emphasis on "the actual labor – the time, effort, resources, and outcomes—necessary in finding and using information, and it accounts for what is done with information it is sought and found." These authors assert that "purpose, conscious, [and] intended actions" (2005) are at the very core of

information work. While the very intent of the illness trajectory model is to draw out the many different forms of work that occur over the course of an illness, omitting serendipitous or inadvertent actions from information work may make certain information actions or activities invisible and is thus in opposition of Corbin and Strauss' model. Much like caregiving-related literature's tendency to quantify more easily observable activities and tasks in care work, Hogan and Palmer's (2005) definition is focused on more objective and concrete aspects of information work, that is, "purposive, conscious [and] intended actions," omitting affective facets, which often comprise the "caring *about*" facet of caregiving and which this thesis' conceptualization of information work includes. In this dissertation, I use a concept of information work that recognizes the actual work family caregivers must do to find, use, and manage information. My definition therefore goes beyond Hogan and Palmer's assertion that information work is a gap-filler between information seeking and information behaviour. In a 2008 study chronicling fifteen qualitative interviews with individuals experiencing a variety of chronic conditions, Souden offers a more holistic approach to information work within the context of health and wellness: "as a type of illness work, information work can play a central role in minimizing and repairing the disruption wrought by illness." This definition of information work allows for the incorporation of affective work and even passive information use or information avoidance as work.

Savolainen (2008) defines everyday-life information seeking (ELIS) as "the ways in which people acquire information in non-work contexts" (p. v). This definition dichotomizes work from everyday life and excludes the workful character of finding, using, or managing information in people's everyday life. Looking to other ways in which information work is framed in LIS, there are references to information work outside of health contexts, though these references tend to be somewhat sporadic and refer to several different conceptions of the term (Huvila, Lloyd, Budd, Palmer, & Toms, 2016). While some researchers explore the work related to different facets of information use, seeking, sharing, or withholding (such as Chatman [1992], in her in-depth exploration of retired women's information worlds), the concept of information work within health and wellness contexts has had little uptake in LIS. McKenzie and Stooke (2007) and later Stooke and McKenzie (2009) studied the different kinds of work

(literacy, information, and caring) embedded in bringing a young child to a public library program are helpful in beginning to delineate the definition of work in LIS. Much like a majority of care work studies, however, their research focuses on mothering. Similarly, Crispin's (2011a, 2011b) institutional ethnographic approach using interviews with school librarians and observations of students in a library is helpful to explicate how school librarians' work is coordinated by social institutions, though these studies focus on paid librarians with existing training in managing information.

My dissertation research sought to understand the construction and organization of family caregivers' information work, a needed addition to Hogan and Palmer (2005), Souden (2008), Kaziunas, Ackerman, and Veinot (2013), and Büyüktür and Ackerman's (2017) patient-focused conceptualizations of information work. This is of particular importance for instances when a patient may be unable to locate, recall, or digest information necessary for their ongoing care and wellbeing (such as the case with older adults living with later stages of dementia). Furthermore, both Souden (2008) and Hogan and Palmer (2005) treat information work in a clinical manner, both in the location where information work may occur (in hospitals or health care organizations) as well as the objective and distant role information work may play; information work's affective, relational, or comforting facets require more attention. Studying caregivers' information work in their everyday lives allowed for a more contextualized and rich understanding of how they use information and how their information activities can be more responsively supported. A departure from the aforementioned LIS studies of information work in its focus on an aging population and on information mediaries, this thesis work expanded and challenged the borders of information work.

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Chapter 2

2 Institutional ethnography: A method of inquiry

Originating in the 1970s by Canadian sociologist Dorothy E. Smith, institutional ethnography (IE) is a method of inquiry that maps how the everyday[1] world of people's experiences is "put together by relations that extend vastly beyond the everyday" (Smith, 2005, p. 1). While rooting itself in individuals' knowledge and the actualities of their everyday experiences, this method of inquiry simultaneously acknowledges that these everyday, local experiences are permeated and coordinated by linkages and institutions that are outside of and may be invisible to those living in their local, everyday environments (what Smith calls "ruling relations"). Mapping and making known these relations that extend beyond the local and the everyday is the crux of institutional ethnography. This mapping metaphor permeates institutional ethnographic inquiries with maps serving "as a guide through a complex ruling apparatus" (Devault & McCoy, 2002, p. 754).

Institutional ethnography has traditionally been a popular method of inquiry in the health sciences and human services settings. Examples of IE studies include an examination of nurses' approaches to quality assurance implementation in a long-term care setting (Campbell, 1998), an investigation of health care reform from a nursing perspective (Rankin & Campbell, 2006), workplace accommodation policies for workers with physical disabilities (Deveau, 2011), and making visible the everyday experiences of people living with HIV/AIDS (Mykhalovskiy & McCoy, 2002) and rheumatoid arthritis (Prodinger, 2012). Existing caregiving-focused IE studies are overwhelmingly from a parent-and-child stance: Griffith and Smith (1987; 2005) examined mothers' work in relation to schooling, Stooke (2004) studied the work needed to support young children's

[1] I use "everyday" in this thesis to conform to the ways that institutional ethnographers have employed this word. I am inclined, however, to use the form "every day" to indicate that people's work is more than commonplace or quotidian, but is repetitive and relentless.

education and development, and André-Bechely (2013) analyzed public school policies from the standpoint of parents.

Stooke and McKenzie (2009) note that institutional ethnography is not yet "widely taken up by library and information science researchers" (p. 660). Indeed, within Library and Information Science (LIS) research, IE studies are slowly gaining traction, with examinations of the actualities of librarians' work (Johnston & Santos Green, 2014), the information practices in midwifery care (McKenzie, 2006), the implications of the evidence-based practice movement (Pilerot, 2016), and the work needed to produce and carry out children's programs in public libraries (McKenzie & Stooke, 2007; Stooke & McKenzie, 2009).

By mapping out the complex work carried out by family caregivers of community-dwelling older adults who are living with dementia, I not only wanted to add to the growing body of LIS IE research, but I wanted to contribute to IE care-focused research that privileges older age.

2.1 Unpacking the problematic

My interest in institutional ethnography emerged from the disjuncture that I experienced as I set up my MLIS research pilot project: the importance governments and policies place on information to support families' care work and yet the frustration and difficulty caregivers experience when locating helpful information. As I began to consider this thesis work, I contemplated how to study the ways family caregivers of older adults "do" information work in their everyday (and night) lives and how to study information work itself – its characteristics, how it is organized, and how it is controlled. What guides and focuses an IE study is locating the "problematic of the everyday world", that is, the "sets of puzzles that do not yet exist in the form of puzzles but are latent in the actualities of the everyday world" (Smith, 1987, p. 91). The ways caregivers' experiences of their information work are changed by or fit within current understandings and affinities

towards aging in place, to me, presented itself as a way to locate the ethnographic problematic.

Studying the problematic draws attention to a "domain of possible questions, questions which have not yet been formulated, but which are implicit in the way the everyday world is organized. The problematic is there prior to the application of concepts and theories; its development takes the form of an inquiry which begins to question how things are organized" (Grahame, 1998, p. 350). Differently put, "the problematic is not the research question to be answered but rather the territory to be discovered" (Prodinger, 2012, p. 72). Starting neither with discourse nor with theory, this study takes up its problematic by taking the standpoint of family caregivers who do information work while caring for an older adult who is still living at home and is living with dementia. Specifically, I wanted to explore the ruling relations that invisibly coordinate or organize family caregivers' experiences of their information work and how these relations may be invisible in an aging in place climate. To do so, I honoured families' knowledge and experiences of their everyday information work encompassed within their care work, to "explore ethnographically the problematic that is implicit in it" (Smith, 2005, p. 43), including how this work is coordinated by linkages of ruling relations.

2.2 The local, the translocal, and IE's data types

A study guided by the institutional ethnography method of inquiry "begins at the local level, with people who are active and whose activities frame and organize their experiences" (Griffith & Smith, 2005, p. 3). Starting in the local actualities of the everyday world enables IE to be "a sociology for people" and makes visible and known commonplace work, such as caregivers' information work. This rooting in and privileging of the everyday enables IE to be a method of discovery that is sensitive to gender issues, of particular importance given the historically and traditionally gendered (and thus invisible) nature of caregiving, and women's work in general.

An IE study must start in the local particularities of everyday experience, though it cannot linger there. Deveau's introduction to institutional ethnography outlines that "in contemporary society the social organization of our daily lives cannot be wholly understood from simply looking at the local setting in which we live our lives; we need to go beyond that" (2008, p. 6). While using the experience of daily life as a starting point, an IE inquiry must go further (to the translocal) in order to penetrate into the ruling relations that enter into and organize family caregivers' lives and work (Griffith & Smith, 2005). By moving to the translocal, I was able to go beyond the work knowledge of any one family caregiver and could trace the ruling relations that influence the information work experiences my informants[2] described.

The institutional complex that encompasses aging in place is coordinated by ruling relations not fully perceptible nor contained in the everyday world (Smith, 1987). As the everyday world is "neither transparent nor obvious" (Smith, 1987, p. 91), caregivers doing information work in local settings may be unable to fully explain their position nor the reasons for their actions. The organizing and coordinating ruling relations within the institutional complex of aging in place originate outside of the local setting and are "not fully present in any one individual's everyday experience" (Smith, 1987, p. 89). As a result, I pieced together the knowledge, experiences, and expertise from each family caregiver; each of the informants' work knowledges afforded a partial view of their everyday world and contributed to an increasingly integrated understanding of the problematic and of the ruling relations that shape caregivers' everyday information work.

This foundation in the local, everyday world yet the concurrent awareness of the external, invisible relations that mold the experience of the local aligns with the types of data collected in IE studies. Campbell and Gregor (2004) outline two types of data collected throughout the course of an IE investigation: entry-level and level-two. The entry-level data in this study originate in the interviews outlined in Chapter Three. This data

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[2] In institutional ethnography, research participants are referred to as informants (Campbell & Gregor, 2004).

illuminate family caregivers' experiences of the information work they do in their everyday and offered "an entry into a problematic in the everyday world" (Campbell & Gregor, 2004, p. 60). An IE inquiry, however, "pushes beyond the local settings of people's everyday experience, and it must do so by finding those extended relations that coordinate multiple settings translocally" (Smith, 2005, p. 49). Therefore, from entry-level data (Chapter Three), my IE inquiry moved to collecting level-two data (Chapters Four, Five, and Six), that is, data that are "positioned outside the setting" (Deveau, 2008, p. 15) that allowed me to work back to see how the experiences collected in the entry-level data happened as they did. Each study, whether based on entry-level or level-two data, created a "window from a different angle into the generalizing social relations that rule our societies" (Smith, 2008, p. 435), and specifically, those ruling relations related to the institutional complex of aging in place that coordinate family caregivers' information work. Through a combination of entry-level and level-two data, I was able to progressively reveal "how people's everyday lives may be organized without their explicit awareness but still with their active involvement" (Campbell & Gregor, 2004, p. 43).

2.3 Constructions of knowledge and ruling relations

What focuses and permeates IE is its firm stance that knowledge is socially organized, socially constructed, and socially situated (Smith, 1990). Knowledge is not accepted merely due to its status or title as knowledge. IE critiques objectified forms of knowledge, calling for the need to expose "the social organization and social relations through which objectified forms of knowledge are created" (Mann & Kelly, 1997, p. 393). As such, IE is a method of inquiry into the social, grounded in the everyday, with an aim to "reorganize the social relations of knowledge of the social so that people can take that knowledge up as an extension of our ordinary knowledge of the local actualities of our lives" (Smith, 2005, p. 29).

Smith uses the term "ruling relations" to describe the "forms in which power is generated and held in contemporary societies" (Smith, 1999, p. 79); those distinct modes of organizing society through networks of coordination and control that transcend time and space. She clarifies, however, that ruling relations are more than relations of domination or hegemony. Smith (2005) lists some of these entities whose interconnecting relations create and contain power in societies: corporations, government bureaucracies, academic and professional discourses, and mass media. Ruling relations are encompassed in and are enabled by this quality of knowledge as socially formed. This study examined how family caregivers of older adults are "caught up in" and how their lives are coordinated by the institutional processes and ruling relations of aging in place, with a focus on understanding how caregivers get their information work done within these coordinating ruling relations.

In LIS research, there is a noted shift from studying how "people interact directly with information systems to the study of the people themselves and how they seek and use information independently of specific sources and systems" (Courtright, 2007, p. 273). While this shift towards a "user-centered paradigm" necessitates consideration of the context within which individuals seek and use information, the conceptualization of what context is (or is not) remains an elusive question within LIS scholarship (Courtright, 2007). IE's simultaneous emphasis on the local and the translocal, and on the ruling relations that organize the local, opens up context to a much broader conceptualization. In a 2007 *Annual Review of Information Science and Technology*, Courtright summarized and commented on LIS context-related research, grouping definitions of context into one of three categories: context as container, context as constructed meaning, and socially constructed context. An institutional ethnography enacts all three definitions, allowing for a more nuanced and complex understanding of the multitude of factors impacting individuals' everyday lives. The investigation of ruling relations' coordination within an IE method of inquiry is in alignment with Weber's understanding of context, "not reduced to the space of physical co-presence of several individuals … [but] may lie at the intersection of several settings" (2001, p. 485) that embraces the complexity of individuals existing in both the local and translocal.

This study, then, in keeping with the aim of an IE inquiry, opened the institutional complex of aging in place by discovering how the everyday doings of family caregivers (specifically, their information work) are articulated and coordinated by ruling relations that are not visible from within their local settings.

2.4 Institutional ethnography's approach to work

Institutional ethnography's inclusive conceptualization of work made it a fitting method of inquiry to understand the local and translocal ruling influences on family caregivers' information work. Smith qualifies her definition of work as "generous" and takes work to mean, "anything done by people that takes time and effort, that they mean to do, that is done under definite conditions and with whatever means and tools, and that they may have to think about" (Smith, 2005, p. 151-152). This definition considers a host of unpaid activities as work and is evocative of the argument put forward in the 1970s by feminists bringing attention to the network of unpaid and often invisible work performed by women in the house, often unrecognized as contributing to the capitalistic economy and therefore not counted as "work".

Smith's concept of work knowledge, that is, "a person's experience of and in their own work, what they do, how they do it, including what they think and feel" (Smith, 2005, p. 151), builds on IE's grounding in the everyday. This privileging of an individual's subjective experience places the expertise in the hands of those caregivers that are doing (and knowing and experiencing) the information work at the focus of this research. Each caregiver's work knowledge is steeped in their own experiences and is based within their local setting. Work knowledges are considered authoritative, not open to reinterpretation. The relaying of each caregiver's work knowledge, both experientially and institutionally, allowed me to piece together and locate the "sequences of action in which [the work knowledges are] embedded and which implicate other people, other experiences, and other work in the institutional process" (Smith, 2005, p. 158). Moving from IE's grounding in the everyday, work knowledges are crucial elements in viewing the

networks and coordination of other people, systems, and texts involved in the ruling relations emanating from the aging in place institutional complex.

2.5 Articulating the study's progression

My dissertation was guided by the following, overarching question: how do family caregivers of older adults living with dementia experience their information work in providing care to an older adult aging in place and in what ways is this work acknowledged and coordinated by different actors engaged in the administration, interpretation, and utilization of aging in place policies and research?

While I had a question in hand, the difficulty in detailing and planning the exact progression of my dissertation stemmed not only from the fact that there is "no 'one way' to conduct an IE investigation" (Devault & McCoy, 2002, p. 755), but because IE is qualified as "research as discovery" (Smith, 2005, p. 2). Devault and McCoy (2002) so aptly summarize this progression:

> *The process of inquiry is rather like grabbing a ball of string, finding a thread, and then pulling it out; that is why it is difficult to specify in advance exactly what the research will consist of. The researcher knows what she wants to explain, but only step by step does she know who she needs to interview, or what texts and discourses she needs to examine.* (p. 755)

As a result, I needed flexibility and openness throughout my research, with amendments occurring depending on what participants and texts revealed. What and who were studied emerged as the research progressed. Based on the experiences outlined by those family caregivers interviewed in Chapter Three and the ruling relations implicated in the local organization of their everyday information work, lines of further research and other sources of inquiry were brought to light. While "the institutional ethnographer may be unable to lay out precisely the parameters of the research" (Smith, 2005, p. 35) at the beginning of a study, the progression of this project was not arbitrarily structured. I carefully selected what or who to investigate next (investigating a document mentioned by a caregiver or interviewing paid dementia care staff, for example) based on what was

revealed or discovered. As I grabbed the ball of string and pulled the thread (Devault & McCoy, 2002), I used descriptions of work knowledges originating from the local (the experiences and actualities of the everyday information work of the family caregivers) to guide my investigation into the larger institutional complexes that enter into and shape that work.

The order in which the following four chapters are presented are not the order in which the dissertation research occurred. There was necessary back and forth between the chapters; data collection and analysis occurred in one chapter and was then set aside to work on another component that would inform it. While I started the ethics application, I began composing the scoping review search protocol. At the same time, in preparation for the interviews, I conducted a pilot study with two family caregivers to trial the interviewing technique as well as the mapping method. I was able to use findings from the scoping review to carry out the consultation exercise during the interviews with the family members. My preliminary analyses of the interviews with families identified subsequent dementia care staff interviewees and policy texts to take up. To maximize my efficiency and timeliness, while I waited for prospective participants to respond, I continued with textual analyses. The final stage of my research involved writing up the textual analyses chapters (scoping review and policy analysis), transcribing the interviews, analyzing the transcripts and policies, taking pause for reflection, and writing up my findings.

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Chapter 3

3 On the fluidity of information: Negotiating tensions in everyday information work in paid and unpaid dementia care[1]

3.1 Introduction

Of the 431,000 Canadians living with the dementia[2], 61% live at home (CIHI, 2018). Caring for an older adult living with dementia living at home relies largely on the willingness and ability of family members to "assume, master, and maintain the caregiving role" (Hepburn, Tornatore, Center, & Ostwald, 2001, p. 451). Recent changes in patterns of care provision for older adults, including those with dementia, have included a "withdrawal of the formal system, and [an] increasing reliance on family care providers" (Ward-Griffin & Marshall, 2003 p. 189). This shifting away from institutionalization and hospitalization is progressively placing a larger proportion of caregiving responsibilities on family members, friends, and the surrounding community, who are estimated to contribute an economic value of $25.5 billion in Canada annually (Hollander, Liu, & Chappell, 2009). Dependence on family caregivers will continue to grow as Alzheimer's disease and related dementias continue to increase in prevalence and cost, coupled with an increasing normalization of older adults aging in their home and in their surrounding community. Family caregivers provide the majority of care for individuals living with dementia (Schulz & Martire, 2004; Ward-Griffin et al., 2012; Wimo & Prince, 2010) and they also bear the majority of costs for care, not only financially, but also physically, mentally, and socially, with added incidences of depression, isolation, stress, and other health complications (Lethin et al., 2018).

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[1] This chapter will be submitted to *Journal of Documentation.*

[2] I use the term dementia as a general term for a range of neurodegenerative diseases with symptoms associated with memory decline and impairment, including, but not limited to, frontotemporal dementia, Alzheimer's disease, mixed dementia, and vascular dementia.

This article focuses on the information-related work that family caregivers do in order to support and guide their work of caring for community-dwelling older adults living with dementia. Family caregivers have complex information needs, requiring interactions with a number of medical, pharmaceutical, legal, and care agencies and organizations to answer questions and access information. As a result, family care providers may frequently experience barriers and frustrations as they negotiate their search for and sense making, management, and sharing of care-related information.

Erdelez, Howarth, and Gibson (2015) describe Library and Information Science (LIS) scholarship as peripheral to current discussions regarding opportunities and challenges associated with the rising incidence of dementia. This article takes up their call for a broader range of information science dementia research and focuses on the informational aspects of family caregivers' care work. This article aims to explicate how family caregivers' experiences of their information-related care work come to be. This study details the results of two sets of interviews, each guided by an institutional ethnography method of inquiry: one with 13 family caregivers of community-dwelling older adults living with dementia and a second set with five dementia care staff. The first interview set provides rich descriptions of the everyday information work that family caregivers do and the latter provides an understanding of how dementia care staff's work practices influence and organize family caregivers' experiences of their information work. This article is part of a larger institutional ethnography study that aims to explore how family caregivers' information work becomes shaped by institutional texts, structures, and processes.

3.2 Literature overview

3.2.1 Canadian dementia care landscape

Alzheimer's disease and other forms of dementia are the most significant cause of disability among Canadians over the age of 65 (Alzheimer Society of Canada, 2012). While estimates of the prevalence of dementia vary, approximately 564,000 Canadians are currently living with dementia, with 25,000 new cases diagnosed each year

(Alzheimer Society of Canada, 2016). By 2031, this number is expected to increase by 66% to 937,000 (Alzheimer Society of Canada, 2016). Dementia is an umbrella term for a range of neurodegenerative diseases with symptoms associated with progressive memory decline and impairment, including, but not limited to, frontotemporal dementia, Alzheimer's disease, mixed dementia, and vascular dementia. A dementia diagnosis is based on unique configurations and constellations of symptoms, including memory loss, disorientation in time and space, changes in mood and behaviour, changes in personality, difficulty with language, and problems with abstract thinking (Alzheimer Society of Canada, 2015). Individuals living with dementia experience progressive deterioration in cognition and behavioural functioning and as a result, have increasingly impaired abilities to contend with activities of everyday life, resulting in complex needs to be supported by others. As a majority of people with dementia live in the community (CIHI, 2018a), the impact of dementia care begins to and will increasingly ripple out to family members and friends, who provide approximately 70-80 percent of care to older adults living with dementia in the community (Schulz & Martire, 2004; Brodaty & Donkin, 2009; Keefe, 2011). Dementia care is cited as the most frequently studied type of caregiving (Schulz, 2000) and is described as a more stressful type of care provision, with families of individuals living with dementia consistently reporting higher levels of stress and burden than other types of caregivers (Bertrand, Fredman, & Saczynski, 2006).

One in five Canadians has experience caring for a person living with some type of dementia (Alzheimer Society of Canada, 2016). In this article, I use family caregiving to refer to the care provided by a spouse, child, relative, or friend with an established social relationship that is characterized by "informal arrangements, personal relationships and intimate bonds" (Weicht, 2015, p. 2) provided in domestic settings, in an unregulated manner. Families care both *for* and *about* their family member living with dementia. Caring *for* others focuses on the nature of the work, examining the visible activities or tasks associated with the activities of daily living, whereas caring *about* involves the emotional or mental work in caring for someone's wellbeing and is associated with the identity of the carer (Bruhn & Rebach, 2014; Neysmith, 1995).

Canadian family care providers assume annual out-of-pocket costs of $1.4 billion to care for individuals living with dementia (Alzheimer Society of Canada, 2016). Family caregivers spend between five to 20 hours per day, with an average of 60 hours per week caring for a person living with dementia (Marziali & Donahue, 2006) and spend, on average, nine years caring for a person living with dementia (Keene, Hope, Fairburn, & Jacoby, 2001). CIHI (2018b) recently reported that Canadian family caregivers of older adults living with dementia spend an average of 26 hours of care per week, seven hours more than the average amount of time provided by caregivers of those without dementia. Family caregivers (sometimes labelled "informal caregivers", in contrast with paid or "formal caregivers") of a person living with dementia are most likely spouses (32%) or adult children (58%), usually daughters[3] (Wong, Gilmour, Ramage-Morin, 2016; CIHI, 2018b). Eighty-five percent of individuals living with dementia rely, at least in part, on family, friends, or neighbours for support for a number of tasks, including: transportation, managing appointments or finances, meal preparation, housework, taking medications, and personal care, including dressing, bathing, toileting, and eating (Wong, Gilmour, & Ramage-Morin, 2016).

3.2.2 Caregivers' information work

Information (including finding information, making sense of it, sharing it, and storing it) underlies each of the above-mentioned care tasks to which family caregivers lend their time, finances, support, and work. This might include seeking out information about medication delivery times or side effects, sharing information about where to access home-delivered meals, sorting through information about in-home modifications, or

[3] Both incidence of dementia and providing care disproportionately affect females. Care work directed towards the elderly is therefore said to "absorb value but not produce it" (Federici, 2012, p. 116), resulting in a double devaluation as not only are older adults no longer "productive" members within the workforce but caregivers are often out of the labor market (whether completely or part-time) when caring. The enduring myth that women have a natural capacity and desire to care reinforces gender inequalities by unevenly charging women with unpaid care work (Hooyman & Gonyea, 1995). Women's disproportionate care contributions within the home, from mothering children to caring for an aging parent, are often taken for granted based on a gendered concept of social obligation, resulting in an invisible and unpaid workforce in the home and community whose work is often not recognized as work nor as contributing to the economy.

making sense and processing the implications of information about the progression of dementia.

With changing patterns of information provision and consumption, family caregivers are increasingly encouraged to actively and independently seek out information. The provision of information is a key component in enabling a caregiver to be involved in the health and wellbeing of the older adult in their care. Dementia Friends Canada, a collaborative, national awareness campaign between the federal government and the Alzheimer Society of Canada launched in 2015, exemplifies and emphasizes the importance of information in caregivers' lives: "the more you know about dementia, the more prepared you'll be to help people with dementia live better". In their examination of policy documents from the Department of Health in England, Barnes and Henwood (2015) similarly find that such documents "share a belief in the transformative power of information, with good care being positioned as a natural by-product of the widespread availability of good information" (p. 148).

This push to use information to be prepared for or to meet the complex medical and social needs of a growing older adult population is tempered by family caregivers' continued reports of feeling inadequately prepared, informed, and supported (Bookman & Harrington, 2007). More than 80% of family caregivers desire more information on caregiving topics (AARP & NAC, 2015), with their "high levels of unmet informational needs" (Morris & Thomas, 2002, p. 186) persisting despite increasing availability of information in online and print formats. While accessibility and quality of information are two desired characteristics in choosing information sources (Harland & Bath, 2008; Zimmer, Henry, & Butler, 2007), ongoing evidence that caregivers encounter difficulties when seeking and using information about or for the older adult in their care (Allen, Cain, & Meyer, 2017, 2018; Washington, Meadows, Elliott, & Koopman, 2011) suggests a different approach to studying caregivers' information needs is needed.

Family caregivers are information mediaries: "those who seek information … on behalf (or because) of others without necessarily being asked to do so, or engaging in follow-up" (Abrahamson & Fisher, 2007; Coward & Fisher, 2010). Caregivers' information

work goes beyond direct transmission of information; their intermediary information work includes a "transform[ation], translat[ion], distort[ion] and modif[ication] [of] the meaning of the elements they are supposed to carry" (Latour, 2005, p. 39). Caregivers make constant judgements as they gather, filter, and translate what they perceive to be helpful information for themselves, the older adult in their care, family members, and for other care partners. Contributing to the work of engaging with information, caregivers require different information at different stages of the dementia trajectory (Wackerbarth & Johnson, 2002). Highlighting the temporality of caregivers' dementia-related information needs, Pálsdóttir (2017) implemented Wilson's (1989) temporal model to describe caregivers' sequence of information behaviours: (1) information about the disease is noticed, (2) interpretation of information – normalizing and discounting, and (3) suspecting – purposive information seeking begins. As a result, the information work involved in taking responsibility for family members "involves much more than simply looking for and locating data relevant to a specific condition … it means sifting through, interpreting and dealing with the implications of the information one finds" (Harris, 2009, p. 78). These information activities, however, are an especially invisible form of care work. The site of care, often the home (especially with the popularity of aging in place), contributes to this invisibility: "at home, information management, self-care, and health maintenance remain largely invisible and underarticulated" (Harris, 2009, p. 80).

A small number of researchers are beginning to critique the ways in which information is constructed in caregiving studies. Provision of and access to information is not sufficient in and of itself; Barnes, Henwood, and Smith (2016)'s study of the influence of caregiver-care receiver relationships on information use concludes that "information is not a panacea for uncertainty … more information might not necessarily lead to greater certainty or clarity" (p. 523). Barnes and Henwood (2015) go on to label (and critique) the *informatization of care*, in which care is marginalized and even replaced by information. In a scoping review, Dalmer (2018; Chapter Four of this thesis) found that authors studying family caregivers' information work frame caregivers as being burdened due to a lack of information, with more information portrayed as a positive and a necessity in ensuring good care and in alleviating a caregiver's stress. The articles framed caregivers as secondary to the primacy of information in the information-care

relationship, portraying information provision as a beneficial way for caregivers to apply new knowledge, solve problems, and decrease burden, ultimately enabling older adults to age in place for a longer duration of time.

Holstein and Mitzen (2001) critique the contemporary discussion surrounding care, finding that it "overemphasizes the emotional and intellectual qualities and ignores its reference to actual work, or overemphasizes care as work at the expense of understanding the deeper intellectual and emotional qualities" (p. 61). To draw attention to and balance the actual work with the deeper intellectual and emotional qualities of families' information-related care work, in this article I use the term "information work" to speak about the information-related care activities that family caregivers engage with in their everyday and every night lives.

3.3 Methods

3.3.1 Conceptual framework

This article takes inspiration from an institutional ethnography method of inquiry. Originating in the 1970s by Canadian sociologist Dorothy E. Smith (1987; 1999; 2005; 2006), institutional ethnography (IE) is a method of inquiry that maps how people's everyday experiences are "put together by relations that extend vastly beyond the everyday" (Smith, 2005, p. 1). IE is predicated on two underlying assumptions: "(a) social 'happenings' consist in the concerted activities of people and (b) in contemporary society, local practices and experiences are tied into extended social relations or chains of action" (DeVault & McCoy, 2006, p. 19). Therefore, while rooting itself in individuals' knowledge and the actualities of their everyday experiences, this method of inquiry simultaneously acknowledges that people's everyday, local experiences are permeated and coordinated by relations and institutions that are outside of and may be invisible to those living in their local, everyday environments. By "empirically link[ing], describ[ing], and explicat[ing] tensions embedded in people's practices" (Rankin, 2017, p. 2), institutional ethnographers describe and explicate the organization and coordination of people's actions. To unearth this coordination, an institutional ethnographer will map

out what Smith calls “ruling relations”, invisible, translocal forms of control and organization that coordinate what people do with what others are doing “elsewhere and elsewhen” (Smith, 2005, p. 225).

Care work is, in many ways, “a nebulous and ambiguous concept and a part of every day life which is taken for granted” (Phillips, 2007, p. 1), making the underlying work of care often invisible to those doing, receiving, organizing, and legislating care. As a result, Dorothy Smith’s conceptualization of work is central both to IE and to the construction of this study. Smith qualifies her definition of work as “generous” and takes work to mean, “anything done by people that takes time and effort, that they mean to do, that is done under definite conditions and with whatever means and tools, and that they may have to think about” (Smith, 2005, p. 151-152). In alignment with this conceptualization of work, I purposefully ascribe the label of “work” to family caregivers’ practices to draw attention to the complexities of care provision. I purposefully use the term “care work” to recognize and emphasize that “care is a labor; it is work even when it goes unremunerated” (Feder Kittay, Jennings, & Wasunna, 2005, p. 444). In this study, I conceptualize families’ care work as “love and labour, both identity and activity, with the nature of demands being shaped by the social relations of the wider society” (Graham, 1983, p. 14). This interpretation of work considers and acknowledges a host of activities that are unpaid and often invisible, including, I argue, family caregivers’ information work.

Corbin and Strauss’ (1985; 1988) illness trajectory and their focus on the “three lines of work” of managing a chronic illness at home guide my own formulation of family caregivers’ information work. Corbin and Strauss describe information work as “the quest for, the receiving of, and the passing of information” (1988, p. 10), including “networking, scouting out, coaching and training, providing and clarifying instructions, distinguishing between needs and wants, searching for people, places, and necessary things” (1985, p. 244). Hogan and Palmer (2005) subsequently took up Corbin and Strauss’s concept of information work while investigating the information work done by individuals living with HIV/AIDS. Importantly, their study expanded Corbin and Strauss’ original understanding of information work, moving “beyond the notion of information as

a resource to account for the actual labor of locating, gathering, sorting, interpreting, assimilating, giving, and sharing information, and the fundamental nature of these activities in living with chronic illness" (Hogan & Palmer, 2005). While information work has been explored by LIS scholars, including Hogan and Palmer (2005), Souden (2008), Kaziunas, Ackerman, and Veinot (2013), and Büyüktür and Ackerman (2017), the prevailing approach to studying information work in LIS focuses on individuals seeking information for themselves. These patient-focused examinations of information work in the context of chronic illnesses occlude the complexities of information work when caring for another. I intentionally frame family caregivers' information practices as *work* to challenge and expand existing conceptualizations of information work by recognizing the additional work of searching on behalf of or because of another rather than for oneself. In borrowing from Smith's broad understanding of work, my use of information work acknowledges its complexities, recognizing that information work can be simultaneously instrumental and affective and allows for the incorporation of information management, sharing, and avoidance as work.

Important for this study and related to IE's understanding of work is Smith's concept of work knowledge - "a person's experience of and in their own work, what they do, how they do it, including what they think and feel" (Smith, 2005, p. 151), which builds on IE's grounding in the everyday. Privileging caregivers' experiences places the expertise in the hands of those caregivers who are doing (as well as knowing and experiencing) the information work that is the focus of the study. As a result, I consider caregivers as embodied knowers, that is, "expert knowers" (Rankin, 2017, p. 2) about their experiences and what happens in their everyday care work. Each caregiver's work knowledge is steeped in their own experiences, is based within their local setting, and is to be considered authoritative, not open to reinterpretation. As a result, I used interviews not to account for individual experiences, but as points of entry to reveal the ruling relations that shape everyday, local experiences (DeVault & McCoy, 2006). In the sections that follow, I present the methods, analysis, and findings each in two parts, divided between interviews with family caregivers and dementia care staff. The discussion will bring together these two sets of interviews to explicate the ruling relations that coordinate family caregivers' information work.

3.3.2 Starting in the local and the everyday: Interviews with family caregivers

Institutional ethnographers learn "by encountering the actualities through … talking with those who are directly involved" (Smith, 2008, p. 433). To find out "what actually happens", I interviewed participants "who participate in such a regime to explore with them the work they are doing and to make visible in this way how the institutional regime enters into the organization of that work" (Griffith & Smith, 2005, p. 4). I recruited the majority of participants from a dementia care facility that hosts adult day programs as well as weekly caregiver support meetings and education sessions (see Appendix A for the recruitment poster). Two gatekeepers - a research coordinator working with and a social worker working in a dementia care facility - were instrumental in the recruitment of family caregivers. Caregivers also inadvertently conducted their own snowball sampling on my behalf: a number of caregivers asked to join my study because other caregivers in their caregiver support group recommended my study. Following approval by The University of Western Ontario's Research Ethics Board (see Appendix B), I interviewed 13 family caregivers meeting the following inclusion criteria: self-reported primary, unpaid caregiver for an older adult (over the age of 65), who had a formal diagnosis of dementia (of any type), and who is aging in place in Ontario (see Appendix C for the Letter of Information). The number of participants in an IE interview study is dependent on the experiences and hints revealed throughout the interview that contribute towards the development of a comprehensive understanding of the ruling relations present in their work (Prodinger, 2012). Interviews therefore continued until I obtained a full picture[3] of the ruling relations that coordinate caregivers' work; that is, until similarities were corroborated and no further differences were exposed (Prodinger, 2012).

I outline key characteristics of the participants in Table 1. Interviews were between 95 to 185 minutes in length and were audio-recorded and transcribed verbatim. Interviews took place in participants' homes, a public café, or a public library meeting room, depending

[3] Full in this case refers to an *elastic* fullness (Charmaz, 1980; 1993), in that it is a full picture insofar as reflecting what informants in this study experienced and elected to report.

on the participant's preference. I took notes throughout the interview and wrote out impressions as soon as the interview finished. I preserved participants' confidentiality through the application of pseudonyms.

Name*	Age	Sex	Length of caregiving	Caring for	Age	Living arrangement	Diagnosis	Diagnosis date
Alice	66	F	7.5 years	husband	67	living together (house)	early-onset Alzheimer's	Fall 2009
Audrey	58	F	12 years	mother	87	living together (house)	Alzheimer's disease	2012
Blanche	77	F	3 years	husband	79	living together (house)	dementia	July 2014
Dorothy	62	F	1 year	mother	78	mom lives with her husband (house)	Alzheimer's disease	September 2016
Harriet	60	F	6 years	mother	85	living together (house)	mixed dementia (vascular and Alzheimer's)	2012
John	73	M	2 years	wife	74	living together (house)	frontotemporal dementia	Spring 2015
Judith	76	F	2 years	husband	83	living together (house)	Alzheimer's disease	February 2017
Lois	50	F	2.5 years	mother	86	mom lives with her husband (house)	dementia	Fall 2015
Marge	76	F	3 years	husband	88	living together (apartment)	mixed dementia (vascular and Alzheimer's)	July 2014
Rose	76	F	5 years	husband	71	living together (house)	Alzheimer's disease	2012
Sophia	70	F	3 years	husband	67	living together (house)	Alzheimer's disease	2012
Sylvia	75	F	6 years	husband	70	living together (condo)	Parkinson's disease dementia	2012
Thelma	64	F	2 years	father	85	dad lives on own (apartment)	Alzheimer's disease	June 2017

Table 1. Participant characteristics

*Pseudonyms used

IE rests on a social ontology, focusing on descriptions of a social world as it actually happens. Institutional ethnographers therefore avoid abstracting or theorizing what people do. My interview process intended not to generalize caregivers' experiences, but instead to detect and make visible the ruling relations that have generalizing effects. I therefore grounded the interviews "in the ongoing activities of actual individuals" (Smith, 1999, p. 232), organized around people's experiences of work (using Smith's generous definition), including participants' associated work knowledges (Devault & McCoy, 2012). I spoke[4] with family caregivers, using empathetic listening to listen to what was latent in caregivers' talk to make visible and understand what information work they do and how they conceptualize this work (see Appendix D for the Interview Guide). One structuring device in the interviews was to ask caregivers to run through a typical day as a means to construct and extract descriptions of the work they do in relation to caring for their aging family member. In another structuring device, I asked caregivers to think about when they first noticed changes in their family member, and where (and why) they decided to go to learn more about these changes. Throughout the interviews, I would often ask caregivers "what did you do next?" or "what happened next?" to tease out and map the chain of work and the different ruling relations at play. The progression of the interview and the questions I asked varied between informants, determined by what participants shared. Devault and McCoy's (2002) description of the broader process of conducting an IE inquiry captures the unpredictability of and flexibility required for my interview process: "the process of inquiry is rather like grabbing a ball of string, finding a thread, and then pulling it out; that is why it is difficult to specify in advance exactly what the research will consist of" (p. 194).

An institutional ethnography "requires the researcher to notice and name the relations in the research setting in which she is stepping" (Campbell & Gregor, 2004, p. 46). Part of this "noticing" and "naming" was more easily accomplished as I am not located within caregivers' everyday contexts as I am not caring, nor have I cared for a family member

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[4] Interviews in IE are framed as conversations or as "talking with people" (Devault & McCoy, 2012, p. 384).

living with dementia. As a result, it was easier for me to ask for clarification for what might be typically "known" by this population and I was more aware when technical terms or vague wording were used by participants for what actually happened.

3.3.3 Mapping exercise

Keeping the interviews grounded in informants' everyday work and resisting generalizing informants' work knowledges was a difficult task. DeVault (1999) begins to explain the potential difficulty in extricating informants' experiences: "most members of society learn to interpret their experiences in terms of dominant language and meaning; thus, women themselves (researchers included) often have trouble seeing and talking about their experiences" (p. 66). To keep the interviews grounded in the "ongoing activities of actual individuals" (Smith, 1999, p. 232) and to provide an alternative way to extract and elicit caregivers' understandings and descriptions of their care-related information work, I embedded an information world mapping exercise in the interviews. This exercise served as a helpful data elicitation technique to make visible the hidden work of finding, using, and making sense of information. Appendix E outlines my own guide for this exercise and Appendix F details the handout that I provided family caregivers.

I based this mapping activity on Sonnenwald's information horizons (1999) and on subsequent mapping exercises outlined by Lingel (2011), Greyson, O'Brien, and Shoveller (2017), and Freund, Hawkins, and Saewyc (2016). While caregivers' information work may occur in a broader, more generalizable context or situation than that prescribed by Sonnenwald, this concept served as a useful framework for understanding caregivers' experiences of their information work. In response to the mapping metaphor that runs throughout the IE method of inquiry, I asked participants to literally map out, by writing and drawing, the information work they described in their interview (and any other information work-related resources or tasks that came to mind as they draw out their own map). While I offered informants the option of creating the map alone (I volunteered to leave the room), all informants allowed me to stay with them as they created their map. This proved particularly helpful as I was able to ask for clarification as informants created their map. Prompting questions included asking informants why they drew their map in a certain order or why items mentioned in the

interview did not appear on the map (or conversely, what items appeared on the map that were not discussed throughout the interview). Following the completion of a pilot study, I created a template information world (Appendix G) so that informants could choose to work from a blank paper or from the template, which made the mapping exercise less onerous.

Twelve of the 13 caregivers agreed to take part in this exercise and each interpreted the creation of their map differently and to different degrees of detail, as depicted in Appendices H, I, and J. Given the difficulty in delineating the boundaries of information, the mapping exercise served as a helpful tool for caregivers to make visible the complexities of their information work, including the amount and the different types of information work they perform throughout their caregiving trajectory, the barriers encountered and inventive strategies they employed to access, use, and translate information needed to guide and support their care work. Each map depicts the caregiver's unique interpretations of their work, representing the information resources (family members, health care professionals, agencies, texts, tools, and websites) they accessed within their care context. In addition to mapping information sites and resources, caregivers included relationship dynamics, quotes, and self-care activities, depicting how information more broadly intersects with and may both support and complicate their care work. A majority of caregivers were unexpectedly eager to participate in the mapping exercise and it served as a memory aid, eliciting a discussion of a number of information activities not mentioned in the interview. As the informants completed the mapping exercise, they articulated their surprise and sense of validation of this particular type of work they do. A number of caregivers asked for copies of their maps to keep for themselves. One caregiver, Sylvia, independently elected to continue her map drawing after the interview finished and later emailed me a map she had made by herself (see Appendix K).

This exercise was instrumental for helping me to avoid institutional capture (when institutional discourse subsumes everyday experiences, trapping writing in specific institutional language and thinking [Smith, 2005]) and from imposing my own generalizing thoughts. As I was rooted in caregivers' actualities, the map served as a tool

to respect and cultivate caregivers' expertise, made tangible how caregivers went from one point to another (making visible "what happened next"), and made visible the sequencing of action and activities that are often difficult to bring to focus.

3.3.4 Moving from the local to the translocal: Interviews with paid care providers

To make better sense of why and how "what actually happens" to family caregivers happens, I subsequently interviewed dementia care staff. These care staff members are positioned outside the family caregivers' local actualities and have access to information beyond what family caregivers know, and therefore provided me another way to understand how ruling relations organize caregivers' information work. I was interested in, for example, understanding how staff located the information they shared with caregivers and the decisions they made about when and how to provide this information.

To determine whom to interview, I selected key informants identified by family caregivers (see Appendix L for the Recruitment Poster). Key informants had to meet the following inclusion criteria: be in a paid position with local government, a caregiver/older adult agency, or a nonprofit organization in the community, and interact with family caregivers of older adults living with dementia (though not necessarily with the caregivers interviewed in the first interview set). Following approval by The University of Western Ontario's Research Ethics Board (Appendix B), I interviewed five dementia care staff to understand how they "do" their work with a specific focus on their work with and about caregivers' information work. I arranged interviews to best suit care staff's schedules. Interviews primarily took place at the participant's place of work though one occurred at a teashop. Interviews were 45 to 75 minutes in length (Appendix M features the Letter of Information and Appendix N details the Interview Guide). I outline characteristics about each of the participants in Table 2.

Name*	Sex	Position	Years in position
Betty	F	Program Manager of Adult Day Programs[5]	10
Elaine	F	Social Worker	6
Maria	F	Director of Adult Day Programs	12
Sarah	F	Social Worker	18
Vikki	F	Manager of Care Coordinators[6]	15

Table 2. Dementia care staff's characteristics

*Pseudonyms used

3.3.5 Analysis

In institutional ethnography, the analytic process begins during the data collection period. Analysis is staunchly rooted in the accounts of things that are actually happening, meaning that my analysis began as I checked and verified my understandings as they evolved throughout the interview. Once I transcribed the interviews, I began to look for "sequences of action in which [the work knowledge] is embedded and which implicate other people, other experience, and other work in the institutional process on which research is focused" (Smith, 2005, p. 158). Owing to the grounding of interviews in a day's experience and work, I mined for clues of ruling relations and organizations embedded within the participant's talk of their everyday (Devault, 1999). Family

[5] Adult day programs offer people living with dementia an opportunity to participate in different social and recreational activities. In addition to providing family caregivers with respite from their caregiving role, these programs often include meals, crafts, exercise programs, music, and assistance with personal care (showering, foot care, etc.).

[6] There were 14 CCACs, or Community Care Access Centres, that delivered and coordinated home and community care throughout Ontario. The Ontario government's Ministry of Health and Long-Term Care funded CCACs. Care Coordinators are key individuals in delivering coordinated community care for the CCAC, serving as the liaison between patients and a number of different health care providers and key care resources. In May 2017, home and community care staff transferred from CCAC to the LIHN (Local Health Integration Network).

caregivers' experiences served as a point of entry into their information work and care staff's experiences were helpful in piecing together "how everyday life is put together" (Campbell & Gregor, 2004, p. 61), working back to see how caregivers' information work can be organized outside their own knowledge and coordination.

It was difficult, however, to use dementia care providers' experiences to trace and explicate the ruling relations that coordinate family caregivers' experiences of their information work, moving my analysis from rich descriptions to the more institutional ethnography-minded explication. This difficulty is partially explained by the noted lack of available explanations and practicalities of conducting analysis in IE (Walby, 2007; 2013). I began to search for "evidence that shows how people's work is tied together across time and location to build a *bigger account* about how people's work is socially organized" (Rankin, 2017, p. 4). As I moved between families' experiences and the broader institutional practices outlined in the dementia care staff's experiences, I employed indexing, an institutional ethnography-focused analytic tool.

Smith (as cited in DeVault and McCoy, 2006, p. 39) suggests that analyzing interviews by indexing avoids the typical interview practice of coding or thematic chunking which can muddle existing ruling relations (Campbell & Gregor, 2004). Rankin (2017) outlines her experiences of indexing, noting it to be a "tool that can be used to cross-reference across work processes, people, and settings" (p. 6). I indexed my transcripts to organize my thinking around linking caregivers' work activities. Fitting both IE's understanding of work and my focus on making visible caregivers' work, I indexed anything that the caregivers did that required time and effort. I created index headings that emerged directly from the participants' descriptions of their information work (this included the work of organizing information, anticipatory information work, the work of sharing information, and the work of avoiding information, among others). The indexing process helped me to focus more on caregivers' work at a broader level and was in alignment with an IE analysis, which "refuses any single view or narrative and supersedes any one account and even supersedes the totality of what informants know and can tell" (Campbell & Gregor, 2004, p. 85).

3.4 Findings

I present the findings in two parts. In the first section, I begin with thick descriptions about the caregivers' doings. In the second part, using the interviews from dementia care staff, I describe dementia care staff members' work that intersects with and shapes family caregivers' information work. Throughout this section, I intentionally make use of and privilege participants' own words, in acknowledgement of their work knowledges and given institutional ethnography's "analytic attention to language" (Deveau, 2008, p. 15).

3.4.1 Family caregivers' doings

Marge repeated a mantra mentioned by a number of informants: "*if you've met one person with Alzheimer's, you've met one person with Alzheimer's*". These differences between individuals living with dementia trickled down to create unique contexts for each caregiver. As a result, informants' information work was extremely varied. Despite this variety, families' information work appeared to be linked and organized by timescales of past, present, and future. Family caregivers engaged with information to draw on the past, remain in the present, and to both avoid and plan for the future. It is in their working through the past, present, and future that the complex tapestry of families' everyday and every night information work emerged. All three timescales involve complex configurations between the caregiver, the older adult living with dementia, their extended family, other dementia care partners, healthcare providers, dementia care services and programs, and their broader community.

Recognizing that "multiple timelines are involved in complex work" (Davies & McKenzie, 2004), caregivers' timescales are not necessarily linear nor are they sequential and may, in fact, overlap, blend, and interfere with one another. In addition to the unpredictability of aging, dementia is a chronic illness that has no neat sequence or predefined trajectory, as Judith articulates:

> *So many things. Because life is so complex, you know, it's not a straight line. Especially when we had this physical illness in the middle – it's not like okay, like 3 years ago I noticed this and then 2 years ago and that. There's been all these ups and down – it's like sierras.*

As a result of this volatility, those caring for a loved one with dementia are involved in information work from different timescales; information work that ebbs and flows over time and information work that transcends or cuts across timescales. These timescales sometimes intersect with one another, simultaneously supporting and complicating family caregivers' information work. One contributor to these intersecting, non-linear timescales is the ways in which caregivers obtain the information they need throughout their caregiving trajectory. Informants described receiving information in a patchwork pattern, at many different points of time and in many different places, as Dorothy explains,

> *I can totally appreciate how difficult and confusing it is for people and I think one of the things that I see … is that with the information, it's like, it's all – there's a little bit here, a little bit over here, a little bit here, a little bit here, little bit here. And that, for families, is very, very difficult. You know and it's like no one gives you the whole – the big picture and you know, if there's, you know, if there's something missing in all of this that's it.*

Audrey's reflection echoes Dorothy's, with the unpredictability of everyday life affecting how she (and other caregivers in similar situations) might need or receive information:

> *There's so much information out there. It's not organized. It is <u>not</u> organized. And yet, I wonder sometimes if it can be because everybody's journey - well it can be. It can be organized. But can you access it in a lock-step way? No! Because everybody's journey is different and you know, somebody at the group the other day – her husband did a sudden, sudden change, like everything was going along, smoothly, not well but smoothly, and all of the sudden for no apparent reason, can't figure it out, there was this sudden change. Now this woman suddenly needs a whole bunch of information that she didn't think she needed 20 minutes before that. Now she needs this – a different kind of information, but you can't live your life, I can't live my life anyway, thinking what am I going to need tomorrow? What am I going to need tomorrow? I just need to live it and know that I can get it when I need it. And that somebody will help me find it or I will be resourceful enough to find it.*

3.4.1.1 Past

Family caregivers drew on past experiences and knowledge to guide and support their caregiving. Often, caregivers drew from their past professional education and training to modulate their care provision. Harriet, for example, is a trained and practicing physiotherapist. As her quote describes, she uses her professional expertise to guide what resources she checks while caring for her mom:

> *On the computer … Web links. Different sites including … oh the American – NIHS? National Institute of Health. Institute of Health Services. Mayo Clinic. And then PubMed. Weekly updates. Oh and I'm a physio … oh my physio journals. And there are sites. So that would be like CPA. Canadian Physiotherapy Association.*

Harriet's own personality also shapes her information work. She calls herself a "*punctual*" and "*scheduled*" person who is "*not afraid to ask questions*", and these qualities influence the way she seeks out, makes sense of, and neatly organizes the information she uses to keep track of her mother's progressing mixed dementia.

Dorothy's career as an addictions counselor has also shaped her information work:

> *I'm used to having a lot of information. You know? Because I worked for an assessment and referral agency, right? So for many, many years in addiction and you know, it was just part of my job to know who was doing what, where and so I was very organized, you know, and again back then I had binders of information and it was, you know, it was all – it was all very well organized because I just – I needed to access it quickly – I'm talking to a client and it's like, okay. This is – this is what we need to do, yeah, and it was my job to connect them up, you know, so for me it's – yeah. That's just part of how I think.*

In looking back to the past, informants invoke what Huvila (2015) calls situational appropriation. Interviewed caregivers creatively appropriated past information accrued in a different situation and applied that information based on the new situation at hand. For example, Sophia explained how her searches about her husband's Alzheimer's disease were similar to the search strategies she developed when her daughter was first diagnosed

with celiac disease. She went on to describe how she was able to adapt her past training as a school administrator and a primary school teacher to more fully engage with and support her husband:

> *I think that my background and I also think not just my background as an administrator but my background in the kindergarten was huge in preparing me for this. Absolutely huge because, and I was a Special Ed person as well, so I have a lot of knowledge about modifying programs, changing things to suit the pupils, the student. And a lot of those things like, story boarding with kids who can't follow instructions or can't handle verbal communication, that kind of thing – I use that with* [husband] *all the time now. I do a lot of storyboarding, which is why he'll be okay today because there's a whole list of little jobs that he can do that will keep him busy until I get home. Empty the compost, take the compost out, gather the garbage around the house. It might be even be stuff he did yesterday but doesn't matter. He'll do it again. Change the water in* [dog's] *bowl. But each one is separate so he can read each strip. He can pick what he wants to do first. He has control over that. He can take as long as he needs to read it and process it. He can decide, I don't want to vacuum the main floor right now so he won't do that one.*

Lastly, informants worked to recall their loved ones' rhythms, routines, and desires. Caregivers drew on their loved one's preferences, hobbies, and personalities to guide what activities they would plan. Not only would informants speak to their family member's likes, but spouses would also speak to their rituals and preferences as a couple. Sophia explains how she made it a priority to enroll her husband in a fine arts program specifically designed for those living with dementia to draw on his lifelong love of the arts and describes how that program remains an integral feature of their routine:

> *He likes* [the fine arts program] *and he still goes to that. It's 2 hours every second week. Monday morning, right now. Up at the* [dementia education organization]. *I drop him off. He used to drive but he doesn't drive any more. I drop him off for 10, pick him up at 12 and they do art with them. So he quite likes that. And he was an art teacher and owned a gallery and grew up in the art world with his uncle in Toronto.*

3.4.1.2 Present

A majority of caregivers' present-focused information work centred on a constant monitoring and scanning for the small changes of daily life, either for new information

about dementia or scanning for changes in their loved one's behaviour, body, or routines or for potential environmental hazards. There was a constant vigilance on the part of caregivers; what information they needed or might need was not always certain. Furthermore, this information varied from caregiver to caregiver and from moment to moment.

Judith explains that she accesses information from a number of sources, including "*you know, TV, newspapers … anytime I spot something I'll read it*." Alice relates the relentlessness of her vigilance and begins to unpack the uneven, inconsistent, and all-consuming boundaries of what information can mean in the everyday and every night lives of caregivers' work:

> *It's your whole day. From the time you get up until you fall asleep and even then as you sleep because you have to be aware of what could happen within the confines of your home and of course you wonder about how your partner's feeling and all of those things that you deal with.*

Part of this constant monitoring included scanning for opportunities to share information with other caregivers. Family caregivers frequently mentioned family caregiver support group meetings as crucial sites of information exchange, accrual, and sensemaking. At the same time, however, informants noted the difficulty in finding time to attend these groups and to find someone (or to secure sufficient Personal Support Worker [PSW] visits) to watch over their loved one while they were away.

Harriet describes how this information sharing can happen in any environment:

> *It's probably word of mouth. So somebody will say to you – you know, I'm seeing something with my father, or my mother, or my spouse. That's probably the biggest part - because it's interesting, right? So I take my mom to see her dentist and the dental hygienist cleans my mom's teeth – we got talking because I always book the appointments at the same time and she says to me, I think my mother-in-law has it and so we talk about helpful resources for her and then her mother-in-law is now in the same nursing home as my dad.*

Caregivers' vigilant information monitoring and sharing was often intertwined with the need to keep track of, organize, and manage information. Family caregivers used a number of creative strategies to keep track of their information work (McKenzie & Dalmer, 2016). Harriet begins to elaborate the intricate and carefully considered methods of organizing the information she has accrued over her six years of caregiving:

> *My BlackBerry. I have calendars. Physical calendars for all her appointments. I have like a briefcase of all her documents. Everything's organized. I have her full history, you know, so if I'm going to appointments, I just have to print it off and it's there. So calendars … Blackberry. What else would I say? Briefcase of all information. Filing cabinet. All her financials are in there. Tax. Government … you have to make sure that you do your taxes. That you file income tax. And all her passports are there.*

Dorothy's mother is in the later stages of Alzheimer's disease: "*there's a lot of grieving that goes on, you know, when you see your loved one kind of losing their – losing their ability to just be who they are, you know?*" She then further explains the reasoning behind the ways in which she has organized her binder:

> *Well it's organized in terms of, you know, these are the medications, you know? This is, you know, the early stage, you know, symptoms and anything related to early stage is in that section. Second section would be middle phase, you know, what – how do people present like say with sun downing behaviours and stuff. So anything related to that and then sort of the later stages, you know, and what you might see in terms of communication and you know, loss of bodily functions, long-term care, and, you know, stuff like that. It's sort of what to expect and then you know there's another section on, you know, what's available in terms of community supports, you know, like weekly visitors, you know, how many hours do you get in terms of weekly visits, how many hours, you know, of programming do you get and that kind of thing.*

3.4.1.3 Future

A large component of family caregivers' future-oriented information work was working to avoid, as best possible, topics related to long-term care. When I asked John when and how he might know it might be time to transition his wife, who is living with FTD, to a

long-term care facility, he responded, *"How will I know then? I'm hoping I never know."* "Imbued with our fears of ageing, dependence, frailty and dying" (Braedley, 2018, p. 45), and likely connected to long-term care's historical connection to poor houses and insane asylums (Davies, 2001; Kaffenberger, 2001) and more contemporary reports of neglect and abuse (McDonald, 2018; McDonald et al., 2012), informants treated long-term care facilities as places of last resort. While family caregivers hesitantly demonstrated an awareness that long-term care placement was likely unavoidable, they actively and strategically worked to avoid or file away information related to long-term care placement or options. Rose captures this work to manage and avoid information related to long-term care placement and the affective connotations in working with and avoiding this topic:

> *I learned right then that it scares the heck out of me to look too far ahead and I can't manage it. I can't manage stuff that isn't relevant. So a lot of the information that I got at the course, both courses, it was too far ahead. Like, I couldn't use it then. Like long-term care? I'm only now, 3 years later, ready to go back and look at that … I'd file under L, but I wouldn't even look at it, you know?*

Informants also described a type of proactive, anticipatory information work, doing information work "just in case". Thelma, for example, discusses her information work related to the careful documentation of her father's medication allotment, should she be unable or unavailable to be present:

> *… he'll just say I have to take 5 pills tonight and 6 in the morning or something but … and yet I've got it all written out very carefully in case somebody else needs to do it, if something happened to me I've got the name of the name of it, what it's for, the color of the pill, the dose, when it's taken, I've got that all written out just because, you know, if I'm away or something and don't happen to get back and somebody needs to do his meds, they need to know what he had - what he's on so.*

Thelma also went on to describe how her future, anticipatory information work has changed and increased in intensity as her father's early-onset Alzheimer's has evolved. This quotation also begins to illustrate how anticipatory information work is often (necessarily) intertwined with the need to keep track of, organize, and manage

information and also explores how information work can impact the structuring and organization of family caregivers' days and weeks:

> *He has a big day book and so any appointment or things he's got coming up, I put in the day book so when he was still driving, he would go and pay the bills - I would figure them out but I would put in, you know, Bell bill or Union Gas bill in his day book or appointments, whatever and that was kind of our Bible, our way of communicating stuff and to keep track of stuff, so any of his appointments and stuff went in – when garbage day is, so. He's pretty good about going and looking at it - not so much now 'cause he can't get out, so, he doesn't really, you know, bills are so - I'm having to be cognizant if a bill is due like next Monday, I need to make sure when I go in Friday I take the bill and go and pay it right? 'Cause he won't think about it now because he doesn't - he's not doing it.*

3.4.2 Tracing the translocal

In this section, I begin to map out the work that came to light as I interviewed five paid dementia care coordinators. As I listened to the informants' descriptions of their everyday work days, weeks, and months, I began to map out the broader institutional, administrative, and economic processes, decisions, and agendas that intersect with and therefore shape the ways that family caregivers interpret, support, and ultimately experience their information work.

Dementia care staff's work coalesced around three main types of interlinked work that influenced both their and the family caregivers' work: that of coordination, that of making do, and that of accountability. The decisions, policies, and administration processes linked to these three types of interlinked work were outside of what families are aware of, but as I will illuminate in the discussion, have a direct influence on families' information-related care experiences.

3.4.2.1 Coordination

Informants spoke about coordination in two different directions: not only would they coordinate adult day programs, caregiver information sessions, and what information was

passed along to family members, but their own work was also coordinated through established steps and protocols (including waitlists, funding, and parent organization's prepared information) that they had to observe.

Interviewed staff members described, for example, the coordinated steps that had to happen before caregivers could activate their services. While any individual can make a referral for an older adult to receive CCAC (Community Care Access Centre) assistance (whether the family, the person living with dementia, a neighbor, or a friend), the CCAC needs to first obtain consent from that patient. With consent, the CCAC then conducts a home visit, using the RAI HC tool (Resident Assessment Instrument for Home Care) to determine whether patients are categorized as community independence, chronic, or complex, corresponding to low, middle, to high RAI scores. These scores, in combination with a home visit by a CCAC care coordinator, became decisive factors for determining what supports (occupational therapy, PSW visits, adult day program referral(s), etc.) are available and offered to the older adult living with dementia and their family.

Waitlists coordinated dementia care staff's work. Each dementia care adult day program had a lengthy waitlist. As Elaine noted, *"getting their first day [in our adult day program] is anywhere from 3-6 months of us getting the referral from CCAC and then after that they can wait up to a year for a second day".* The CCAC was a frequently noted gatekeeper, by both paid and family caregivers. As described by Maria, paid caregivers also discussed their struggle with the rankings that CCAC coordinators assigned to older adults living with dementia, which determined which services both they and their family care providers could access, including adult day programs and access to education sessions.

> *And we juggle them* [waitlists], *so it's based on the level of priority they've been assigned by the care coordinator, so it's a 1, 2, or 3. Priority One bump everyone else, so I could get a referral today that's Priority One but I could have 50 that are Priority Two. The Priority One will get there first. I think everybody is still struggling with that because it's very subjective to the care coordinator and to what the family story is right so we will get a Priority One today and a Priority*

> *One tomorrow and think, why was yesterday's our Priority One? So it's all circumstantial and subjective, really.*

Betty explains how her ability to provide information leaflets and booklets to family caregivers and individuals living with dementia is coordinated by parent organizations at the federal and provincial level, who dictate what information she and her colleagues are able and allowed to carry and pass along to families and individuals living with dementia:

> *We have 2 main sources. One is* [a national dementia education organization] *– they see themselves as the dispenser of information. They produce all of the – they have a certain look. The ones that you see in our resource room on different topics, like different types of dementia, different medication, communication, risk management, all those different topics. They produce those and they provide us with those … That's where we get the vast majority of our materials. For the actual learning series – that is a curriculum that was developed by* [a provincial division of the national dementia education organization]. *They're the other source for our info.*

3.4.2.2 Making do

In making do, informants spoke of the creative ways they were finding to make do with less. Informants were frustrated that they were working with fewer resources and were still required to do more, including using "*evidence-based*" care to "*wrap care around patients*" (Vikki).

Vikki spoke to the increasing care complexities of patients in the community: *And I mean, we're finding compared to years ago the complexity of the patients in the community, it's unbelievable. So much more – so many more complex medical issues, social issues, lots. It's very challenging, I'm not going to lie.*

She then went on to discuss the implications that a current scarcity of personal support workers (PSWs) has on family caregivers, who, as a result, may be increasingly called on to locate resources and information by themselves:

> *We're at a bit of a crisis with PSWs – there's not enough staff. Not enough PSWs to service the clients. In my 15 years, it's never been like this where we have the money to service people but the service providers don't have the staff. There's a lot of competition. Hospitals, retirement homes are hiring – and those are controlled. Whereas in the community, every time you open the door, it could be a different scenario. And there's a huge, huge wage disparity between institutional and community. The service providers are going to have figure that out and recruit PSWs. That's our biggest, biggest issue. We're having very difficult conversations with patients and families about you have to have a backup plan. What's your plan? Private pay? Many people don't have that. Family as a backup? We're having to rely a lot more on families, especially around services in the home.*

Finances also factored into dementia staff's ability to make do, as Elaine explains:

> *We all have limits. We are all under financial constraints, we have this much money and the number of people you serve has been this and this and year it's this* [gestures "more" with hands] *and next year it's gonna be this* [gestures even more] *so it's – I don't see it as rocket science, if they want to keep people out of the hospital and they don't want people using hospital beds, then the money has to go to the community and you have to – but we have limits. On our chronic community independence team, we can only provide 60 hours a month of PSWs. On our complex team they can have 90 hours a month.*

This need to "make do" extended into more practical issues, including room logistics for community programs. Betty explains that "*part of my role is to plug in, figure out where all this can fit in. Book the rooms."* She elaborates, "*another big factor here is room use. Some of our courses require both rooms. We only have two rooms. For* [an Alzheimer's disease information program]*, we need both rooms so we can't have any other social rec or programs going on. We run dozens of rec programs all the time. Monday and Friday afternoons are the only times that we can have access to both rooms."* Betty indicated that a great deal of planning goes into strategically picking which education courses to place at which times and at which points in the year, balancing caregivers' needs as well as the availability of the meeting rooms in her building.

3.4.2.3 Accountability

Betty, Sarah, Elaine, and Maria all spoke to the portion of their work that went towards keeping track for each interaction with family caregivers. Sarah describes the work that goes towards keeping track of her work, including her interactions with patients and family caregivers.

> *Basically we keep track of everybody that we see* – [another social worker] *and I are pretty good at keeping track in our heads – our memories are pretty good still that, you know, I met with that person for an hour, two hours, ten minutes. Every phone call we at least give it one unit, which equals 10 minutes. If we meet face to face with a caregiver, we do also have to keep track of that. We keep track of the groups and who attends and all those things. We write those down and then we transfer all that into an Excel spreadsheet and basically now it takes us a whole day to do our stats.*

Betty begins to explain why keeping track of statistics is so important, as these numbers validate the receipt of funding to continue her engagement with older adults living with dementia and their care providers.

> *Our statistics are based – we have to produce statistics for the LIHN and for* [a provincial dementia organization]. *For any of our funders. We only get 30% of our funding from the government so we have to raise 70% of our operating budget which is a lot. A lot of that comes through grants monies. So when you get grants you have to show results so a lot of stats are directly related to - what you done? Show us what you have done.*

Interestingly, in building a base of tracked statistics, dementia care's staff interactions, including the exchange of information with family caregivers, are translated into a standardized or fixed "datafied" language and thus become defined based on the boundaries of these tasks. The framework comes to be based on more easily measured tasks, including time elapsed or which information packages or website links were recommended, and less about the relationship building that takes place while passing along information and the work that takes place to ensure that information provision leads to understanding.

3.5 Discussion

Results from the two sets of interviews with family caregivers and dementia care staff reflect an underlying tension between what Barnes and Henwood (2015) have called *informing with care* and *informing to care*. In an *inform to care* approach, information is "understood as separate and outside of care, while nevertheless acting upon it to produce care" whereas in an *inform with care* approach, "information is understood as inextricably linked to care (with care) but not in any predetermined or uni-directional sense" (Barnes & Henwood, 2015, p. 147). Based on this tension, I argue that the two sets of interviews ultimately reveal an ongoing negotiation between the very conceptualization and understanding of the role of information in family caregivers' everyday lives.

An increasingly important issue for care staff is "how to maintain acceptable standards of care and quality of life in dementia with limited funds and staff, inadequate training of care staff, and increasing comorbidity and dependency levels in dementia" (Chenoweth et al., 2009, p. 317). Such was the case for interviewed dementia care staff, who worked within structures established by CCAC in-home assessments, RAI HC scores, fiscal constraints, and waitlists, among others. Such structures permitted a particular way of engaging with family caregivers informationally, within a framework *of informing to care* (Barnes & Henwood, 2015). The structures and regulations of paid dementia staff's workplace places constraints on the ways in which staff can think about and engage with information. These structures force an *inform to care* approach, restricting dementia care staff to a more static and less flexible conceptualization of information and of information interventions that are helpful across a number of caregivers. This may explain the proliferation of standardized information booklets, educational photocopies, and brochures that staff pass out to family caregivers.

While the structures that determine paid dementia staff's work ultimately prescribe and set boundaries around information, family caregivers' experiences of information that ebb and flow in time throughout the caregiving trajectory destabilize this static interventionist approach to information. As family caregivers translate information into the contexts of their everyday and every night lives (Kaziunas, Ackerman, & Veinot,

2013), their information work supports Harland and Bath's (2008) assertion that "information is dependent on the individual user and that 'best' information, as an objective reality, does not exist" (p. 468). Distilling the rich descriptions of the lived actualities of family caregivers in this study revealed the ambiguities in family caregivers' information work and accommodated the overwhelming differences in each caregiver's ongoing negotiation of their everyday and every night information work. The family caregivers' experiences of their information work exposed a specific quality of information that is in opposition of paid dementia staff's experiences of information: fluidity. In mobilizing the metaphor of the fluid to talk about information in the everyday lives of family caregivers, I draw from de Laet and Mol's (2000) examination of the Zimbabwe Bush Pump 'B' type. These authors were intrigued by this water pumping device, not only because of this technology's ability to provide clean water to villages, but because of what they describe as its fluidity. The pump, while solid and mechanical, is deemed fluid given that its boundaries are "vague and moving, rather than being clear or fixed" … and its "many grades and shades of 'working'; there are adaptation and variants" (de Laet & Mol, 2000, p. 225). Morgan, the creator of the pump (as cited in de Laet and Mol, 2000), indicates that

> *in travelling to 'unpredictable' places, an object that isn't too rigorously bounded, that doesn't impose itself but tries to serve, that is adaptable, flexible and responsive—in short, a fluid object—may well prove to be stronger than one which is firm.*

As family caregivers 'travel' to unpredictable places and experiences of time as the manifestations of dementia progress in strange, unpredictable, and non-linear ways, their experiences of information as fluid, as not too rigorously bounded, appear to be more reflective of reality than the more static or ossified experiences of information, which are more closely aligned with paid dementia staff's ways of engaging with information.

In this way, taking up their information work as fluid and contextual provided an understanding of information work that is more reflective of family caregivers' actualities. Interviewed family caregivers' experiences of information in their everyday lives suggest that information can be interpreted as what de Laet and Mol (2000) call

"mutable mobiles"[4]. Moser (2005) summarizes mutable mobiles as "flexible and responsive objects that become modified and adjusted as they are moved into new contexts and configurations – rather than upon fixed, stable and so immutable mobiles" (p. 367-368). Interpreting information as a mutable mobile lends itself to what Barnes and Henwood's (2015) *inform with care,* as a "new ethical approach to information provision … which is able to recognise and address the complexity, situatedness and relationality of information-care-giving and care receiving to move beyond the currently dominant 'inform to care' approach" (p. 153). It is important to note, however, that simply because information is fluid does not mean that the flow is uninterrupted or smooth. Family caregivers spoke of the frictions and obstacles that they encounter, including the affective work of dealing with information related to long-term care and the difficulties in piecing together information received from multiple locations and individuals. One source of friction reported by all families was managing and avoiding information related to the timing of long-term care placement or long-term care options. While LIS scholars have explored motivations for or behaviours related to information avoidance (Case, Andrews, Johnson, & Allard, 2005; Lambert, Loiselle, & Macdonald, 2009; Sairanen, & Savolainen, 2010; Savolainen, 2014), results from this study suggest a different facet of information avoidance. Interviewed family caregivers would simultaneously keep, store, and keep track of the long-term care-related information they were attempting to avoid in the present, but knew they would need in the future.

Another corollary of interpreting information as fluid is that it, in part, begins to explain why information requires so much work and effort on the part of family caregivers. Family caregivers experience information as "variable, materially heterogeneous, and context-dependent, as well as emergent, processual, and fluid" (Moser, 2005, p. 361). As a result, family caregivers made and managed information, using "carefully invented arrangement, practices, distributions, routines and procedures" (Moser, 2005, p. 344) that, at times, intersected with and at other times, transcended timescales. Family

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[4] Inspired by and in contrast to Latour's (1987) concept of the immutable mobile, something that moves around but that also holds its shape.

caregivers' information work is therefore also made prominent when considering the orchestration and coordination of their timescales. While McKenzie and Davies (2002; 2015), Davies and McKenzie (2004), Hartel (2010), and Savolainen (2006) have begun to examine temporal contexts in information studies, these authors note that temporal factors are either overlooked or lay implicit in models or studies of information practices. Not only does an examination of the multiple timescales in people's lives bring forth a new angle to understand and study families' information work, it also further demonstrates how family caregivers' everyday work is "embedded in complex, multiple, overlapping, and dynamic contexts" (Courtright, 2007, p. 291).

Family caregivers' experiences of doing information work as they do care work makes visible that the information they require comes from individuals and locations distributed in time and space, and crucially, "what these sources and elements of information are, and which of them turn out to be important, is not only variable but also *unpredictable*" (Moser, 2005, p. 355). In taking up information as a mutable mobile, as fluid, and unstable in the lives of family caregivers, it then becomes evident that predicting what information might be important to a family caregiver becomes nearly impossible, as information is emergent and processual in family caregivers' lives.

3.6 Conclusions

This study advances the use of an institutional ethnography method of inquiry to more broadly understand people's everyday information practices. In particular, by drawing on both the local and the translocal, this study sought to make visible the social organization of family caregivers' information work. As revealed through a combination of interviews with family caregivers and dementia care staff, families' experiences of their information work are coordinated by decisions made extralocally. Decisions made by dementia care staff about coordination, making do, and being accountable for their decisions creates a particular context in which families are able to find, use, and manage information while they care. These rich and complex findings would have not been possible without the application of a generous conceptualization of "work" or using a combination of locally

and translocally-situated informants. This study aims to serve as a prompt for future LIS studies to consider examining the translocal in addition to the local as a means to better understand the contextual influences on people's everyday information practices.

I join Erdelez, Howarth, and Gibson (2015) in calling other LIS scholars to bring our unique skill sets to the interdisciplinary research groups that investigate the challenges and impacts of dementia studies. Future studies may elect to involve family caregivers from a broader range of socioeconomic statuses to determine what different organizations they engage with throughout the caregiving trajectory and, in turn, the impact of these agencies' decisions on their everyday information work. This study highlighted a number of facets of information work that each require greater investigation to more fully understand the scope of caregivers' information work: the interaction between time work (Flaherty, 2003) and care work, the impact of a multiplicity of timescales on the experiences of information work when contending with a chronic illness, and the interaction between information mediation and personal information management.

My study's findings make visible the array of care-related information work that happens in the home and calls into question the boundaries that formal care providers place around information. Throughout the interviews and the mapping exercise, it was evident that caregivers do care work through information work and do information work through care work; there is a reciprocal relationship between information work and care work. As families contend with information that is "fluid" and, at times, ambiguous, this necessitate an acknowledgement that more formal supports are required in order to support family caregivers' information needs throughout the caregiving trajectory. Engaging with families as they manage this "mutable mobile" information requires a great deal of work from outside, formal supports, and requires moving beyond simply providing information interventions. This is a difficult and tenuous position to take, as this means greater investment of time, resources, and finances. Understanding information as fluid in the lives of families may also explain the increasing responsibility families undertake to become informed while caring for a community-dwelling older adult who is living with dementia. As information takes on a more permeable and loose

structure or role in the everyday lives of families, its boundaries can diffuse into increasingly numerous areas of one's life.

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Chapter 4

4 "Add info and stir": An institutional ethnographic scoping review of family caregivers' information work[1]

4.1 Introduction

Family members are increasingly assuming the role of care provider, acting as the front line of support for those living with dementia (WHO, 2012). Family and friends provide between 70 to 80 percent of the care provided to older adults (Keefe, 2011), enabling older adults to age in their communities and saving costly placement in long-term care facilities or hospitals. Recent changes in patterns of older adult care provision include a "withdrawal of the formal system, and [an] increasing reliance on family care providers" (Ward-Griffin & Marshall, 2003, p. 189). As Baines, Evans, and Neysmith (1998) explain, family caregiving "signals not only the reality that this work is frequently invisible and usually undervalued but that it also takes place in the context of relationships in which the norms of obligation, responsibility and feelings of affection and resentment intertwine" (p. 4, 5). Accessing, navigating, and managing information on behalf of family members are especially complex and invisible forms of care work. The information work involved in taking responsibility for family members "involves much more than simply looking for and locating data relevant to a specific condition … it means sifting through, interpreting and dealing with the implications of the information one finds" (Harris, 2009, p. 78). With government endorsement of community living (Federal/Provincial/Territorial Ministers Responsible for Seniors Forum, 2015), the contributions of family caregivers' information work (the seeking, use, evaluating or sharing of information) within their care work requires further study and articulation to assess the sustainability of a growing reliance on family caregivers.

Information work is crucial to the work of caring for oneself and for others. Care-related policies from the United Kingdom's Department of Health (2012a; 2012b) exemplify the

[1] This chapter is published in *Ageing & Society*.

construction of the centrality of information to carers' lives, portraying information as fundamental to good care, enabling and empowering carers to make better choices and take control. Such policies reflect an increasing expectation that individuals should play a more active role in caring for themselves and managing their own health (Henderson & Petersen, 2002) and rest on the speculative supposition that "if people are provided with 'good' information, they will be 'empowered' to make 'good' choices" (Harris, Wathen, & Wyatt, 2010, p. 212). Despite a closely entwined relationship between information and care, extant research examining caregivers' information work consistently conveys caregivers' frustration with unmet information needs (Vaingankar et al., 2013; Washington, Meadows, Elliott, & Koopman, 2011; Mastel-Smith and Stanley-Hermanns 2012; Morris & Thomas, 2002). As Given, Sherwood, and Given (2008) elaborate, "little information is available about the knowledge and skills that family caregivers need to provide care … or how their knowledge and skills affect care" (p. 115). With these persisting gaps, this scoping review serves as a baseline for subsequent research on this topic. By mapping the existing literature on the information practices of family caregivers of community-dwelling older persons with dementia, I investigate how academic scholarship studies family caregivers' information work.

This article stems from a larger institutional ethnography study that seeks to understand and make visible the intricacies and invisibility of family caregivers' information work. Pioneered by Canadian sociologist Dorothy Smith (1987; 1999; 2005; 2006), institutional ethnography (IE) is a method of inquiry that brings attention to people's everyday work while simultaneously highlighting the broader institutions that may be invisibly coordinating that work. One of the coordinators that IE studies take up are texts, often in the form of policies, forms, signage, and other formal documentation. To my knowledge, this is the first institutional ethnography study to examine scholarly literature using a

scoping review[2]. Scoping reviews rapidly map key concepts and types of evidence underpinning a research area (Mays, Roberts, & Popay, 2001). As this article reveals, an IE inflection enhances the scoping review process through four key means: an awareness of what remains unsaid, a valuing of lived experiences, an emphasis on invisible forms of work, and an attentiveness to authors' positioning. I also utilize IE to examine how academic research and writing might come to shape family caregivers' experiences of their everyday information work. In a companion article (Dalmer, forthcoming; Chapter Five of this thesis), I detail the affordances of a scoping review for IE investigations, by interpreting scoping reviews as both a text and as a process.

4.2 Literature review

The seeking, use, and dissemination of health information has "taken on enhanced importance in recent years because of the growing emphasis on the consumer/client in the health arena" (Johnson & Case, 2012, p. xi). Evolving producer-consumer boundaries enable more traditional *consumers* of information (patients, family members, caregivers) to join health care providers and researchers as *producers* of information. Health information continues to expand in volume and increase in complexity. The process of using, interpreting, and assessing the authority of health information is consequently becoming more arduous (Harris, 2009), particularly with the increase of online health sources. With access to a wealth of information, increasing responsibility falls to

[2] While one "critical ethnographic literature review" details the development of oral hygiene in nursing literature (Dale, Angus, Sinuff, & Mykhalovskiy, 2013), the authors do not make known the specific type of literature review they are framing nor do they fully explore the affordances and constraints of an institutional ethnographic approach to analyzing existing scholarly literature. Similarly, Prodinger, Shaw, Rudman, and Townsend (2012) examined peer-reviewed literature on occupation and rheumatoid arthritis to trace translocal relations and "learn how and why occupational therapy works in broadly generalised practices in health services" (p. 465). These authors do not, however, detail the particular type of literature review framework employed. Finally, Malachowski, Skorobohacz, and Stasiulis' (2017) recently published a scoping review detailing the appearance and applications of institutional ethnography (IE) in peer-reviewed literature.

individuals, with “their effectiveness determined by their ability to gather, then intelligently act on, health information” (Johnson & Case, 2012, p. 5).

4.2.1 Information and the work of caregiving

Persisting gendered divisions of care work reflect economic, political, and power relationships that idealize women as natural caregivers and uphold the home as the site of care (Baines, Evans, & Neysmith, 1998; Glazer, 1993; Hooyman & Gonyea, 1995). Just as women are often regarded as “natural” caregivers, so too have they internalized and assumed responsibility for information work within the home (Harris, 2009; Marton, 2011). Harris (2009) points to the invisibility and gendered nature of information work: “regardless of where it takes place, the health-informing support women provide to others is work, although it is a form of work that is seldom acknowledged” (p. 80). The site of care, often the home (especially in aging in place policies), is also a contributing factor to this invisibility, “at home, information management, self-care, and health maintenance remain largely invisible and underarticulated” (Harris, 2009, p. 80). Moreover, care work directed towards older adults is said to absorb value but not produce it (Federici, 2012), resulting in a double devaluation as not only are older adults no longer “productive” members within the workforce but caregivers are often out of the labour market when caring. Characterizing caregivers’ information practices as *work* brings attention to the time, effort, and resources that scholarly literature and policy often make invisible by constructing caregiving as a gendered concept of social and familial responsibility.

Categorizing family caregiving as a “labour of love” occludes the work, including information work, needed to care for another. This study takes the concept of information work into the domain of older adult care, highlighting information work as an under-studied facet of care work. Troubling the concept of *work* is a central tenet of institutional ethnography. Smith defines work generously, as “anything done by people that takes time and effort, that they mean to do, that is done under definite conditions and with whatever means and tools, and that they may have to think about” (Smith, 2005, p. 151-152). This definition considers a host of unpaid activities as work and is evocative of arguments put forward in the 1970s by feminists bringing attention to the network of unpaid and invisible work performed by women in the home. Feminist scholar Silvia Federici (1975)

explains that making work visible is the "most indispensable condition to begin to struggle" (p. 5) against its social organization.

Corbin and Strauss (1985) were the first to conceptualize information work as a facet of their illness trajectory theory. They framed information work as "networking, scouting out, coaching and training, providing and clarifying instructions, distinguishing between needs and wants, searching for people, places, and necessary things" (Corbin & Strauss, 1985, p. 244). Information work is central to clinical processes, occurring between physicians and patients "when making arrangements for tests, explaining when, where, and how those tests are to be conducted, discussing what preparation is needed, and communicating during the actual test procedure" (Corbin & Strauss, 1988, p. 26). The prevailing approach to studying information work in library and information science (LIS) focuses on individuals seeking information for themselves. Souden's (2008) and Hogan and Palmer's (2005) patient-focused examination of information work in the context of chronic illnesses occludes the complexities of information work when caring for another. Framing family caregivers' information practices as *work* challenges and expands existing conceptualizations of information work by recognizing the additional work of searching on behalf of or because of another. I assert that care work "has an information component and presumes some degree of information processing whether the work is manual labor or highly abstract decision making" (Huvila, 2009, p. 3). This understanding of information work acknowledges its complexities, recognizing that information work can be simultaneously instrumental and affective and allows for the incorporation of information management, sharing, and avoidance as work.

4.2.2 Family caregivers' information practices

Family caregivers fall under the category of information mediaries: "those who seek information … on behalf (or because) of others without necessarily being asked to do so, or engaging in follow-up" (Abrahamson & Fisher, 2007). Other terms used to describe information mediaries include: gatekeepers, proxies, encounterers, information-acquirers-and-sharers, information stars, and natural helpers (Coward & Fisher, 2010). Latour (2005) illuminates the distinction between intermediaries and mediaries: the former are conduits for information, applying no input or outside meaning while the latter, at the

focus of this study, “transform, translate, distort and modify the meaning of the elements they are supposed to carry” (p. 39). Caregivers’ information work goes beyond direct transmission of information. Caregivers make constant judgements as they gather, filter, and translate what they perceive to be helpful information for themselves, the older adult in their care, family members, and other care partners.

A cross-country survey identified Canadian family caregivers’ top information needs, including: pain management, navigating complex health care systems, respite, the illness progresses, legal and financial questions, emotional and spiritual support, and culturally appropriate services (Dunbrack, 2005). Many authors identify accurate and timely information provided in simple, easy to understand language as essential for a positive caregiving experience (Dunbrack, 2005; Kelly & Innes, 2016). Washington et al. (2011) found that family caregivers require information that is individualized, understandable, and designed to meet their unique needs. Wald, Fahy, Walker, and Livingston (2003) devised a “rule of threes”, suggesting that information should be delivered to caregivers in a series of scaffolded sessions, with three topics per session to avoid information overload. Some of the informational complexities stem from the need to integrate and mediate information from health care professionals, other family members, websites, and social media (Hirakawa, Kuzuya, Enoki, & Uemura, 2011; Vaingankar et al., 2013; van Vliet et al., 2011; Peterson, Hahn, Lee, Madison, & Atri, 2016). This information mediation process can prove difficult, particularly as health information is often overly technical and contains jargon which complicates caregivers’ ability to assess the information’s authority and validity (Abrahamson, Fisher, Turner, Durrance, & Combs Turner, 2008). Specific to caregivers of older adults living with dementia, Wackerbarth and Johnson (2002) found American caregivers valued information about finding helpful care services, diagnosis and treatment, and information about legal and financial issues. Studies continue to document the inadequate dementia-related information provided to both patients and family members (Downs, Clibbens, Rae, Cook, & Woods, 2002; Van Hout, Vernooij-Dassen, Jansen, & Stalman, 2006; Bee, Barnes, & Luker, 2008; Greenwood, Mackenzie, Cloud, & Wilson, 2009). Contributing to the work of engaging with information, caregivers require different information at different stages of the dementia trajectory (Wackerbarth & Johnson, 2002; see also Chapter Three of this

thesis). Highlighting the temporality of caregivers' dementia-related information needs, Pálsdóttir (2017) implemented Wilson's (1989) temporal model to describe caregivers' sequence of information behaviours: (1) information about the disease is noticed, (2) interpretation of information – normalizing and discounting, and (3) suspecting – purposive information seeking begins.

Recognizing that family caregivers risk increases in physical and mental health problems, social isolation, and financial distress (Winter & Gitlin, 2007; Marziali & Garcia, 2011), a number of studies examine the utility of caregiver support groups, networks, and intervention sessions. Support provided to caregivers over the telephone, for example, enhances skills, imparts information, and links caregivers to peer support (Martindale-Adams *et al.* 2002). While early studies examined the effects of in-person support groups and interventions (Haley, Brown, & Levine, 1987; Mohide *et al.*, 1990; Gonyea, 1991; Collins, Given, & Given, 1994; Mittelman *et al*., 1995), more recent studies implement different technologies, including telephones (Winter & Gitlin, 2007), video conferencing tools (Marziali & Donahue, 2006), and websites (Marziali & Garcia, 2011) to deliver support and information. While these intervention or support group-based studies are likely rich sources of information seeking, gathering, and exchange for family care providers, a majority of these studies focus their findings on caregivers' health-based outcomes, including changes in burden, depression, sleep patterns, stress, or health status. Hepburn *et al.*'s (2001) training curriculum, featuring a combination of classroom instruction and assignments with readings, revealed that caregivers prefer information provided in an ongoing manner. In what Hepburn *et al.* (2001) qualify as "linkages" (p. 455), the authors begin to describe the work needed to engage with and process information, indicating that caregivers respond to specific information about services, including "salience (what a service did and how the caregiver and care receiver could benefit from it), access (whom to call), quality (who does the best job), and reasonable expectations (e.g., it may take a person a month to become accustomed to day care)" (p. 455). A number of studies also speak to the relational aspects of caregivers' information practices. In a survey of 214 family and friend caregivers of individuals living with dementia, Allen, Cain, and Meyer (2018) found that health and social care professionals are preferred over the internet as a first point of access. Relational information, that is,

information obtained from another person, is receiving increasing attention in research given family caregivers' desire to hear personal experiences, to receive emotional support, and to be seriously and empathically heard (Barnes, Henwood, & Smith, 2016; Robinson *et al.,* 2009; Allen, Cain, & Meyer, 2018). Accordingly, this study builds on caregiver support and training research by explicitly focusing on the informational component of these training programs and by highlighting the work family caregivers do to process, make sense of, and use of the information gleaned and shared in these programs.

More than 80% of family caregivers request more information on caregiving topics (AARP & NAC, 2015). Ongoing evidence that caregivers encounter difficulties when seeking and using information about or for the older adult in their care warrants a different approach to studying caregivers' information needs. There is a dearth, however, of research that critically examines how studies involving family caregivers are conducted and the contexts within which the results are unearthed. In response, this study takes a different approach from other investigations of caregivers' information practices, examining instead existing research on the topic to document how it has, over time, studied and constructed caregivers and their information work.

4.3 Method

In institutional ethnography, texts are "integral to courses of action" (Smith, 2006, p. 87) as they coordinate people's activities. Therefore, as one component of a larger institutional ethnography study, this article took up a scoping review to examine how the "site" of academic texts come to coordinate caregivers' information work. First articulated by Arksey and O'Malley (2005), scoping reviews are "a preliminary assessment of the potential size and scope of available research literature'' (Grant & Booth, 2009, p. 95), a form of knowledge synthesis that summarizes the "extent, range, and nature of research activity … to convey the breadth and depth of a field" (Levac et al., 2010, p. 1).

This scoping review follows the framework of Arksey and O'Malley's (2005) five stages: identification of research question, identification of relevant studies, selection of included studies, data extraction and charting, and summarization and dissemination of findings. This review also takes up Arksey and O'Malley's (2005) sixth recommended, yet rarely implemented, consultation stage with stakeholders (family caregivers) to determine whether the review's findings reflect participants' everyday experiences. Following approval by The University of Western Ontario's Research Ethics Board, I interviewed thirteen family caregivers of community-dwelling older adults living with dementia about their everyday information work. I preserved participants' confidentiality through the application of pseudonyms.

Davis, Drey, and Gould (2009) cite the need for "greater transparency and methodological rigor" around decision-making in scoping reviews to "increase the legitimacy of findings and assist in peer review processes" (p. 1398). Similarly, Levac et al. (2010) state that more consistently applied and structured guidelines would enable transparent scoping review reporting. In response to these appeals, this scoping review provides an auditable analytical approach to aid in the continued and evolving formalization of this method's definition and processes.

4.3.1 Identification of research question

Scoping reviews are guided by "a requirement to identify all relevant literature regardless of study design" (Arksey & O'Malley, 2005, p. 22). I intentionally kept the research question broad to capture a range of disciplines, methodologies, theoretical underpinnings, and different ways of knowing: "how does scholarly research conceptualize informational components of family caregivers' work and to what degree are these components acknowledged as work?"

To get a sense of the extent, range, and nature of the research on this topic, I posed the following narrower questions:

- What are the publication trends of studies examining information work?
- What methods and types of data are used in these studies?
- Who are the populations under investigation in these studies?
- What theoretical framing is used to guide these studies?

- In what ways is information (and information work) acknowledged and framed?
- In what ways is the information-care relationship articulated?

4.3.2 Identification of the sample

I searched a variety of databases from the social sciences, health sciences, and LIS: LISTA (Library, Information Science and Technology Abstracts), Library Literature & Information Science, Medline (including in-process and other nonindexed citations), CINAHL (Cumulative Index to Nursing and Allied Health Literature), Academic Search Complete, Social Science Abstracts, Scopus, SocINDEX, Social Sciences Abstracts, Web of Science Core Collection (including Social Science Citation Index), and AgeLine. Searching a broad spectrum of databases captured the multidisciplinarity of the topics of caregiving, aging, and information. In addition to those databases listed above, given the diversity of topics that may be differently indexed, I hand searched via reference harvesting and forward citation searching, retrieving a total of 19 additional articles.

Table 3 outlines the five key concepts (aging in place, information, older adult, dementia, and family caregiver) and corresponding search terms used in the search:

Older adult
aged/aging/ageing/elder*/older adult/senior/ older people/older person/older wom?n/older m?n/geriatric*, gerontolog*
Dementia
dementia*/Alzheimer's Disease/Alzheimer*/vascular dementia/frontotemporal dementia
Family caregiver
family caregiver(s)/informal caregiver(s)/unpaid caregiver(s)/care work/care labor/care labour /((daughter* or husband* or spous* or wife or wives or son or sons) adj3 caregiv*)
Aging in place
community living/aging in place/ageing in place/community dwelling/in the community
Information
information dissemination/information services/access to information/information seeking behavior?r*/information seeking behaviour*/information need*

Table 3. Search terms used

I limited results to the English and French language and then further to a timeframe of twenty-five years (1990-2015). A sample Medline search is listed below in Table 4.

Independent Living/ OR ("aging in place" or "ageing in place" or "age in place" or "community living" or "housing" or "living at home" or "living in the community" or “community dwelling” or “in the community”).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
AND
Caregivers/ OR ("care labor*" or "care labour*" or caregiv* or "informal caregiv*" or "family caregiv*" or "unpaid caregiv*" or "care work*" or ((daughter* or husband* or spous* or wife or wives or son*) adj3 caregiv*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
AND
Information Dissemination/ or Information Services/ or Consumer Health Information/ or Health Information Systems/ or Access to Information/ or Information Seeking Behavior/ or "Information Storage and Retrieval"/ OR (“information need”).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] OR information.ti OR information.ab
AND
"Aged, 80 and over"/ or Aged/ or Geriatrics/ OR (aged or aging or ageing or elder* or "older adult*" or senior* or "older people" or "older person" or "older wom?n" or "older m?n" or gerontolog*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] AND Alzheimer Disease/ or Dementia/ or Dementia, Vascular/ or Frontotemporal Dementia/ OR alzheimer*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]

Table 4. Sample search in Medline

To contribute to the ongoing development and formalization of scoping review methods, I documented the identification, screening, and selection processes using a modified PRISMA Flow Diagram, included in Appendix O. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) is a set of standardized tools typically used with systematic reviews and meta-analyses (Liberati et al., 2009), though its standardized flow diagram is helpful for replicability and transparency in scoping reviews.

4.3.3 Sample selection

An initial search retrieved a total of 2043 records (2024 imported from database searching and 19 from hand searching) after which I removed 645 duplicate records. A title and abstract-level screening removed 1264 of the remaining 1398 records (refer to Appendix O for exclusion criteria). I read through the remaining 133 articles, assessing each article for its eligibility for inclusion. Of these articles, I removed 71 articles that met the exclusion criteria. I then conducted a second search in August 2017 to update the initial January 2016 search, adding an additional ten articles. A total of 72 articles were included for analysis in this scoping review.

As Levac, Colquhoun, and O'Brien (2010) corroborate, this third stage is not as linear as Arksey and O'Malley (2005) suggest. In fact, both the second and third stages were iterative in nature; as I searched databases and reviewed articles for inclusion, I continually reevaluated and refined search terms, search strategies, and inclusion and exclusion criteria. This need to continually revisit search terms is due, in part, to two of the concepts searched: information and aging in place. Information is a concept that can be vague and amorphous, conceived of and enacted differently in different disciplines. Similarly, aging in place is differently described and indexed by differently-located scholars and by different databases. Determining how to best employ these two concepts within the different databases made the identification of eligible studies a lengthy and tedious process. As a majority of the retrieved articles were from outside the LIS discipline, resorting to the broader term 'information' proved most helpful in retrieving articles, though this general term required a closer reading of each candidate article. To

determine how to best capture the housing context of each article, no one term was especially fruitful. Ultimately, articles had to be scanned to determine whether they fit the inclusion criteria. At all three levels of screening (title, abstract, and full text), a majority of eliminated articles focused on caregivers of older adults moving into or already living in an institutional setting. While this moment of transition is undeniably a catalyst for information seeking, the number of articles on this topic is not in alignment with Canadian older adults' desires, with 85% wishing to age indefinitely in their homes (Canada Mortgage and Housing Corporation, 2015).

4.3.4 Data extraction and charting

Scoping reviews are known for their ability to provide a "comprehensive and panoramic overview" (Davis et al., 2009, p. 1388), rather than an assessment of the quality of the evidence in each article (Arksey & O'Malley, 2005). Because of these two qualities, the data extraction and charting stages are not focused on any one article. Instead, data are described to illuminate "key themes, trends, and patterns in the articles under study – all at a general level rather than highlighting individual studies or particular findings" (Rumrill, Fitzgerald, & Merchant, 2010, p. 403). Analyzing texts within an institutional ethnography, however, necessitates a different kind of reading; searching for and identifying "how the [article's author] is located, the purposes for which a particular account is written and what activities this particular account supports – or, alternately, makes invisible" (Campbell & Gregor, 2004, p. 83). Therefore, in addition to a scoping review's traditional bibliographic summary, I attended to IE's acknowledgement of authors' positioning and attentiveness to invisible forms of work that a traditional scoping review may omit. I actively interrogated language that hid caregivers' work and read across articles to understand how family caregivers' information work is linked within broader institutional processes of aging in place.

To summarize the 72 articles' findings, I created a data abstraction table using the following categories: (a) citation, (b) first author's department/faculty, (c) study's location, (d) research question, (e) theory or framework, (f) study design, (g) sample size, (h) sample composition, (i) information delivery mechanism(s), (j) information topic(s), (k) indications of information work, and (l) additional notes. As I reviewed the sample, I

added an additional column, (m) change/time, to capture whether articles demonstrated an awareness that caregivers' information practices evolve over the course of the caregiving trajectory.

4.4 Results

The 72 articles under analysis fell into one of three broad categories that I label descriptive, desire or difference. The first category of articles (descriptive) featured descriptions of family caregivers' information practices (35 of 72; 49%), the second category (desire) included studies documenting caregivers' wishes or appeals for a different or changed way to receive or use information as they provided care (14 of 72; 19%), and the third category (difference) included studies that sought, through the implementation of an experimental intervention, to change information delivery systems (23 of 72; 32%).

4.4.1 Publication trends

The earliest article meeting all the inclusion criteria was published in 1990. Since that time, as depicted in Figure 1, while there is an overall upward trajectory in the number of articles published on this topic, there is a high degree of variability from year to year. While no relevant articles were published in 1996, 1997 or 2000, there is a notable increase in both the regularity and the number of articles published on this topic since the beginning of the twenty-first century.

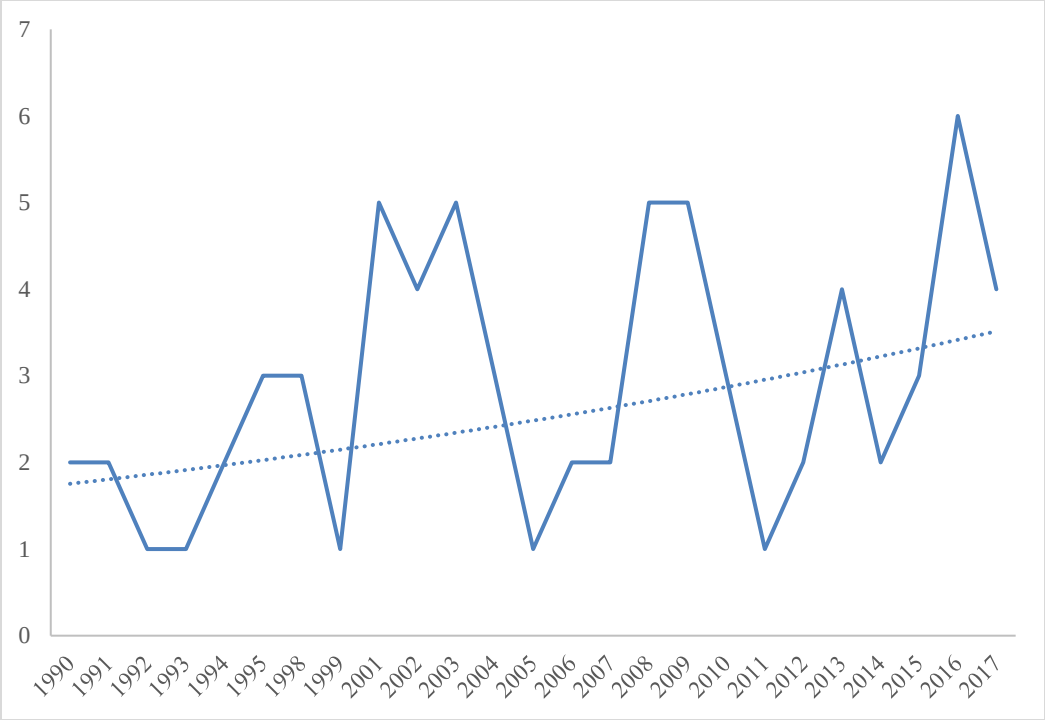

Figure 1. Number of articles published, by year, with trend line

The 72 articles were published in 39 distinct journals, representing a wide array of approaches, disciplines, and publishers. Journals that published three or more of the included articles were primarily from the biomedical sciences: *International Journal of Geriatric Psychiatry* (n = 8), *International Psychogeriatrics* (n = 5), *Dementia* (n = 5), *The Gerontologist* (n = 5), *Aging and Mental Health* (n = 4), *Research in Nursing and Health* (n = 3), and *BMC Geriatrics* (n = 3). Twenty-five of these journals only published one of the included articles.

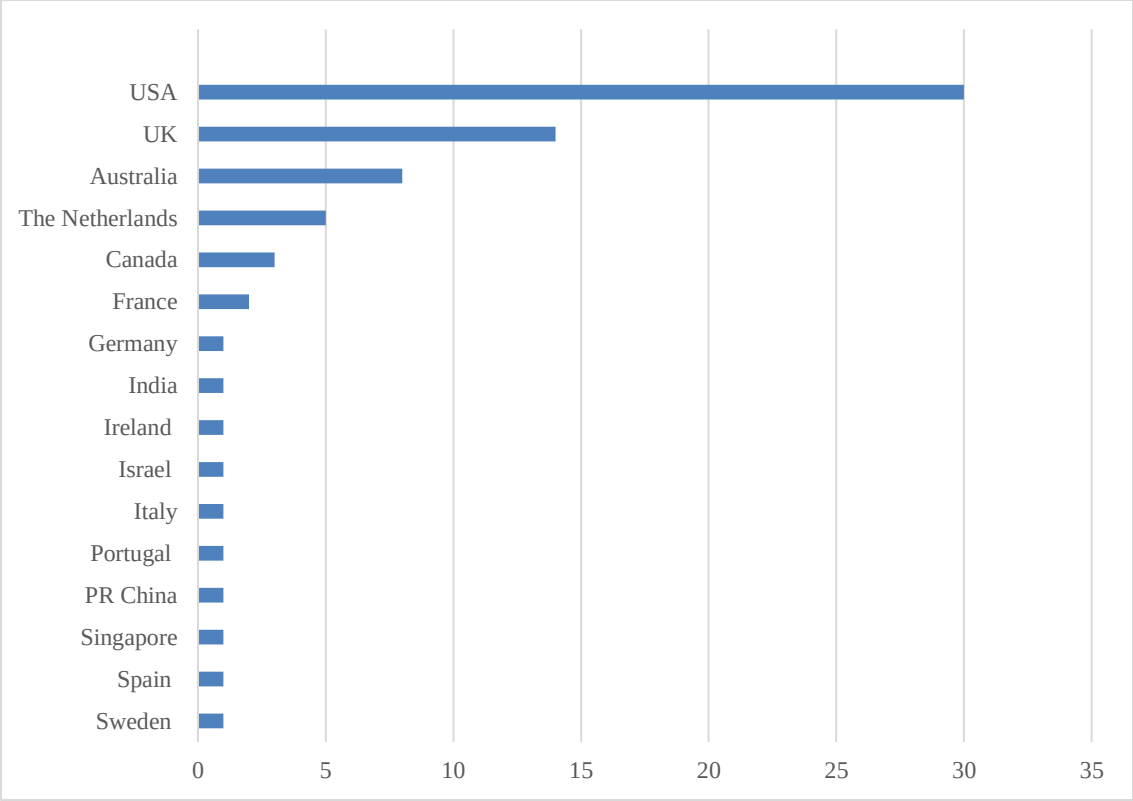

Figure 2. First author's country affiliation

The first (or sole) authors of the included articles hailed from 16 different countries, as depicted in Figure 2. South American and African countries were not represented in this sample, which may be due to the exclusion of articles in languages other than English or French. First authors affiliated with an institution from the United States of America (n = 30) far outnumbered any other country affiliation, more than all articles written by European authors combined.

As illustrated in Figure 3, a majority of first authors originated from a biomedical background, with 33 (46%) articles from the medical or health sciences, 13 (18%) from nursing, and eight (11%) from psychiatry departments. Eight articles (11%) were written by researchers affiliated with the social sciences (including gerontology) or humanities, and two articles (3%) were written by researchers in an information or communication studies department.

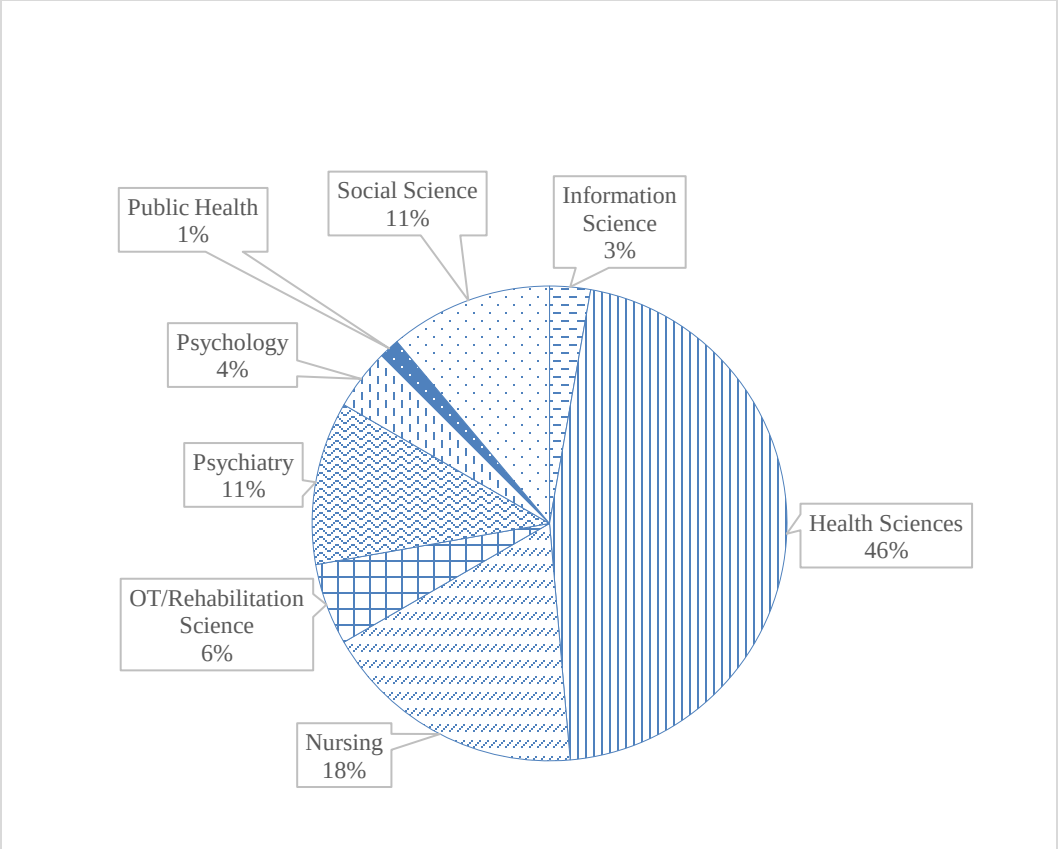

Figure 3. Primary author's departmental affiliation

4.4.2 Study design

Of the 30 (41.6%) qualitative studies in the sample, a majority directly engaged with caregivers: 20 (66.7%) studies used interviews to understand caregivers' information practices and seven (23.3%) implemented focus groups. Only 16 articles (22.2%) used quantitative approaches, with the majority of these (75%) gathering data using surveys or questionnaires. Of the 26 (36.1%) mixed method-based articles, 21 employed interviews, 13 used surveys or questionnaires, seven used standardized measures, and six applied experimental conditions. Eight articles (11.1%) were literature reviews, three of which were systematic reviews.

4.4.3 Relationships between caregiver and care recipient

The 72 articles under analysis engaged with a variety of populations and combinations of populations. Nearly three quarters of the articles (72%; 52 of 72) studied family caregivers in isolation from other individuals or groups. Twelve articles (17%) studied both caregivers and their care recipient (the older adult) in trying to understand the caregivers' information needs, and four (6%) studied a combination of family caregivers and health care professionals (HCPs). As depicted in Figure 4, a smaller percentage of articles studied other unique population combinations.

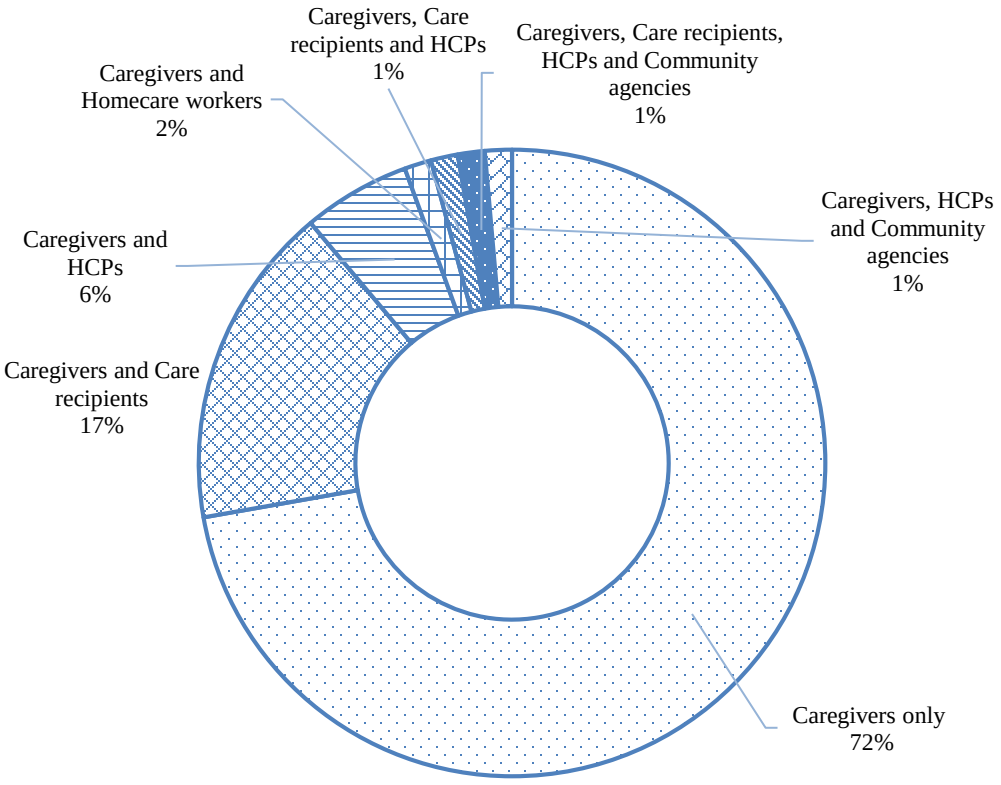

Figure 4. Populations studied

Authors predominantly defined caregivers by their relationship to the older adult. As I documented which participants were considered, counted or examined as a "caregiver" in

each article, 26 unique combinations of family and friend caregivers emerged. Categories of caregivers as they relate to the care recipient studied by two or more articles include: spouses and adult children (14), spouses, adult children, and daughters-in-law (9), spouses (7), spouses, adult children, and friends (6), spouses, adult children, and other (6), spouses and daughters (4), and spouses, adult children, and siblings (4). Three articles did not describe the composition of their caregiver population.

Few articles provided clear operational definitions of care or caregiving. The articles primarily focused on physical, instrumental, and observable dimensions of care, such a medication management, steps to creating a safe home, issues with showering or dressing, and how to manage challenging or troubling behaviours.

4.4.4 Representations of information

Paralleling the lack of an operational definition of care or caregiving, no author provided a working definition, a description or a set of parameters of "information" for their study, nor did any two articles discuss information in a similar manner, making comparisons between articles challenging. Authors used the following terms interchangeably with or as substitutes for information: training, knowledge, skills, communication, advice, education, support, understanding, a mediator that decreases burden, and social support services. An underlying premise to a majority of articles was that more information is beneficial and a lack of information is detrimental for the caregiver and the older adult. Authors ascribed caregivers a number of different descriptors regarding their role or interaction with information: accessors, seekers, recipients, navigators, and mediators. In addition to this tangle of terms and labels, the theoretical framing around the study of information was equally inconsistent: 60 articles (83%) provided no theory, system or model from which or in which their study was rooted. Of the remaining twelve articles, the Stress Process Model was most often used (n = 5). Theories relating to technology include Eysenbach's Law of Attrition (n = 1), Diffusion of Innovation Theory (n = 1), and the Problematic Integration Theory (n = 1). The remaining theories tended towards behaviour or thought change, including cognitive reframing (n = 1) and the stress-buffering model (n = 1). One article implemented two approaches specific to caregiving: Corbin and Strauss' notion of the illness trajectory and Bowers' conceptualization of

caring. Finally, one article combined five models (from Wilson, Dervin, Kuhlthau, Johnson, and Miller) from the LIS field.

There was an equal amount of variety in the information topics studied. Twenty-seven articles spoke about information in a general manner, not explicitly discussing or identifying any particular topic. Of the remaining 45 articles (63%), the information topics listed in Table 5 were the primary focus of the study:

Topic	Number of articles
Diagnosis	11
General education	9
Navigating resource systems	7
Behavioural changes	4
Medications	4
Food	2
Legal issues	2
Respite	2
Safety	2
Assistive technologies	1
Exercise	1

Table 5. Primary topics covered

Twenty-nine (40%) articles explicitly spoke of information as an intervention or as part of an intervention, designed and provided by the study's author(s) and intended to be applied by caregivers to boost their knowledge about dementia and care resources. There are a variety of possible intervention categories, including psychoeducation, specialized skill development training, and psychotherapy/cognitive-behavioural therapy programs (Gallagher-Thompson et al., 2012). As detailed in Table 6, however, of these

information-as-intervention articles, the most prevalent type of intervention was technological in nature. Twenty-five articles (86% of intervention-based articles) integrated one or more forms of technology (such as computers, telephones or videophones) to deliver information to caregivers. These technological information interventions were lauded for their capacity to remove barriers when accessing information as well as facilitating caregivers' ability to access necessary support (read: information) at the touch of a button. In these 25 articles, "information" was not differentiated from the information and communication technologies used to provide, mediate or relay it. A majority of these technology-based information interventions were designed by authors based in the health and medical sciences, including health sciences (n = 9), nursing (n = 8), psychiatry (n = 4), and occupational therapy/rehab (n = 2), as compared to six authors from the social sciences.

Technology	Number of articles
Computer	10
Telephone	9
Videophone	4
Internet/email	2
VHS	1
Assistive technology	1

Table 6. Information technology interventions

Four articles (6% of the scoping review sample) tangentially addressed the work involved in mediating information. Early in my analysis, it was apparent it would be difficult to find articles that acknowledged caregivers' information work. Therefore, to differently assess how articles may acknowledge information work, I began to read articles for indications that caregivers' engagement with information might change over time, assuming that the dementia trajectory changes over time in a non-linear fashion (Giebel,

Sutcliffe, & Challis, 2015). Nearly three-quarters of the sample (74%; 53 of 72) provided no obvious evidence that caregivers' information needs or contexts may change as the needs of the care recipient evolve or as their role as caregiver changes. As the average length of care for a person living with dementia is nearly nine years (Keene, Hope, Fairburn, & Jacoby, 2001), caregivers will likely need different types of information as changes arise in caregivers' status, role expectations, responsibilities, identity, and care demands (Gaugler & Teaster, 2006; Montgomery & Kosloski, 2009), changes that catalyze different information needs. These changes, however, were not reflected in a majority of the scoping review articles.

4.4.5 Consultation exercise

Pham et al.'s (2014) scoping review of 344 scoping reviews reported that stakeholder consultations were conducted in 39.8% of reviews. The majority of these reviews (75%) implemented the consultation stage during the search phase (stage 2) to assist in the selection of keywords. To determine the degree to which my scoping review articles' findings resonated with family caregivers' experiences of their information work, I implemented the consultation exercise at a different point in the process, during the analysis and interpretation phases (stage 4 and 5).

Disrupting the unidirectional delivery of information (from researcher to participant) observed in the majority of 72 articles, I used the consultation stage as an opportunity to foster a culture of information exchange and to provide family caregivers a voice in the research process. This consultation exercise was rooted in institutional ethnography's privileging of people's work knowledge, that is, "a person's experience of and in their own work, what they do, how they do it, including what they think and feel" (Smith, 2005, p. 151). The consultation exercise took place at the end of the 13 interviews with family caregivers, so as to not influence the informants' understandings and descriptions of their information work. I provided an overview of the preliminary findings of the scoping review and asked informants to comment on their general impressions of the scoping review results as well as the degree to which the findings were in alignment with their own care experiences.

Overwhelmingly, informants indicated that other people are crucial for both information provision and accrual. Unlike the articles' foci on studying caregivers independently from other individuals (Figure 4) and diverging from the emphasis on information intervention technologies (Table 6), the informants extolled their network of individuals (other caregivers, other family members and friends, and health care professionals) who provided and sought information. Alice, a wife caring for her husband diagnosed with early-onset Alzheimer's explains that, "Without people, I would be … I don't know where I would be. I think people like to be connected. And they are some of your biggest resources – those people." Secondly, while some of the articles hinted at time-related considerations, informants were quick to discuss the need to be able to use information only as the need arose. Getting the right information at the right time was a key priority for informants, although this was often a difficult balancing act, as Audrey, a daughter caring for her mother who is living with Alzheimer's disease, describes: "there's a fine line between what you want to know and what you will learn when the time demands." Caregivers spoke about different tools they used to store information so that it could be accessed when the illness trajectory entered a new phase. As Sophia, a wife caring for her husband with Alzheimer's disease, elaborates,

> *But I learned right then that it scares the heck out of me to look too far ahead and I can't manage it. I can't manage stuff that isn't relevant. So a lot of the information that I got at the course [an eight-week caregiver education course] … it was too far ahead. Like, I couldn't use it then. Like long-term care? I'm only now, 3 years later, ready to go back and look at that. So I'd file that information under "L", but I wouldn't even look at it, you know? It's back there. But as you get closer to things, then you start, oh yeah, I've got some information about that and I'm going to look.*

None of the articles discussed or studied Sophia's work of strategically managing, organizing, and storing information. The work associated with information management is especially salient given the changes that occur over time as the older adult's dementia progresses. Sophia's difficulty in dealing with information about long-term care and associated end-of-life issues speaks to the affective work that caregivers take on throughout the caregiving trajectory, having to deal with the implications of the

information they find. Informants also highlighted the embodied dimension of information work. As John, a husband caring for his wife who is living with frontotemporal dementia (FTD) elaborates, “I don’t want [people] telling me about FTD, I’ve got enough on FTD just living with and looking at my wife.” Older adults living with dementia served as unique sources of information for their care partner, from changes in their daily rhythms and routines to appearances of challenging behaviours. This type of information was particularly vital when verbal communication was difficult or strained. This corporeal modality (Lloyd, 2011; Bonner & Lloyd, 2011) underscores caregivers’ experiential and tacit information work. Learning the older adults’ preferences, habits, and idiosyncrasies, caregivers accrued an array of experiential information that they incorporated into their information work.

The consultation exercise served as an opportunity for family caregivers to resist dominant discourses handed down by scholars and the “provider-centered, one-way practices of information transfer” (Lee & Garvin, 2003, p. 462). By revealing how research findings may or may not reflect the everyday lived experiences of participants, this study contributes to an increasing number of scoping reviews that advocate for the integration of stakeholder consultations, and in particular, the use of consultation exercises in later stages of scoping reviews.

4.5 Discussion

Family caregivers’ information work was visible in four of the 72 articles in this scoping review. Perhaps unsurprisingly, the work involved in caring for a community-dwelling older adult living with dementia was also invisible. One contribution to this invisibility may stem from the way(s) in which information was conceptualized, written about, studied, and shared in the 72 articles. Information was not defined and was generally narrowly constructed, often conflated with training, knowledge, skills, communication, advice, education, support, understanding, and a mediator that decreases burden. Three consequences arise as a result of the articles’ uncomplicated approach to information. First, writing about information under the guise of other concepts or terms dilutes our

understanding of the centrality of information in people's everyday lives. Second, over time, this simplistic writing about and limited understanding of caregivers' information work (and, often, care work) stifles or makes it more difficult for ensuing researchers to take up different ways of writing about and thinking about caregivers' engagement with information. Much like health and science professionals' distinct ways of speaking about health issues (McCoy, 2006), research writers studying caregivers' information work write about this concept in a distinct way, as if it is self-evident (Campbell, 2003). Smith (2006) goes so far as to call the term information "deceptive", as it "hides the production and reading of texts" (p. 72). And third, with an overly simplistic understanding of information, there is a tendency to conflate information with being informed. This signals an "add info and stir" mentality which neglects the work (including resources, time, emotional impacts, etc.) that makes becoming informed possible.

Authors framed caregivers as being burdened due to a lack of information, with more information portrayed as a positive and a necessity in ensuring good care and in alleviating a caregiver's stress. The articles portrayed information provision as a beneficial way for caregivers to apply new knowledge, solve problems, decrease burden, and enable a more supportive caregiving relationship, thus enabling older adults to age in place for a longer duration of time. As a result, caregivers were treated as secondary to the primacy of information in the information-care relationship. This finding is reminiscent of what Barnes and Henwood (2015) call the *informatization of care*, in which care is marginalized and even replaced by information. Twigg and Atkin (1994) have previously alluded to this imbalance and the need to view family caregivers not as resources but instead as active partners in the care process. Barnes and Henwood (2015) label some of the tensions within the information-care relationship: the *inform to care* approach, dominant in policy and research and evidenced in this review, positions good care as a result of the availability of good information, with information as "separate and outside of care, while nevertheless acting upon it to produce care" (p. 147). Barnes and Henwood's *inform with care* approach (2015), is attentive to the "affective aspects of information and the ways in which new information can destabilise as well as support caring relationships" (Barnes & Henwood, 2015, p. 159). This approach links

information with care as situated knowledge and acknowledges experiential knowledge and the complexities of information within care.

Corbin and Strauss (1988) contend that managing a chronic illness, such as dementia, is best understood from a sociological rather than a medical perspective. Three elements appearing in the scoping review articles, however, collectively point towards the existence of the biomedicalization of care (Hooyman & Gonyea, 1995) circulating throughout the ongoing thinking, studying, and writing about family caregivers' information work. Under biomedicalization, thinking, processes, and services are "increasingly brought under the domain and rationality of biomedicine, and elements of the community delivery systems are increasingly drawn toward the provision of medically related, medically supportive, and/or medically oriented services" (Binney, Estes, & Ingman, 1990, p. 762). The biomedicalization of aging, on which the biomedicalization of care is based, is built on two premises: the social construction of aging as a medical problem and the praxis of aging as a medical problem (Estes & Binney, 1989).

1. Construction of information as an intervention delivered through technologies

Twenty-nine articles wrote about family caregivers' use of information as an intervention to prevent or reduce the negative consequences of caregiver burden or stress. Classifying information as an "intervention" to be delivered to and used by caregivers imposed a clinical tone to the construction of information. Furthermore, 86% of those 29 information-as-intervention articles integrated one or more technologies, such as computers or telephones, to deliver or make information accessible. What was not acknowledged or discussed, however, was the work caregivers would need to do to learn to use the intervention (and the associated technology) and the work required to integrate the intervention into their daily lives. Information interventions were provided in such a way that they were "bereft of meaning, judgment, sense making, context and interpretation" with the potential to create "considerable frustration and distress and increase marginalization and disempowerment" (Simpson, Hall, & Leggett, 2009, p. 39-40). Caregivers' information work requires context, reflection, and understanding, work

that the articles ignored or took for granted. This focus on interventions combined with the privileging of experts over laypersons (explained below) pathologizes caregivers who are presented as needing more information or an intervention (or both) from an expert or from a technology (or both) to be "fixed" or made into more competent or empowered carers.

Summarizing traditional approaches to health-promotion projects, Lee and Garvin (2003) indicate that interventions "have been … designed in isolation of the social, cultural, and structural constrains experienced by most patient and users" (p. 462). A small number of articles focused on the impact that differences in ethnicities might have on caregivers' information work. There were few attempts, though, to locate and study caregivers with varying socioeconomic statuses, educational backgrounds, geographic locales, religious affiliations, etc., to determine how these impacts on caregivers' everyday lives will contextualize and influence how they locate, assess, and use information to guide and support their care work.

2. Privileging expert perspectives

The privileging of professionals' expertise over patients' is a recognized limitation in current health-related information exchange practices (Lee & Garvin, 2003). This may be due, in part, to traditional biomedical approaches to health, with their "limited view of the role of communication, [seen] primarily as a vehicle for transferring authoritative knowledge to compliant patients" (Johnson & Case, 2012, p. 6). My consultation exercise demonstrated that caregivers are creative and active sites of information contemplation, digestion, and production. In contrast with the consultation exercise, the articles portrayed caregivers as passive subjects on which knowledge acts. As a result, articles placed a great deal of agency in information and positioned information as being held or owned by individuals other than family care providers, whether health care professionals or the author(s) of the study. Authors and creators of the interventions did not provide an opportunity for participants to define what information is or might include for them; instead authors unilaterally determined a priori the boundaries of information (what topics to be covered, how information should be best delivered) and what technology

would be used to deliver the information. Authors constructed information provision as a monologue (Lee & Garvin, 2003), with information flowing unidirectionally, in a centralized fashion, from an expert (the author) to an often-passive layperson (the caregiver), with the implication that "the provider can exercise power over the receiver" (p. 451). The sample's reliance on one-way information transfer as opposed information exchange is reminiscent of what Freire (1970) describes as a banking concept. As Lee & Garvin (2003) explain, this concept infers those who are knowledgeable will bestow knowledge upon the ignorant; the ignorant are constructed as unquestioning containers to be filled by the knowledge of the knowledgeable. Portrayed as empty containers, caregivers were denied the recognition and acknowledgement of their experiential, tacit, and embodied information work. The articles constructed caregivers as lacking and therefore in need of training, education or support. Contributing to this general state of being "in want", authors often described caregivers as being burdened, frustrated, confused, and poorly prepared. Problematically, caregivers' difficulties were constructed in such a way that information or information interventions were the only possible solution to settle their deficit or burden. This construction amplified information's agency while simultaneously stripping caregivers' agency.

3. Individual as the unit of analysis

This scoping review revealed how research "both produce[s] and transform[s] as well as limit[s] and regulate[s]" (Katz, 1996, p. 48) its population in the process of studying it. Another characteristic of the biomedicalization of care observed in the sample is a trend toward individualization as a form of reductionism (Estes & Binney, 1989). A potential contributor to the invisibility of caregivers' information work is a focus on the family caregiver as a "lone ranger" information seeker (Urquhart & Yeoman, 2010). More than half of the articles (72%; 52 of 72) focused on caregivers as the sole users of information. Caregivers were the unit of analysis, keeping broader social and environmental factors from being considered (Estes & Binney, 1989). This focus on the individual may explain why information interventions were primarily targeted at the level of the individual and were developed as one size fits all. At the same time that family caregivers are kept separate from other groups, the articles cast caregivers as a population, not as individual

subjects. Katz (1996), documenting the formation of the discipline of gerontology, speaks of Foucault's notion of population, where populations become subjects; sites of standardization that serve to more easily regulate risks, efficiencies, and dangers. Authors' construction of caregivers as population-made-subject and as decontextualized objects of study served to minimize caregivers' troubles while organizing them with maximum efficiency (Katz, 1996). These tactics collectively draw attention away from larger political, cultural, and economic forces that shape, constrain, and conceal the experiences of using information while providing care to an aging family member and may explain why information interventions ignored the relational practices underpinning (and often complicating) caregivers' information work (Barnes, Henwood, & Smith, 2016).

4.6 Conclusions

This scoping review sought to gain a better understanding of the current state of research's conceptualizations of family caregivers' information work. More specifically, this review aimed to uncover the degree to which academic studies acknowledge caregivers' work of "sifting through, interpreting and dealing with the implications of the information one finds" (Harris, 2009, p. 78). As Anderson et al. (2008) indicate, trying to make sense of a topic that crosses multiple, complex fields of enquiry "which lend themselves to interpretation through many academic and theoretical disciplines" (p. 6) is a limitation of the scoping review method. In response to this limitation, this IE scoping review stretched existing scoping review parameters. Looking not to solely provide descriptive, bibliographic summaries of existing literature, this review actively sought out invisible work and purposively went beyond rehearsing the narrative surrounding family caregivers' information practices that articles have carried forward over time. Each article I reviewed established patterns of thinking, giving shape to a particular discourse of care work and information work. An IE inflection enhanced the scoping review process through four key means: attention to invisible forms of work, an awareness of what remains unsaid, a valuing of everyday, lived experiences, and an attentiveness to authors' positioning. Approaching the scoping review with an IE lens highlights texts as

"productive relays between power and knowledge" (Katz, 1996, p. 102), revealing the often-invisible practices of funding institutions, teaching curricula, relations of prestige, and university programs (Katz, 1996) that each article encapsulates. Through the use of a scoping review, I sought to deconstruct academic textual authority, bringing attention to those aspects of texts that organize research problems in "professionally legitimizing ways" (Katz, 1996, p. 77-78).

When transfers of care work occur between institutions, families, and older adults, "people who need information must learn to find it in new ways … [with] a risk that people who cannot find the new information or understand the changing rules will have their important needs go unmet" (Stark, 2005, p. 25). Information's touted ability to decrease caregivers' burden rests on a tenuous assumption that individuals are able and willing to engage with information. Authors presume information interventions will impart caregivers a myriad of benefits, including decreased stress, increased sense of competence, and empowerment. Articulating the information-care relationship, however, remains elusive. Authors discuss the positive, enabling effect information has on the caregiver and their relationship with the care recipient as an assumed cause and effect relationship. What is lacking, however, is an exploration of how, where, and why this relationship is able to develop and succeed. This may be due to the inconsistent application of theories or models in the articles, the lack of critical or feminist angles, and the glaring lack of contributions from LIS scholars who may be able to speak to the complexities of grappling with information and illuminate why more "information is not a panacea for uncertainty … more information might not necessarily lead to greater certainty or clarity" (Barnes, Henwood, & Smith, 2016, p. 523). Adopting an understanding of caregivers as mediaries (not intermediaries) who inform *with* care may be a means by which to elevate information within care as more than a practice, a skill, a passive occurrence or content that can be simply packaged and delivered in a technology, but as a complex and visible form of work.

While information work remains an uncommon way to talk, think about, and study how people come to grapple and engage with information, it is in attempt to highlight the effort, time, and resources needed to deal with the information needed to provide care.

The findings from this scoping review, including the consultation exercise, are an invitation for those investigating how family caregivers engage with information to challenge the prevailing unidirectional delivery of information, moving from an information transfer monologue to information exchange between researchers and participants. Decreasing the polarization between experts and lay persons and the dichotomization of experience and expertise may be a means to move forward in this conversation, focusing instead on the middle ground between these two extremes, that is, "the collective knowledge" (Wilcox, 2010); the summation of knowledge accrued through many sources and interactions. In alignment with Harland and Bath's (2008) finding that "information is dependent on the individual user and that 'best' information, as an objective reality, does not exist" (p. 468), these findings serve as a call to not simplify how individuals conceptualize, use, and interpret information, nor to view information as static or necessarily curative. Instead, this scoping review serves as a prompt to resist simplifying the complexities of information work and to recognize caregivers' embodied, relational, and experiential information practices as vital facets of their everyday information work.

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Chapter 5

5 Disrupting knowledge synthesis methods using institutional ethnography: Reflections on the scoping review as a critical knowledge synthesis tool[1]

5.1 Introduction

Evidence-based practices (EBP) emerge from the evidence-based medicine movement of the 1990s, where "the conscientious, explicit and judicious use of current best evidence" (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996, p. 71) is incorporated with clinicians' expert practices to make decisions about patients' care (Pope, 2003). Knowledge synthesis methods are cornerstones in EBP (Chambers et al., 2018; Grant & Booth, 2009; Kastner et al., 2012). One increasingly popular knowledge synthesis method is the scoping review, "a preliminary assessment of the potential size and scope of available research literature'' (Grant & Booth, 2009, p. 95). In contrast to systematic reviews' exhaustive synthesis of the best available evidence on a particular question (Grant & Booth, 2009), scoping reviews aim to "map *rapidly*" (Mays, Roberts, & Popay, 2001, p. 194; emphasis in original) the body of available literature on a particular topic, regardless of study design or method (Pham et al., 2014). This method of knowledge synthesis is quickly gaining traction: Colquhoun et al. (2014) identified "consistent yearly increases" (p. 1291) of scoping reviews published between 1997 and 2013. Such methods for synthesizing available evidence have, however, received criticisms for their positivistic leanings and their presenting procedural objectivity (Pope, 2003; Eakin & Mykhalovskiy, 2003; MacLure, 2005). Mindful of these criticisms, Chambers et al. (2018) provide an insightful reflection regarding their unanticipated journey of "ontological and epistemological (re)knowing" (p. 183) as they struggled with the "Western ways" of doing a scoping review while synthesizing literature on decolonizing, Indigenous, and Afrocentric knowing.

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[1] This chapter will be submitted to *Social Problems.*

In this article, I unpack and analyze the process of conducting a scoping review as part of an institutional ethnography (IE) study of the information-related work of Canadian family caregivers of older adults living with dementia[2]. To my knowledge, this is the first article to examine the tensions and insights that emerge when conducting a scoping review within an IE method of inquiry. This companion article to the scoping review results already published (Dalmer, 2018; Chapter Four of this thesis), is inspired by Chambers et al. (2018) as well as Harden et al.'s (2004) reflective analysis that stretched conventional approaches to systematic reviews in order to integrate individuals' perspectives and experiences. In this article, drawing from other frameworks offered for critical knowledge synthesis, including Alvesson and Sandberg's problematization approach (2011) and Dixon-Woods et al.'s critical interpretive synthesis approach (2006), I critically reflect on the scoping review as an analytic strategy and as a text and I offer guidance for thinking critically about the scoping review as a method for knowledge synthesis and for employing the scoping review within an IE method of inquiry. In doing so, I join Chambers et al. in a reflective process of "dialoguing with the tensions" (2018, p. 175) between the ways of knowing set out by an institutional ethnography method of inquiry and the prescribed processes of conducting a scoping review.

After providing a brief overview of my scoping review, I examine the specific epistemic and ontological assumptions of IE that enable a tracing of the textually-mediated social organization of knowledge synthesis methods. I then consider how an IE lens prompts a deviation from the confines of three specific stages of the scoping review. Critically unpacking how information-related activities within dementia care work are constructed and synthesized in academic literature is significant for two reasons: first, academic texts create and perpetuate knowable and governable categories and frameworks that subsequent researchers, articles, and disciplines take up and second, these works contain assumptions that are often taken as influential evidence that underpin policies and

[2] I use the term dementia as a general term for a range of neurodegenerative diseases with symptoms associated with memory decline and impairment, including, but not limited to, frontotemporal dementia, Alzheimer's disease, mixed dementia, and vascular dementia.

practices that shape caregivers', older adults', and their communities' experiences and quality of life.

5.2 An overview of the scoping review exemplar

The scoping review exemplar (Dalmer, 2018; Chapter Four of this thesis) that I draw upon in this article is one part of a broader institutional ethnography study of the ways family caregivers of community-dwelling older adults living with dementia use information to guide and support their care work, and how their information-related care work is shaped and coordinated by aging-in-place policies and processes. In this scoping review exemplar, I gathered current conceptualizations of and approaches to studying the complex relationship between information work and care work.

Arksey and O'Malley's (2005) foundational articulation of a scoping review outlines a six stage framework: identification of research question, identification of relevant studies, selection of included studies, data extraction and charting, summarization and dissemination of findings, and a consultation stage with stakeholders. Following this six stage structure, I designed a scoping review, asking "how does scholarly research conceptualize informational components of family caregivers' work and to what degree are these components acknowledged as work?", in order to capture the degree to which scholarly writing about family caregivers might come to alienate, obscure or overlook their everyday information work. I searched twelve databases using keywords and terms to capture peer-reviewed research articles written between January 1990 and August 2017 that studied the informational activities of family and friend (unpaid) caregivers who were caring for a community-dwelling older adult living with dementia. I then examined the 72 articles meeting the inclusion criteria for the positioning, range, and nature of the research on this topic and for the language used to frame and understand information and caregivers in relation to one another. In the sixth stage (the consultation exercise), I interviewed 13 family caregivers to understand whether the scoping review's findings were in alignment with their own lived care experiences.

I found that the prevailing approach to studying information work focuses on individuals seeking information for themselves. Souden's (2008) and Hogan and Palmer's (2005) patient-focused examinations of information work in the context of chronic illnesses, for example, do not address the complexities of information work when caring for another. Characterizing caregivers' information practices as *work* brings attention to the time, effort, affect, resources, etc. that are often made invisible in practice, literature, and in policy, owing to the construction of caregiving as a gendered concept of social and familial responsibility.

5.3 Institutional ethnography and texts

Pioneered by Canadian sociologist Dorothy Smith (1987, 1990a, 1990b, 1999, 2005, 2006a), institutional ethnography is a method of inquiry that brings attention to people's everyday work while simultaneously highlighting broader sites of administration and governance that may be organizing that work. Smith defines work generously as "anything done by people that takes time and effort" (Smith, 2005, p. 151). To explicate the invisibility of people's everyday work, an institutional ethnographer will map the ruling relations, that is, the invisible, translocal forms of organization that coordinate what people do with what others are doing "elsewhere and elsewhen" (Smith, 2005, p. 225). To trace how people's experiences come to be hooked into ruling relations, an institutional ethnographer will often analyze the role of texts in the invisible coordination of individuals' everyday work. These texts may be policy documents, forms, signs, guidelines, or other formal documentation. Smith's term, "textually-mediated social organization" (1990a; 1990b) is in recognition that texts are more than a specimen or sample for study, but are instead a "means of access, a direct line into the relations it organizes" (Smith 1990a, p. 4). Texts can acquire the capacity to coordinate the actions and experiences of people, even if people are not in direct contact or engagement with them. My desire to more specifically examine how the "phenomena" of families' information-related care work are constructed and studied in scholarly texts stemmed from my readings of the conditions that instigated the advent of institutional ethnography:

Smith (1987) grew frustrated with mainstream sociological research's tendency to objectify, alienate, or distort different groups' experiences (women included).

Text-based IE studies typically focus on policy documents and institutionally-developed or -sanctioned forms. Examples of past policy-focused IE investigations include an examination of policies that shape educational governance in public schools (Nichols & Griffith, 2009) and the activation of texts in United Nations forest policy deliberations (Eastwood, 2005). A second category of IE text-based studies include investigations of texts that invisibly enter into and shape people's daily lives, including youth intake and assessments forms (Halsall, 2004), hospital computer software systems that manage nurses' work (Rankin & Campbell, 2014), and flyers distributed in the process of land development and municipal planning (Turner, 2003).

While a popular tool to survey and generate a topography of scholarly findings in the health sciences, scoping reviews are overlooked data for textual analyses in IE[3]. As Rankin (2017b) explains, "people's use of texts gives ruling relations a material form that institutional ethnographers can use to investigate social organization" (p. 2). If texts serve as instruments through which ruling relations take shape and can be identified, this raises the question of whether a scoping review that aggregates a number of texts could be an appealing data source for institutional ethnographers.

As a student, a researcher, and a librarian, I had carried out a number of scoping reviews, but never before had I critically examined or questioned the conceptual work inherent in the selection, revision, and synthesis processes that structure a scoping review's six stages. I therefore began to contemplate the ways an institutional ethnographic approach

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[3] One "critical ethnographic literature review" details the evolution of oral hygiene discourse in nursing literature (Dale, Angus, Sinuff, & Mykhalovskiy, 2013), the authors do not identify the type of literature review used nor do they fully explore the affordances and constraints of an institutional ethnographic approach to analyzing existing scholarly literature. Similarly, Prodinger, Shaw, Rudman, and Townsend (2012) examined peer-reviewed literature on occupation and rheumatoid arthritis to trace translocal relations and "learn how and why occupational therapy works in broadly generalised practices in health services" (p. 465). These authors do not, however, detail the particular type of literature review framework employed.

to synthesizing the articles had disrupted my assumptions about the scoping review stages, allowing me to go beyond the "rational-technical thrust" (Pope, 2003, p. 279) characteristic of knowledge synthesis methods. It was through this process of upholding an institutional ethnographic method of inquiry while selecting, reading through, and synthesizing the scholarly literature that my relationship with the articles and my understanding of the scoping review method began to shift. As I attempted to reconcile institutional ethnography's epistemological and ontological assumptions with the linear procedures prescribed by the six scoping review stages, reflecting on the *process* of reviewing and synthesizing the scholarly literature became of analytical and methodological interest. In the following three subsections, I outline how IE's unique conceptualization of texts avoided knowledge replication (Thorne, 2017) and mirroring (Lather, 1999) common in knowledge synthesis methods and instead transformed my scoping review into a critical knowledge synthesis tool.

5.3.1 The active text: Institutional ethnography's approach to texts

Scoping reviews are often characterized by verbatim summaries of the articles meeting prescribed inclusion criteria. The impetus for looking beyond scholarly articles' content for indications of their textually-mediated organization originates with ethnomethodology. Garfinkel (1967) observed that records themselves cannot be treated as objective accounts nor as independent from the organizational contexts from which they arise. Smith, drawing from this ethnomethodological philosophy, observed that "textual materials have generally presented themselves to the sociologist as sources of information about something else, rather than as phenomena in their own right" (1990a, p. 120).

IE offers an epistemology not commonly used within traditional knowledge synthesis methods, in part because IE emphasizes the centrality of texts' organizational and coordinating abilities. In IE studies, texts are broadly construed as "material objects that carry messages" (Smith & Turner, 2014, p. 5). Texts include paintings, music, television, writing or "words, images, or sounds that are set into a material form of some kind from which they can be read, seen, heard, watched, and so on" (Smith, 2006b, p. 66). Smith (2005) stresses that texts are "occurring"; as texts are drawn into sequences of activity,

they acquire the capacity to coordinate actions and consciousness. Focusing not on the text but instead how it becomes activated as it "enters into and coordinates people's doings" (Smith, 2005, p. 170) helps to "escape our experience of [texts] as passive and enables us to see them as in action" (p. 169), exposing how local activities extend beyond to the extralocal. Smith (2005) outlines two key characteristics of texts that enable ruling relations to proliferate: the replicability of texts and their ability to be read or heard by any number of individuals in identical form across time and place. These two characteristics enable institutional ethnographers to map and expose the ruling relations that simultaneously exist outside of, yet have direct impact on, people's everyday work. A text's replicability enables its coordination of people's work from a distance and across local settings. This replicability also ensures a certain degree of standardization of people's doings and thinking regardless of time, person or place. As a result, texts, such as peer-reviewed research articles, become instances of "crystalized" ruling relations (Campbell & Gregor, 2004, p. 79) and ultimately "provide for the standardized recognisability of people's doings as organizational or institutional" (Smith, 2001, p. 160).

Texts are ubiquitous in academic environments. While students, researchers, and scholars engage with textual materials on a daily basis, these textual events, that is, the engagement with and activation of texts, go "almost entirely unnoticed" (Smith, 2005, p. 122). This pervasive, yet undetected use of texts ensures a standardized framework and a particular way of "produc[ing] and transform[ing] as well as limit[ing] and regulat[ing]" (Katz, 1996, p. 48) knowledge that is replicated for other academics to read and take up. In my scoping review considered herein (Dalmer, 2018; Chapter Four of this thesis), I discovered that particular framings of caregivers' information work were taken up and replicated in subsequent studies, eventually legitimizing the boundaries and categories that academic knowledge synthesis practices place around caregivers and their information work. As texts are replicated and standardized across time and place, institutional ethnographers can begin to map out how scholars activate other texts within their own writing through the use of citations to other texts and ideas, ultimately revealing how texts coordinate disciplinary thinking over time.

5.3.2 Forms of textual organization: Intertextual hierarchy and intertextual circles

As scoping reviews aggregate and synthesize articles from many disciplines, regardless of method or research design, institutional ethnographers can identify the concepts and terms that surface and may be taken for granted as they become progressively integrated into a discipline over time. As McCoy (2006) elaborates, "many linguistic forms that organize knowledge in institutionally relevant ways have spread so far into common speech that we are not always aware how they are operating" (p. 122). Smith outlines two concepts integral to the analysis of texts' organizational capabilities: intertextual hierarchy and intertextual circles. Adopting an institutional ethnography lens sensitized me to the presence of these forms of textual coordination in my scoping review.

Institutional ethnographers carrying out a scoping review can identify intertextual hierarchies by tracing the lineage of references and citations to other scholarly articles. In Smith's (2006b) definition of intertextual hierarchy, "higher-order texts regulate and standardize texts that enter directly into the organization of work in multiple local settings" (p. 79). An early, highly-cited article could be interpreted as an example of a higher-order, regulatory text as it enters directly into differently-located scholars' thinking and writing. Institutional ethnographers can also use the chronology of publication as an indication of earlier texts' regulation and activation of subsequent research. While texts in and of themselves do not regulate other texts (Smith, 2006b), because texts are "active", they become activated as their ideas, results, or conceptualizations of a concept are projected into subsequent articles. As I searched for the presence of intertextual hierarchies in my own scoping review, I was able to approach the analysis of scholarly texts with a unique lens: each component of the scoping review (each article) was interpretable as an expression of a ruling relation, as a higher source of organization emanating from past articles or disciplinary thinking and independent of any particular author or article.

My scoping review also provided evidence of Smith's (2006b) concept of intertextual circles, the "characteristic circularity discernible in the ongoing organization of this intertextual hierarchy" (p. 85). This circularity is evident in the activation of earlier

published articles, which influence later-produced articles, reflecting what was published in earlier articles. As a catalyst for perpetuating intertextual hierarchies, intertextual circles are crucial in enabling, constructing, and propagating ruling relations.

Using intertextual hierarchies and intertextual circles as analytical structuring devices when reading through and synthesizing the 72 included articles, I was able to go beyond the traditionally descriptive findings in a scoping review. I traced how the study and writing about the information-care relationship has evolved and has, over time, made family caregivers' information work invisible. As I read through these articles, I recorded the ways that the authors[4] conceptualize information. Much like Greyson and Johnson (2016) uncovered in their scoping review of the use of information as a concept within public health behaviour models, authors in my scoping review conceptualized information as a "thing" (Buckland, 1991) to be sought, used and understood, ignoring information's more invisible or intangible qualities (such as information-as-process). Twenty-nine (40%) articles explicitly spoke of information as an intervention or as part of an intervention, designed and provided by the study's author(s) to deliver information to prevent or reduce the negative consequences of caregivers' burden, with an unstated assumption that more information is necessarily helpful. Furthermore, 25 articles (86% of intervention-based articles) integrated one or more forms of technology (including computers, telephones, videophones, internet/email, assistive technology, and VHS tapes) to deliver information to caregivers. Articles advocating these technological information interventions lauded the intervention's ability to remove barriers to access information and to facilitate caregivers' access to assistance (equated with information) at the touch of a button. Eleven of these technology-based, intervention-focused articles (44%) were written between 1990-1999, representing 73% of the sample published during this time period. These early "higher-order" articles established a standardized way upon which more contemporary authors base their thinking and writing about caregivers' information-based care work. Based on these findings, I identified two intertextual circles

[4] While this chapter is text-focused, in using the term "author", I intentionally draw attention to the authors writing the texts under analysis as a reminder that it is the authors that activate the texts.

working in tandem in my scoping review articles (information as intervention and information as technological intervention) that appear throughout the scoping review's timeframe (1990-2017) due to an intertextual hierarchy. Information as a technological intervention appeared in the two earliest articles (Goodman, 1990; Goodman & Pynoos, 1990) and in 13 (52%) of the articles written in the most recent decade. These early-established intertextual circles have regulated the ongoing invisibility of family caregivers' information work; technological devices were conceived from the earliest articles as doing the work of providing and making information available. As a result, authors of the scoping review articles treated caregivers as secondary to information and its delivery mechanisms in the information-care relationship. Authors therefore attributed any measured or reported decline in caregivers' burden to the information itself (and the technology delivering the information) and not to the work the caregivers performed in order to obtain, understand, manage, or share information.

Through the interconnected processes of the intertextual hierarchy and intertextual circles I identified, my scoping review findings (Dalmer, 2018; Chapter Four of this thesis) suggest that the concepts information and care come to constitute a particular shared and objectified mode of organizational consciousness, as empty conceptual shells[5], at the level of academic discourse. As Smith (1990a) explains:

> *Progressively over the last hundred years a system of organizational consciousness has been produced, constructing 'knowledge, judgement, and will' in a textual mode and transposing what were formerly individual judgements, hunches, guesses, and so on, into formulae for analyzing data or making assessments. Such practices render organizational judgement, feedback, information, or coordination into objectified textual rather than subjective processes* (p. 158).

Not one of the 72 included articles provided an operational definition of either concept, nor did the authors include caregivers' understandings of care or information. The articles' authors primarily focused on physical, instrumental, and observable dimensions

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[5] Smith (2005) borrows "shells" from Schmid (2000) and takes it to mean "a type of noun that lacks specific content" (p. 112).

of care. Furthermore, they did not define information and generally constructed it narrowly, often conflating information with training, knowledge, skills, communication, advice, education, support, understanding, or a mediator that decreases burden. With this simplified understanding of information, authors tended to conflate information provision or information access with being informed, neglecting the work (including the resources, time, relationships, emotional impacts, etc.) that makes becoming informed possible. Failing to involve participants in the creation of definitions of information or care may not only result in the gradual removal of these terms from participants' everyday lives, but the authors' understandings of and approaches to information and care are what come to count and proliferate in subsequent academic writing. This makes it increasingly difficult to elude the prevailing (narrow) ways of thinking about and defining information and care. Better understanding how authors create or adopt the categories and discourses about information and care not only deconstructs textual authority but makes visible that academics (and their works) are not outside of and may, in fact, contribute to the ruling relations that impact the people or concepts they study.

5.3.3 Nominalization: Challenges to the visibility of information work

Maintaining an IE lens during the analysis of my scoping review highlighted the proliferation of Smith's concept of nominalization (1990b; 2005) in which authors suppress the presence of active subjects: "things are getting done, but no one is present to do them" (Smith, 2005, p. 111). In my scoping review, authors of the articles treated information as a nominal, as an "abstract noun capable of functioning as an agent" (Smith, 1990b, p. 44). This nominalization resulted in the extraction, depersonalization, and decontextualization of information from its everyday contexts, enabling the proliferation of the textually-mediated ruling relations that coordinate this term. The articles' authors used information synonymously with training, knowledge, skills, communication, advice, education, support, and understanding. The use of these synonyms conceals how things are getting done and overlooks "the idiosyncrasies of experiences, interest, and perspectives" (Smith, 2005, p. 43). As authors employ these synonyms for information, it gradually occludes this type of care work and separates

family caregivers from what information actually means to them in their everyday lives. Furthermore, authors' use of these synonyms suppresses family caregivers' work, including the work of understanding and implementing the information interventions and of manipulating the many forms and topics of information they need to guide or support their care work. I suggest that as a result of nominalization, information becomes subject to conceptual inflation, whereby a term comes to mean almost anything, and, relatedly, conceptual conflation, where similar terms are merged, erasing their variances (Frohmann, 2004; Sandelowski, Voils, Barroso, & Lee, 2008).

Nominalization occurs not only in the articles that a scoping reviewer synthesizes but also in the scoping review process itself. Scoping reviewers must collect and summarize highly divergent data, necessitating conversions, manipulations, modifications, and reconfigurations (Sandelowski, 2008) to make the included articles pliable to the scoping review stages. This creates an environment in which scoping reviewers may inadvertently conflate or inflate the concept or topic under investigation. As I attempted to synthesize the 72 articles in my sample, I became aware that I was unintentionally removing family caregivers from their information work. As authors differently labeled and described information in each article (due, in part, to nominalization), I was creating a broader, more ambiguous concept of information in order to capture the varied conceptualizations in the sample. As a result, my scoping review came to represent a double decontextualized account of caregivers' information work; removed once in the writing of the articles included in my scoping review sample and a second time in the construction of my scoping review. This finding supports Lather's observation that "a review is gatekeeping, policing, and productive … in short, a review constitutes the field it reviews" (1999, p. 3).

5.4 Rethinking the scoping review in response to institutional ethnography

In their articulation of the scoping review, Arksey and O'Malley (2005) call for their article to be but a starting point and conclude with an invitation to discuss and debate "the

merits of scoping studies" (p. 31) to further develop the method. While this invitation is slowly gaining traction (Levac, Colquhoun, & O'Brien, 2010; Daudt, van Mossel, & Scott, 2013; Colquhoun et al., 2014), most scoping reviews operate within and retain the structure of Arksey and O'Malley's original six stage framework. While conventional scoping reviews implicitly acknowledge an article as an objective piece of the knowledge puzzle, IE rests on an epistemic assumption that all knowledge is socially constructed, containing particular positions and interests (Smith, 2005, 2006a; Rankin, 2017a). Smith critiques objectified forms of knowledge, calling for the need to expose "the social organization and social relations through which objectified forms of knowledge are created" (Mann & Kelly, 1997, p. 393). My scoping review became a critical knowledge synthesis tool in part because of IE's resistance to viewing texts as inert or accepting knowledge merely due to its status as knowledge. In this section, I demonstrate how IE's ontological and epistemological assumptions trouble and modify three specific stages of the scoping review method.

5.4.1 Stage four: Data extraction and charting

Scoping reviews are known for their ability to provide a "comprehensive and panoramic overview" (Davis, Drey, & Gould, 2009, p. 1388) of the literature. Arksey and O'Malley (2005) describe scoping reviews as not seeking to assess the quality of the evidence in each article, one of the key aspects that differentiate this review type from systematic reviews. Because of these two factors, the fourth stage (data extraction and charting) is not focused on any one article. Instead, scoping review authors describe data so as to illuminate "key themes, trends, and patterns in the articles under study – all at a general level rather than highlighting individual studies or particular findings" (Rumrill, Fitzgerald, & Merchant, 2010, p. 403). This approach to analyzing a scoping review is in alignment with the suggested approach to IE analysis, which refuses any single view or narrative and "supersedes any one account and even supersedes the totality of what informants [and texts] know and can tell" (Campbell & Gregor, 2004, p. 85).

While traditional analytical approaches to scoping reviews will take inventory of topics such as articles' date of publication, author's affiliation, populations under study, methods used, and key themes found, this approach lacks a critical reading into the

invisible, including what remains unsaid, undisclosed, or understudied. The very work of writing scholarly articles is in and of itself shaped by ruling relations emanating from institutions of health care and academia (Solomon, 2008). Authors' decisions regarding which articles to include and cite are also influenced by ruling relations. Hemmings (2011) draws attention to authors' citations tactics that excludes certain texts from the historical record and to "citation practices [that] secure the chronology and affect central to narrative momentum" (p. 163). Therefore, analyzing the activation of scholarly literature in keeping with an IE study necessitates that institutional ethnographers undertake a different kind of reading, identifying instead "how the [article's author] is located, the purposes for which a particular account is written and what activities this particular account supports – or, alternately, makes invisible" (Campbell & Gregor, 2004, p. 83). Turner's (2003) summary of texts' activation and how texts come to coordinate people's everyday work is a helpful framework for an institutional ethnographer analyzing the contents of their scoping review:

- The active (text) organizes institutional processes and relations that govern and regulate the society that we produce and live;
- We are constantly engaged in textually mediated forms of action and thus in ruling relations;
- The operation of texts is pervasive, relatively unnoticed in people's behaviour; and
- Textually-mediated social organization is observable as people's actual practices (p. 91).

With its generous conceptualization of work, an IE scoping review is attuned to illuminate invisible forms of work that a traditional scoping review is not designed to examine. I read each of the articles in my scoping review sample looking for instances of assumed or unrecognized work and for connections between articles; treating each article simultaneously as a separate entity but also as part of a body of work in and through which ruling relations may be operating. Only four articles (6% of the scoping review sample) tangentially addressed family caregivers' information work. I therefore broadened my conceptualization of information work in attempt to capture a greater number of articles, examining whether articles demonstrated an awareness that caregivers' information practices might evolve over the course of the caregiving trajectory. Nearly three-quarters of the sample (74%; 53 of 72) provided no evidence that

caregivers' information practices may change as their caregiver role shifts or the needs of the care recipient evolve.

It is institutional ethnography's privileging of people's standpoint and their experiences of their everyday lives that prompts a focus and an emphasis on ensuring their voices are not muddled or lost through the knowledge synthesis processes. While scoping reviewers often convey the fourth stage as an impartial process, an institutional ethnographic lens on this process reveals that the growing body of scoping review methods-based papers (Pham et al., 2014; Anderson, Allen, Peckham, & Goodwin, 2008; Morris, Boruff, & Gore, 2016; Colquhoun et al., 2014) draw exclusively from Arksey and O'Malley's (2005) six stage protocol. This protocol prescribes a specific way for conducting and reporting scoping reviews and could be interpreted to "represent efforts to shape, direct, orient and otherwise intervene in how and what" (Mykhalovskiy, 2003, p. 332) academics read, think, write, and research. Without an IE lens on this process, it is easy to lose sight of the ways by which the construction of a scoping review contributes to the textually-mediated organization of knowledge synthesis. Following Arksey and O'Malley's framework in my own scoping review, I struggled against the activation and analysis of the articles in stage four (and stage five) that took a two-stage, parallel process that further contributed to the double decontextualization of caregivers' everyday information work: that of disentanglement and qualification. Moreira's (2007) analysis of the social organization of knowledge making in healthcare-related systematic reviews noted that disentanglement occurs when "knowledge practices attempt to extricate data from the milieus in which they are commonly found (databases, texts, other research centres, etc.)" (p. 180) and qualification refers to "endowing data with new qualities – such as precision, unbiasness or 'fairness' – through the use of templates, graphical platforms and techno-political debates" (p. 180).

Anderson, Allen, Peckham, and Goodwin (2008) illuminate the hidden decisions scoping reviewers make throughout the six stage process: "contextualising knowledge in terms of identifying the current state of understanding; identifying the sorts of things we know and do not know, and then setting this within policy and practice contexts." The scoping reviewer's judgements, decisions, and compromises that manipulate articles into

"arbitrary and reductionist categorizations" (O'Shaughnessy & Krogman, 2012, p. 504) are a reflection of the social organization of knowledge synthesis. In order to adhere to the six stage protocol, the scoping reviewer must make articles "docile" to the review process (Moreira, 2007, p. 181) while simultaneously "distort[ing] them into clarity" (Law, 2004, p. 2). One facet of making articles docile is ignoring the ruling relations that shape academic and clinical authorship. A scoping reviewer's need to make articles "docile" is especially acute when creating a scoping review that deals with nebulous, transdisciplinary concepts, such as information or care, which are constructed and interpreted differently between articles, databases, and disciplines. Maintaining an institutional ethnography lens on my own scoping review, for example, highlighted that my data extraction and charting practices were less about caregivers' experiences and more so about the contexts and interests of the articles' authors and my own decisions of making the articles compliant with the fourth stage. The boundary and category-making inherent in a scoping reviewer's "practices of including and excluding" (Lather, 1999, p. 3) allow institutional ethnographers to acknowledge that "data are never simply 'extracted intact'" (MacLure, 2005, p. 394) and contemplate the scoping review as "not exhaustive; it is situated, partial, perspectival" (Lather, 1999, p. 3).

5.4.2 Stage five: Summarization and dissemination of findings

As previously noted, institutional ethnography rests on an epistemic assumption that all knowledge is socially coordinated and constructed, containing particular positions and interests (Smith, 2005; 2006a; Rankin, 2017a). IE therefore brings attention to the often-imperceptible ways texts, including scoping reviews, interact with and serve as organizers of different forms of knowing and power. Approaching the scoping review with an IE lens highlights academic articles as "productive relays between power and knowledge" (Katz, 1996, p. 102), revealing the invisible ruling relations emanating from funding institutions, teaching curricula, university programs, and academic institutions that each article encapsulates. With this lens, an institutional ethnographer can interpret the scoping review as a textual technology that summarizes knowledge and therefore orients readers to a particular segment of the literature, ultimately shaping how readers think about and engage with large numbers of academic articles.

In analyzing how power enters into and manifests in scoping reviews, I argue that the development and application of the fifth stage can be simultaneously interpreted as a method that can repress or constrain what literature is summarized and as opening up fields for interventions; promoting "new ways of being and acting in relation to evidence" (Mykhalovskiy, 2003, p. 335). A scoping reviewer's summarization practices in the fifth stage are inextricably linked with IE concepts concerning authoritative knowledge and expertise. An institutional ethnographer can differently approach the scoping review's fifth stage by attending to the centrality of textual practices in the organization of contemporary forms of power (Frohmann, 2004). As Mykhalovskiy (2003) (and later with Weird [2004]) observed while deciphering the social organization of evidence-based medicine, thinking more broadly about power, not as a negative mechanism, but as a productive relation offers an innovative way to summarize family caregivers' information work in academic writing. Taking up power not as a limiter but as a productive relation (Foucault, 1978) provides an explanation for the prevalence of the information interventions that I identified in my scoping review. I interpreted these information interventions as extensions of the article authors' expertise (a form of power). In this fifth stage, an IE lens helped me to question the characteristic scoping review summarization practices that would preserve the power (expertise) enacted in these interventions with the creators of the intervention and would reduce family caregivers and the experiences of their everyday information-related care work to objects of techno-scientific intervention. Without this lens, my scoping review would have removed caregivers from their experiences of their own work. Conceptualizing caregivers as objects of intervention, not as creators (or co-creators) of an intervention, occludes the complexities and contradictions of each caregiver's experience of their information work. Without an institutional ethnography lens, the fifth stage becomes a summary of the authors' view of caregivers' experiences, that is, knowledge replication (Thorne, 2017) or knowledge mirroring (Lather, 1999). The actualities of family caregivers' information work are rendered knowable, not by the caregivers, but first through the authors of each article and second through the scoping reviewer. Combined with the effects of nominalization, the fifth stage provides further evidence of a scoping review's double decontextualization of family caregivers' information work.

5.4.3 Stage six: Consultation exercise

The rarely-implemented sixth stage of a scoping review (Pham et al., 2014), the consultation exercise with stakeholders, supports institutional ethnography's privileging of informants' work knowledges: "a person's experience of and in their own work, what they do, how they do it, including what they think and feel" (Smith, 2005, p. 151). This rooting in people's standpoint stems from institutional ethnography's social ontology and focus on descriptions of the social world as it is actually happening (Smith, 2005; 2006a; Rankin, 2017a). An IE-grounded consultation exercise is an opportunity for an institutional ethnographer to contextualize the knowledge (and power) uncovered in the scoping review, to challenge the articles' authors' expertise, and to prioritize elucidating the everyday work done by those who are the focus of study. This corresponds to the institutional ethnographer's overall aim to explore the "ruling relations as they are encountered by people whose experiences are under study … maintain[ing] that standpoint throughout" (Dalmer, Stooke, & McKenzie, 2018, p. 50).

For my larger IE study, of which the scoping review is one component, I interviewed thirteen family caregivers about the intersections of their care and information work. At the end of each interview, I provided informants an overview of the findings of the scoping review (biomedical/expert approaches to information, information as intervention, information as intervention via technology, and information as a one-time, stagnant application [Dalmer, 2018]) and asked them to provide their general impressions as well as the degree to which the findings were in alignment with their own care experiences. I considered the 13 caregivers to be "standpoint informants" or "expert knowers" (Rankin, 2017b) about their everyday care (and information) work. Adopting a specific standpoint (such as the standpoint of family caregivers of community-dwelling older adults living with dementia) affords the opportunity to "examine how knowledge works; whose knowledge counts" (Rankin, 2017b, p. 2). My understanding of the ruling relations coordinating caregivers' experiences of their information work grew recursively and abductively in alignment with the discovery-laden nature of institutional ethnography, as summarized by Devault and McCoy (2002, p. 755):

> *The process of inquiry is rather like grabbing a ball of string, finding a thread, and then pulling it out; that is why it is difficult to specify in advance exactly what the research will consist of. The researcher knows what she wants to explain, but only step by step does she know who she needs to interview, or what texts and discourses she needs to examine.*

This consultation exercise was especially adept at distilling caregivers' points of disjuncture - that is, when a caregiver or I identified a mismatch between what I had reported in the scoping review and what the expert knower experienced. Points of disjuncture represent differences in reality, the "knowing something from a ruling versus an experiential perspective" (Campbell & Gregor, 2004, p. 48), revealing the "trouble that arise for people at the interface between their everyday lives and translocal relations of knowledge and coordination" (Devault & McCoy, 2012, p. 384). Points of disjuncture surrounded one of three areas. Firstly, that of information as a stagnant tool (caregivers talked about their information needs changing over time as the prognosis of dementia changed and their relationship with the older adults changed). Secondly, an emphasis on technology (caregivers primarily relied on receiving information through word of mouth from other caregivers, family members, and health care professionals). Thirdly, the construction of information as an intervention (this appeared to be a formal construction created by the authors that did not match the everyday lives, experiences, or understandings of caregivers' interactions with information).

Alice, a wife caring for her husband diagnosed with early-onset Alzheimer's, illuminates the first disjuncture (information as a stagnant tool) as she describes the work she does to gather, filter, and store information; work that evolves with the fluctuating trajectory of her husband's dementia:

> *I sift through what I need for now and I can put the info over there because I don't need that yet and I know it's there. So this information that I've got here … I don't need to really act upon that now. It's in a folder and it's in the back of my head. When there was a first diagnosis, there's a need to know. I was trying to grab as much information as I could. Over time, you filter and you use what is needed - use what is needed in the present.*

Sophia, a wife caring for her husband who is living with Alzheimer's, speaks to her relationally-influenced information work:

> *Without people, I would be … I don't know where I would be. And I feel that with the people I have met at the Alzheimer's Society, like the other caregivers … I think people like to be connected. And they are some of your biggest resources – those people … They're really good. People going through it. The voice of experience, that's what they are. Empathetic. Empathy is a huge thing. Huge.*

Sophia's quote is evidence that the second and third points of disjuncture (information as an intervention and information delivered through technology) work in tandem, much like the intertextual circles of the same name. Sophia's work knowledge corroborates Barnes, Henwood, and Smith's (2016) findings, in that "we should not understand information simply as a neutral or cognitive resource that can be drawn upon" (p. 520). Like other interviewees indicated, Sophia prefers to both receive and deliver information in person and places great value in other care providers' experiences. This may be because Sophia imbues information with a deeply affective element. The information she decides to share, with whom she shares information, and what information she decides to share and receive is dependent on the relationships and care contexts she is in.

In my scoping review, I used these points of disjuncture as opportunities to begin to question the nominalization of information and to highlight family caregivers' hidden information work. These disjunctures have the potential to serve as openings for researchers, policy makers, and institutional leaders to better understand how academic writing may inadvertently marginalize or remove those it studies and provide an opportunity to reunite caregivers (the "expert knowers") with their information work from which they have been separated through the scoping review process.

5.5 Conclusions

Smith (2006) articulates that "texts don't achieve the capacity to regulate just by their existence" (p. 81). Indeed, it is not the texts, but the intertextual circles identified in my scoping review (information as intervention and information delivered through

technology) passed (via the intertextual hierarchy) from the earliest articles to those most recently published that have enabled academic writing to regulate family caregivers' information work. As contemporary authors draw from and cite earlier works within these intertextual circles, earlier articles accrue authority over time, legitimizing the boundaries placed around the methods applied and the language used to study and describe the information work done by families of community-dwelling older adults living with dementia. The nominalization of information (closely linked to conceptual inflation and conflation) combined with the summarization practices in the fifth stage result in a double decontextualization of family caregivers' information work.

Institutional ethnography's focus on "active" texts prompts researchers to acknowledge that knowledge synthesis methods are neither neutral or objective exercises. While academics study individuals or concepts and then write about and share their findings, this is not where the reach of scholarship ends. IE illuminates how the writing about and dissemination of studies begin to give shape to and coordinate the everyday experiences of those individuals under study, for example by informing the development of policies (see Chapter Six). The self-perpetuating nature of the complex of intertextual hierarchy, circles, and nominalization legitimizes and organizes a particular way of approaching, studying, and thinking and writing about caregivers' information work, making it difficult to break out from this institutional discourse that defines and shapes the understandings of caregivers' information work. My findings serve as an invitation for future studies to examine how database configurations in conjunction with scoping reviewers' inclusion and exclusion decisions in stage two (identification of relevant studies) and three (selection of included studies) coordinate knowledge synthesis.

The process of undertaking the first institutional ethnography scoping review was a creative (and sometimes tedious) sequence of iteration and contemplation as I reflected on each stage of the scoping review independently as well as on its contribution to the whole. My critical reflections regarding the reconciliation between the ways of knowing set out by an institutional ethnography method of inquiry and the prescribed scoping review stages aim to support researchers in mindfully and reflexively questioning and troubling the six stage framework, ultimately transforming the scoping review into a

critical knowledge synthesis tool. Exposing the structures that scoping reviews impose contributes to continued discussions of the evolution of the scoping review method as well as institutional ethnography's conceptualizations of texts.

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Chapter 6

6 A logic of choice: Problematizing the documentary reality of Canadian aging in place policies[1]

> *And so, while we may have been lured into thinking, as young adults, that the home is a place of refuge from the politics of administering human life, growing old and frail forces us to confront that this is no longer the case - and may never have been in any case.*
> (Purkis, 2012, p. 32)

6.1 Introduction

Ninety-two percent of the five million older adults over the age of 65 recorded in the 2011 Canadian census lived in a private home. The home environment plays a central role in mediating individuals' physical, mental, and social wellbeing throughout the life course (WHO, 2007; Tanner, De Jonge, & Aplin, 2012). As older adults are estimated to spend 80% of their time at home (Oswald & Wahl, 2005), the home is especially pivotal in the lives of older people, intimately intertwined with one's sense of self and belonging (Oswald & Wahl, 2010). A sense of control in choosing one's home environment is not only helpful for continuity in social connectedness, identity, and emotional attachments (De Jonge et al., 2011; Tanner, Tilse, & De Jonge, 2008), but is also crucial for older adults' social, mental, and emotional wellbeing (Bailey et al., 2011).

Supporting older people to continue living at home "benefit[s] the[ir] quality of life and also provide[s] a cost-effective solution to the problems of an expanding population of very old people" (Sixsmith & Sixsmith, 2008, p. 219). Aging in place (AIP) means continuing to live in the same or a familiar place or community for as long as possible (Pynoos, 1990), "without relocating to a living environment designated for aging, such as a continuing care retirement community, assisted-living facility, or skilled nursing facility" (Cicero, 2012, p. 17). AIP also means remaining in one's residence despite

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[1] This chapter is in press in *Journal of Aging Studies*.

changing needs, including death of a spouse, loss of income, or declining health (Pastalan, 1990). Aging in place is now "part of the common lexicon" (Pynoos & Nishita, 2007, p. 185) and is a global policy response to the rising number of older adults (Vasunilashorn, Steinman, Liebig, & Pynoos, 2012; Caro & Fitzgerald, 2016). Nationally, in addition to fulfilling an economic imperative, AIP aligns with the wishes of 85% of older Canadians, who prefer to age in place (Canada Mortgage and Housing Corporation, 2015).

Internationally, the 2002 *Political Declaration and Madrid International Plan of Action on Ageing* and the 2002 World Health Organization's (WHO) *Active Ageing: A Policy Framework* have guided population aging-related policy development. The WHO's inaugural *World Report on Ageing and Health* recommends changes in the way policies for aging populations are created, asserting that "with the right policies and services in place, population ageing can be viewed as a rich new opportunity for both individuals and societies" (2015, p. vii). This *Report* acknowledges that the development of policies about aging populations faces four challenges: diversity in older age, the influence of inequity, outdated stereotypes, and broad social and cultural change (WHO, 2015).

The WHO launched its guide for age-friendly cities, asserting that making cities more age-friendly is "a necessary and logical response to promote the wellbeing and contributions of older urban residents and keep cities thriving" (2007, p. 4). In 2010, the city of London, Ontario became the first Canadian city to join the WHO's Global Network of Age Friendly Cities. An age-friendly community is a "place where older people are actively involved, valued, and supported with infrastructure and services that effectively accommodate their needs" (Alley, Liebig, Pynoos, Banerjee, & Choi, 2007, p. 4). An age-friendly city purports to enhance older adults' quality of life, support their ability to age in place, and "encourages active ageing by optimizing opportunities for health, participation and security in order to enhance quality of life as people age" (WHO, 2007, p. 1). Recognizing the impact of the local environment on older adults' quality of life (Hodge, 2008), Canadian municipal, provincial, territorial, and federal governments are increasingly supporting AIP and the development of age-friendly cities and communities (Sinha et al., 2016). The government of Ontario, for example, adopted

an AIP approach with their 2007 *Aging at Home Strategy* and Ontario's 2012 *Action Plan for Health Care* set out to make the province the healthiest place in North American to grow up and grow old (Government of Ontario, 2012). Such policy texts that plan and promote AIP or age-friendly communities contribute to unique experiences of aging and caring for those who are aging. Despite policies' contributions to differing experiences of aging, the potential bearing of the narratives embedded within AIP or age-friendly policies remains unexamined. One specific narrative this article explores is the work needed to care for older adults who are aging in place.

As sites of care for Canadian older adults shift from formal institutions to the home, responsibility for ongoing management of care transfers from paid health care professionals to older adults, family members, and friends (Sadler & McKevitt, 2013; Chappell, 2007). As government agencies champion deinstitutionalization, caregiving has become an expected part of the life course for many Canadian families and friends who provide between 70 to 80 percent of care needed by older adults (Keefe, 2011). Chappell (2011) argues that one key policy challenge associated with an aging Canadian population is to recognize family caregivers in the process of establishing a comprehensive community care system. While availability of family support influences decisions relating to aging in place, this role "tends to be assumed rather than explored in the current research literature" (Silverstone & Horowitz, 1992, p. 27). McDaniel and Gee (1993) stress the need for greater research to explore how policies interact with and impact the everyday experiences of caregivers.

Within an institutional ethnography method of inquiry, this article applied Bacchi's "What's the Problem Represented to be?" (WPR) approach as an analytical tool to structure the discovery of governing narratives about familial care work embedded within Canadian AIP policies at the municipal, provincial, and federal level. I analyzed these policies for their role in coordinating the experiences of caring for an older adult who is aging in place in London, Canada's first age-friendly city. Of particular interest for this study is uncovering whether these texts recognize the work (time, energy, resources, etc.), and in particular the information work, of providing care to an older adult who is

AIP. A critical appraisal of these assumptions can help to question and record how these texts problematize different facets of AIP.

6.2 Literature review

6.2.1 Aging in place

While no one definition exists, aging in place was initially and remains predominantly defined by avoiding institutional relocation (Conard & Goldberg, 1990; Pynoos, 1993; Bookman, 2008). Perhaps most simply, aging in place is "aging *at home* rather than *in a home*" (McDermott, Linahan, & Squires, 2009, p. 246, emphasis in original). AIP discourse is positively positioned, idealizing the home and surrounding community as privileged sites in which to grow old. Embraced as a social objective, AIP is also positioned as respecting older adults' wishes and is "presented as a necessary way of restraining the increase of expenses in a financing crisis of publicly funded care services related to the rising dependency ratio" (Vasara, 2015, p. 56). This framing enables government agencies and other support services to withdraw programming and support structures, placing this work on family members, friends, and older adults themselves. Indeed, while the proportion of Canadian older adults in long term facilities has declined over the past thirty years, the Canadian Council on Social Development (2015) notes that this is primarily a result of governments' desire to reduce health spending and not a reduction in older adults' needs.

Existing AIP-focused research centers around four topics: gauging a region's preparedness for an aging population (Hartt & Biglieri, 2017; Wilson, Osei-Waree, Hewitt, & Broad, 2012), features of environments that enable AIP (Menec et al., 2015; Spina & Menec, 2015), the lived experiences of those aging in place (Novek & Menec, 2014; Brittain, Corner, Robinson, & Bond, 2010; Heatwole Shank & Cutchin, 2010), and the deployment of technologies to support AIP (Peek, Wouters, Luijkx, & Vrijhoef, 2016; Luijkx, Peek, & Wouters, 2015). Studies have shown that factors influencing an older person's desire and/or ability to age in place include: economic power to purchase in-home assistance or make home modifications (Scharlach, 2012), government planning

and market conditions (Warner, Homsy, & Morken, 2017), community characteristics (Alley, Liebig, Pynoos, Banerjee, & Choi, 2007), and availability of assistive technologies and smart homes (Brittain, Corner, Robinson, & Bond, 2010). Negative experiences associated with AIP, including isolation and loneliness and a lack of continuity of relationships and roles, receive less attention, with a few exceptions (Vasunilashorn, Steinman, Liebig, & Pynoos, 2012; Sixsmith & Sixsmith, 2008).

Recent studies taking up this concept begin to point to AIP's multiple dimensions, including: maintaining autonomy and independence in one's place of living (Kaup, 2009) and staying in a place with physical, social, emotional, and psychological dimensions that resonate with the older adult (Knapp, 2009). Bookman and Hooyman (2008), however, point out that few (if any) of these AIP conceptualizations are possible unless older adults are in active connection with family members and community organizations and services. While availability of family support and assistance prevents institutional living (Canadian Mortgage and Housing Association, 2013), few AIP studies focus on the family and friend care networks that support an older person who is aging in place. In light of this gap, I take up a series of municipal, provincial, and federal-level AIP and age-friendly community policies to examine their construction of family's care work (and more specifically, the information work) needed to support an older adult who is aging in place.

6.2.2 The home as a site of care and information work

Home environments are intertwined with family and care. In later life, the home can become the site for higher levels of care. Care work, "the work of looking after the physical, psychological, emotional, and developmental needs of one or more other people" (Standing, 2001, p. 17) is a complex practice. Care work is an intimate experience and is connected to how we define ourselves and those we are in relationship with. This particular type of work is also a societal phenomenon, "fundamental to the human condition and necessary both to survival and flourishing" (Barnes, 2012, p.1). Care work therefore demands a complex balance of "love and labour, both identity and activity, with the nature of demands being shaped by the social relations of the wider society" (Graham, 1983, p. 14).

One facet of care work that I take up in this study is information work. The term information work first appeared in Corbin and Strauss' articulation of their illness trajectory theory (1985; 1988). Corbin and Strauss (1985) outline different information work activities, such as networking, scouting out, coaching and training, providing and clarifying instructions, searching for people, places, and necessary things. Hogan and Palmer (2005), Souden (2008), and Kaziunas, Ackerman, and Veinot (2013) have all examined information work in the contexts of chronic illnesses, however, these conceptualizations of information are patient-focused and do not consider the information work done by caregivers on behalf of a patient.

Characterizing caregivers' information practices as *work* brings attention to the complexities of searching and using information on behalf of another as well as the time, effort, affect, and resources that are often made invisible in practice, literature, and in policy, owing to the construction of caregiving as a gendered concept of social and familial responsibility. Gordon et al. (1996) discuss the utility of investigating the dichotomy of public and private spheres that maintain the discourse of care work as non-work: "only through disclosing and naming the practices that constitute human life can we create an expanded public discourse that integrates our private lives and our public policies and preoccupations" (p. xv). Information work is one such practice that constitutes human life, but has yet to be fully disclosed and named, a gap this study will begin to remedy.

Just as women are often regarded as "natural" caregivers (Baines, Evans, & Neysmith, 1998; Glazer, 1993; Hooyman & Gonyea, 1995), so too have they internalized and assumed a major responsibility for guarding and gatekeeping their family's information (Warner & Procaccino, 2004). Harris (2009) is one of few scholars who illuminates the hidden information work women do, pointing to the gendered nature of this specific type of work and its invisibility: "regardless of where it takes place, the health-informing support women provide to others is work, although it is a form of work that is seldom acknowledged" (p. 80). The site of care, often the home, is also a contributing factor to this invisibility: "at home, information management, self-care, and health maintenance remain largely invisible and underarticulated" (Harris, 2009, p. 80). The site of

information work (the home) and the fact that women typically self-identify as “health information managers” (Harris, 2009, p. 74) collectively contribute to the overall culture of invisible information work.

It is the aim of this study to privilege and make visible family caregivers’ everyday information work. To critically appraise AIP policies’ coordination of caregivers’ work and to address the lack of understanding of caregivers’ contributions to experiences of place (Kearns, 1993; Williams, 2002), in this study I take the home and surrounding community as sites of power, where social, political, economic, and cultural values and perspectives comingle and organize family caregivers’ everyday and every night experiences.

6.3 Method of inquiry

6.3.1 Institutional ethnography

This article is part of a larger institutional ethnography (IE) study that explores how family caregivers’ information work becomes shaped by institutional texts, structures, and processes. Institutional ethnography is an especially useful method of inquiry from which to structure the close reading of AIP policies given its focus on texts and on work. Originating in the 1970s with Canadian sociologist Dorothy Smith, institutional ethnography is a method of inquiry that maps how people’s everyday experiences and work are “put together by relations that extend vastly beyond the everyday” (Smith, 2005, p. 1). Institutional ethnography makes visible the work that enables everyday life to happen. Smith (2005) purposefully defines work generously, as anything that people do that requires time and effort. While starting with and privileging the work done by individuals in local settings, IE simultaneously acknowledges that people’s work is coordinated by broader sites of governance and translocal institutions. Texts are one way to make this coordination visible, serving as an important bridge between local and translocal contexts.

Smith and Turner (2014) describe texts as material objects that carry messages. Texts are fundamental to institutional ethnography studies (Smith, 2006; Smith & Turner, 2014). Texts are replicable and can be read in identical form across time and place. These characteristics enable texts to be influential translocally and to coordinate people's actions locally (Smith, 2005). Smith's term, "textually-mediated social organization" (1990) is in recognition that texts can acquire the capacity to coordinate the actions and experiences of people, even if people are not in direct contact or engagement with them. In this article, I use IE to draw attention to the role that texts (AIP policies) play in organizing family caregivers' information work. To critically examine the underlying assumptions in AIP policies, I investigated the documentary reality of AIP.

> *Our knowledge of contemporary society is to a large extent mediated to us by documents of various kinds. Very little of our knowledge of people, events, social relations and powers arises directly in our immediate experience. Socially organized practices of reporting and recording work upon what actually happens or has happened to create a reality in documentary form … A documentary reality is fundamental to the practices of governing, managing and administration of this form of society.* (Smith, 1973, p. 257)

Like Eastwood's IE investigation of the United Nations' forest policy deliberations (2005; 2006), this study looks at higher-order texts, "texts likely not visible in actual settings, but [that] coordinate other texts that become active in actual settings of people's work" (Prodinger & Turner, 2013, p. 359). These texts establish "the concepts and categories in terms of which what is done can be recognized as an instance or expression of the textually authorized procedure" (Smith, 2006, p. 83). To structure my process of teasing out the shape and character of the concepts and categories in the AIP policies, I integrated Bacchi's (2009) "What's the Problem Represented to Be?" approach, described in the next section.

6.3.2 Selection of texts

In order to locate publicly available age-friendly and AIP policies, I first started a search on the Age Friendly London Network website, from which I selected the most recently published text. I then searched the Ontario's Ministry of Seniors Affairs' website, the Federal/Provincial/Territorial Ministers Responsible for Seniors Forum, the Public Health

Agency of Canada, and the Canada Mortgage and Housing Corporation's websites. On each of these sites, I searched for any policy related to age-friendly communities or aging in place. Finally, I conducted an advanced Google search to identify any texts not affiliated with these different governments' sites. After reading through the texts identified through these multiple searches, I then made note of any additional policies mentioned for potential inclusion. A majority of the policies listed the WHO's *Global Age-Friendly Cities: A Guide* as a central, guiding text to their own creation and I therefore included it for analysis.

One characteristic of the texts selected for inclusion in a WPR analysis is that they must be prescriptive, "as a *form of proposal* and a guide to conduct" (Bacchi & Goodwin, 2016, p. 18). In addition to this inclusion criterion, included texts had to have AIP or age-friendly communities as their central focus and had to have relevance to AIP or age-friendly community contexts in London, Ontario. These inclusion criteria excluded, for example, the Federal/Provincial/Territorial Ministers Responsible for Seniors' *Age-Friendly Rural and Remote Communities: A Guide*. As listed in Table 1, I identified a total of seven policy texts from the municipal, provincial, and federal level for inclusion in this policy analysis. For ease of reading, I have assigned an acronym to each policy and have followed the acronym with a designation of -M, -P, -F, or -G, to denote whether policies are from a municipal, provincial, federal, or global, respectively, creator. These seven texts are from two non-governmental agencies (Ontario Non-Profit Housing Association [APSH-P] and Co-operative Housing Federation of Canada [CAP-F]), four government or government-endorsed committees or organizations (AFL-M, FRF-P, AFCC-F, and TAYF-F), and one global organization (WHO [GAFC-G]). I repeatedly read these policy texts, making notes of similarities and differences between policy texts and of quotations and facts appearing in more than one text.

6.4 Analytical framework

To analyze the texts, I used Carol Bacchi's (1999; 2009) Foucauldian-inspired, poststructural analytical tool, WPR, or, "What's the Problem Represented to Be?". If,

according to Bacchi, policies propose to change or fix issues, they begin with an assumption that there must be a problem that requires fixing or solving. Within a framework of six interrelated questions, WPR focuses on problematizations, bringing attention to "how the 'problem' is *made to be* a particular kind of problem" (Bacchi & Goodwin, 2016, p. 17) within a policy.

Jurisdiction	Title	Abbreviation	Creator(s)	Year	Number of Pages	Aging in place / age friendly community definitions
Municipal	Age Friendly London Action Plan 2017 – 2020	AFL-M	Age Friendly London Network *(government-endorsed)*	2017	36	Most older adults want to live in the residence of their choice, usually an existing home or within an existing neighbourhood, for as long as they are able, as they age. This is called "aging in place" and includes being able to access services or other supports as their needs change over time (p. 25).
Provincial	Finding the Right Fit: Age-Friendly Community Planning	FRF-P	Ontario Seniors' Secretariat (OSS), the Accessibility Directorate of Ontario (ADO), the University of Waterloo, and McMaster University *(government-authored)*	2013	119	An age-friendly community responds to both the opportunities and challenges of an aging population by creating physical and social environments that support independent and active living and enable older people to continue contributing to all aspects of community life (p. 5).
Provincial	Aging in Place in Social Housing	APSH-P	Ontario Non-Profit Housing Association *(non-governmental agency)*	2016	28	Aging in place has seniors stay in their homes as they age, instead of living in hospitals or long-term care facilities (p. 3).
Federal	Canada's Aging Population	CAP-F	Co-operative Housing Federation of Canada *(non-governmental agency)*	2011	40	More and more seniors would like to remain in their own homes as long as possible without having to move into facilities for assisted living (p. 1).
Federal	Age-Friendly Communities in Canada: Community	AFCC-F	Nova Scotia Centre on Aging, Mount Saint Vincent University, Public Health Agency of Canada	2012	26	Making communities age-friendly holds promise as an effective way to help seniors remain healthy, active and independent, and contribute to their families and communities (p. 5).

	Implementation Guide		*(government-authored)*			
Federal	Thinking About Your Future? Plan Now to Age in Place	TAYF-F	Federal/Provincial/ Territorial Ministers Responsible for Seniors Forum *(government-authored)*	2015	20	Aging in place means having access to services and the health and social supports you need to live safely and independently in your home or your community for as long as you wish or are able (p. 1).
Global	Global Age-friendly Cities: A Guide	GAFC-G	World Health Organization *(government-endorsed)*	2007	82	An age-friendly city encourages active ageing by optimizing opportunities for health, participation and security in order to enhance quality of life as people age (p. 1).

Table 7. Aging in place and age-friendly policy texts under analysis

I used Bacchi's six questions (Bacchi, 2009, p. 2) to identify and unpack the shape and character of problematizations in the seven AIP policies:

1. What's the problem represented to be in specific policy?
2. What presuppositions or assumptions underlie this representation of the 'problem'?
3. How has this representation of the 'problem' come about?
4. What is left unproblematic in this problem representation? Where are the silences? Can the 'problem' be thought about differently?
5. What effects are produced by this representation of the 'problem'?
6. How/where has this representation of the 'problem' been produced, disseminated and defended? How could it be questioned, disrupted and replaced?

Bacchi's WPR analytical tool shifts the focus of analysis from the conventional understanding that policies address problems to the ways that policies productively or creatively give shape and meaning to problems (Bacchi, 2016). The WPR approach, therefore, does not focus on the language used in a policy but instead uses policies as levers to "open up reflections on the forms of governing, and associated effects, instituted through a particular way of constituting a 'problem'" (Bacchi & Goodwin, 2016, p. 18). Working backwards from the policy solution, the analytic task becomes "teasing out the conceptual premises underpinning problem representations, tracing their genealogy, reflecting on the practices that sustain them and considering their effects" (Bacchi & Goodwin, 2016, p. 17). In using Bacchi's framework, my objective was not to place a value on or gauge the policies' effectiveness, but rather to adopt a critical practice of "problem-questioning" (Bacchi, 2012b, p. 23) in order to critically analyze the underlying assumptions and the hidden narratives woven through each of these policies.

Bacchi's (2009) articulation of WPR suggests that WPR analysis is designed to be selective, uncovering the problem representations related to the topical concern or question of interest. Choosing policies, she states, "is itself an interpretive exercise" (Bacchi, 2009, p. 20). My WPR analysis was attuned to uncovering problematizations in AIP policies, and in particular, problematizations related to families' information work. That said, given that WPR analysis includes "a search for deep-seated cultural values – a kind of social unconscious – that underpin a problem representation" (Bacchi, 2009, p. 5), I took on an iterative reading of the policies, looking for my specific topic of interest

as well as for broader epistemological and ontological assumptions that contextualize my particular area of concern.

I took up Bacchi's first and second question in tandem, as I began to look at how each policy problematizes AIP or certain facets of AIP. By examining the solution(s) each policy presents, I was able to move backwards to trace, deconstruct, and then question the implied problem behind these solutions. For example, if a policy presents a series of checklists as a helpful and necessary tool for older adults to ensure their ability to age in place, the underlying problem is older adults' insufficient planning and preparation. For question three, I began to identify demographic, social, economic, and related contextual elements that have contributed to the representation of each problem in a specific way. The fourth question was especially important in helping me attune to the ways that omissions or silences in each policy contributes to the overall problem representation. Institutional ethnography's attention to often-invisible, local experiences of everyday work was especially helpful in navigating this fourth question. Using the fifth analytical question, I considered the impact of the problematizations on housing-related policy creation and Canadians' experiences of older age, more broadly. The sixth question was bolstered by institutional ethnography's focus on textually-mediated social organization and documentary reality. I considered how the problematizations of AIP occurred throughout and between the texts I analyzed. As I scrutinized each policy, I traced its impact on subsequent policy creation and examined the degree to which policy texts take up the documentary reality established by previously written policies. In the following section, I draw on specific examples and quotations from the seven policies to demonstrate how the texts construct or reproduce problematizations.

6.5 Findings

Common to all policies was an introductory paragraph or section that conveyed an unease regarding the rising number of older Canadians. While not in and of itself a problematization, the reoccurring alarmist demography (Katz, 1992) framing of this demographic trend as somehow overwhelming or unmanageable contextualized the

remainder of the policies and the problem representations contained within. While the texts expressed this apprehension in different ways, policy creators deftly applied current and projected statistics to corroborate their statements. Described as an "important turning point in our society" (AFL-M, p. 5), the Ontario Non-Profit Housing Association (2016) speaks of the "alarming rate" (p. 27) of Ontario's changing demographics, explaining that "by 2041, over 4.5 million seniors will live in Ontario, each with their own aging needs and challenges" (p. 27). FRF-P mentions the doubling of the older adult population by 2036, indicating that "this major change affects every jurisdiction in Canada and in Ontario" (p. 1). These projections and statistics imbued an overall sense of urgency throughout the texts, making it more important than ever "to support older Canadians in the places where they live … [this] holds promise as an effective way to help seniors remain healthy, active and independent, and contribute to their families and communities" (AFCC-F, p. 5).

Policies are complex texts; they combine a number of strategies and solutions and are nested within a network of other, interconnected policies. As a result, Bacchi (2009) argues that a single policy likely contains more than one problem representation. My analysis identified two main "solutions" (and accompanying "problems") in the policy texts:

Solution one: "Plan for the future today to help you live the life you want tomorrow"

A "solution" common to a majority of the policies was an unquestioned impetus for older adults to judiciously prepare and plan to age in place. Whether through a series of checklists, a toolbox, the very title of the policy ("Plan" or "Action Plan"), or an itemized flow chart, this solution represented the problem as an insufficient amount or a complete "absence of long-term planning" (CAP-F, p. iii). The catchphrase "plan for the future today to help you live the life you want tomorrow" (TAYF-F, p. 1) is indicative of this attitude that older adults are responsible for proactively choosing to plan to age in place by controlling their life, decisions, and ultimately, their future. Having a plan is said to "help you to make the most of your later years and have more control over your decisions … giv[ing] you the best chance to have a satisfying and positive experience as you age"

(TAYF-F, p. 1). This advocacy of self-reliance and self-management encroaches on other age categories, with the TAYF-F policy encouraging "near seniors" (p. 1) to start planning now. Presenting aging in place solely in terms of planning or a lack thereof presents AIP as an individual imperative and places the enormity of an older adult's housing situation completely on the older adult. The underlying assumption is that if an older adult plans and is sufficiently prepared, they can age in place. Using this assumption, if an older adult is unable to age in place, it then follows that they must have not sufficiently planned or prepared. As the site of the problem, older adults become the targeted site for a solution (Huot, Bobadilla, Bailliard, & Rudman, 2016). With an estimated one third of older adults facing functional limitations that jeopardize their ability to age in place (Fuller-Thomson, Yu, Nuru-Jeter, Guralnik, & Minkler, 2009), this reasoning highlights a troubling assumption about the type of person who is able to plan to age in place. This focus on individual choice and responsibility reflects a consumerist, neoliberal discourse of choice that "encourages and reflects an atomised, individualised view of social life, a society in which private citizens are presumed to act alone and only in their best interests" (Lippman, 1999, p. 283) and overlooks the complex network of paid and unpaid care partners that support older adults to age in place.

Solution two: Continue to contribute

The second reoccurring "solution" in the three government-authored (FRF-P, AFCC-F, and TAYF-F) and the two government-endorsed (AFL-M and GAFC-G) texts was for older adults to be a resource and be resourceful for their community. This is most explicitly articulated in WHO's policy: "Older people are a resource for their families, communities and economies in supportive and enabling living environments" (p. 1). Policies convey aging in place as being able to "support independent and active living and enable older people to continue contributing to all aspects of community life" (FRF-P, p. 5). The WHO policy (later repeated in FRF-F) explains that enabling older adults to AIP allows them "to continue to contribute to their communities" (GAFC-G, p. 51; FRF-P, p. 24) and engages and empowers older adults to be "leaders in the community" (AFL-M, p. 14). These five texts direct "solutions" away from social factors or formal institutions and towards individuals. To continue to age in place "successfully" and to be

a resource for their communities, older adults are expected to live healthfully, independently, and actively in their own homes. As other contemporary constructions of older age centre on youthfulness, productivity, and staying active in what Katz (2003) calls the "wider political assault on the risk of dependency" (p. 148), it is dependency, particularly dependency on federal, provincial, or municipal-level supports or interventions, that is problematized in these policies. The framing of the rising number of older Canadians as a concern lends itself to this solution of productivity and resourcefulness; if older adults are actively contributing to their communities, their increasing numbers will be less of a burden to manage.

The role of information in the construction of problematizations

Policies introduced information as a helpful tool to secure and preserve older adults' independence and usefulness to their community. Information is qualified as "vital for active aging" (AFL-M, p. 32) and the WHO policy suggests that "relevant information in appropriate formats … contributes to personal empowerment" (p. 72). A majority of policies (AFL-M, FRF-P, AFCC-F, TAYF-F, and GAFC-G) explicitly established a connection between information and the ability to be a resource: "getting timely, practical information to manage life and personal needs is vital for active aging" (GAFC-G, p. 1; FRF-P, p. 24). Not one of the texts account for the work (including the time, resources, emotional outputs, etc.) necessary to locate this timely, practical, or relevant information nor the work needed to apply and make sense of that information within each older person's unique contexts. Furthermore, these statements assume a rational individual who is able to responsibly self-govern and rest on a speculative supposition that "if people are provided with 'good' information, they will be 'empowered' to make 'good' choices" (Harris, Wathen, & Wyatt, 2010, p. 212). The policies also place a great deal of information-related responsibility onto the older adult aiming to age actively in order to age in place. For example, the TAYF-F policy outlines the following "nine areas of your life" to consider when determining whether an older adult is sufficiently prepared to age in place: health, home, transportation, finances, connections, safety, supports and services, community, and my partner and me. Under the area of health, older adults need to ensure that "I am aware of electronic tools, such as medication reminders and health

management systems that will allow me to remain healthy" (TAYF-F, p. 3). Under the area of transportation, older adults are encouraged to consider that "If I am able to continue driving, I plan to take a refresher course to maintain my skills and knowledge of the rules and regulations" (TAYF-F, p. 5). Under each of these nine areas, information is mobilized to task older adults to do the work to ensure their ability to AIP.

What is left unproblematic?

As I considered WPR's fourth question, I identified a number of silences within and across policies. An overall focus on an independent, autonomous older adult who is well, able, and empowered to age in place means that care networks, in particular family and friend care partners, were largely absent. Family care networks are crucial for community-dwelling older adults living with a chronic illness (Williams et al., 2016), and especially so for the 33% of Canadian community-dwelling older adults living with multiple chronic conditions (Gilmour & Park, 2006). However, the policies seldom mentioned or acknowledged family care partners as active participants. When families did appear, it was for their ability to foster social connections with the older adult. Policies framed these social connections pragmatically, for their ability to allow an older adult to age in place for a longer time: "the ability to draw on social networks of friends or family is known to make an important contribution to general well-being and quality of life" (TAYF-F, p. 9). The affective or caring components of familial relationships were secondary to the primacy of the connections and social participation that families could provide an older person. This focus on the older adult creates policies where family members are acknowledged only for what they are able to provide the older adult: "Interacting with family and friends is an important part of positive mental health and community awareness" (FRF-P, p. 7). Similarly, these texts conceptualized families as a resource for information, as WHO states (GAFC-G, p. 38) and FRF-P (p. 22) subsequently cites:

> *Social participation and social support are strongly connected to good health and well-being throughout life. Participating in leisure, social, cultural and spiritual activities in the community, as well as with the family, allows older people to continue to exercise their competence, to enjoy respect and esteem, and to maintain or establish supportive and*

> *caring relationships. It fosters social integration and is the key to staying informed.*

Perhaps most glaring was a lack of recognition of older adults who may be unwell and yet wish or need to age in place. The majority of texts assumed, unproblematically, that all older adults are "living longer, healthier lives than ever before" (FRF-P, 2013, p. 1). Indeed, policies largely assumed older adults to be "well" in all aspects of their lives – financially, cognitively, physically, spiritually, emotionally, etc. And so, while a majority of the texts champion AIP and the development and proliferation of age-friendly communities, there was, for example, no indication of whether different supports or accommodations might be required for older adults living with dementia who choose to, who need to, or who are forced to age in place. This silence is especially notable given that 402,000 older Canadians are currently living with dementia and 76,000 new cases of dementia are diagnosed each year (CIHI, 2018). Over the next 20 years, it is estimated that the number of Canadians living with dementia will almost double due to the aging population and population growth (Public Health Agency of Canada, 2014).

Paralleling this unidimensional understanding of wellness in older age, policies exhibited a narrow understanding of the concept of home. While there were nods to the home as "essential to health and quality of life … a place that is familiar and loved" (AFL-M, p. 25), policies primarily focused on the home as a built environment. Home was conceived as a piece of physical infrastructure that needs to be adapted and modified to avoid safety risks and to prolong the home's use as a place for an older adult to age (AFL-M; FRF-P; TAYF-F; CAP-F; GAFC-G). Checklist items about the home include: "I will make changes as needed to my home to help me to age in place (e.g. night lights in the stair areas, solid handrails on both sides of the staircase and a grab bar in the tub area)" or "If my health changes and I need to use a wheelchair or another mobility device, I am prepared to modify my home to accommodate my needs (e.g. widen doorways, build a ramp, or install a walk-in bathtub)" (TAYF-F, p. 4). Both checklist items assume older adults can acquire the information needed to make such changes and possess the time, labour, and financial resources to make these modifications. These statements occlude the variability in homes, materially and culturally (Procter et al., 2014), as well as the

intertwined complex of identity, memory, affect, and support that a home can symbolize or represent.

In both understandings of older age and the home, policies fail to address the complex entanglement of factors and conditions that influence experiences of older age and home, such as class, gender, ethnicity, economics, and cultural values (Estes, 2001). As the texts exhibit interpretations of older age and home as static, monolithic processes, instead of moment-to-moment, tenuous and managed work, these texts make it difficult to fully contemplate the multiplicity of meanings of what is home and what it means to age in Canada.

Not all policies were created equal, however. The two policies created by independent organizations (the Ontario Non-Profit Housing Association and the Co-operative Housing Federation of Canada) were quick to call upon all levels of governments for increased support for older adults who are aging in place. Interestingly, these were the two texts that did not draw upon or quote the WHO policy. These two texts recognized and drew attention to the potential difficulties of AIP and the inequalities that occur across individuals that might contribute to different (and even unpleasant) experiences of AIP. The Ontario Non-Profit Housing Association, for example, demonstrates a nuanced understanding of the prevailing myopic AIP perspective: “while aging in place approaches offer a vision of old age that is appealing to seniors and governments alike, they offer little insight into what happens when seniors’ aging needs are not met” (p. 17). These two policies also were unique for their attribution of responsibility. Neither policy blamed older adults for failing to plan for long-term options, but instead positioned the planning responsibility as belonging to broader organizations and agencies, including federal and provincial governments.

6.6 Discussion

The policies’ overall focus on self-reliance, independence, and resourcefulness frames aging in place as a process that can and should be responsibly managed. This

construction mirrors recent trends in the construction of retirement (Rudman, 2006) and is nested in broader shifts towards positive aging (Katz, 2001), productive aging (Holstein, 1999), successful aging (Katz & Calasanti, 2014), and active aging (Boudiny, 2013). These shifts collectively reflect a rise in neoliberalism, where an emphasis on individualism means that "people who are dependent on the state for financial support become the targets of policies and rhetoric that foster self-reliance and engagement in economically useful activity" (Rudman, 2006, p. 185). This focus on an active, rational, responsible community-dwelling older adult may also explain why policies infrequently recognized or included families and friends. Framing families merely as a resource to be called upon to support the older adult to actively age in place is counter to Procter et al.'s (2014) findings that AIP is socially and collaboratively accomplished through bricolage and customization. These authors bring attention to "the efforts of a range of informal carers" (p. 256) needed to co-produce aging in place.

The policies' problematizations and related solutions reflect a healthy living imperative (Henwood, Harris, & Spoel, 2011), which frames and understands healthy living (and aging) as governed through a logic of choice. A logic of choice "carries a whole world within it: a specific mode of organising action and interaction; of understanding bodies, people and daily lives; of dealing with knowledge and technologies; of distinguishing between good and bad and so on" (Mol, 2008, p. 8). In a logic of choice, complex problems are framed as simple matters of choice. Mol contrasts logic of choice with a logic of care, an alternative logic that more intricately captures how care might be practiced. These two logics exist in dynamic tension. Beckman (2013) explains Mol's logic of care in the following way:

> *Good care means providing emotional support in the context of uncertainty and anxiety and disentangling the practicalities the patient has to deal with in finding ways to make life more bearable. Rather than moralising and judging the patient, the logic of care aims to mutually adjust technology, everyday habits and constraints, people's skills and propensities, and their social environments* (p. 172).

Constructing AIP as both an ideal and as a choice casts older adults as the site of both the problem and the solution. This individualization of the problems implicit in the AIP

policies “enables governments to absolve themselves of responsibility for addressing issues” (Huot, Bobadilla, Bailliard, & Rudman, 2016, p. 140). While the policies offer a number of different “solutions” or “choices” for older adults to plan for or to maintain their status as aging in place, a critical unpacking of the problematizations reveals the choice to AIP to be illusory. There is only one option presented in the policies and that is to age in place. This “choice” to age in place is therefore “regulated through a new set of social obligations bounded by neo-liberal rationality” (Rudman, 2006, p. 197).

As I examined the relationship between information and choice within a logic of choice framework, I detected that majority of the AIP polices use information within a framework of informed choice. Informed choice parallels the emergence of an informed patient discourse, which equates information provision with patient empowerment (Henwood, Wyatt, Hart, & Smith, 2003). The texts in this study conceptualized information as that which provides older adults the ability to make rational, informed choices to age in place and to be independent, actively aging individuals. Richard Gwyn explains that informed choice, in opposition to paternalism, occurs when “the doctor lays out the pros and cons of each and every possible course of action without prejudice, and allows the patient to make a choice based on this information” (2002, p. 79). While analyses of informed choice often focus on formal care settings, given that the home is intimately interwoven with experiences of care, informed choice became a helpful lens through which to interpret my findings.

Informed choice can be a valuable technique, allowing individuals to question medical authority and participate and shape their care. As Spoel (2006) elaborates, however, in the more problematic dimensions of informed choice, the “dominant consumerist, neo-liberal ideologies of health care” (p. 197) that focus on individual freedom and choice occlude contributions of gender, class, age, ethnicity, etc., to experiences of choice. Indeed, the AIP policies privilege the role of information for its ability to inform older adults. If older adults are informed, policies operate under the assumption that older adults can choose to age in place and remain independent and empowered contributors to their community. Where the information is found and the work needed to become informed, including “sifting through, interpreting and dealing with the implications of the

information one finds" (Harris, 2009, p. 78) is inconsequential in the policies. There is no acknowledgement of the work of managing the information needed to be or become informed. The framing of informed choice makes assumptions about the type of person who is able to become or be informed as a means to successfully age in place. This overriding language of autonomy risks "hid[ing] the workings of privilege and mask[ing] the barriers of oppression" (Sherwin, 1998, p. 25) that can influence where information is found, how it is interpreted, with whom it is shared, and how that information might be put into action or practice.

The policies' framing of information reflects the WHO policy's conceptualization of information. The WHO policy is a defining text, demarcating and legitimatizing particular ways the four government-authored or -endorsed policies (AFL-M, FRF-P, AFCC-F, and TAYF-F) consider information, in addition to older age and housing options and contexts. As a result, I take up the WHO policy as a boss text (Smith, 2006), as its categories and concepts establish the frameworks for subsequently-published policies. Smith calls this phenomenon intertextual hierarchy (2006), where boss texts "regulate and standardize texts that enter directly into the organization of work in multiple local settings" (p. 79). The WHO policy lists "Communication and Information" (GAFC-G, p. 60) as one of its eight domains to enhance the age-friendliness of cities. Despite this display of the importance of information and the communication of information in age-friendly communities, this policy mobilizes information in a very particular way. For example, within the WHO policy, the "Communication and Information" domain recognizes the need for widespread distribution of information (GAFC-G, p. 60), the importance of formatting and design GAFC-G, (p. 63), using plain language (GAFC-G, p. 65), and the need for public access to computers and the Internet (GAFC-G, p. 65). According to this text, "older people have a personal responsibility to keep abreast of new information by staying involved in community activities, and to make an effort to adapt to change and take the risk to learn" (GAFC-G, p. 64). Keeping abreast of new information is framed as a benefit to the older adult as a means to age in place in their age-friendly community for a longer period of time, and not necessarily as a benefit for the older adult themselves. The actual content of information or information

topics are not discussed. Information is treated as a "thing" (Buckland, 1991) that enables an older adult to successfully and responsibly age in place. In this way, information carries little weight in these texts, as information itself nor the value of information are discussed. There is no differentiation between "good" or "bad" information, of information that is more or less trustworthy, or of information that can mislead or overwhelm. It is ultimately the act of becoming informed that is beneficial to being able to successfully age in place, with being informed as a key activity to promote AIP, akin to going for walks or being connected with community.

6.7 Conclusions

This article adds to a small but growing number of critically-minded AIP-based studies that grapple with the predominantly positive positioning of AIP (Kenner, 2002; Golant, 2008; Procter et al., 2014; Plouffe, Kalache, & Voelcker, 2016; Buffel & Phillipson, 2018). My analysis reveals that problematizations in the AIP policies relevant to the first age-friendly city in Canada's most populous province echo broader, discursive trends towards individualism and active, productive, and successful aging. The policies reflect a larger trend towards expanding self-determination into older age as individuals are increasingly called upon to be responsible for their own wellbeing and care throughout the life course. In these policies, being informed is conveyed as a tool through which older adults who are or who wish to AIP can and should take responsibility to actively and successfully age in place.

This study demonstrates the utility of using WPR as an analytical tool to extricate the assumptions embedded within policy texts. Furthermore, institutional ethnography's understanding of documentary reality was instrumental in my analysis in that it "provide[d] for the standardized recognisability of people's doing as organizational or institutional" (Smith, 2001, p. 160). The policies examined in this study overlook the work (including the information work) performed by the complex network of family and friend caregivers to support an older Canadian to age in place. By its very name, AIP fixates on the built environment (the private home), paying little attention to the different

people doing work in the home to enable oneself or another to age at home. I suggest that this static focus on place, the physical infrastructure that makes up a house, within the policies makes invisible the many different kinds of work done by different people to enable age in place. This suggestion draws parallels to the arguments of feminists in the 1970s who fought to have housework recognized as legitimate work. The home has traditionally been a gendered space, where women's altruistic, collective work in the household has remained sequestered in the private (domestic) sphere, upholding their invisible care work in the home (Gordon, Benner, & Noddings, 1996; Hooyman & Gonyea, 1995). Building on Hochschild's (1989) mothering-focused "second shift", given that current demographics of care make it increasingly likely that women will be caring for an older family member at some point in their lives (Chappell, 2011), this "second wave of nurturing" (Sheehy, 1995) demands this "new" form of house-focused work to be recognized as such. Shifting the construction of AIP policies from a logic of choice to a logic of care might be a way to bring attention to families' work in aging in place and to recognize their work as more than adjuncts to or enablers of older adults' autonomy and empowerment.

Procter et al. (2014) found that "successful support for ageing in place depends on making better use of the contributions of all participants" (p. 260), including formal and informal networks of carers and older people themselves. To support the beneficial aspects of AIP, policies must question who benefits from the suggestions, checklists, and frameworks published. Policies must also acknowledge and support the non-government-funded work, including information work, required to sustain it. An acknowledgement of the limitations of current conceptualizations of AIP is also needed to be able to move beyond supporting older adults who are "well" or "able" to AIP. To provide supportive care for the entire population, policies must acknowledge that there are situations when older adults are better supported outside of home environments. Homes are not necessarily places of harmony or tranquility but can be sites of conflict (Wiles, Leibing, Guberman, Reeve, & Allen, 2012), for those who may be experiencing abuse or for migrant populations who may not feel at "home". Also of consideration are the increasing number of older adults experiencing homelessness (Grenier, Barken, & McGrath, 2016).

Accordingly, an intersectional approach is needed to more responsively and equitably identify and make careful and sensitive recommendations on the conditions under which the demands of AIP exceed the capacities of the care team in the home environment and provide supports and solutions, both at home and in a home.

Returning to Pynoos' (1990) early-articulated understanding of AIP is a helpful starting point, as he highlighted the complexity and fluidity inherent within aging in place, not only connoting the changing needs of an aging person but the dynamic changes and tensions associated with the one's lived environment. This articulation is a means to move beyond the existing unidimensional understandings of older age and housing implicit in the analyzed policies, to a multidimensional conceptualization that acknowledges the complex interactions and continual changes between community, home, family, work, identity, and later life.

6.8 Bibliography

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Chapter 7

7 Information and care: Concluding remarks

In Marjorie DeVault's (1991) institutional ethnography that took up the work of feeding a family, she brought to light the "'workful' character of this activity [that] is often unrecognized even by those who do it" (p. 228). The intention of this thesis was to make family caregivers' information work visible while also tracing the social organization of their information work. I sought to highlight the complexity, the effort, and the skill that information work requires, while making explicit the "workful" character of this work and its relationship to care work. That said, merely making families' information work visible was insufficient, as Beneria (1999) explains: "the effort to account for unpaid work must be viewed not as an end in itself but as a means to understand who contributes to human welfare and development and to what extent, and what action is required to distribute equally the pains and pleasures of work" (Beneria, 1999, p. 302). Therefore, by situating family caregivers within an entanglement of translocal influences, I was able to map out the ruling relations and taken-for-granted assumptions that bundle the many discrete, workful elements of information work together, often rendering that work invisible within an already invisible care work.

Guided by an institutional ethnography method of inquiry, each of the four articles that comprise this thesis represent a different angle through which to capture the social organization of family caregivers' information work. In Chapter Three, interviews with family caregivers of community-dwelling older adults living with dementia opened up the complexities of their information work while interviews with dementia care staff helped to map out the influences happening at an organizational level that trickle down to influence families' experiences of their information work. While I privileged family caregivers' everyday and every night information work, to more deeply understand how their experiences come to be, I investigated the institutions and decisions happening outside of families' everyday contexts. Therefore, moving from local contexts to broader, more translocal contexts, Chapter Four applied Arksey and O'Malley's scoping review method to map out the ways that academic texts (articles) have studied and constructed

family caregivers' information practices over time. Based on my findings and because a scoping review had not yet been applied within an institutional ethnography study, I was intrigued by this combination. This curiosity resulted in the development of Chapter Five, where I began to tease apart the ways by which an institutional ethnography approach to texts might bolster or enhance some of the noted limitations of the scoping review method. Lastly, in Chapter Six, I applied Bacchi's "What's the Problem Represented to Be?" analytical tool for policy analysis to examine and dissect the problematizations implicit in aging in place or age-friendly community policies.

7.1 Explicating families' experiences of information work

In this concluding section, I bring together the previous four studies, briefly illuminating the findings from each chapter. Each of the four chapters progressively reveals the character and complexity of families' information work within dementia care work and also helps to map out different influences on families' information work. After brief summaries, I then weave the four studies' conclusions together to explicate how family caregivers' information work is experienced the way it is.

The interview chapter (Chapter Three) served as an opportunity to better understand how family caregivers' everyday and every night lives are actually accomplished, with a particular focus on the ways that information both enables and complicates their care work. This chapter illustrates that family caregivers take part in a great deal of work (including time, resources, and coordination) to find, use, make sense of, share, and store information. While the information work that each of the family caregivers described was predominantly invisible to them (and to researchers and policy creators, as is revealed in the other chapters of this dissertation), this work is essential for keeping their family member living at home. The interviews with paid dementia staff explicate how families' experiences of their everyday information work are traceable to translocal decisions and work practices, including managing waitlists while navigating priorities handed down from other organizations.

While the caregiver informants in this dissertation are experts in how they operate and work within their everyday world, their actions and activities are also organized through texts. Chapters Four, Five, and Six rested on the assumption that in a knowledge-based economy, "text-based forms of knowledge … play a central role in shaping people's everyday/everynight lives" (Deveau, 2008, p. 9). As "text-mediated relations are the forms in which power is generated and held in contemporary societies" (Smith, 1998, p. 79), examining the scholarly practices of synthesizing research about families' information practices and analyzing aging in place policies uncovered "the ideological practices that produce a certain kind of knowledge practical to the task of ruling" (Sharma, 2001, p. 421).

Intrigued by the decisions that academics make while studying family caregivers' information practices, Chapter Four outlined a scoping review of 72 articles. The work of using information while providing care was invisible. Information was valued and espoused for enabling caregivers to be better, less burdened, and more supportive caregivers. A number of articles framed information as an intervention (often in tandem with some sort of technological device) which further removed family caregivers from the work of having to manipulate and integrate these interventions and tools into their everyday care work.

In Chapter Five, based on my observations and practices of combining an institutional ethnographic way of thinking about texts while conducting the scoping review in Chapter Four, I uncovered how the process of conducting a scoping review moves academic writing and synthesis further and further away from the grounds of participants' experiences. In both Chapters Four and Five (and Six), I brought attention to the capacity of texts to be taken up in identical form across time and space, therefore having the capacity to be activated by authors, academics, policy makers, and members of the general public. In Chapter Five, I called the subjectivities of researchers as well as the scoping reviewer into question. As a result of the scoping review framework, the ways family caregivers are studied become replicated over time, giving shape to particular ways of engaging with, understanding, questioning, and recognizing (or occluding) families' information work.

In Chapter Six, I once again took up texts, using Carol Bacchi's "What's the Problem Represented to Be?" technique to focus on the problematizations in aging in place or age-friendly community policies. Common to a majority of the policies was an insistence on responsibilizing the individual (the older adult who "should" want to age in place), through an imperative to plan and to remain a contributing member to the community. It was in examining the silences in the policies that the invisibility of families' work in supporting or guiding an older adult to age in place was made clear. Information work was also invisible, with information positioned as an intervention or tool to maintain independence and be engaged with one's community to "successfully" age in place for a longer duration of time.

What rang through families' detailing of their work knowledges about their everyday work was the sentiment that "care cannot be reduced to particular practices as reactions to certain needs; rather, care forms a feeling, an identity, a commodity and a way of thinking" (Weicht, 2015, p. 6). Information similarly took on a fluid characterization in families' everyday and every night lives. This fluidity, however, was in direct conflict with the ways that academic studies, aging in place and age friendly policies, and dementia care staff portray or conceive of information, in an instrumental, interventionist manner. Information is that which enables either families or older adults to age in place for a longer duration of time. Aging in place, then, is an unquestioned reason and motivation for the ways that information is understood beyond the local.

7.1.1 Aging in place as an ideological code

As I reflect on the interactions between my four chapters, I am perhaps most intrigued by the unquestioned and assumed "goodness" of aging in place. Living at home for as long as possible (and perhaps even beyond that point) is assumed to be the "best" option for all involved. Aging in place, in these studies, can be viewed through the lens of an ideological code (Smith, 1993). This lens begins to structure the ways in which information is interpreted by those existing outside the local contexts of family caregivers of community-dwelling older adults who are living with dementia. An ideological code, analogous to a genetic code, is a "constant generator of procedures for selecting syntax, categories, vocabulary in writing and speaking, for interpreting what is written and

spoken, and for positioning and relating discursive subjects. It is not as such social organization, but it is a social organizer" (Smith, 1995, p. 26). Ideological codes "operate as a free-floating form of control" (Smith, 1999, p. 175). As a social organizer, these codes structure text, talking, hearing, writing, and thinking. Once established, ideological codes are self-reproducing and can replicate anywhere. Smith (1993) identified the Standard North American Family (SNAF) as an ideological code, governing census data, formulation of welfare policies, and economic theories of the family while excluding kin relations that do not fit within the confines of the married man and woman. Within Library and Information Science (LIS), McKenzie, Davies, and Williams (2014) studied people's work of keeping track of everyday life. These authors uncovered an ideological code of managerialism in participants' work of keeping track, with participants use of time management techniques and organizational systems to maximize their efficiency and effectiveness.

Ideological codes are ubiquitous, operating to "coordinate multiple sites of representation" (Smith, 1999, p. 160). Aging in place (AIP) has become a powerful organizing frame, which explains its normative character. The imperative to age in place is reproduced throughout the articles in the scoping review and the policies in the policy analysis. Aging in place is unquestioned and is implicitly placed at the highest rank, with all other housing arrangements, such as institutionalization, assumed as deficient or "lesser" alternatives. Interviewed families took up and took part in this ideological code, shaping their information work practices. All information work ultimately went to keeping their family member or spouse at home. Likewise, in the academic articles or in the policies, information (often stripped away from the caregiver who has to work the information) is mobilized purely for its ability to keep an older adult at home, and not in a home.

Minninch (1990) speaks to the challenges and opportunities the measuring and highlighting of unpaid work brings, in that it requires the transformation of knowledge beyond traditional boundaries or categorization: "rethinking mystified concepts, ideas, notions, categories and the like that are so deeply familiar they are rarely questioned" (p. 51). Just as McKenzie, Davies, and Williams (2014) found, using the ideological code

was a helpful tool to understand "how and why people are socialized to create information in various contexts" (Trace, 2007, p. 142). As I critically examine and take up the concept of the ideological code in my dissertation, my research indicates that the ideological code of AIP appears to rest on the ideals of healthism, where issues of health are situated at the level of the individual (Crawford, 1980), and familism, or a family ethic, centered on "traditional" family values (Hooyman & Gonyea, 1995). These two ideals are nestled within broader contexts of austerity and neoliberal reasoning. As a result of the interactions between healthism, familism, austerity, and neoliberalism, there is a trend to individualize the many supposed risks and problems attached to later life, with the management of these risks and problems passed to older adults and their family and kin. Informants implicitly conveyed that caring for their family member was their duty and their responsibility. Not only was caring for their family member their responsibility, but caring for their family member at home was of utmost importance. Keeping their family member at home was linked to their "success" as a caregiver and as a family member. Participants further relayed that should their family member living with dementia have to be moved into a formal, long-term care institution, this would reflect poorly on their abilities as a caregiver and as a family member, and for some, would be an indication of failure.

As families assumed this responsibility for the work of caring, this work, along with their information work entered the domain of a "labour of love". As a "labour of love" that takes place in the home, their information work is no longer work that "counts" as it falls under the norms of familial obligation, commitment, and responsibility. As families' "labours of love" are common, pervasive, and routinized, the significance and existence of the work that makes up care work becomes invisible. Families' information work becomes subsumed by the "free-floating form of control" (Smith, 1999, p. 175) of the ideological code of aging in place.

Part of this invisibility stems from what DeVault (1991) argues is a "lack [of] adequate language for the work of everyday caring" (p. 228). As a social organizer, the aging in place ideological code structures and privileges its own language, a specific way of talking, hearing, writing, and thinking that is replicated across space and time. As

evidenced in this dissertation, the informants' information work is organized by the language that the aging in place ideological code has established. This language supports an *inform to care* framework (Barnes & Henwood, 2015), which gradually uncouples and distances information from care. This increasing distance between information and care may begin to explain why information is treated as a separate intervention that is used to act on care.

Without a language that reflects informants' experiences of their information work, it becomes easy to ignore, to fail to see, to distort, or to lack the tools to express the complex information work that supports aging in place, thus making that work invisible. Furthermore, without a language that can resist, identify, or make known the workful character of information work, families' care work, including information work, is operationalized in ways that best serve or are most conducive to the aging in place ideological code. Mol, Moser, and Pol (2010) argue: "if care practices are not carefully attended to, there is a risk that they will be eroded. If they are only talked about in terms that are not appropriate to their specificities, they will be submitted to rules and regulations that are alien to them" (p. 7). Without the language that best reflects families' experiences of their information work, that of *informing with care*, it becomes difficult to understand the character of and to find ways to support families' information work. Without the language that best reflects families' experiences of their information work, the disjuncture between the experiences of information as fluid or as an ossified intervention persists.

7.2 Contributions and implications

From the outset, I intended my dissertation research to be interdisciplinary, crossing boundaries between LIS, feminist thinking, sociology, and gerontology, with an aim to "understand the character of household caring, to explore its traditional norms, and to reconsider the social structures that limit its functions" (Fisher & Tronto, 1990, p. 51). And so, while this thesis is based in an LIS disciplinary approach, this research has broader implications for disciplines studying aging, caregiving, and aging in place, and it

additionally contributes to a growing body of IE research. By working within and across a number of disciplines, I was able to more fully consider the relationship between information and care. The 13 informants in this thesis work demonstrated that they do care work through information work and do information work through care work; there is a degree of reciprocity between information work and care work. The frustrations I experienced as I read through the care literature that spurred the creation of Chapter 4 (the invisibility of caregivers' information work in current care-focused research) prompted me to intentionally keep information work isolated from other forms of care work. This tactic is to open communication between information and gerontology scholars and to make explicit to care-focused researchers the information work that underpins care work. Older adults have been a traditionally marginalized group in LIS research (Dalmer, 2017; Joseph, 2009), with Chatman's (1992) in-depth investigation into the information worlds of retired women a notable exception. This dissertation therefore serves as a prompt for LIS scholars to "press forward issues of age and aging" (Katz, 2014, p. 19) into our field. More specifically, this dissertation research responds to Erdelez, Howarth, and Gibson's (2015) call for a broader range of information science dementia research.

Case's (2002) summary of LIS research on how individuals seek out or need information begins to illuminate some of the interconnected research contributions of this dissertation:

> *One thing that these studies have in common, however, it is a concern with sources and channels - typically interpersonal channels versus mass and/or specialized media... Despite an effort to examine the process of information seeking, much of it still comes down to "who or what do people consult for information?" This is an old question within the information needs, uses and seeking literature and continues to dominate the discussion of findings.* (p. 256)

As this dissertation reveals, attending to the ways that individuals engage with information requires moving beyond who or what sources people consult. In using an institutional ethnography method of inquiry, this research demonstrates the richness in data and understanding that occurs when a user-focused study is attuned not only to the local contexts of the user but to the translocal contextual influences that produce "life as

usual" in a particular way. This study points to the utility of an institutional ethnography in LIS, demonstrating that this method of inquiry enables a "way of seeing, from where we actually live, into the powers, processes, and relations that organize and determine the everyday context of that seeing" (Smith, 1987, p. 9). As a result, for user-focused studies in LIS, detailing users' work knowledges about what information they need or they seek should not be the totality of a user-focused study, but rather the beginning or starting point. An IE LIS study understands that a user should not be divorced from their translocal contexts. This approach to studying users' information practices has the potential to provide more comprehensive clues about the contexts, organizations, texts, and other bureaucratic decisions, for example, that each bring to bear on users' decisions about engaging with or accessing certain information. It also has the capacity to achieve a more "accurate design of social policies and the organization of social safety nets" (Beneria, 1999, p. 302).

This thesis contributes to the small but growing number of LIS studies that take up an understanding of information practices as *work*. In alignment with recent movements in critical librarianship as well as existing feminist LIS research, I view an acknowledgement of the work of finding, using, mediating, sharing, and storing information an important and crucial issue. This work must be made visible and known if it is to be recognized and more responsively and fully supported. A generous conceptualization of work enables a fuller understanding of the physical, mental, and emotional work that occurs as individuals interact with information, opening up a wide array of options and possibilities for future LIS studies. In interpreting family caregivers' information practices as work, this dissertation furthers prevailing understandings of information work by focusing on the work of an individual searching on behalf of or because of another. As a result, this dissertation contributes to a fuller conceptualization of information work within Corbin and Strauss' illness trajectory theory (1985; 1988), moving beyond existing patient-focused information work studies. Ultimately, this study brings attention to information work and contributes to making information work a more visible component of care work.

Because I affix the label of *work* to families' information activities and because I keep both the local and the translocal in focus, my work prompts a questioning of ELIS' work/non-work dichotomy. ELIS is defined as "the ways in which people acquire information in non-work contexts" (Savolainen, 2008, p. v). Results from this study, however, reveal that family caregivers' everyday information work are subject to and are embedded in organizational and institutional work practices. I join McKenzie and Davies (2012), Prigoda and McKenzie (2007), and Stooke and McKenzie (2009) in suggesting that studying individuals' everyday information work in non-work contexts forces a false dichotomy between work and non-work and removes some contextual cues and richness in fully understanding people's everyday information work. As a result, I suggest that ELIS studies need to take into account and investigate participants' work (paid) contexts not only to examine the skills, habits, and sources that arise from paid work environments, but also for the organizational constraints and coordination that work contexts establish and impose on people's experiences of their everyday information practices.

This thesis makes three contributions to institutional ethnography methods. First, in taking up IE's mapping metaphor literally, the information world mapping exercise discussed in Chapter Three proved to be a helpful exercise, not only in avoiding my own institutional capture, but in privileging informants' expertise and work knowledges. It was served as an opportunity for family caregivers to resist "provider-centered, one-way practices of information transfer" (Lee & Garvin, 2003, p. 462) from researcher to participant. Forthcoming studies in institutional ethnography may elect to take up a similar mapping exercise during interactions or interviews with informants. As rigor in institutional ethnography is established through transparent and accurate descriptions of "what is actually happening within the social relations" (Prodinger, 2012, p. 89), mapping exercises can be mobilized to ensure the authenticity of informants' descriptions is maintained and respected. Secondly, in Chapter Five, my deconstruction of scoping review methodology has the potential to enable a questioning and critique of textual authority in knowledge synthesis practices while also promoting the inclusion of different kinds of texts in institutional ethnography textual analyses. Findings from this chapter

also enable a reconsideration of scoping reviewers' citation practices as "a set of tactical responses to the problems of citation in the securing of the dominant narratives" (Hemmings, 2011, p. 164). Third, in Chapter Six, I present a novel way for institutional ethnographers to structure the discovery of problematizations and governing narratives embedded in texts. Bacchi's "What's the Problem Represented to Be?" analytical tool can structure and enhance the ways institutional ethnographers can question and examine policy texts' documentary reality.

In addition to making contributions to research on family caregiving, dementia care, information work and care work, and institutional ethnography, this thesis also carries policy implications. In addition to drawing attention to and questioning the implicit "goodness" that AIP connotes, the findings of this thesis prompt readers and those engaged with policy creation to more fully consider the host of individuals that contribute to enabling an older individual to age in place. This thesis highlights the unrecognized commitments of families and the communities within which older adults are located. As such, there requires more community-level support to enable AIP to happen in a way that supports each of the individuals (families, in the case of this thesis) that are supporting older adults to age in place. Aging in place itself is a concept that appeals to a majority of Canadians. As such, it is a policy ideal that resonates with many. It does, however, require support distributed in a different manner. More specifically, informationally, families responded favourably to the receipt of information from other individuals, preferring information received through relationships than from pre-packaged information packets. To meet family caregivers' desire for information at different points in time throughout the caregiving trajectory from individuals, support for families may need to be redistributed across a longer time continuum. This includes being mindful of the accessibility of the spaces in which family caregivers might gather to share information or insights with one another and also means making available care at home to enable family caregivers to leave to attend caregiver support or information exchange sessions.

7.3 Limitations

As I look back at this dissertation and its many working parts, perhaps the greatest question I had to contend with was the order in which I would complete and present the study. The current order of chapters is not the order in which I completed the study. An institutional ethnography ideally begins in the local as a starting point, using data collected from each of the level-two articles to explore the linkages and movements between the local in which the caregivers are situated and the translocal ruling relations that organize their local actualities (Smith, 2005). The logistics of acquiring ethics approval in a timely manner made this difficult. Mindful of my available time, I elected to start with the scoping review. While completing the interviews near the end of this study made it possible to ask the informants to comment on the findings of the scoping review in the consultation exercise, I wonder how the dissertation might have unfolded differently starting first with interviews with family caregivers.

Recruitment also proved difficult. As evidenced throughout family caregivers' interviews in Chapter Three, family caregivers have many demands on their time and fitting in an interview is not likely high on their priority list. As a result, it took a great deal of time to recruit family caregivers and a relatively small number of informants ultimately participated. Furthermore, informants who participated in my study presented predominantly as female, Caucasian, settler, heterosexual, from a middle to upper socioeconomic status, and living in an urban setting. The older adults living with dementia were also Caucasian, heterosexual, and from a middle to upper socioeconomic status. While I repeatedly attempted to recruit caregivers differently placed along a socioeconomic continuum, this proved to be much more difficult than expected. The experiences and work knowledges that are articulated in this dissertation are therefore representative of only certain family caregivers whose socioeconomic status (in addition to other intersecting factors and contexts) may ascribe certain privileges when locating or managing information, including having a computer at home or having the finances to pay for extra respite time in order to attend caregiver support groups. This limitation reflects prevailing limitations of current work in gerontology, including "its focus on the developed West, and within that on the experiences of relatively affluent and often

‘white’ elders” (Twigg & Martin, 2015, p. 9). Interviews with lesbian, gay, bisexual or transgender family caregivers as well as ethnic and minority family caregivers (and/or a similarly diverse composition of older adults living with dementia) may bring to light different ruling relations that impact or mediate their information work. Taking up an intersectional lens to conduct additional research with a more diverse array of family caregivers and/or older adults living with dementia is needed to ascertain whether certain cultural practices could protect against the aging in place ideological code.

Certain aspects of the study’s limitations only came to light as I conducted my interviews with family caregivers. During the interviews, family caregivers spoke about their information work by referring to a number of documents, binders, calendars, and other tools. While I was able to take field notes of these devices and tools, obtaining ethics clearance to take photographs of these items may have enrichened the dataset. Similarly, I conducted several interviews in the caregivers’ homes and was able to observe interactions between the caregiver and their family member living with dementia. These unforeseen interactions, while often brief, shed light on the ways in which information might be indirectly acquired from movements, grunts, or changing facial expressions. Involving the older adult living with dementia in the interview process or having permission to record interactions may be a technique to respect the personhood of the individual living with dementia (Kitwood, 1997) and to actively involve the person living with dementia “in research ‘with’ rather than ‘on’ them” (Cowdell, 2006, p. 85).

7.4 Future work

I am excited to continue working with the ideas and data from this dissertation as I continue to investigate the complex relationship between information and care. I am especially eager to continue thinking and working with the rich data from the interviews with family and paid caregivers. In order to address some of the limitations outlined above, future research may elect to interview family caregivers with the individual living with dementia to ensure this latter group is not “positioned as third parties in stories about their own lives” (Nilsson, Ekström, & Majlesi, 2018, p. 1). Participatory methods that

include people with dementia and their families are increasingly gaining attention in academic research (Branco, Quental, & Ribeiro, 2017) and might be a helpful way to examine how the construction of the relationship between caregiver and care recipient (Hydén & Nilsson, 2015) impacts how and what information is sought and shared. This can also open up deeper investigations into the impact of relationships, including power dynamics, between family members on information work (Veinot, Kim, & Meadowbrooke, 2011; Harris, Veinot, & Bella, 2010).

I want to explore the role of boundary objects in families' information work. Boundary objects "have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation" (Star & Griesemer, 1989, p. 393). Huvila, Anderson, Jansen, McKenzie, and Worrall (2017) suggest that "the in-betweenness of the concept of [boundary objects] makes it a valuable analytical device for examining ensembles of people, information, and technology that are ever-shifting and multisited" (p. 1816). The family caregivers' work knowledges hint at a number of boundary objects that warrant further investigation. I am interested in taking up the information packets and binders that family caregivers receive from dementia education organizations and associations and the information binders they create for themselves, other family members, and other caregivers to understand how these binders structure and coordinate the timelines of the complex work of dementia care. In addition to these documents as boundary objects, I want to explore the body of the individual living with dementia as a boundary object, serving as a tool for "maintaining coherence across communities" (Huvila, Anderson, Jansen, McKenzie, & Worrall, 2017, p. 1808), between caregivers and health care professionals, between caregivers and dementia education associations, and between family members, for example. I want to understand how the body serves as a boundary object that mediates information work across and throughout the dementia trajectory. This also has the potential to open up important and necessary conversations about autonomy, personhood, and consent in dementia; questioning not only how those living with dementia can be more inclusively involved in research, but how their bodies, ideas, and actions are documented and studied.

Within an institutional ethnography way of thinking, this study can prompt further investigations into the relationship between information work and the coordination of multiple timelines that occur throughout a chronic illness. More specifically, I am interested in uncovering the ways that families' information work comes to be aligned with or support institutional timelines, such as navigating waitlists, caregiver education sessions, planning for psychogeriatrician appointments, Personal Support Worker home visits, etc. I am especially curious about a particular time period that was particularly difficult for families to negotiate practically and emotionally: pre-diagnosis phase. While families suspected or knew that something was "wrong" or "off", without an appointment to obtain an official diagnosis, informants commented that they did not have the specific tools or vocabulary to begin looking for information or specific agencies in order to bring some sense of insight or understanding. As there are current shortages of geriatricians and psychogeriatricians, caregivers had to exist in this in-between, liminal space for up to a year.

Methodologically, I enjoyed the exercise of thinking through the implications and opportunities of conducting a scoping review method within an institutional ethnography. Moving forward, I want to similarly look at the synergies when combining a policy analysis tool, WPR, within the conceptual framework of institutional ethnography. I also will delve deeper into the agency that the information world mapping exercise afforded the family caregivers and explore how physical mapping might be a helpful tool to amplify the mapping metaphor that runs throughout institutional ethnography. While I used the information world maps as data elicitation tools for the purposes of the dissertation, I would like to return to these maps as data in and of themselves, to more deeply examine their content for indications of work, information topics, and key information sources.

Inspired by recent writings by Huvila (2015) and Gorichanaz (2017), one additional area of research I hope to explore includes a deeper investigation on the relationship between information, experience, and situational appropriation. I want to return to my data to contemplate how family caregivers mobilize their decades of experiences of interaction with the individual living with dementia and how that experience is appropriated into

helpful information in new situations or in new environments or as new phases of trajectories of the disease present themselves. Part of this investigation will involve more closely examining how family caregivers interpret changes in bodily rhythms, routines, and habits.

Finally, taking up the relationship between information and care, as I look towards building an "adequate language for the work of everyday caring" (DeVault, 1991, p. 228) that more responsively captures families' information work, I want to delve more deeply into examining the links and tensions between trends towards the informatization of care (Barnes & Henwood, 2015) and the biomedicalization of care (Hooyman & Gonyea, 1995). In doing so, I aim to build a more comprehensive definition of information work by creating a language that more fully recognizes the complexities and workful character of family caregivers' everyday information work.

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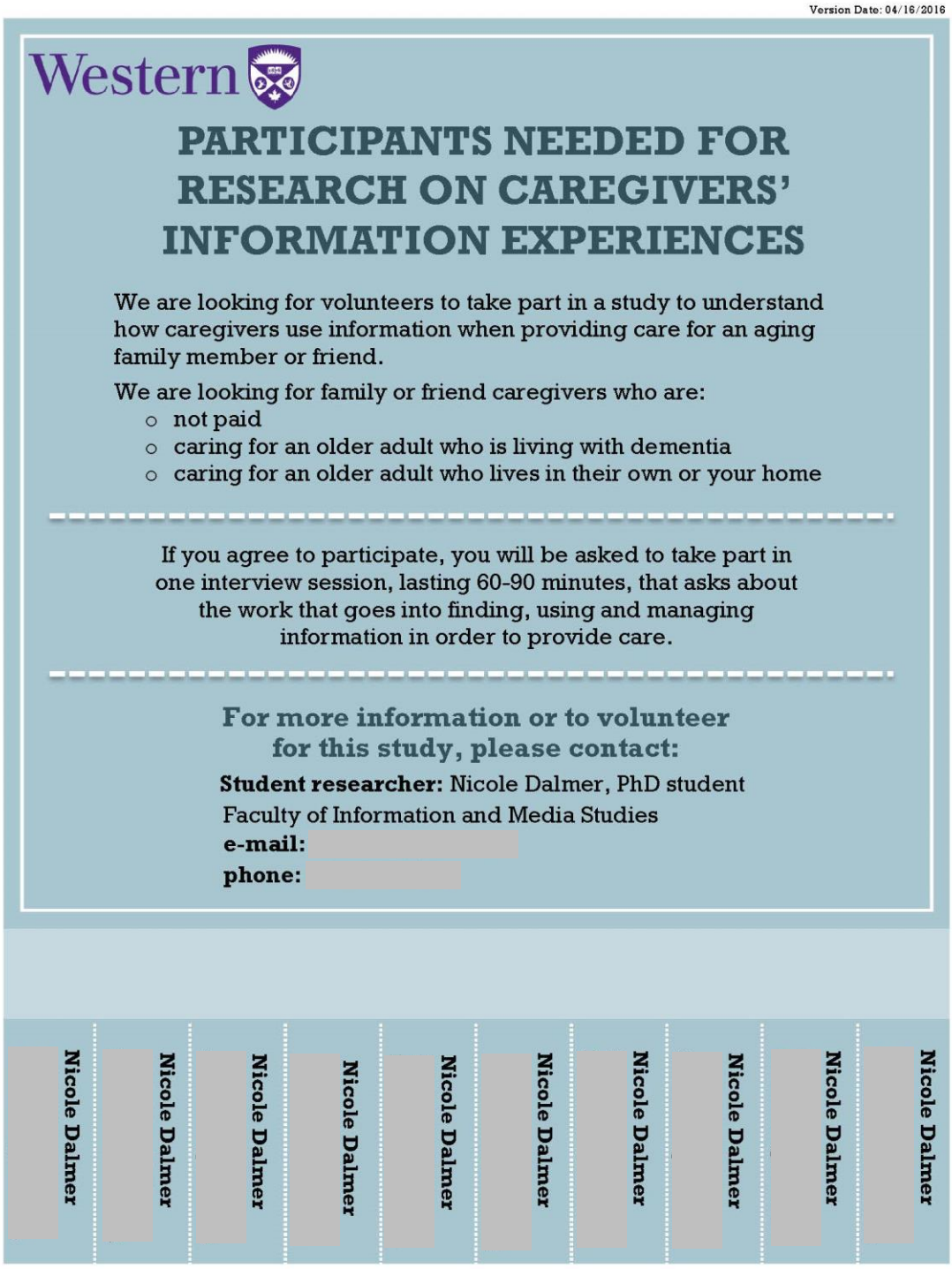
Appendix A. Recruitment Poster for Family Caregivers



Appendix B. Ethics Approval NMREB 107992

Western Research

Western University Non-Medical Research Ethics Board
NMREB Delegated Initial Approval Notice

Principal Investigator: Dr. Pamela McKenzie
Department & Institution: Information and Media Studies\Faculty of Information & Media Studies,Western University

NMREB File Number: 107992
Study Title: Information as Work: Mapping Intersections of Information Work and Eldercare Within an Aging in Place Climate

NMREB Initial Approval Date: May 03, 2016
NMREB Expiry Date: May 03, 2017

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Instruments	Information World Exercise_Worksheet	2016/04/16
Recruitment Items	Poster_Caregivers	2016/04/16
Recruitment Items	Poster_Key Informant	2016/04/16
Western University Protocol	Received April 27, 2016	
Caregiver Letter of Information & Consent		2016/04/26
Letter of Information & Consent	Key Informants	2016/04/26
Instruments	Interview Schedule for Caregivers - Duplicate	2016/04/16
Instruments	Information Worlds Exercise Material for Caregivers - Duplicate	2016/04/16
Instruments	Interview Schedule_Key Informants - Received April 19, 2016	
Instruments	Interview Schedule_Caregivers - Received April 19, 2016	

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the above named study, as of the NMREB Initial Approval Date noted above.

NMREB approval for this study remains valid until the NMREB Expiry Date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario.

Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

[redacted]
Ethics Officer, on behalf of Dr. Riley Hinson, NMREB Chair or delegated board member

Ethics Officer to Contact for Further Information: Erika Basile ___ Nicole Kaniki ___ Grace Kelly ___ Katelyn Harris ✓
Vikki Tran ___

Western University, Research, Support Services Bldg., Ste. 5150
London, ON, Canada N6G 1G9 t. 519.661.2161 f. 519.661.3907 www.westernu.ca/research

Appendix C. Letter of Information (Family Caregivers)

Western

LETTER OF INFORMATION AND CONSENT

STUDY TITLE: Mapping Intersections of Information Work and Eldercare Within an Aging in Place Climate

Student Researcher:
Nicole Dalmer, LIS PhD student
Faculty of Information and Media Studies
The University of Western Ontario
e-mail: [redacted]
Phone: [redacted]

Principal Investigator:
Dr. Pamela McKenzie, Professor
Faculty of Information and Media Studies
The University of Western Ontario
e-mail: [redacted]
Phone: [redacted]

Invitation to Participate
You are being invited to participate in this research study about the work that goes into finding, using and sharing information in order to care for a family member or friend who is living with dementia. You are invited to participate in this study because you are an unpaid family or friend caregiver living in the London, Ontario area and you are providing care to an older adult (65+) who is living with dementia and who is living in their own home or in a family member's or a friend's home.

Why is this study being done?
The purpose of this study is to understand the many ways in which information is used, managed and shared when taking care of an aging family member or friend.

What are the study procedures?
The study will require one interview that will last between 60-90 minutes. You will be asked questions about what kinds of information you have needed as a caregiver, including where you look for information and what you do with the information. You will also be asked to draw a map that represents how you search for and use information in the London area.

The interview will be scheduled at a time and a space that is convenient and comfortable for you, such as in a meeting room at a public library branch close to you.

Possible Benefits and Risks

You may not directly benefit from participating in this study but information gathered may provide benefits to society as a whole, including the development of more suitable information resources for family and friend caregivers of older adults living with dementia.

You may experience some discomfort talking about some aspects of your caregiving experiences. Should you experience any distress, please contact the following local resources:

Alzheimer Society (London and Middlesex) Caregiver Drop-In Support Groups

VON Caregiving Information and Support:

Alzheimer Outreach Services of McCormick Home - Family Support Services:

Is my participation voluntary?
Yes. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time without having to provide any reasons and without any consequence. If you decide to withdraw from the study, you have the right to request withdrawal of information collected about you. If you wish to have your information removed please let the researcher know.

What happens with my responses?
If you consent, the interview will be audio-recorded, and then transcribed into print, which will then be used in this research. You may also participate if you would prefer not to be audio-recorded. In this case the researcher will take written notes during the interview to use in this research.

All information that could identify you will be removed from the data, and pseudonyms will be used to further protect you identity. The researcher will keep any personal information about you in a secure and confidential location for 5 years following the completion of the study after which time it will be destroyed. A list linking your study number with your name will be kept by the researcher in a secure place (the principal investigator's university office), separate from your study file. All personal information collected will remain confidential and will be accessible only to the researchers. Representatives of The University of Western Ontario Non-Medical Research Ethics Board may require access to your study-related records to monitor the conduct of the research.

The results of this study, including the use of direct quotes from interviews may be published in papers, books, or presented at conferences or used in teaching materials, if you consent to the use of unidentified direct quotes. Your name will not be used in any research publications. If you are interested, you may request copies of the interview transcripts as well as copies of any future possible publications.

While we do our best to protect your information there is no guarantee that we will be able to do so. Additionally, if data is collected during the project which is required by law to report, we have a duty to report this data.

Will I be compensated for my participation?
There is no financial compensation for participation.

Who do I contact if I have questions about this study?
Nicole Dalmer, PhD Student
Phone:
email:
Supervisor: Dr. Pamela McKenzie,

If you have any questions or concerns about your rights as a research participant or the conduct of this study you may also contact:

The Office of Research Ethics

Thank you.
Your interest in participating in this research study is greatly appreciated!

This letter is yours to keep for future reference.

STUDY TITLE: Mapping Intersections of Information Work and Eldercare Within an Aging in Place Climate

CONSENT FORM

Principal Investigator:
Dr. Pamela McKenzie, Professor
Faculty of Information and Media Studies
The University of Western Ontario
e-mail:
Phone:

Student Researcher:
Nicole Dalmer, LIS PhD student
Faculty of Information and Media Studies
The University of Western Ontario
e-mail:
Phone:

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.
You do not waive any legal rights by signing this consent form.

I agree to be audio-recorded in this research: ☐ **YES** ☐ **NO**

If no to above, I agree to allow written notes to be made during the interview: ☐ **YES** ☐ **NO**

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research: ☐ **YES** ☐ **NO**

Participant's Name (please print): _____

Participant's Signature: _____

Date: _____

Person Obtaining Informed Consent (please print): _____

Signature: _____

Date: _____

Version Date: April 26, 2016 Participant Initials____

Appendix D. Interview Guide (Family Caregivers)

Information as Work: Mapping Intersections of Information Work and Dementia Care within an Aging in Place Climate

Interview Guide for Family/Friend Caregivers

Ask all or some of these questions, depending upon the nature of the conversation

Establishing rapport

- Inquire how participant is doing.
- Plans for the weekend?
- How long have you been taking care of [older adult]?
- Does older adult live with you?
- Inquire about diagnosis of dementia
    - What is suspected diagnosis? (Alzheimer's disease? Vascular? Lewy bodies?)
    - When first started to exhibit signs of changes in memory or behaviour?
        - When were you first aware that your family member/friend had some form of dementia?
    - Who did you initially talk to about the changes you were aware of?
        - What happened following this?

To ease into thinking about information use

Could you think of a time when you recently needed to find something about [context to be filled in depending on the caregiver or older adult's specific situation]?"

- Why did you need to know about that?
- How did you decide where to start looking for an answer?
    - Why did you start there?
- Did you find answer helpful?
    - Why or why not?

Specific, probing questions about using, finding, sharing and managing information

- When you need to find out something about [older adult], where do you start?
    - Why start there?
- If you needed to find out something completely new about [older adult], where would you start?
    - Why there?
- What motivates or brings you to need to look for information?
    - When does this happen?
    - Particular events? (Appointment with health care professionals, change in medication, change in health status, etc.)
- What type of information or topics do you most often look for?
    - Why?
- What type of resources do you consult?

    - Do you look online?
        - Where do you go online? How do you know to search there?
        - Are there any sites that you avoid? Why?
        - Are there any sites that you turn to first? Why?
    - In magazines? Books?
        - Where do you access these?
- Who do you turn to if you need to find something out?
    - Why?
- Who do you share the information with once you've found something new out?
    - Why?
- Who (people, family, services) asks you for information about your family member or friend?
    - How do you provide this?
    - What information have you given?
- Who (people, family, services) asks you for information about yourself as a caregiver?
    - How do you provide this?
    - What information have you given?
- What do you do with that information you've found?
- What has been easy or comforting about finding information about [older adult]?
    - What makes those aspects easy? Comforting?
- What has been difficult or frustrating about finding information about [older adult]?
    - What has made it difficult? Frustrating?
- If you were starting this journey again, what would you recommend to do and what would they do differently?
    - Why so?

Note: The questions asked throughout the interview conversation will be posed to gain clarification to uncover what actually happens in caregivers' everyday care work (with a particular emphasis on information work). Asking "what did you do next?" or "what happened next?" to map the chain of work is of crucial importance in this institutional ethnography study.

Questions for drawing activity

Participants will be provided with a handout as well as a pencil (or pen) and paper and will be asked to talk out loud as they draw a map representing their movement(s) throughout London as they seek, use, share and manage information about the older adults in their care.

Please see separate document for the full instructions and handout for this exercise.

At conclusion of interview

- Is there anything that we haven't covered that you'd like to add or mention?

- Would you feel comfortable sharing my contact information with other family/friend caregivers of community-dwelling older adults living with dementia?

Thank participant for their time and participation.

Appendix E. Information World Mapping Guide

Information World Mapping Guide

Throughout our conversation today, we've talked about examples of when you've needed and found different types of information to help you provide care for [name of older adult] and how you went about finding that information and what you did once you found that information.

In addition to what you've already told me in the interview, I'm asking if you'll draw your "information world" as it relates to your caregiving. What this means is that I'll give you some paper and a pen and I'll get you to place yourself on that piece of paper and then draw in all the different people, places and things in your life that either provide information to you or receive information from you – with regards to the care you give to [older adult's name].

Different people think of and draw their "worlds" in different ways and there's no right or wrong way to draw your information world.

Things you might want to consider and include in your information world:

- sources for information you look to when you have a question about [older adult's name]
    - will you include helpful and not so helpful sources?
- sources of information you get (whether you were looking for it or not)
- people you share information with or give information to
- people, places and things that help you find, understand or use information
- things or people that help you store, manage or retrieve information
- places – physical or virtual – where these information activities take place

Take some time to draw your unique world and then we'll talk about what you drew. I'll also ask if you'll allow me to keep your map to use in my study.

Follow up (or prompting, as needed or requested) questions might include:

- Why did you draw your map in that order?
- Where would you go next?
    - Who would you talk to next?
        - How do you know to do that?
    - How would you get there?
    - How often do you see this person?
    - How often do you go to [clinic, library, care centre, etc.]?
- I noticed you mentioned [a place, a person] in your interview but it is not drawn on your map – why is this?
- I noticed you've drawn [a place, a person] on your map but it was not mentioned in the interview – why is this?

If participant is anxious or confused about this exercise, there is a sample template that I can go over with the participant to more concretely explain the exercise

Appendix F. Participant Handout - Information World Mapping

Information World Mapping - Participant Handout
Mapping your Information World

In this activity, I'm asking if you'll draw out your "information world" as it relates to your caregiving.

I'll give you some paper and a pen and I'll get you to place yourself on the paper and then draw in all the different people, places and things in your life that either provide information to you or receive information from you – with regards to the care you give to your family member or friend.

Different people think of and draw their "worlds" in different ways and there's no right or wrong way to draw your information world.

Things you might want to consider and include in your information world:

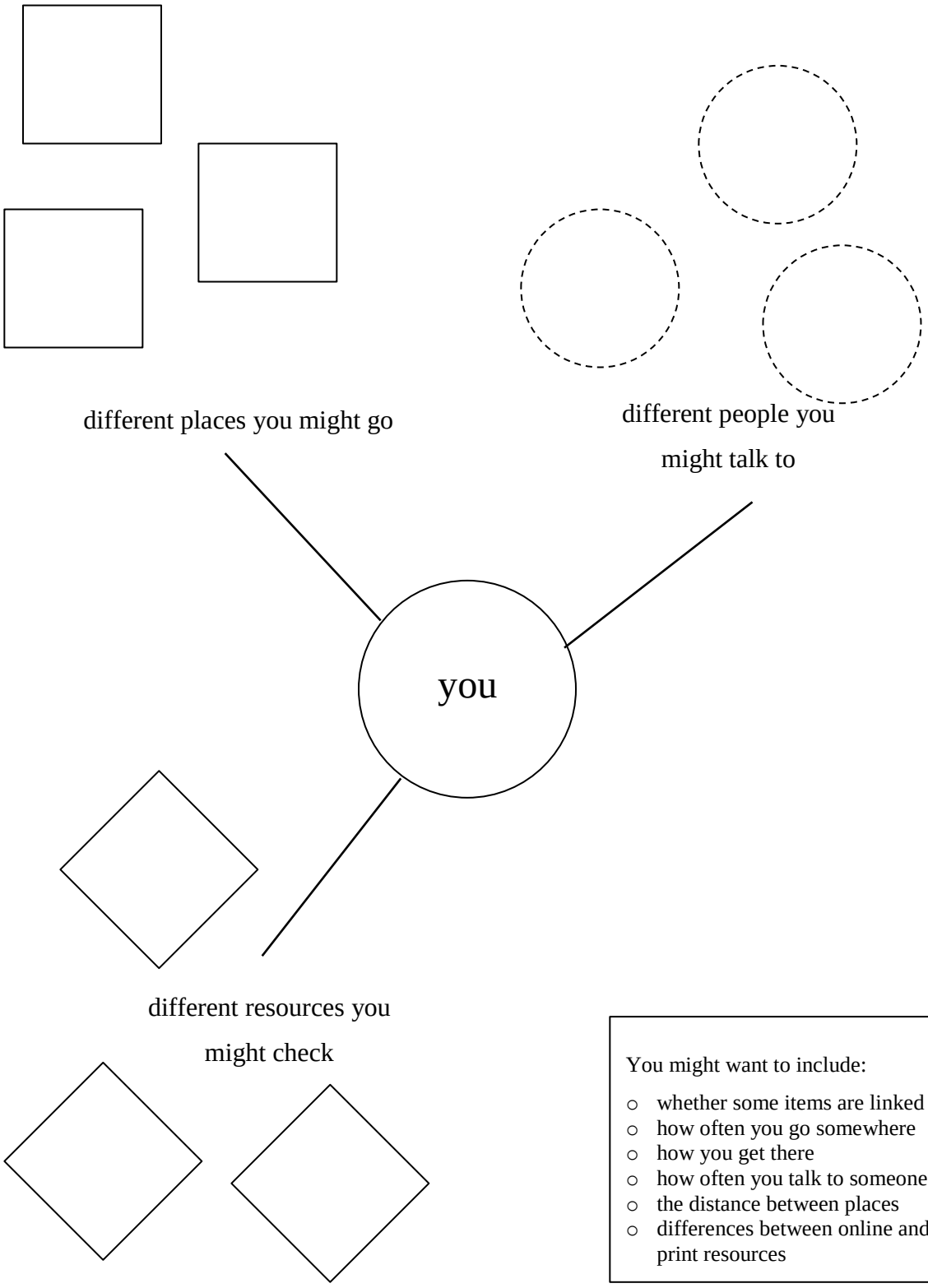
- sources for information you look to when you have a question about the older adult in your care
- sources of information you get (whether you were looking for it or not)
- people you share information with or give information to
- people, places and things that help you find, understand or use information
- things or people that help you store, manage or retrieve information
- places – physical or virtual – where these information activities take place

You can talk out loud about what you're drawing or you can draw without talking – it's up to you!

After 10 minutes or so, I will ask you to tell me about the information world you drew.

Appendix G. Information World Template

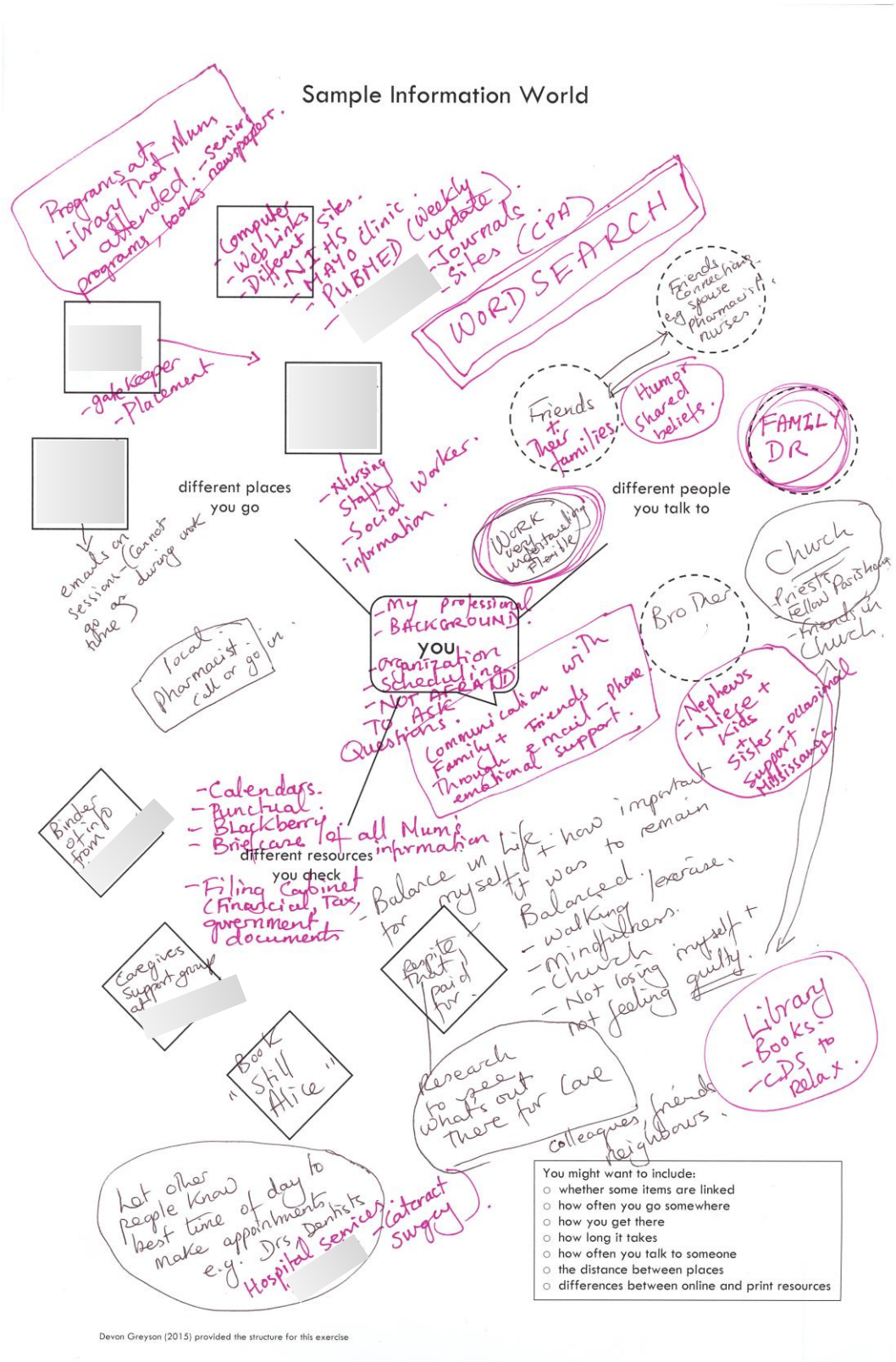
Sample Information World



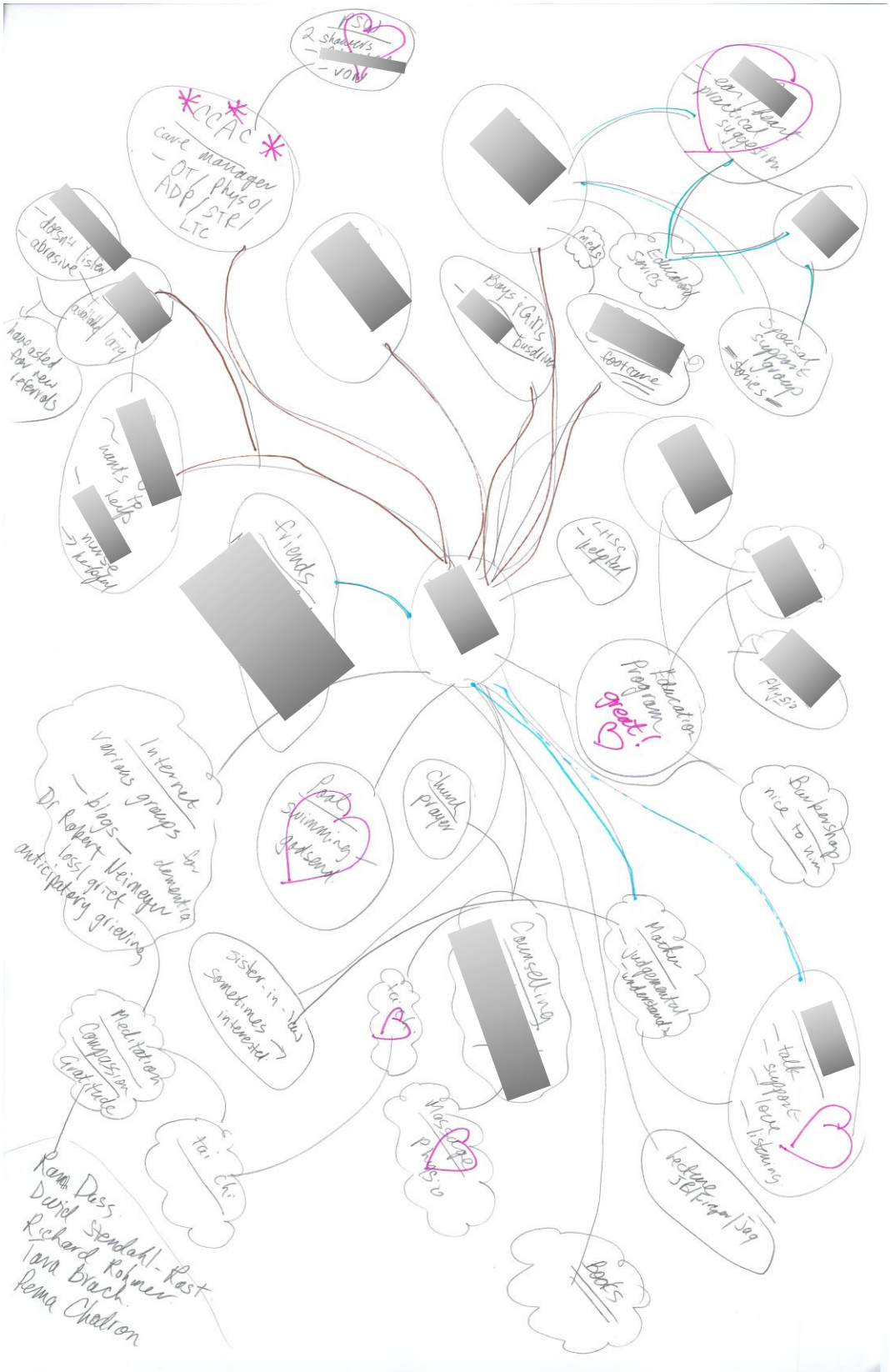
You might want to include:

- whether some items are linked
- how often you go somewhere
- how you get there
- how often you talk to someone
- the distance between places
- differences between online and print resources

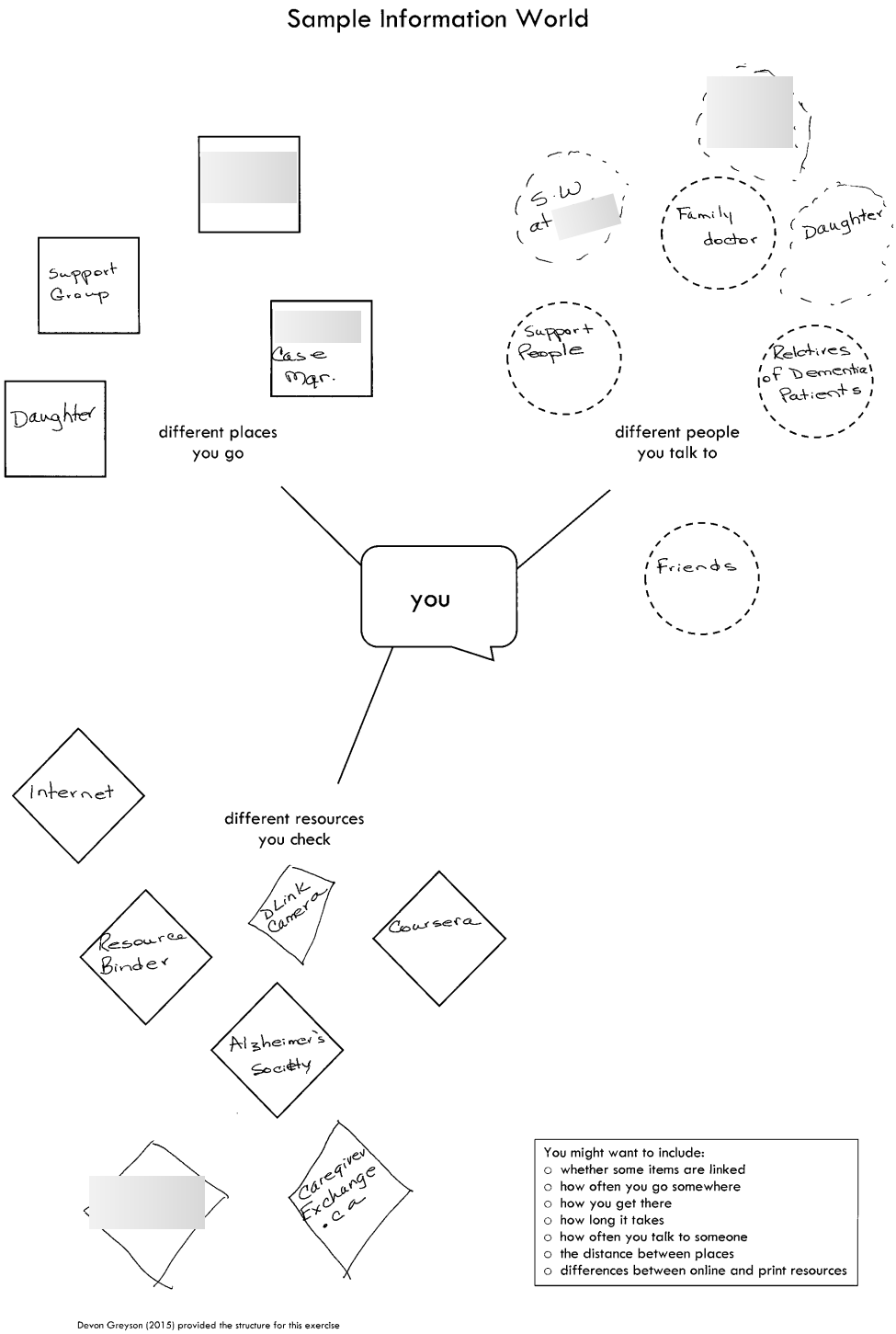
Appendix H. Harriet's Information World



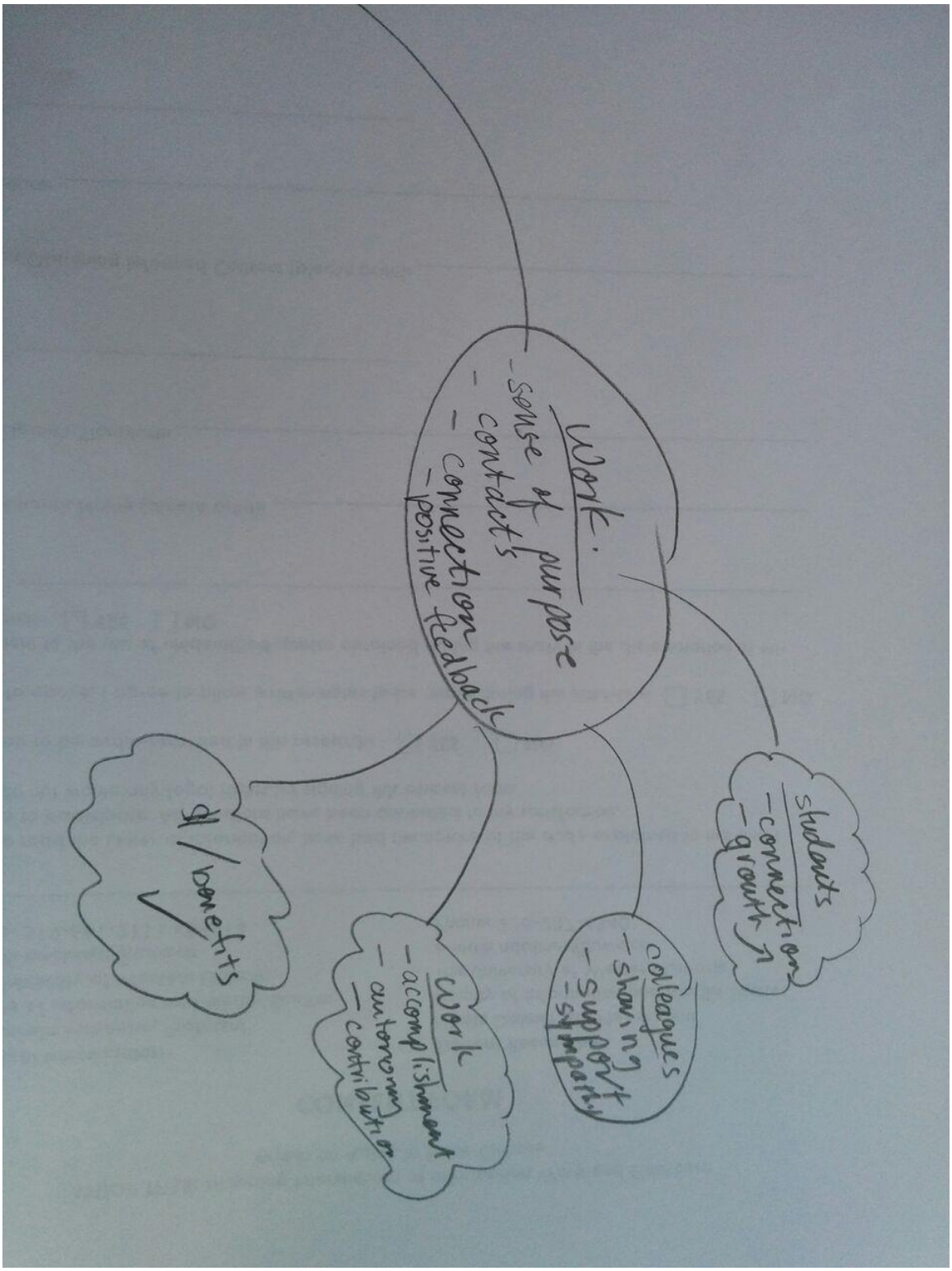
Appendix I. Sylvia's Information World



Appendix J. Marge's Information World

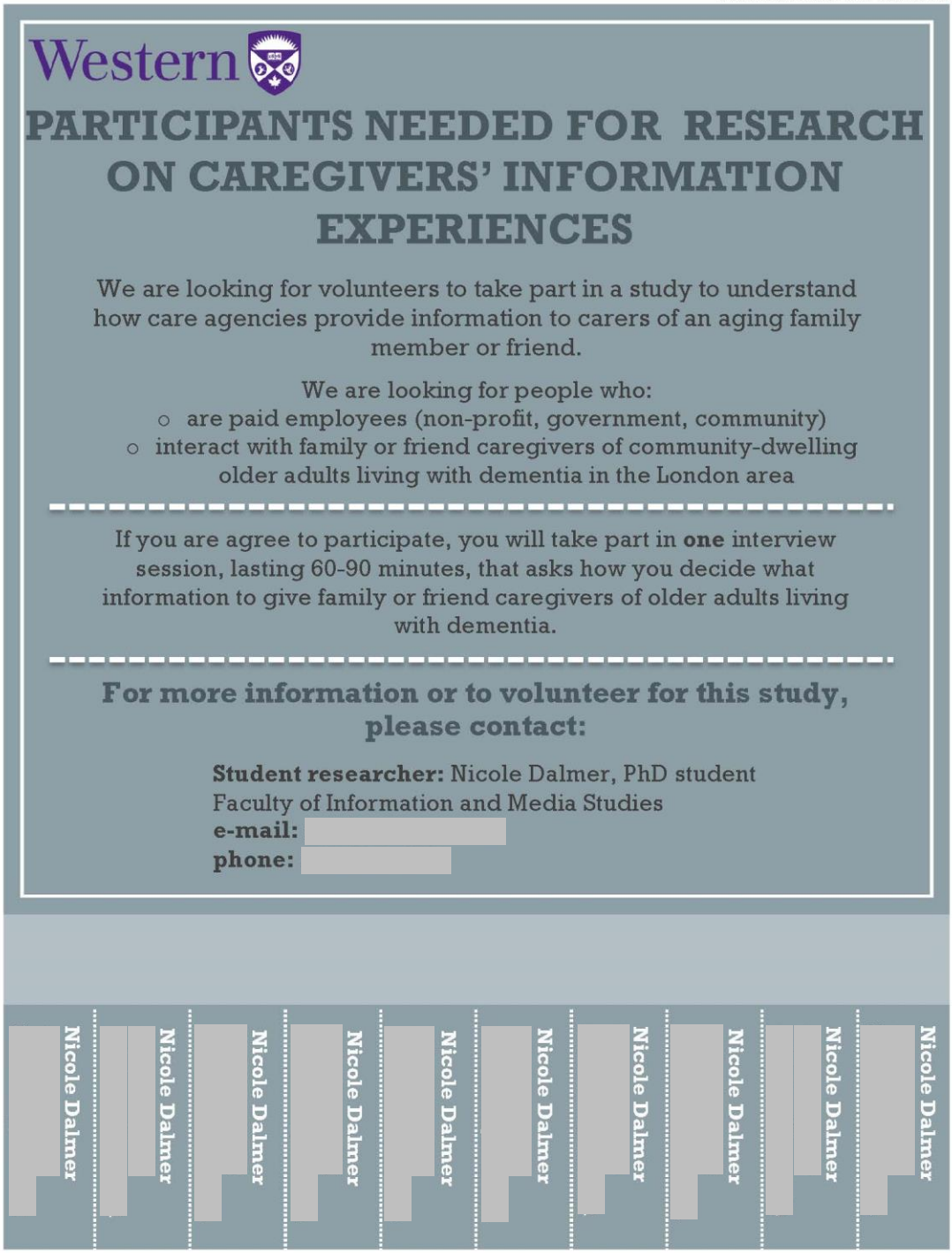


Appendix K. Sylvia's Information World (Addition)



Appendix L. Recruitment Poster for Dementia Care Staff

Version Date: 04/16/2016



Appendix M. Letter of Information (Dementia Care Staff)

Western

LETTER OF INFORMATION AND CONSENT

STUDY TITLE: Mapping Intersections of Information Work and Eldercare Within an Aging in Place Climate

Student Researcher:
Nicole Dalmer, LIS PhD student
Faculty of Information and Media Studies
The University of Western Ontario
e-mail:
Phone:

Principal Investigator:
Dr. Pamela McKenzie, Professor
Faculty of Information and Media Studies
The University of Western Ontario
e-mail:
Phone:

Invitation to Participate
You are invited to participate in this research study that aims to better understand the work that goes into finding, using and sharing information in order to care for a family member or friend who is living with dementia. You are invited to participate in this study because you are in a paid position in a local government, caregiver agency or non-profit organization in the London community and you interact with and/or support family and friend caregivers of older adults living with dementia who are aging in place.

Why is this study being done?
The purpose of this particular study is to understand how organizations that support older adults and/or caregivers decide how and when to provide information to family and friend caregivers of community-dwelling older adults who are living with dementia.

What are the study procedures?
The study will require one interview that is expected to last between 60-90 minutes. You will be asked questions about how you decide what information to give to family or friend caregivers of older adults living with dementia (what format, what content) and how you determine the timing of this information delivery.

The interview will be scheduled at a time and a space that is convenient and comfortable for you, such as your place of work or in a meeting room at a public library branch close to you.

Possible Benefits and Risks
You may not directly benefit from participating in this study but information gathered may provide benefits to society as a whole, including the development of more responsive information resources for family and friend caregivers of older adults living with dementia.

Is my participation voluntary?
Yes. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time without having to provide any reasons and without any consequence.
If you decide to withdraw from the study, you have the right to request withdrawal of information collected about you. If you wish to have your information removed please let the researcher know.

What happens with my responses?
If you consent, the interview will be audio-recorded, and then transcribed into print, which will then be used in this research. You may also participate if you would prefer not to be audio-recorded. In this case the researcher will take written notes during the interview to use in this research.

All information that could identify you will be removed from the data, and pseudonyms will be used to further protect you identity. The researcher will keep any personal information about you in a secure and confidential location for 5 years following the completion of the study after which time it will be destroyed. A list linking your study number with your name will be kept by the researcher in a secure place (the principal investigator's university office), separate from your study file. All personal information collected will remain confidential and will be accessible only to the researchers. Representatives of The University of Western Ontario Non-Medical Research Ethics Board may require access to your study-related records to monitor the conduct of the research.

The results of this study, including the use of direct quotes from interviews may be published in papers, books, or presented at conferences or used in teaching materials, if you consent to the use of unidentified direct quotes. Your name will not be used in any research publications. If you are interested, you may request copies of the interview transcripts as well as copies of any future possible publications.

While we do our best to protect your information there is no guarantee that we will be able to do so. Additionally, if data is collected during the project which is required by law to report, we have a duty to report this data.

Will I be compensated for my participation?
There is no financial compensation for participation.

Who do I contact if I have questions about this study?
Nicole Dalmer, PhD Student
Phone:
email:
Supervisor: Dr. Pamela McKenzie,

If you have any questions or concerns about your rights as a research participant or the conduct of this study you may also contact:

The Office of Research Ethics

[redacted]

Thank you.
Your interest in participating in this research study is greatly appreciated!

This letter is yours to keep for future reference.

STUDY TITLE: Mapping Intersections of Information Work and Eldercare Within an Aging in Place Climate

CONSENT FORM

Principal Investigator:
Dr. Pamela McKenzie, Professor
Faculty of Information and Media Studies
The University of Western Ontario

Student Researcher:
Nicole Dalmer, LIS PhD student
Faculty of Information and Media Studies
The University of Western Ontario

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.
You do not waive any legal rights by signing this consent form.

I agree to be audio-recorded in this research: ☐ **YES** ☐ **NO**

If no to above, I agree to allow written notes to be made during the interview: ☐ **YES** ☐ **NO**

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research: ☐ **YES** ☐ **NO**

Participant's Name (please print): _____

Participant's Signature: _____

Date: _____

Person Obtaining Informed Consent (please print): _____

Signature: _____

Date: _____

Version Date: April 26, 2016 Participant Initials____

Appendix N. Interview Guide (Dementia Care Staff)

Information as Work: Mapping Intersections of Information Work and Dementia Care within an Aging in Place Climate
Interview Guide for Key Informants

Establishing rapport

- Inquire how participant is doing
- Plans for the weekend/week?
- Ask about the organization/agency that they work for
    - Their mandate/mission
    - History of the organization
- Ask about their role/position in the organization

Specific, probing questions about the organization's use of information

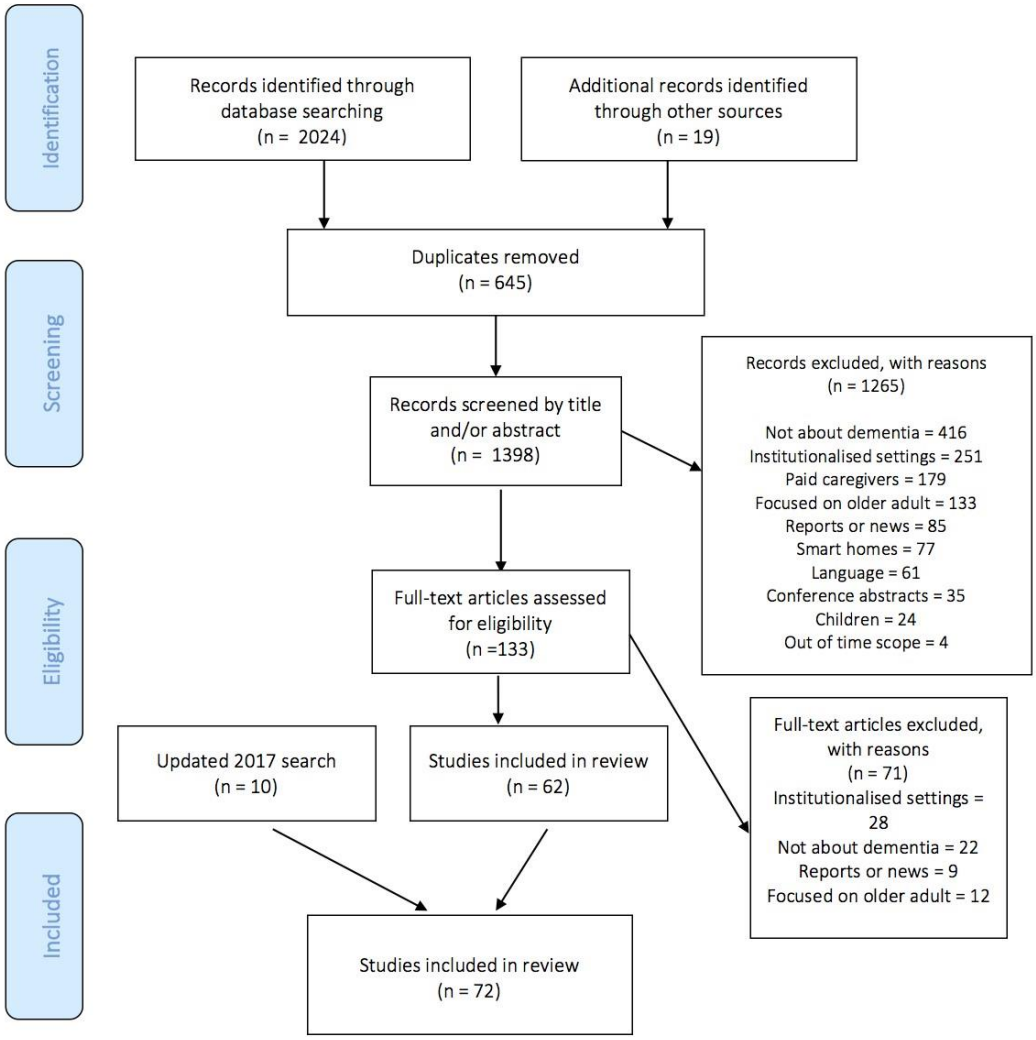
- What type(s) of information do you provide to caregivers?
    - What is the content?
- How is this information given to caregivers?
    - Who decides what information the caregiver needs?
        - What role does the caregiver play?
- Who prepares this information?
    - Who decides what topics are needed?
- From what sources is this information gathered?
    - How were these sources found?
    - Why are these particular sources used?
- How do you know when to provide this information?
    - At what point in the caregiving trajectory is this information given?
- In what format is this information given?
    - Who decides this?
- Who can caregivers ask if they require further information?
    - Where can caregivers go if they require additional information?

Note: The questions asked throughout the interview conversation will be posed to gain clarification to uncover what actually happens in key informants' care work (with a particular emphasis on information work). Asking "what did you do next?" or "what happened next?" to map the chain of work is of crucial importance in this institutional ethnography study.

At conclusion of interview

- Is there anything that we haven't covered that you'd like to add or mention?
- Would you feel comfortable sharing my contact information with other individuals in your or similar agencies/organizations that oversee or are responsible for interacting with family/friend caregivers of community-dwelling older adults living with dementia?

Appendix O. PRISMA Flow Diagram



Curriculum Vitae

Name:	Nicole Kerralea Dalmer
Post-secondary Education and Degrees:	The University of Western Ontario London, Ontario, Canada 2013-2018 PhD
	University of Alberta Edmonton, Alberta, Canada 2010-2012 MLIS
	University of Alberta Edmonton, Alberta, Canada 2003-2007 BSc
Honours and Awards:	American Library Association Carnegie-Whitney Grant 2018
	Social Science and Humanities Research Council (SSHRC) Michael Smith Foreign Study Supplement 2018
	Medical Library Association Eugene Garfield Research Fellowship 2017
	The University of Western Ontario Doctoral Excellence Research Award 2016-2017
	Social Science and Humanities Research Council (SSHRC) Joseph-Armand Bombardier Canada Graduate Scholarship (Doctoral) 2015-2018
	Ontario Graduate Scholarship (OGS) 2014-2015
Related Work Experience	Teaching Assistant: Information Sources and Services The University of Western Ontario 2017

Sessional Instructor: Services and Materials for an Aging Population
The University of Western Ontario
2016

Research Assistant: Dr. Grant Campbell
The University of Western Ontario
2015; 2016-2018

Sessional Instructor: Collection Management
The University of Western Ontario
2015

Teaching Assistant: Research Methods
The University of Western Ontario
2014; 2016

Research Assistant: Dr. Paulette Rothbauer
The University of Western Ontario
2014

Teaching Assistant: Information Literacy: Theory and Practice
The University of Western Ontario
2014

Teaching Assistant: Managing and Working in Information Organizations
The University of Western Ontario
2013

Publications:

Dalmer, N. K. (In press). A logic of choice: Problematizing the documentary reality of Canadian aging in place policies. *Journal of Aging Studies.*

Dalmer, N. K. (2018). 'Add info and stir': An institutional ethnographic scoping review of family care-givers' information work. *Ageing & Society*, 1-27. doi.org/10.1017/S0144686X18001125

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Dalmer, N. (2013). Health literacy promotion: Contemporary conceptualizations and current implementations in Canadian health librarianship. *Journal of the Canadian Health Library Association, 34*(1), 12-16.