Understanding How Day Programs Work as Care in the Community For People Living with Dementia and their Families

by

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Abstract

In Canada, most people living with dementia live at home, with family, friends and neighbours providing most of the care. While often mentioned in policy as an ideal, it seems that ‘care in the community’ is much more elusive to implement in practice for people with dementia and their families. Day programs are an example of a community care intervention considered an essential support for both people with dementia and family caregivers. Despite their frequent reference in policy, over 40 years of research on day programs for people with dementia have resulted in ambiguous findings and concerns regarding the under-theorization and limited analysis of their effects. The research question for this study was: How do day programs work as ‘care in the community’ for people with dementia living at home and their families? Related to this question were two objectives: First, to explore the ways in which day programs affect the everyday life of people with dementia living at home and their families and second, to understand how day program care practices relate with other formal and family care practices for the person with dementia. To answer these questions, an ethnography guided by material semiotics was used to focus on the sociomaterial care practices of family and day programs for the person with dementia. Using methods of participant observation, interview and document analysis, four people with dementia attending one of two day programs in the Edmonton region, were followed for six to nine months in their daily life with family members in their home, in the community and at the day program. Several findings were highlighted: 1) The day program is a contested space with multiple, precariously coordinated enactments 2) Working as a health technology, day programs configure and are configured within specific care arrangements with effects on both people with dementia and family members’ subjectivity, agency and relations to space. 3) The day programs’ possibilities for care and social inclusion were limited by the broader normativities of community infrastructure. These findings are practically relevant to the growing movement for planning dementia-friendly communities. They also give rise to questions regarding the cosmopolitics of ‘care in the community’ and what comes to matter when the practices of home, formal care, and community infrastructures come together.

Preface

This thesis is an original work by Holly Symonds-Brown. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Health Research Ethics Board, "Understanding How day Programs Work for People with Dementia and their Families", Ethics ID# pro00086731, January 16, 2019.

Dedication

“*A world obsessed with ones and the multiplications and divisions of ones*
creates problems for the conceptualization of relationships”

(Marilyn Strathern, 2004, p. 53)

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Table of Contents

Contents

List of Figures

Chapter 1: Introduction

Understanding How Day Programs Work as Care in the Community for People Living with Dementia and their Families

Dementia is a group of degenerative neurological conditions that occurs predominantly in older age and results in progressive decline in cognitive, motor, psychological, behavioural and social functioning. The course of decline for people living with dementia and the severity of symptoms experienced varies but increased needs for assistance and supervision are expected (Alzheimer Society of Canada, 2017). Worldwide, dementia is considered a public health priority. As a result, both policy makers and researchers expend great effort to identify affordable and humane approaches to providing care to people living with dementia outside of institutions for as long as possible (World Health Organization (WHO), 2017). Currently in Canada, it is estimated that there are over a half million people living with dementia and over half of these people live at home, with family and friends providing much of the care (Alzheimer Society of Canada, 2016; Wong, Gilmour & Ramage-Morin, 2016). In many policy narratives, the need to support people living with dementia at home is built on an ideal of 'care in the community' as the most ethical and economical option (Means, Richards & Smith, 2008). While commonly part of policy narratives related to chronic illness or disability, 'care in the community' emerged from a variety of discourses and is situated within conflicting values, making implementation of cohesive care in community a rare accomplishment. (Baranek, Deber & Williams, 2004; Dobransky, 2014; Means, et al., 2008). Day programs are an example of a programmatic intervention built on ideals of 'care in the community.' These programs evolved from their original design for other populations, such as those with mental health issues, to secure a niche in community care for dementia in the western world. Yet significant limitations in the design and evaluation of day programs exist (Dabelko & Balaswamy, 2000; Dabelko & Zimmerman, 2008; Gaugler, 2014; Weir & Fouche, 2017). Like much 'care in the community,' day programs are designed and studied drawing on assumptions that tend to ignore the contested nature of care and home (Ceci, Bjornsdottir & Purkis, 2012). Several key authors have identified a persistent gap in knowledge related to theorizing how day programs work, how they achieve their effects and the types of outcomes possible (Gaugler, 2014, Dabelko & Zimmerman, 2008; Zarit, 2018). This under-theorization of day programs as an element of ‘care in the community’ is the focus of this dissertation. In line with Moser’s (2006) recommendation that "one investigates what something is by asking what it is made to be and how it emerges" (p. 376), I begin this critical examination of day programs by considering the common claims related to ‘care in the community’ and dementia that have positioned day programs as they stand now.

Context of the Problem: The Ideal of Care in the Community

In Canada, like much of the western world, delaying the institutionalization of people living with dementia relies on providing adequate care in the community. 'Care in community' is a nebulous term used to describe what is commonly understood as a system of care organized around the needs of people with chronic conditions who require forms of care to continue living at home instead of an institutionalized setting. Arguably an aspirational term rather than an actual care delivery model, ‘care in the community’ is a taken-for-granted concept constituted through multiple assumptions and logics (Ceci, 2012). As such, ‘care in the community’ is situated in relation to ideas about independence, care, and responsibility that have evolved over time.

Over the 20th century an increasing influence of neoliberal values such as individualism, autonomy, and responsibility occurred across much of the public domain of the western world. In the health sector during the second half of the 20th century, a large deinstitutionalization movement occurred, relocating care from state-run institutions to community settings. Reflective of a shift in the relationship between the state and individual responsibility for welfare, deinstitutionalization was accomplished through discourses highlighting individual autonomy, freedom, and personal responsibility (Armstrong, 2014; Ceci & Purkis, 2009; Godin, 2006 Powell & Hendricks, 2009). As a result, the transfer of care to community settings was framed as creating a collective resource for people to enhance their health and well-being. At the same time, this shift in the location of care meant increased expectations for individuals, rather than the state, to assume responsibility for meeting health and social care needs (Powell & Hendricks, 2009). In this context, concerns about ageing populations, including anxiety about an increasing prevalence of persons living with dementia, took shape in discourses urging successful or active ageing that promoted individual responsibility to age without disability (Ballenger, 2006; Broer & Pickersgill, 2015; Williams, Higgs & Katz, 2012). For those unable to age 'successfully,' this emphasis on individual responsibility meant an offloading of care responsibility from the state to the family (Armstrong, 2014). Alongside these ideologies of individualism and responsibility, the home is framed as an ideal and idealized location of care, representing freedom of choice, a space of relaxation, and an expression of an individual self and privacy (England, 2010; Exley & Allen, 2007).

Home and Community as Spaces of Care

A key assumption within the deinstitutionalization movement was the belief that institutional models of medical care could be simply relocated to the community (Bachrach, 1989; Baldwin, 1993; Kane & Kane, 1978; Perry, 2016). Because of this, care, though now located in community settings, remains mainly characterized by assumptions of a dominant biomedical model which allocates services based on medically defined need, making the social needs of community living less visible (Baldwin, 1993; Kane & Kane, 1978; Means et al., 2008; Twigg, 2002). Within this model, home is positioned as mere setting, albeit one chosen by a care ‘consumer,’ simplified as a stable space, and easily adjustable to accommodate medical actions around the individual patient (Exley & Allen, 2007). A professional ordering of home and family roles within a framework of healthcare practice routines and surveillance measures occurs, resembling an institutionalized environment rather than a place of everyday life (Askham et al., 2007; England & Dyck, 2011). Most care delivery systems are based on disease models, which tend to reduce and categorize life events into 'problems' that can be treated or intervened upon. Within these disease models, the realities of community living which often "resist linear thinking" are difficult to account for (Ceci, Symonds-Brown, & Judge, 2018; Gubrium, 1990, p.27; Gubrium & Järvinen, 2014).

Politics of Care in the Community

Means, Richards and Smith (2008) explain that 'care in the community' emerged as a necessary central objective for both service users and policy makers in conjunction with trends in the deinstitutionalization of people with chronic illness and disability. The term 'community' is often used in an idealistic way to signify normative ideals of "solidarity, participation, and coherence" (Taylor, 2003, p. 34). Historically in Canada, responsibility for care for people in the community has been divided amongst different levels of government in different ways across the country (Alexander, 1995). The rise of neoliberalism during the late twentieth century resulted in a reshaping of healthcare policy and politics resulting in further complexity (Baranek et al., 2004; England, 2010). Complicating this in Canada, was that much of the services of care in the community were not covered under the federal health policy that guides and funds provincial delivery of services. As a result, unlike the "medicare mainstream" (Baranek et al., 2004, p. 291) of the hospital and physician-provided services, the 'soft services' of community-based long-term care rest on a field of fragmented policy and related financial precarity. The result of this is a network of social and health services with conflicting or overlapping mandates and priorities with multiple points of entry that do not necessarily connect (Dobransky, 2014; Perry, 2016). This stands in stark contrast with common portrayals of 'care in the community' as an organized continuum of care. Typical evaluation approaches maintain these political discourses of 'care in the community' by attributing and measuring outcomes to an isolated delivered service, leaving the interactions and relational effects of family arrangements unexplored (Ceci, Symonds Brown & Purkis, 2018; Twigg & Atkin 1994).

The Taken for Granted Nature of Care

Alongside the political and ideological underpinnings of the ideal of ‘care in the community’ is what Twigg (2002) describes as the taken-for-granted nature of care itself, whereby the assumptions informing care - what it is, how it works - are mostly unproblematized in the research and policy through which its conditions are structured. Care has been present in daily life throughout human history, although its visibility and status within society has varied due to its inherent social and political shaping (James, 1992; Mol, et al, 2010; Twigg, 2002). Since the Enlightenment, an emphasis on mind and rationality led to less acknowledgement of the body and consequently, care, and its related practices moved into the private sphere of social life - a move that led to care work's invisibility, with its nuances mostly ignored and under-theorized (Mol, Moser & Pols, 2010). The traditional affective notions of care, that were deemed essential qualities for some members of society, led to assumptions of an inherent natural caring that simply just happened, reinforcing beliefs about familial obligations and roles (Wiles, 2003).

It was not until the latter part of the 20th century that the normative and theoretical underpinnings of care began to be explored first by nursing and then social researchers (Mol, Moser & Pols, 2010; Rummery & Fine, 2012). The work of feminist theorists did much to liberate care from its private and essentially feminine status, establishing it as work or labour with specific ethics (Fine & Glendinning, 2005). While this theorizing was significant for recognizing gendered aspects of ‘care work’ and its social reproduction, it did not necessarily expand understandings about the complexity of care. Feminist care theory tends to maintain the positioning of the carer and the dependent person in opposition where care is delivered from caregiver to care recipient as a unidirectional mode of action. This positioning leaves the specificities of care and its fluid, mutual nature obscured (Fine & Glendinning, 2005; Mol, Moser & Pols, 2010). This dyadic framing of care work is significant because these assumptions about the nature of care have formed the basis for programs of ‘care in the community,’ resulting in practices of substituting or supplementing the work of what is assumed to be a lone family caregiver (Twigg, 2002). From this analysis, it seems clear that current understandings of ‘care in the community’ are the product of multiple contingencies, both political and ideological, that work to construct it in specific ways (May, 2012). The following section will discuss the effects of the assumptions underlying the constructions of 'care in the community' for persons living with dementia and their families and the relevance of supports available.

The 'Problem of Dementia'

Presently, there is much talk of what to 'do' about dementia. The stated policy goal of providing sustainable alternatives to institutionalization while mitigating the burden placed on families has been difficult to achieve (MacLeod et al., 2016; Purkis & Ceci, 2014; Zarit, 2018). Often framed as a highly complex disorder, dementia, both in its effects on the individual and the related care required, challenges neoliberal values of autonomy, independence, and discourses of successful ageing. Equally problematic in the dissolution of the state's welfare role in many western countries are the apocalyptic demographics (Robertson, 1990) and system sustainability issues often paired with any discussion of dementia care options. While identified as a significant challenge for health and social planners today, historical analysis shows people living with dementia positioned as a longstanding 'problem' for health and social systems management. This is evident in Andrew's (2017) historical analysis of documents relating to the institutionalization of persons with dementia in 19th century England. In this analysis, Andrews argues that the "seeming intractability of dementia" (p. 255) made the people affected by it a poor fit for any of the available care settings. Thus the institutionalization of people living with dementia was a social event rather than a medical one, occurring when the person with dementia and their related behaviours became a problem for those around them. Despite the growth of welfare policy at the time and a recognition of the significance of issues faced by people living with dementia and their families, their needs were not seen as something policy makers could address. This led Andrews to conclude that "ambivalence towards people living with dementia is in the very roots of the welfare state" (p. 255). In current policy and practice, similar issues persist within the health and social system response to people living with dementia and their families. In 1984, Brody, Lawton and Liebowitz described the unique challenges people living with dementia present for family care due to the lack of suitable community supports, closure of mental hospital beds, and the poor fit of the person with dementia with institutional policies of medically-focused care within acute and long-term care institutions. Currently in Canada, acute care hospitals and institutionally based long-term care have been situated as places of last resort for people living with dementia. As such, ‘care in the community’ is positioned as a form of prevention or an alternative for these institutional settings. 'Care in the community' for people living with dementia is typically pieced together with components of community support services and home care, predominantly modelled after acute and rehabilitative models of care, respite care, and outpatient medical care, which are not specific to the needs of people living with dementia. So while there have been definitive shifts from the state to the family and home in terms of responsibility for care (Bjornsdottir, 2009), there also appear to be longstanding issues related to health and social care planning and the fit of extant services for people living with dementia.

Current Approaches to Knowledge Development

Beyond its historical origins, the design of ‘care in the community’ has also been limited for people living with dementia and their families through the prevailing research approaches used to study it. Inherent to the common methodologies used for intervention research, the heterogeneity of dementia and community care are posed as major obstacles to clear evaluation, resulting in a field of work that does not seem to quite fit with dementia as it is lived (Ceci, Symonds-Brown & Judge, 2018; Zarit, 2018). Twigg and Atkin (1994) explain that much of community care evaluation is often done from the gaze of the service provider resulting in a narrow focus on discrete units of service provided as a measurement of care, leaving the specific materialities of care to be overlooked. These materialities are the taken-for-granted and mundane activities, material objects, as well the "strategic ideas," that care materializes through. Latimer (2018) outlines the significance of attending to materiality for understanding how care is enacted and lived. Dominant trends in dementia research leave much left unexplored regarding care, particularly how it actually happens in the home and community for persons with dementia and their families (Ceci, 2012; Twigg, 2002). Understanding or knowing about family care practices requires attention to the multiple and diverse socio-material activities that produce care.

A range of socio-material activities used to produce care were evident in a recent study by Ceci, Symonds-Brown and Purkis (2018) who examined family care practices of people living with dementia at home and found, unsurprisingly, that "families [living with dementia] work out highly specific ways to live their lives" (p. 16). Family care practices involved an ongoing gathering of many things, people, and resources. For the families in that study, the community care supports of case management, day programs, home care assistance, and respite were essential aspects of the 'care collectives' arranged by families. However, while playing a critical role in the caregiving arrangements that families worked out, formal care practices did not seem to facilitate or recognize this arranging work. Similar issues have been found by other studies of intersections between formal and family care practices (Egdell, 2013; Exley & Allen, 2007, Gubrium, 1990; Pickard & Glendinning, 2002). An area of interest related to 'care in the community' resulting from Ceci, Symonds-Brown, and Purkis’s study was the ambiguous role of day programs for persons living with dementia and their families. These programs seemed to be critical to family care arrangements yet were observed to have a superficial relationship with the specificities of the families themselves or the people living with dementia. These programs have been present in community dementia care since the 1970s, but have recently received more policy attention, often posed as a solution to help distribute 'care in the community' for people living with dementia (Government of Alberta, 2017). The next section will further examine the emergence of day programs as a form of care for people living with dementia.

Day Program History

Day programs originated with early deinstitutionalization trends in the 1940s for people with psychiatric illness or disabilities. Since then, day programs have functioned in different ways and in different places to respond to different population needs (Weissert, 1989). Day programs come in a variety of forms but are generally thought of as a centre-based program that people attend for a certain number of daytime hours each week for the purposes of family respite, social support, and maintenance of health and social needs (Gaugler & Zarit, 2001; Tretteteig et al., 2016). Several day program care models exist, such as short-term acute day programs, those with a rehabilitation focus, a health monitoring model, and a social model (Baumgarten et al., 2002; Connis et al., 1993; Weissert, 1989). In Canada, most day programs use a generic model for the delivery of health and social services (Savard, Leduc, Lebel, Beland, & Bergman, 2009).

History of Day Programs for People Living with Dementia

In the post-war period, day programs shifted from providing psychiatric treatment to serving patients with more physical and medical needs. Later during the 1960s they began to include older people and eventually people living with dementia (Goldstein et al.,1968; van Beveren, & Hetherington, 1995). Historical articles from the 1960s discuss the usefulness of day programs for geriatric populations but specifically mention the unsuitability of persons with "organic" brain disorders (a common term at the time for dementia and other more permanent sources of cognitive impairment) (Goldstein et al., 1968). The rehabilitative focus of day programs was predominant at this time, and people with progressive cognitive or functional impairment were seen as unsuitable for benefitting from the day program's therapeutic regime (Goldstein et al., 1968).

By the 1970s, geriatric medicine had gained its footing as a medical specialty, and there was much discussion in the North American gerontological literature about the potential role of the geriatric day programs for both optimizing health of older people and the efficient allocation of hospital resources (Hefferin & Wilner, 1971; Wadsworth, Sinclair & Wirz, 1972). In the 1980s, after significant closure of mental institution beds, a common concern was what to do with the large number of older people living with dementia who, because of their relatively good physical health and challenging behaviours, were considered unsuitable for nursing home placement (Brody et al., 1984). In the United States (US), day programs posed a potential solution to this problem, and several pilot programs began. Since this time, growth in day programs has continued, making them a primary form of 'care in the community' for people living with dementia (Anderson et al., 2015; Sands & Suzuki, 1983; Smyth Henry et al., 2000; Weissert, 1989).

In Canada, there is no clear record of when people living with dementia began to be considered for day programs, but a gradual shift from the mid-1980s to 2000s can be seen in published research studies where samples show more people with cognitive impairments being included (Baumgarten et al., 2002; Molzahn et al., 2009; Warren, et al., 2003). In Alberta specifically, the first day program for older adults started in 1973, and in 1991 a provincial pilot was completed. This pilot included the establishment of 14 day programs (Warren et al., 2003). These centres were trialled as a potential intermediate level of care for people who needed more supervision and intervention than their local community senior centres could provide (Warren, et al., 2003). It is unclear from the evaluation studies of these programs if dementia was either not a common diagnosis or just not included in the general profiling of participants.

Approaching Care in the Community from New Perspectives

As discussed earlier in this chapter, the complexity of 'care in the community' for people living with dementia seems to be well established. However, approaches to understanding this complexity have had limited success at unravelling it, limiting the responsiveness of services like day programs for people living with dementia and their families. Rather than seeing the complexity as something impossible to address, another approach is needed to decipher what is at stake. Haraway (2016) teaches us that how we think about things matters, and in that mattering certain things come to be. Day programs are one example of how the ideas of 'care in the community' for people living with dementia are made material. Studying day programs offers an opportunity to unpack how this material form of care is ordered and made to exist as a separate space defined through particular practices. In policy, placed between both health and social care and on the margins of home and institution, day programs are predominantly positioned as a form of respite care for families supporting people living with dementia to live at home longer (Cho, Zarit, & Chiriboga, 2009; McCann et al., 2005, Ono, et al., 2014; Wilson et al., 2007), as well as a means to ease the transition to institutional care (LeBlanc, 2010; Weissert, et al., 1989). For the people living with dementia, the goals of program use have been less obvious; early programs focused on the management of dementia symptoms (Cohen-Mansfield, et al., 1996; Cohen-Mansfield et al., 1995a) and more recently, their subjective well-being (Braatas et al., 2010; Strandenaes et al., 2017). While forty years of research have produced ambiguous results, there does seem to be something appreciated about the day programs by families and people living with dementia. Given the significance of day programs in both policy and daily life, it seems important to better understand those aspects of day programs that contribute positively to 'care in the community' and how the ways we use to think about them might matter.

Material semiotic-inspired studies of care practices offer an approach of how to think differently about care and ideas of programmatic solutions like day programs. This approach focuses attention on the ‘practices' of care or the localized systems of relations between people and things in organized units of activity through which care is accomplished (Mol et al., 2010; Schatzki, 2002). From this practice perspective, care is intentionally a loose concept; instead of limiting care to be an affective notion or specific type of action such as respite or support, care is figured as an ongoing social accomplishment achieved by multiple actors associated within a web of relations (Law & Mol, 2008). Rather than comprised of stable or fixed actions, care is understood as fluid, with specific configurations shifting in different practices, such as those of the day program or the home. In this context of fluidity, the taken-for-granted divisions between home and day programs or formal and informal care are effects of particular sets of relations that are themselves shifting, ongoing and recursive. Mol (2006) explains how material semiotics offers a unique approach to evaluating health or social care by studying services like day programs as the package of relations that make up the realities in which they are lived, thus allowing for 'unravelling' of how these services work well, when they do not, and how they might work better.

Chapter 2

Review of the Literature on Respite Care and Day Programs

The political and ideological constructions of care in the community require that family caregiving be sustained ethically and economically, and as such the search for both effective and affordable strategies has been a focus of research and policy advocacy for several decades (Rummery & Fine, 2012). Common forms of formal support for family caregivers of people living with dementia include psycho-education; skills training; support groups; online delivery support and education; case management; and respite care (Gallagher-Thompson et al., 2012; Gitlin, Marx, Stanley & Hodgson, 2015). Although there has been considerable research conducted into many of these interventions, respite care in its varied forms is perhaps the least studied area of dementia support (Vandepitte et al., 2016; Zarit, 2018). At the same time, respite supports which include day programs are posed as solutions for decreasing family caregiver burden in much of the family caregiver support policy. The following literature review explores the current state of the research regarding respite care and, more specifically, day programs.

Research on Respite Care

Respite care can include the informal help of friends and family or the formal system services of in-home, short-term residential care or day programs (Mason et al., 2007). Respite is identified as a “cornerstone service for home management of people living with dementia” (Neville et al., 2015, p. 51) and family caregiver advocacy focuses on the need for formal system provision of respite care as critical support for family caregivers (Canadian Caregiver Coalition, 2014; Canadian Healthcare Association, 2012). Lilly, Robinson, Holtzman, and Botoroff’s study (2012) of 19 family caregivers of people living with dementia in British Columbia noted respite services were the most requested form of support. A larger study by Low, White, Jeon, Gresham, and Brodaty (2013) in Australia, using an even mix of care consumers and service providers (n=64) in Australia, described respite as being ‘pivotal’ to family caregivers’ ability to maintain the care of people living with dementia at home. Despite this expressed need, many studies and policy narratives cite the low uptake of respite services by family caregivers, leading to questions of either the effectiveness of respite as a supportive intervention or family caregivers’ self-awareness of their needs (Brodaty et al., 2005; Neville et al., 2015; Phillipson et al., 2014; Strang, 2001).

Benefits of Respite for Family caregivers

Vandepitte et al. (2016) recently completed a systematic review of the effectiveness of respite care for caregivers of people living with dementia. This review synthesised the findings from 17 quantitative studies, all published since 2000, and included 16 studies of institutional respite care (12 day program and 4 residential) and one study focused on in-home respite. Despite significant issues with the comparability of interventions and measures used, the authors concluded that day program respite has positive effects on family caregiver stress, and in-home respite showed promise in reducing family caregiver morbidity and mortality. These authors caution that their findings should be taken in light of the methodological issues of small sample sizes, lack of control groups and samples that were inclusive but not specific to dementia. Analysis of the four residential respite studies included in this review concluded that there was potential for adverse effects for family caregivers related to the extra stress experienced during the adjustment period after the persons living with dementia returned home. In a previous systematic review, Mason and group (2007) concluded that the use of respite care resulted in high satisfaction and small benefits for family caregivers’ burden and their associated psychological and physical health, with the possibility that some family caregivers benefit more than others. A more recent systematic review by Maayan, Soares-Weiser, and Lee (2014) found insufficient evidence to claim respite care either helped or harmed family caregivers or care receivers. More contradictory were the findings of Schoenmakers, Buntinx, and DeLepeleire's (2010) metanalysis of home care interventions for family caregivers of people living with dementia, who found respite care significantly increased burden for family caregivers. This was also found in a recent updated meta-review of family caregiver supports by Dalton et al. (2018). Similar to Vandepitte et al. (2016), all these systematic reviews cited significant issues with the methodology of studies limiting the reliability of the findings in terms of usefulness to inform policy.

Barriers to Respite Use

There are unintended consequences of respite use for family caregivers related to the work involved in preparing the person living with dementia for respite service, such as disruption in routine, orienting new staff or rushing to get chores done within respite hours (Mason et al., 2007; Neville et al., 2015; Tretteteig et al., 2016). Lilly et al.'s (2012) study found family caregivers reported that the promotion of respite as self-care sometimes entailed an added sense of responsibility rather than providing relief. Additional barriers reported by family caregivers included the lack of information on access, inflexibility in hours and inconsistency in staffing (Lilly et al., 2012; MacLeod et al., 2017; Phillipson & Jones, 2011). In a meta-ethnography of 23 qualitative studies examining key stakeholders' experience with respite services, O'Shea, Timmons, O'Shea, Fox and Irving (2017a) found consistent themes of organizational-level barriers for access, flexibility of delivery and the ability of respite services to provide tailored meaningful activity for people living with dementia.

Conceptualizations of Respite Care

The findings of ambiguous effects such as high satisfaction rates combined with low uptake have prompted several researchers to question whether respite care is appropriately conceptualized. O'Shea and group (2017b) argue in their recent evolutionary concept analysis of respite that the term respite is used interchangeably as both a service and an outcome, which has affected its evaluation. They noted that research on respite has been unclear in its components, the intended outcomes and whom it serves. They propose respite, as currently conceptualized, is not indicative of a mutual reciprocal relationship between family caregivers and people living with dementia and recommend that service design should address the needs of both family caregivers and people living with dementia. In a meta-ethnography, O'Shea et al. (2017a) also identified a lack of recognition in the literature of the mutuality of the respite care experience between the family caregiver and the care receiver and suggested this often affects family caregiver perception of benefit. Evans (2013) proposed in his concept analysis that respite should be envisioned as an "individualized service and complex intervention" rather than a simple support strategy (p. 1911). A systematic review of respite service models by Mason et al. (2007) supported this idea of complexity and found respite decision-making involved navigating complex intersecting barriers of emotional, informational, financial, regulatory/statutory policies and practicalities. Stirling, Dwan, & McKenzie (2014) drew similar conclusions in their mixed-methods study of 126 family caregivers and advocated for an understanding of respite care beyond a task-oriented or time allotment perspective, suggesting instead a recognition of the primacy of the dynamics of family caregiver-care recipient relations in the use of respite services. Philipson, Jones, and Magee (2014) conducted a narrative synthesis of 14 studies of factors associated with non-use of respite and concluded that there was a need to expand the understanding of the types of care pathways that might exist for family caregiving and as well as how these interact with the respite services available. Chappell, Reid & Dow (2001) found that 60% of the family caregivers in their qualitative study (n=294) defined 'respite' in ways that were much different from those typically defined by policy makers, agencies, and researchers. Most of the family caregivers in this study identified respite with "stolen" moments intertwined with daily life and connected their respite to the comfort of the care receiver. Other researchers have explored role expectations as a barrier to respite for family caregivers. Strang (2001), in her narrative study of 8 female family caregivers of people living with dementia, found that respite was identified as leisure and due to gendered views of caring obligations, caregivers did not feel entitled to use respite unless it was considered absolutely necessary. Women in this study reported feeling not only obligated to provide care for their spouses living with dementia but also felt as if they were the only one's qualified to do so. These feelings of obligation and expertise were also found in other studies of in-home respite for both male and female family caregivers (MacLeod et al., 2017; Phillipson & Jones, 2011).

This body of literature suggests that while respite care seems a popular or common-sense strategy for supporting family caregivers, it remains underdeveloped in its conceptualization. An underestimation of its complexity, dynamic nature, and how it may or may not redistribute care has affected both how it has been studied, implemented and evaluated as a service. Mason et al. (2007) concluded, after an extensive systematic review of respite care models, that there was inadequate evidence available to inform policy or practice. Recognizing that the significant issues with the methodological quality of quantitative studies might be related to insufficient theoretical development, Mayaan et al. (2014) recommended further qualitative exploration of respite care to establish its functions. These findings indicate that a richer understanding of respite services, including what respite is and how it is done, is needed to ensure we plan and evaluate services effectively for people living with dementia and their families.

Research on Day Programs

Day programs are the form of respite care that has received the most research attention but are affected by the same issues of theoretical underdevelopment seen in the larger field of respite care. Though the research to date has been critiqued as inadequate in quality and theoretical underpinnings (Dabelko & Zimmerman, 2008; Gaugler, 2014; Gaugler & Zarit, 2001; Maayan et al., 2014; Manthorpe & Moriarty, 2014), there has been considerable growth in the use of day programs over the past 40 years throughout the western world. Day programs are now a significant service in community care for some people living with dementia (Anderson et al., 2013). They have also become a focal point in many dementia policy narratives as a potential solution to keeping people living with dementia at home longer, which has renewed interest in their effects (Manthorpe & Moriarty, 2014; Weir & Fouche, 2017). The effects most attended to in the research are effects on the participants, family caregivers, or healthcare utilization rates. A recent problematization of research on day programs has been published (Symonds-Brown, et al., 2019), this next section will cover a more traditional review of the literature on day programs with a discussion of the limitations of the base of evidence available for day program research.

Definitional and Geographical Issues with Day Program Research

While day program research has been ongoing over five decades, there remain significant definitional issues in developing the evidence base. There is a consistent vagueness of the definitions in most research on day programs regarding what they are, how they work and whom they serve. Manthorpe and Moriarty (2014) found in their scoping review of day programs in the UK that the term ‘day program’ usually “describes a building rather than the service or the aims of the intervention" (p. 353). Globally, the terms day hospital, day program, day center, day services and day care are all used to describe a type of service delivery, sometimes interchangeably, and at other times to distinguish between the types of medical or social care provided. Additionally, much of the research does not describe the kind of programming involved, its dosage or characteristics of the participants and specific program (Gaugler & Zarit, 2001; Manthorpe & Moriarty, 2014). van Beveren and Hetherington (1995) warned early on that without clarity concerning what day programs were actually doing, and for whom, there were risks of not capturing effects reliably, setting unrealistic goals for the programs and inappropriate targeting of suitable participants. Adding to the complexity of reviewing the day program research are the differences in national health care system designs and the resulting relationships between formal and informal care (Tucker et al., 2016). Tucker and group (2016), in a comparative study of national health and social policies for dementia, identified that community and institutional service delivery varied between countries according to different funding models, cultural norms and infrastructure development. Consequently, there is significant inter-region variability in day program role, design, target population, uptake, and different aims for research outcomes. A quick overview situates some of the key geographical differences that may help with the interpretation of the review of the research.

Day Programs in the United Kingdom

The United Kingdom (UK) has notably had the longest use of day programs for seniors starting in 1948, with origins in both the voluntary and statutory sectors resulting in varied integration into care systems regionally (Nies, Tester, & Nuijens, 1991). Despite being considered the leader in day program development, especially for the geriatric population, a considerable shift in health and social care funding occurred in the past decade, with a recent report citing a 30% decrease in funding and, as a consequence, a 30% decrease in people accessing day programs (Mortimer & Green, 2015). Historically, day programs have been positioned as primarily complementary to other forms of community care in the care of older adults. This is changing with the shift to personalized budgets for community care, where individuals have control over the allocation of funding for their care (Needham, 2014; Tester, 1989). The individualized focus of the personalized budget and allocation of funding has challenged the more collective institutional approach of day programs (Manthorpe & Moriarty, 2014; Needham, 2014). As a result of the policy agenda of personalization, research has focused on understanding what types of community programming models are best for meeting individual needs (Manthorpe & Moriarty, 2014; Mason et al., 2007). There is also increased policy promotion of community hub models such as informal drop in centres yet to be implemented in practice (Manthorpe & Moriarty, 2014; Mason et al., 2007; Needham, 2014).

Day Programs in the United States

Most of the day program outcome research comes from the United States (US) (Mason, 2007). The use of day programs for older adults in this country began in the 1970s guided by a national initiative looking for alternatives to institutionalization (Weissert, 1977). Since that time day programs have had significant growth (35% increase between 2002-2010) as a sector of care delivery and are positioned as an alternative to both long-term care and home care (Anderson, Dabelko-Shoeny & Johnson, 2013; National Adult Day Services Association [NADSA], 2010). Day programs provide most dementia-related community care (Anderson et al., 2015). The predominant models of day programming have shifted over time from a significant medical rehabilitation focus to a more social focus, and currently include many dementia-specific day programs (NADSA, 2010). The mix of non-profit and profit-based services and variable insurance coverage combined with lower overall rates of institutionalization in comparison to Canada and Northern Europe affects both the types of programming offered and outcomes valued. Day programs are positioned in a substitute service role; as such, there is more focus on activities of daily living (ADL) type services such as baths, case management, and integrated care models with family caregiver support (Anderson, Dabelko-Shoeny & Johnson, 2013). The fiscal environment of managed care has resulted in the evaluation focus to be on measurable outcomes such as attendance, timing and dosage of day programs and effects on health care utilization (Dabelko & Zimmerman, 2008; Gaugler & Zarit, 2001; Liou & Jarrot, 2013; Weissert, 1989).

Day Programs in Europe

There is much discussion in the literature of day programs in many European countries, but few describing their role and development except for the Netherlands (Nies, Tester & Nuijens, 1991; Tretteteig et al., 2016; Tucker et al., 2016). In the Netherlands, day ‘hospitals’ began in the mid-1960s and were closely aligned with nursing homes. Later in the mid-1980s with changes to health policy and regionalization, a more community-based model of ‘day centres’ began and saw rapid expansion (Nies, Tester & Nuijens, 1991). Research on Dutch day programs highlights program content (Dröes et al.,2006; deBruin et al., 2015; Nowak et al., 2015; van Haeften-vanDijk et al., 2016). The Netherlands has developed several creative approaches to programming which have spread to other countries, an example is the Green Farms model of day programs, where farm settings are used for day programming (de Bruin et al., 2015; Nowak et al., 2015). The Meeting Centre Support Program Model (MCSP) is another Dutch-based model that is beginning to be adapted into other countries (Brooker et al., 2017). This model of day programming integrates both care support interventions such as psycho-education and support groups for family caregivers, into the same setting as the daytime activities for people living with dementia, as well as community events organized for both family caregivers and people living with dementia (Brooker et al., 2017).

Day Programs in Canada

Canadian development of day programming for seniors developed under different provincial health jurisdictions resulting in regional variation in its availability and use (Sambrook et al., 2004; Tam-Tham et al., 2016). The most common model is a generic day program for older adults designed to provide health and social care with few dementia-specific models in use (Savard et al., 2009). The attendance issues focused on in much of the US literature are less relevant in Canada, where attendance is predominantly limited by the capacity of the centres and wait-listing is common (Savard et al., 2009). Day programs for people in Canada are usually positioned as supplementary care within home care services yet researched as stand-alone interventions (Chappell & Blandford, 1983; Desrosiers et al., 2004; Kelly, 2017; Kelly et al., 2016, Kloseck et al.,1995; Molzahn et al., 2009; Savard et al., 2009; Strang & Neufeld, 1990; Warren, et al, 2003), or sometimes as part of a package of community-based services (Levesque et al., 2000; Tam-Than et al., 2016; Sambrook et al., 2004).

Day Program Outcomes for People Living with Dementia

The issue of who day programs serve is a topic of long debate in the literature. Most of the research focused on the effects of day programs for people living with dementia has been conducted in the US (Gaugler & Zarit, 2001; Mason et al., 2007). The rationale for this focus is likely related to the program model and funding requirements at the time. Initially, in the US, the predominantly medical-based day programs were based on a rehabilitative model where much of programming and evaluation was focused on resolving or preventing further functional decline

(Hasselkus, 1992). Additionally influential was the importance of demonstrating medical-related outcomes for obtaining funding reimbursement through government and veterans insurance benefit programs (Smyth Henry et al., 2000). As well, the positioning of day programs as an alternative to institutional care for people living with dementia (Brody, Lawton, & Leibowitz, 1984) made demonstrating their ability to delay the need for institutionalization very important. As a result, the focus of early US research on day programs for people living with dementia was examining the effects of programming around cognitive stimulation, reminiscence and reality orientation aimed to arrest or delay functional decline and behavioural symptoms of dementia (Cohen-Mansfield et al., 1995a; Cohen-Mansfield et al., 1996; Cohen-Mansfield et al., 1995b, Cohen-Mansfield et al., 1996; Hageman & Thomas, 2002; Zarit et al.,1999). These studies' findings were varied but generally showed no effect on ADL dependency, behaviours, or other health changes (Fields et al., 2014; Gaugler & Zarit, 2001). What was found was that people living with dementia who attended day programs had increased life satisfaction and well-being improvements which became the larger focus of client outcomes in later research (Brataas et al., 2010; de Bruin et al., 2015; Hochgraeber et al., 2013; Strandeneas et al., 2017; Williams & Robert, 1995; Zank & Schacke, 2002). Targeting those who might benefit most from the programs is mentioned by several authors (Fields et al., 2014; Gaugler, 2014; Mävall & Malmberg, 2007), as well as a research interest in deciphering the specific dosage and program strategies that may have optimal effects on people living with dementia, especially on those behaviours that create stress for family caregivers.

Responsive Behaviours of Dementia

Responsive behaviours of dementia (previously known as the behavioral and psychological symptoms of dementia [BPSD]) are perhaps the most problematic effects of the illness across its trajectory and have significant negative effects for the family caregiver and the person living with dementia's quality of life (Braun et al., 2018; Femia et al., 2007). Day program effectiveness for relieving responsive behaviours has been mixed, with some authors questioning the value of day programs for people living with dementia-related behavioural symptoms (Mävall & Malmberg, 2007). Other recent studies show some positive effects on behavioural signs such as agitation (Mossello et al., 2008; Straubmeier et al., 2017) and depressive symptoms (Logsdon et al., 2016; Woodhead et al., 2005). A recent systematic review of 17 international studies on day programs by Vandepitte et al. (2016) concluded that benefits for people living with dementia are related to some sleep and behavioural improvements. Femia and group (2007) conducted a quasi-experimental designed study comparing responsive behaviours in 133 people living with dementia enrolled in day programs to 68 people living with dementia not enrolled over a two-month period and found day program attendance had a significant effect on decreasing the duration of nighttime sleep disturbance. No other significant differences in responsive behaviours were found between groups, although within-group analyses of the day program attendees showed decreased agitation and depressive symptoms on days of attendance (Femia et al, 2007).

For day programs, responsive behaviours are an issue not only for the quality of life at home but are a common cause of day program termination (LeBlanc, 2010). Leblanc (2010) noted in a discussion paper that day programs often have the same difficulty managing behaviours as family caregivers do in the home, which often leads to premature termination of attendance. This was also a finding by Zarit et al. (1999) in a study of 445 family caregivers of people living with dementia comparing brief versus long-term users of day programs. Increased behavioural problems and ADL dependency were related to a third of the sample discontinuing the day program within the first three months. Interestingly, satisfaction, transportation and cost were not associated with their brief use. Upon interview at discharge, family caregivers in this study reported behavioural problems interfered with getting the person ready for the program or the program's ability to manage the responsive behaviours of person living with dementia. Zank and Schacke (2002) found significant effects of day program attendance on well-being, memory, and agitation for people living with dementia. Of note in this study was that 48% of the experimental group had dropped out of day programs before the second time point of data collection. No follow-up was done with study dropouts, so whether a selection effect occurred for those people with responsive behaviours is unknown. In Mävall and Malmberg's (2007) Swedish study of 51 family caregivers of people living with dementia attending a day program, they found patients with responsive behaviours or ADL dependency were most likely to discontinue use within the first four months. In this study, follow-up was done with participants who dropped out, which helped identify the responsive behaviour issues as a reason for discontinuance. Specifically, problematic for early discontinuance was depression-related behaviour such as "being unable to occupy oneself" (p. 39). As the data for this study was gathered only from family caregivers, there are limitations in understanding how the behavioural problems interfered at the day program. Woodhead et al. (2005) tried to better pinpoint whether certain activities of day programs might affect the incidence of responsive behaviours in their study of 94 people living with dementia attending day programs in the US. This study found an increase in restlessness and mood-related behaviours over three months of day program attendance as well as a significant increase in patients' positive behaviours. Equally ambiguous in the findings was that engaging activities had an effect of decreasing restless behaviour, yet a higher dose of day program attendance overall resulted in an increase in restlessness and mood behaviours. A key limitation in this study was the reliance on staff reports for both activity description and behaviour problems, and the assumption that behaviours observed were only attributable to the immediate activity.

Perceived Benefits of Day Programs by People Living with Dementia

There is little evaluation of the subjective experience of people living with dementia with respite care (Maayan et al., 2014; O'Shea et al., 2017a). A few studies examining day programs from the perspective of people living with dementia have reported an increased sense of belonging (de Bruin et al., 2015; Hochgraeber et al., 2013; Strandenaes et al., 2017), of having a structured day (Brataas et al., 2010; de Bruin et al., 2015; Strandenaes et al., 2017; Williams & Robert, 1995; Zank & Schacke, 2002), and general well-being (Hochgraeber et al., 2013; Zank & Schacke, 2002). Participants reported dissatisfaction was associated with types of activities offered at the day program, as well as relational difficulties with other people in the program and staff perceived as non-relational in their approach (Strandeneas et al., 2017; Zank & Schacke, 2002).

Day Program Effects for Family Caregivers

While day programs have not been established as a definitive form of treatment for people living with dementia or an intervention that delays institutionalization, they are commonly considered a form of respite for family caregivers. It is this role that is most dominant in the dementia policy narratives. Family caregiver burden is the focus of much research in dementia care, and the limitations on its measurement and intervention have been well critiqued (Purkis & Ceci, 2014; Zarit, 2018; Zarit & Femia, 2008). As with other areas of dementia care, issues of measurement and conceptualization of family caregivers' stressors have plagued research about day program effects on family caregivers. In a study focused on family caregiver strain with 15 family caregivers of people living with dementia, Graham (1989) concluded that the response to day programs was “variable and complex” (p. 27), and it seems this finding persists. Vandepitte’s (2016) systematic review of 12 quantitative studies of day programs concluded that despite a wide range of measures and significant outcomes, day programs have some positive effect on family caregiver distress levels. Different studies have found different positive effects. Gaugler and group (2003), in their 3-month longitudinal study of 400 family caregivers, found an effect of day programs on restructuring caregiving time and decreasing time of family caregiver exposure to the behavioural problems of the person with dementia. In a comparative longitudinal study of 77 family caregivers (37 in day program and 40 with in-home services), Schacke and Zank (2006) found that day program attendance resulted in family caregivers having specific rather than overall changes in stress levels, such as decreased conflicts between caregiving and other responsibilities and the availability of leisure time. Family caregivers’ perceptions of time spent on supervision and being restricted from regenerative activities were not affected by day program use. Schacke and Zank observed that information elicited through the qualitative interview component of their study revealed a possible issue with admission processes and information sharing with family caregivers regarding the program’s services. Significantly, this study had a high dropout rate of close to 50% of the family caregivers in both groups between the first and second points of data collection, predominantly related to physical health deterioration of the care receivers. Liu, Kim, and Zarit (2015) and Mävall and Thorslund (2007) found mixed results on family caregiver health and coping. A more recent trend in examining stress biomarkers in family caregivers has shown some potentially positive effects of day program use for family caregivers’ health (Leggett et al., 2016; Zarit et al., 2014a; Zarit et al., 2011; Zarit et al., 2014b).

Family Use of Day Programs

Research on family satisfaction with day programs and facilitators to regular attendance has been common (Cohen- Mansfield et al., 1994; de Jong & Boersma, 2009; Donath et al.,2011; Phillipson & Jones, 2011, 2012; Takai et al., 2013; Townsend & Kosloski, 2002; Tretteteig et al., 2016). Satisfaction of family members with the day program is facilitated by trust of staff (Bull & McShane, 2008; Stirling et al., 2014; Townsend & Kosoloski, 2002) and match of programming to interests of the person living with dementia (Stirling, 2014; Tretteteig et al., 2016; Weir & Fouche, 2017). Commonly cited barriers for use outside of the behavioural issues discussed previously included transportation (Cohen-Mansfield, 1994; Gaugler, 2014; Tretteteig et al., 2016) and costs (Cohen -Mansfield, 1994; Phillipson & Jones, 2012). An effect of familial relation type has been found in several studies with spousal family caregivers more likely to have higher dropout rates from day programs than adult-children family caregivers (Cho et al., 2009; Ono et al., 2014; Zarit et al., 1999). While much of the research on day programs does not extend far into its effects on home-life, there has been consistent recognition of the preparation work families do to facilitate day program use (Berry et al., 1991; Bull & McShane, 2008; Gaugler, 2014; Weir & Fouche, 2017). Takai and group’s (2013) study of 16 family caregivers explored the work of Japanese families of people living with dementia related to using day programs. Through interviews, families described how they worked to find a match between the program and their family member, adjusting the program or using strategies of convincing, conforming or coercing the family member to attend. These authors raised the concern that much of this work is unaccounted for in day program admission processes or delivery. Given the significant dropout rates of day programs and the stated goal of providing relief for caregivers, it is important that families’ unaccounted work is further explored. This would include a better understanding of families' methods in the convincing and coercing of family members to attend day programs and the potential effects on the quality of life for people living with dementia. If these practices were further understood, day programs might better support and facilitate the work of families and the attendance of people living with dementia in an ethical and less burdening way.

Essential Components of Day Programming

Defining the essential components comprising a day program has proven elusive to most researchers and program regulators (Manthorpe & Moriarty, 2014). Interestingly in the UK, Canada, US, and the Netherlands, there has been no national/provincial oversight into day program standards (Anderson et al., 2013; Manthorpe & Moriarty, 2014; Nies et al., 1991; Silverstein et al., 2010; Weir & Fouche, 2017). Variability of programming and the previously mentioned international differences have posed challenges in establishing effects and comparisons between programs. A lack of programming description in most day program research has been discussed previously as a methodological limitation. In the literature reviewed, a more recent interest in examining effects on engagement through certain types of day programming activities for people living with dementia is evident (Anderson et al., 2015; Chalfont, 2011; Grinberg et al., 2007; Hafford-Letchfield, 2013; van Haeften- van Dijk, 2016). Day program design concerning the types of services offered to families, namely case management and caregiver support groups, has also been the focus of a few studies (Anderson et al., 2013; Dröes et al., 2006; McCann et al., 2005).

Organizational Goals and Programming

Weissert (1989), in a study of 60 US day programs, found separation between day program goals and mandates and their operations. Dabelko and Balaswamy (2000), in a comparative study of users from 62 various day programs, noted that even though day program users tended to be elders with more cognitive issues than physical ones, programming has remained centered on a physical health model. Several authors have questioned the ability of day programs to offer the individualized and culturally responsive approaches advocated for in the discourses of person-orientated care in dementia (Kirkley et al., 2011; Manthorpe & Moriarty, 2014; O'Shea et al., 2017b; Weir & Fouche, 2017). The few observational studies conducted in day programs have identified similar issues. Abramson (2009) completed an ethnography of a day program in the US and found day programs were unable to achieve their organizational goals of improving the lives of people living with dementia due to limited resources. He noted that due to resource constraints and structural designs, the program had shifted from an intervention focus to a respite focus, resulting in routinized custodial types of care. A few other ethnographic studies observed day to day activities in day programs, and these cited concerns of infantilization of older adults (Lyman, 1988; Salari & Rich, 2001) and noted the routinization of activities with a predominant focus on preserving order and safety (Abramson, 2009; Hasselkus, 1992; Salari & Rich 2001). Abramson (2009) also noted that the staff's efforts at maintaining order were frequently impeded by the inconsistent behaviours related to dementia, which affected the enactment of even more restrictive practices. Alternatively, Gustafsdottir (2011) noted in her ethnography of a day program in Iceland that knowledgeable staff extended day programs services beyond their mandate of respite for family caregivers, enacting an enriching program for people living with dementia. In a different setting of the US, Black et al. (2018) found the patients themselves formed a community and sense of identity that sometimes surpassed the program culture's expectations for them.

Day Programs Connections with Other Health System Components

Despite being part of the nebulous concept of 'community care' for some time, in much of the research reviewed, day programs have predominantly been examined as stand-alone units of care. This separation of the day program from other forms of care seems to be the case even in regions where day programs are positioned as supplemental to, rather than substituting for other forms of care. Health care system resources and funding models may affect how integrated the day program is with other forms of care (Tucker et al., 2016), but this is rarely described in much detail in the articles reviewed. Some time ago, in a sizeable descriptive study of over 225 day programs for older people in the UK, Tester (1989) found significant isolation of day program services from other health and social care services. This concern continues to be addressed with more recent integrative care models for day programs, including case management, support groups, and specialty consultation provided onsite (Anderson et al., 2015; Femia et al., 2007; McCann et al., 2005). Others remain focused on the service substitution approach of day programming evaluation (Iecovich & Biderman, 2012; Kelly, 2017; Kelly et al., 2016; Skarupski et al., 2008), where the effectiveness of day programs is connected to their ability to prevent other service use. Challenging this idea were the results from a large comparative study that included 400 older adult day program users in Israel where Iecovich and Biderman (2012) found use of health care services was dependent on morbidity rather than day program use. In Canada, where day programs are positioned within the home care services sector, there is little research describing day program models or their relational effects on or from other parts of the health and social care systems. One research group in Canada (Kelly, 2017; Kelly et al., 2016) examined the interaction between day programs and other health system utilization using secondary data from financial and service use systems in BC. These studies found a decreased use of emergency or acute care resources by older adults in day programs (Kelly, 2017), and decreased use of home care services (Kelly et al., 2016). None of the studies on health care utilization were specific to people living with dementia and no research examined the relations or distribution of care between other formal services and the day program.

Delaying Institutionalization

In the US the initial hope that day programs would be an alternative to institutionalization proved to be short-lived with several early studies discovering that day program clients often had higher institutionalization rates (Weissert, 1989; Gaugler & Zarit 2001; Zarit et al., 1999). In 1999, Zarit, Gaugler and Jerrot questioned the appropriateness of delayed institutionalization as a reasonable measure of day programs' effectiveness. While delaying institutionalization is still commonly tied to the effects of day programs and other forms of respite care, there seems to be little evidence available to support this claim (Vandepitte, 2016). However, this historical idea of day program care replacing nursing home care continues to structure much of how day program staff see the role of the program, positioning their work in the "shadow" (Gaugler, 2014, p.50) or the "spectre" (Hasselkus & LaBelle, 1998, p.16) of the nursing home admission. In contrast, some studies have noted that using day programs requires families to 'let go' of responsibility and can be used as a point of transition to institutional care for families (Gaugler & Zarit, 2001).

Conceptual Frameworks of Day Programs

Interestingly, after years of research into day programs, several researchers have identified a need for more focus on how day programs work for people and families living with dementia (Dabelko & Zimmerman, 2008; Gaugler, 2014), including the need for a more complex view of caregiving and ideas of respite (Anderson et al., 2015; Zarit, 2018). Both Gaugler (2014) and Dabelko and Zimmerman (2008) describe day programs as being 'black boxed' in terms of how they work for people and advocate for a need to unravel further the processes involved, leading to more recent attempts to model the pathways and processes of day programs.

Dabelko and Zimmerman (2008) addressed what they described as an “atheorethical” approach to previous day program studies by building a conceptual model based on a review of the existing research of how and why day programs work. Based on the review, they postulated that day programs work through influence on clients' physical and psychosocial functioning that are targeted through program service components. Through their logic modelling of day programs, they proposed that through the rehabilitation therapy and activities of day program, proximal outcomes of personal growth, relationships with others, purposeful activity and maximizing independence occur, leading to distal outcomes of improved well-being. This model is based on day program services for older adults in general. Purposefully individualistic and linear in its focus for using the logic model, this model assumes the ability to isolate people attending day programs away from their other relations and thus includes individual-level outcomes and the immediate environment of the day program. From a specific program outcome evaluation perspective, this kind of model is ideal but lacks depth for understanding the processes involved and external factors that might be influential.

Bull and McShane’s (2008) study to explain the “how” of day programs focused on the effects on family caregivers transitioning to use of day program services. Using a grounded theory study of 16 family caregivers of people living with cognitive impairment who were starting to attend day programs, Bull and McShane created a situation-specific theory of family transition to day programs. This linear three-stage model includes the ‘steps’ of transition, including recognizing a need for more respite, finding a program, and integrating the program into their daily life. In this model, the common barriers of transportation and preparation work along with matching program activities with the interests of the older person, are key adjustment tasks that families must do to successfully transition to regular day program use. Noticeable in this model is the assumed norm of full attendance being best for all families and little discussion of the dynamic nature of everyday life in the model. A stepwise task-focused progression may not reflect the more fluid nature of care, family relationships, environments, dementia, and group programs.

Gaugler (2014) described the process of day program use from both family and program perspectives in his conceptual model of day program use. This model is perhaps the broadest in scope of the three available models to date. Using grounded theory and participant observation in two day programs, Gaugler recognized that the effects of lives “outside the program walls influenced and shaped activities” (p.50). In this model, he also noted the complexity of factors that went into decision-making regarding the use of day program from family, program and policy environments, and the balancing of other services with the day program required by the family. In terms of effects, Gaugler found a person-centred philosophy worked to engage participants and noted the program's practices travelled home to structure interactions between family and the person attending the day program, something he identified as “programmatic permeability” (p.53). In this model, family benefits resulted from the sense of security felt when their relative was in ‘responsible hands’ and from the information and coaching received from the program over time. This model is promising in acknowledging what seems to be commonly cited benefits in family day program satisfaction research.

While these models have attempted to address the need for increased theorization of day programs, the conceptualization of day programs as stand-alone units of care in the community seems prevalent in all of them. All three are general models of day programs, although many involved specific considerations of people living with dementia. While Gaugler's (2014) model seems to account for the interactions between home and day program, an understanding of how the processes of the day program connect and interfere with care processes at home and other services are underexamined. Gaugler certainly makes no claims for his model's completeness and calls for additional qualitative and ethnographic research to develop it further. Of note in both Gaugler and Bull and McShane's (2008) models, the family perception of sharing responsibility for caring seems to be accounted for only from the family's perspective. This sharing of responsibility has routinely appeared in research on day program effects for families (Schake & Zank, 2006; Tretteteig et al., 2016) and seems to challenge the widely held view that day programs simply fulfill a time and space function for families.

Limitations of the Current Understandings of Day Programs

Despite being the most researched form of respite care, and with a widespread consensus that day programs must be helpful, the actual field of evidence is limited, with both ambiguous results and little theoretical development. In 1989, during the rise of day program popularity in North America, Canadian researchers van Beveren and Hetherington (1995) warned that the research on day programs was limited in its practical worth for those using, providing, and building policy. The risk, they argued then, was that without an adequate understanding of how day programs work, the development of necessary evaluative strategies and innovation might be stifled or misguided. Recently Zarit et al. (2017) concluded that efficacy research about day programs has produced few evaluative outcomes that are useful for policy. As mentioned previously, Maayan et al. (2014) and Mason et al. (2007) also concluded through systematic review of respite care research that included day programs, that there is insufficient evidence available to inform policy and practice. These are significant issues for a service that is muchtouted in policy frameworks as a potential solution for sustaining care of people living with dementia in the community, suggesting that it is time for a necessary reconsideration of how day programs are conceptualized and studied.

Methodological Limitations of the Research

In this review, much of the research was quasi-experimental in design, thus using predominantly quantitative measures. Critique of the methodological limitations of day program research has been ongoing, with several authors citing the use of small sample sizes, non-experimental designs, lack of definitions of programming or dosing, and the lack of theoretical models as being significant to the ambiguous state of findings (Gaugler & Zarit, 2001; Anderson et al., 2013; Maayan et al., 2014; Mason et al., 2007; Manthorpe & Moriarty, 2014). Zarit et al. (2017) observe that the predominant approaches to studying day programs illustrate classic translation research issues in community settings where controls are difficult and at times unethical to achieve (Zarit et al., 2017).

From a qualitative standpoint, interviews have been well used in day program research, but there has been limited use of observational studies (Abramson, 2009; Black et al., 2018; Gaugler, 2014; Gustafsdottir, 2011, Hasselkus, 1992; Lyman, 1988; Salari & Rich, 2001). Observational studies performed to date have been helpful in understanding the processes of the day program use and organizational influences on care (Abramson, 2009; Gaugler, 2014), staff perceptions and interactions with patients (Abramson, 2009; Gustafsdottir, 2011, Hasselkus, 1992, Lyman, 1988; Salari & Rich, 2001) and patient experiences (Black et al., 2018). Reflecting the common trope of the day program as an isolated unit of care delivery, these observations occurred only at the site of the day program, except for Gustafsdottir (2011) who also included interviews with families in their homes.

Common the Assumptions of Research

Beyond methodology, family caregiver and dementia intervention research as a whole has struggled with narrowness in its underlying assumptions and day program research is no different (Ceci, Symonds-Brown & Judge, 2018; Purkis & Ceci, 2014). Alvesson and Sandberg (2011) suggest that when a field of research becomes narrowed or stifled, the problematization of the key assumptions underlying the research can be a valuable step in expanding it.

Narrow Focus on Outcomes

Day program research has inherited issues from the larger field of respite care research, including the limitations created by targeting care burden as an outcome. The use of stress theory predominates much of the research (Zarit, 2018), and while helpful in understanding individualized responses to stress, the use of this psychological theory has isolated examination of effects to the sole family caregiver, restricting attention to other relational effects day programs might have on systems, family, or the public. In a recent editorial, Zarit (2018) cited the research on day programs as an example of how family caregiver support research may be misguided regarding the assumed goals of treatment. Zarit (2018) reflects that in the services sought, family caregivers may not be seeking a relief in burden, depression or distress, and he questions whether it is time to rescue caregiving from the disease model of problem identification – targeted intervention to understanding caregiving as a complex life situation requiring ongoing flexible support strategies. From the qualitative research findings, family caregivers have been consistent in their appreciation of the shared responsibility, monitoring and relationships day programs provide. The few studies on subjective experience of the people living with dementia describe a sense of belonging and structure. These are important effects that could have significance for quality of life, yet to date we understand very little about how these effects are achieved.

Day Programs as Isolated Units of Care

Day programs are mostly studied as isolated units of care, making the ways in which day programs fit with and affect other forms of service used by families also relatively unexplored. A lack of understanding of the organizational and relational processes of day programs limits the forms of care it can provide.

The Nature of Care

Uncontested assumptions about the nature of care and home are also evident in the research reviewed. Throughout the literature, care is commonly portrayed as labour easily quantified into hours, which can then be simply divided between home and the program. As mentioned previously, this portrayal of care ignores the political and material nature of care practices (Mol, Moser & Pols, 2010). The materialities of care, such as the activities of preparing a person for day program, a communication log sent home from the program, the strategies of preventing family caregiver burnout, can be very powerful in their effects. However, these effects are not accounted for when the focus of analysis is either placed only on human actors or when care gets rendered into hours delivered or burden felt. Other studies taking a materiality of care approach have uncovered interesting relations between formal care systems and the home. For example, Langstrup’s (2013) ethnographic study of chronic illness care at home showed that care was constituted through sets of socio-material practices, the effects of which were the extensions of care ‘infrastructures’ from the formal system into the spaces of home and everyday lives of patients with chronic illness. This type of formal care extension into the home was also seen by Danholt and Langstrup (2012) in their ethnographic study of home medication practices.

In this study, formal care extensions were political in that they enacted differences among actors and structured relations in a particular way. Observational approaches are required to follow the materiality of care and can better reveal the infrastructural extensions of day programs in structuring family care practices and relations.

Remaining Questions about Day Programs

Families and people living with dementia require care and support to live a good life in the community. The research on supporting family caregivers to date has been impressive in scale and effort and has oriented health and social care efforts towards family members and people living with dementia in some helpful ways. Respite and day program research are the least empirically developed areas of family caregiver supports (Vandepitte et al., 2016; Zarit, 2018). Situated within the previously discussed nebulous environment of care in the community, these programs rely on significant assumptions that might not be working well for people living with dementia and their families. As discussed in the previous chapter, the research done to date on care in the community and day programs has contributed to our current understandings of care supports for families living with dementia at home. While having made some important contributions, the predominant approaches to knowing about day programs include unproblematized assumptions concerning care, home, and community, which have left much of the theoretical underpinnings of how day programs work underexplored. After several decades of research, it is evident that some crucial questions remain unanswered, the most significant being: How do day programs work as ‘care in the community’ for people living with dementia living at home and their families?

Chapter 3

Methodology

Rationale for Research Approach

Considering the limits of the current conceptualizations of ‘care in the community,’ and the call for increased understandings of how day programs work for people living with dementia and their families, an approach is needed that can account for the entangled nature of care and the everyday life of people living with dementia and their families. Material semiotics offers a theoretical vocabulary and research approach (Law, 2009a) that refocuses the research gaze to the networked, fluid, and political nature of care, and thus brings new insights into how ‘care in the community’ is theorized, understood, and enacted in services such as day programs. This research approach resituates care as a practice and reflects the view that “care takes place in various shapes and forms” (Pols, 2012, p. 17), and that there are many activities beyond what is traditionally understood as caregiving that constitute care. With this in mind, this study considered ‘care’ as the range of activities that helped to sustain and improve the everyday lives of people living with dementia and their families. To study these practices and the materialities that support them, attention was given not just to the people and what they said, but also to their knowledgeable social activity. That is, what people did and the materials that mediated their actions, the ends they strived for, and what it made sense to do in particular interactions. Through this material semiotic approach, phenomena such as day programs, family, care, home and community, typically considered stable and fixed, became instead a dynamic and diverse group of practices made up of materially heterogeneous actors and objects. ‘Care in the community’ then, was understood and approached as a web of multiple enactments of care done through the relations of day program, family and community practices. The following research question and objectives guided all elements of the study:

Research Question

- How do day programs work as 'care in the community' for people living with dementia living at home and their families?

Research Objectives

- To explore the ways in which day programs affect everyday life of people living with dementia at home and their families.
- To understand how day program care practices relate with other formal and family care practices for people living with dementia.

Research Design

Ethnography is a research approach that uses observation and description of people's everyday lives in their natural settings (Hammersley & Atkinson, 2007, p. 3). Originating in anthropology and often mistaken to be a unified approach, ethnography has evolved over time to be utilized by a variety of disciplines with a wide range of theoretical and methodological alignments and related practices (Greener, 2011; Hammersley, 2018). Consistent in ethnographic approaches is an inductive analysis and the use of immersive experiences to understand social processes (Greener, 2011; Hammersley, 2018).

Specifically, from a material semiotics approach in the traditions of science and technology studies (STS), an ethnomethodological (EM) influenced multi-site ethnography is commonly used (Hine, 2007; Lynch, 2013; Pollner & Emerson, 2001). This approach draws on the EM work of Harold Garfinkel, a sociologist, who proposed that the only way to capture how social processes were organized was to recognize social interactions as local and "practical accomplishments" achieved by knowledgeable actors within specific situations (Garfinkel, 1967). The practical knowledge these actors draw on is a sort of invisible backdrop of understandings (Pollner & Emerson, 2001) present in all social situations, and which actors use to read and respond to each other in a way that makes sense for that situation (Munro, 1995; Purkis & Ceci, 2016). Garfinkel (1967) explained that the backdrop of ground rules and expectancies can be taken for granted by those with competency in the practice, and yet are available for empirical study through participant observation and the constant question from the observer of 'what is going on here?

While resistant to formal categorization, this EM-influenced ethnography is skeptical of an objective account of an "out there" reality being possible and instead embraces realities as enacted through relations (Greener, 2011; Law, 2015). Using a multi-site ethnographic design accounts for a theoretical concept such as care as the object of study, such that care can be followed as something fluid, mobile, and multiply situated (Hannerz, 2003; Hine, 2007; Nadai & Maeder, 2005). Through this multi-sited, relational approach to ethnography, the researcher moves from studying a geographically bounded field into following both people and things into different social worlds to trace practices as they travel and connect (Hannerz, 2003; Marcus, 1995; Nadai & Maeder, 2005).

The strengths of ethnography include its in-depth descriptive accuracy and ability to trace processes of social phenomenon with minimal reactivity effects on those being researched (Hammersley, 2018). Limitations of ethnography are related to its local, descriptive orientation, limiting the ability for prescriptive and universal conclusions (Hammersley, 2018).

Settings of the Study

In this study, to examine how care in the community happened between day programs and the home for people living with dementia, several settings were used, including day programs, homes, and the community. The study took place in two Alberta cities: Edmonton, a mid-sized city with a population of close 1 million people, and St. Albert, a suburban city of 65,000 people. (See Chapter 4 for more information on the settings and participants of the study).

Day Programs in the Edmonton area

During the time of this study the continuing care division of the provincial government health authority (Alberta Health Services [AHS]) administered day programs across the province. According to the regional manager of day programs, there are currently 19 day programs in the Edmonton region. Most programs are staffed and managed directly by the health authority and a few (4) are contracted out to non-profit agencies. The programs serve approximately 750 older people, with about 100 people on the waiting list. Wait times for program enrolment range from six to twelve months. (Michelle Jessop, personal communication, June 2018). People living with dementia who attend day programs in this region typically attend either one or two days per week, with occasional exceptions of three days per week in exceptional circumstances. The programs, located in various places, including institutional settings such as hospitals, community centers, and churches, run Monday to Friday from 9:00am -3:00pm. All but one of these programs runs mixed group programming meaning there are both older people with and without cognitive impairment included in the same program. The range of cognitive impairment varies between clients living with dementia at each program, with some being more affected than others. One day program opened in the fall of 2018 for people living with dementia only. The multiple access points for all these publicly funded day programs are outlined in Appendix A. At the beginning of the study (2018) all of the access points led to home care being in charge of the allocation of day program care, however, in the last two months of the study (2020) another department of continuing care at AHS called “Transition Services” took over this role.

The study sites included two programs in the Edmonton Region. Program A is located in a community setting of a senior’s organization in Edmonton. Program B is located within the outpatient department of a hospital. A non-profit agency (ElderCare) administered program A under contract to AHS, and Program B was run directly by AHS. These two programs were selected to provide variation in location and spatial design, as well as for ease of travel time between sites.

Family Homes

A second setting for this study was the private homes of participants. Access to the home was coordinated through the family member identified as the primary contact via telephone and permission was sought at the start of each visit.

Community Settings

Following people through their everyday activities during outings accompanied by family or other support people included going to settings such as public venues and social organizations (e.g. shopping mall and community Minds in Motion group). Access was negotiated verbally with participants and the related gatekeepers of the Minds in Motion group after receiving an invitation to attend by several members, then discussing the study with the facilitator and group members and asking permission to observe the session. Because shopping malls are public venues and no direct interaction with other people in the mall occurred, no access permission was required.

Participants

There were five types of participants included in this study:

- Participants living with dementia
- Family members of the participants living with dementia
- Day program staff and milieu participants
- Key informants or persons with special knowledge of the research context
- Persons encountered during fieldwork in day to day activities of the family units

Sampling and recruitment of each group is discussed below under the heading of each participant group.

Participants Living with Dementia and Their Family Members

Sampling. Ethnography's orientation towards descriptive depth requires a closeness of the researcher to the subject of study, where small sample sizes are typical and with emphasis placed on the collection of a broad sampling of practices within cases (Hammersley & Atkinson, 2007; Pols, 2004). For this study, I recruited a sample of four people living with dementia and their related family units who were using one of the two selected day programs. This sample size allowed for adequate time to be spent collecting observations of different practices in a variety of settings and offered an opportunity for comparison.

Study participant inclusion criteria for older people living with dementia participants was: over the age of 65, living at home using one of two day programs in the Edmonton area, with the support of family units where all members identified by the primary caregiver who agreed to participate in the study and who had an ability to communicate in English. Exclusion criteria included: people living with dementia living in institutional care or assisted living facilities, those with no informal supports, and family units where one or more members refused to be part of the study.

Recruitment. While the representation of a general population is not the goal of ethnography, purposive sampling is a strategy used to ensure both the inclusion of typical cases and diversity in the sample (Hammersley & Atkinson, 2007). In this study, to sample a range of experiences with the use of day programming, people living with dementia and their family units were purposely recruited. For example, I focused on a diversity of living arrangements and program attendance patterns. Thus the sample had two people attending program A and two attending program B, two men and two women, one person who lived alone with a paid live-in caregiver, and the remaining three living with their spouses. I also tried to capture a range of attendance durations by including one person who had just started a day program, one who had attended for 12 years, and two who had been in attendance for one to two years. One participant with significant behavioural issues was recruited because of the current research showing responsive behaviours of dementia are positively linked to discharge/non-attendance from day programs (Le Blanc, 2010; Mävall & Malmberg, 2007). Within this sample, there were also diverse attendance patterns from the minimum of one day/week to the maximum three days/week allowed at these day programs.

Recruitment was accomplished in a variety of ways: mailed flyers to all the participants of the two programs, in person recruitment and flyers were used at a variety of Edmonton area dementia caregiver support groups, and posters were posted at the programs (Appendix B). To avoid interpretation by people living with dementia and their families that participation in the study was tied to the participation in the day program, there were no recruitment efforts linked to the intake processes of day programs.

Day Program Staff and Milieu Participants

A convenience sample of the staff and participants of the two different day programs in the Edmonton region was used for this study. Program A had four to five staff, two managers, three volunteers and 42 clients who were included in observations. Program B had ten staff, one manager, three volunteers, and 28 clients who were included in observations.

Before starting observations, I met with staff of the day programs during a regularly scheduled staff meeting to inform them of the study, answer questions, and obtain consent. Over the course of the study, anytime I came to the site and met a newly hired or casual staff or volunteer I would go over the study information sheet and obtain written consent from them before I began my observations.

Because I was not collecting data about other participants of the day program but my presence as a researcher could have had an intrusion effect for them, I sought ongoing passive consent and assent from them. This passive consent process included both posters describing my presence and role posted within the program milieu (Appendix C), and an opt-out information letter sent home with all other day program participants (Appendix D) explaining my presence in the milieu and the process of passive consent or dissent. Due to fluctuations among day program participants, the sharing of research project information and gathering of ongoing consent and assent occurred throughout the study. Each time I attended the programs, I would remind people who I was and what I was doing and their right to tell me that they did not want to talk to me.

Key Informants

A purposive sample of four key informants was recruited for open-ended qualitative interviews. Over the course of the study, through observation of practices, and reading of policy documents, I identified key informants involved in the formal system planning, coordination, or delivery of day program care and including people from different levels of program administration and dementia policy planning levels.

Recruitment of key informants was done through a formal request by email (Appendix E). Participants who were interested in the study contacted the researcher, and written consent was obtained in person/or via video conferencing and email before data collection (Appendix F).

Other People Encountered During Fieldwork

During fieldwork with people living with dementia and their families, interactions occurred with diverse other actors as I followed the person living with dementia in their everyday activities, i.e. in-home care, case managers, small social communities. I informed tangential actors such as these of my presence as a researcher, the general focus of the research (i.e. the care activities of participant families), and how consent to be present was assumed where the person was free to converse or not, and was free to determine the level and nature of their interaction with the researcher.

Data Collection Methods

Ethnographic methods of participant observation, interview, and document analysis were used for empirical analysis of the care practices related to day programs. These data collection methods were used to attend to how the participants enacted care for the person living with dementia, how they drew on shared knowledge to act, interact, use space and objects, and how they accounted for what made sense in any given interaction.

Participant Observation

To learn about the implicit knowledge that underpins a practice, observation as well as participation in the interactions, actions, space, and objects that are a part of it is required (Beuger, 2014; Pols, 2004). Both Garfinkel (1967) and Goffman (1989) advocated that researchers should immerse themselves within a field to feel and react to the contingencies experienced. Additionally, participant observation also includes the collection of naturally occurring oral accounts that may be solicited and unsolicited (Hammersley & Atkinson, 2007). These accounts were used to develop understanding of "what is going on?" (Garfinkel, 1967)

In this study, participant observation occurred at multiple sites, including family homes, during public outings and at the day program for a period of nine months. This included notation of conversations, actions, use of objects, space, and other people in relation to the participants living with dementia. Ongoing observation of care practices in multiple sites allowed for an in depth understanding of how the care practices of day program and the family for the person living with dementia were enacted and how they existed over time and space, how they changed or remained stable, and how they may have interacted (Beuger, 2014). While accounts were noted through observing general conversations, the use of informal reflexive interviewing in the field was also used at times to elicit participants own frames of reference in accounting for events, making available the types of social knowledge that participants drew on.

Over the course of the study, 137 hours of observation were completed. This observation was of two main types:

Observation of the Participant Living with Dementia and Family. Short periods of observation time were requested weekly to monthly at the convenience of the people living with dementia and family to observe basic everyday activities and outings. Based on the different preferences for home and community outing visits of each family, the number of observations varied. Regular monthly home visits (bi-weekly at first for Participant 1) were completed with participants 1 and 3. After the fourth home visit, Participant 2's spouse requested most observations at the day program rather than home. Participant 4 had only two home visits due to her spouse reporting her suspicion of visitors and my desire to minimize intrusion effects. The total number of home and community visits were as follows:

- Participant 1: twelve home visits
- Participant 2: four home visits
- Participant 3: eight home visits and two visits to community outings
- Participant 4: two home visits and one visit to community outing

Day Program Observation. Observation at each day program began with a general preliminary observation of the site that included mapping the space and learning about routine day program practices. These initial visits involved several full and half days of observation over three weeks. Ongoing observations then involved weekly visits following the participants living with dementia for one to two hours at different times of the day at the program. Program B had more outing-like events than Program A, so some of the site visits were longer in duration.

- Participant 1 = 30.5 hours at day program A
- Participant 2 = 8.5 hours at day program A
- Participant 3 = 61.5 hours at day program B
- Participant 4 = 54 hours at day program B

Case sampling methodology was used to identify specific events or times that participant observation occurred related to the objectives of the study (Hammersley & Atkinson, 2007). For this study, I planned for purposeful ‘within case’ sampling of observations of the person living with dementia that would occur at different times and contexts of the day, such as when they attended the program and days they did not. I also planned to observe morning preparation activities and in-home services, but I found that all the families were not receptive to the idea of me observing their morning preparations for the program and often scheduled my visits away from other home-based services. Exceptions included Participant 3, who had a live-in caregiver who was included in most home visit observations, a home care-family meeting with Participant 1 and several community outings with Participants 3 and 4.

All participant observations were guided by a general observation guide (Appendix G) and were documented in a field note journal then transferred into a word document in an ongoing fashion.

Interviews

Open ended qualitative interviews were conducted with four key informants involved in the planning and coordination of day program related practices. These included:

- Two program managers from Eldercare (a non-profit agency that ran Program B). These managers were both female health care assistants, one was the new manager of program A, and the other had been the manager of program A for several years (including most of my time at the program) and had recently transferred to a different program.
- The regional coordinator of day programs for AHS, a woman with a BScOT who had been managing day programs in the Edmonton region for over 20 years.
- A representative from the government health ministry (Alberta Health) responsible for managing quality improvement and dementia policy implementation. This woman had a background in gerontology and had worked within her position at the government for five years and in previous continuing care quality improvement roles for 12 years prior.

The purpose of these interviews was to understand how day programs were accounted for by the formal system and to learn about any related practices through which they were seen to work. Information gathered provided accounts of formal system practices. These open-ended qualitative interviews explored areas included in the interview guide (Appendix H). The interviews were done in person face to face and over skype and lasted 45 to 60 minutes. The interviews were prearranged with interviewees at a setting and time of their preference.

One open-ended qualitative interview was also used to gather initial information from family participants to orient to family membership, roles and the history of their present situation regarding living with someone living with dementia and using the day program (Appendix I). Family participant interviews included the members chosen by the family's primary contact at a time that was convenient for them.

All interviews were recorded and transcribed into anonymized formats. Unfortunately, the first recording of the interview with Participant 1 encountered technical difficulties and was lost, so it was not transcribed. Notes taken during this interview were recorded within the field notes to account for some of the information shared by the family during the interview.

Documentary and Material Artefacts

Data collection also included collection and analysis of documents and materials involved with family and day program care practices. Documents and material artefacts were chosen based on their observed role in creating or translating the implicit knowledge related to the day program care practices. Program documents included schedules, checklists, admission packages, information sheets, job allocation, and tracking sheets.

Day Program Chart Information. AHS Data & Health Information Resources Procedures were followed for accessing hard copy charts (admission and progress notes, progress notes, and behavioural plans) at the day program under the supervision of the program manager. Documents reviewed from the participant living with dementia's health record included: care planning forms, charting forms, admission assessments, and any documentation shared with the program from home care or physicians. These health records were reviewed using the guiding questions from the data collection sheet (Appendix J): What is included as evidence of care needs related to the person living with dementia? What types of goals are planned or monitored at the day program? What is attended to in the admission or discharge documentation processes of the day program? How is the information recorded for the day program care connected to other support services or sites of care? Under the program manager's supervision, I reviewed each hard copy chart at the program in full during one of my initial visits to observe each participant and then I would check the chart at each program visit and take note of any additions.

Home Living Electronic Chart Information. AHS Data & Health Information Resources Procedures were also followed for accessing extracted data from Home Living (home care) electronic health records (where day program care plans are charted). While a data analyst started data extraction from the Home Living records with AHS in March 2020, my access to the extraction files required that I access an AHS site-based computer which became inaccessible with the pandemic-related closure of program B. It was impossible to access this data from the Home Living records, so it was not collected.

Other Documents or Materials. These data sources included any family-day program communication or education tools, family-specific tools for record-keeping or communication, as well as related policy or procedures that were observed or reported to guide care practices. Data collected from these items included: observations about the document's content, the discursive style, and assumptions concerning family and day program relations.

Data Management

Observation data was recorded in raw notes while in the field and transferred into formal field notes in an electronic encrypted anonymized format on a password-protected computer. Raw interview recordings and transcripts as well as scanned artefacts were also stored in this format.

Timeframe for Field Work

Over a period of nine months, I was able to follow a variety of care practices related to the daily life of the person living with dementia and their family and their use of the day program. Originally, I had assumed this timeframe would capture some of the typical day program discharge patterns cited in the literature. For example, in the Woodhead et al. (2005) study a dropout rate of 65% of families occurred within nine months of starting day programs. This seemed reasonable for the Alberta context of the study as there are currently long waitlists for day programs. Many of the people entering day programs are at a stage in their functioning where the family is seeking additional supports and, as noted by several authors, day programs are sometimes used as a point of transition to institutional care for families (McCann, et al., 2005; Zarit, et al., 1999). None of my participants discontinued their use of the day program during the time observed, but two families (1 and 2) requested an increase in a number of attendance days. At the program, I was able to observe practices related to a few discharges from the programs, new admissions, and admissions that failed.

Researcher Positioning and Reflexivity

The material-semiotic guided ethnographer does not make claims to an insider-outsider status before entering fieldwork and considers their positioning as insider or outsider to be a form of “an interactional accomplishment” achieved in specific situations throughout the study

(Hunt & Benford, 1994, p. 491). This means the researcher's positioning is fluid and dependent on how the researcher draws on social knowledge reading and responding to others (Allen, 2004), as well as by the ways different participants throughout the fields 'take account' of them (Rudge, 1996). While other forms of observational studies try to remove or contain the influence of the researcher on the research, this form of ethnography does not pretend that being in the field with people would not influence the practice being observed. It is considered inevitable and part of the analysis that is expected. This does not mean that careful consideration is not given to the researcher's actions in the field. Reflexivity of the researcher is considered essential for the researcher's ongoing understanding of themselves as part of the practices and the accountability of the study's analysis (Anspach & Mizrachi, 2006; Law, 2004; Rudge, 1996).

For this study, my previous work as a community mental health nurse and my personal experience of being a family caregiver provided challenges and benefits to me as I negotiated my position in the field. Gerrish (2003) points out that this privileged position of being a nurse and researcher can help gain access to research settings and build rapport with participants of the practices studied. I negotiated the routines of the day program, intake and assessments with some familiarity of the 'stock knowledge' of healthcare, and my comportment and comprehension/use of the participants' common language facilitated some of my acceptance into the field. My familiarity with healthcare settings also posed challenges for me to take notice of the taken-for-granted aspects of familiar practices and my ability to observe and not intervene during a few health concerns with day program participants. It also posed ethical challenges where I gained access to fields that may not have been based on my researcher status but the perception of me as a health professional (Gerrish, 2003; Rudge, 1996), such as facilitating staff with the collection of a urine test for one of my participants. In addition to reflexivity, this required ongoing vigilance to ensure that participants I interacted with were aware of my status as a researcher.

I attempted to maintain my reflexivity by keeping a journal of emotional responses and personal thoughts that arose during the research process. At times throughout my field work, I would discuss these thoughts and feelings with my supervisors. These notes and meetings allowed me to reflect on how my positioning and personal beliefs were part of what I needed to attend to in the field (Roper & Shapira, 2000). Further, Allen (2004) points out that reflexivity cannot be limited to a phenomenological perspective. Instead, reflection and observation of the researcher’s methods to negotiate and maintain their positions in the field are critical to analyzing the social practices under study (Allen, 2004). These reflections were documented in the field notes and included in the analysis.

Rigour

Validity and reliability are ensured in ethnographic fieldwork through the collection and use of multiple sources of data, sampling for variation of cases, maintaining adequate records of data, and the practice of clarifying developed descriptions and interpretations in an ongoing manner with participants (Hammersley & Atkinson, 2007; Lofland et al., 2006). Not quite the same as traditional triangulation methods, where data are correlated together to ensure accuracy, this form of triangulation is focused on ensuring the scope of interpretation and ample opportunity for pattern recognition to occur (Hammersley & Atkinson, 2007). Credibility is demonstrated through documentary evidence of having and using sufficient data to support study claims (Hammersley & Atkinson, 2007).

Data Analysis

Data were analyzed congruent with the material-semiotic approach to the study. The ethnomethodological principles privilege participants’ ability to look back on actions and give accounts for why they make sense over external or researcher-oriented explanations. Unlike other approaches, these accounts are not taken as a truthful interpretation of experience or analyzed for underlying motivations but instead are considered empirical evidence of the person's reading and responding to that interaction's social organization (Purkis & Ceci, 2016). In terms of data analysis, Law (1994) acknowledges this necessitates "giving up most of the explanatory resources" (p.16) and letting the accounts and observations speak for themselves. Detailed descriptions of processes observed and accounts of the rationale given helped to "unbracket practicalities" (Mol, 2002, p. 56) involved with care practices. Through this unbracketing, I looked for how the taken-for-granted activities of care practices observed between home and the day program were maintained and supported. This process involved describing what I often saw in the field as taken-for-granted explanations and phenomena and creating re-scriptions of the relational materiality upholding their apparent solidity or givenness. This work required looking and listening closely while in the field and tracing events, objects, and practices across contexts. Simple conversations with staff would result in pages of description as I traced the practices represented in their accounts and examined the work and effects created from them. In compiling these descriptions, an analysis of the 'modes of ordering' for different practices observed occurred. Modes of ordering are the fluid and multiple organizing principles that shape a practice and are shaped from it (Law 1994; Purkis & Ceci, 2016). In analyzing these, I looked in the data for patterns of how certain things come to matter more than others within particular practices (Law, 2004). As I annotated my field notes, I looked for effects that travelled from this mattering into other relations. I paid attention to what Mol (2002) refers to as the "ontological politics" of how these 'realities' enacted through different practices interact, interfere or relate, and how certain enactments come to matter more than others. All of these analytical standpoints were included in the ethnographic writing of thick descriptions and empirical case studies, which for material semiotics, is how stories of practices are told. After creating these case studies of thick description, I moved on to an interactive methodological approach where I took descriptive examples from the data and interpreted these using key theoretical concepts (Law, 2009b; Moser, 2003).

Comparisons. Comparison within and between case studies also occurred as part of the analysis. This comparison was not a traditional approach to the direct evaluation of one case with another where the need for homogeneity would matter. Because fluidity and multiplicity of practices is expected, I looked for instances of partial connection or at times disconnection between case studies (Niewöhner & Scheffer, 2010). Schmidt (2010) asserts that comparison can be used analytically to demonstrate or uncover "uniqueness of social phenomena" including an opportunity for re-description (p.96). Mol (2002) also emphasizes that it is essential to follow the locality of the practice and attend to what changes when it travels from one location to another, meaning comparison between localities can also tell a story about the practice.

Ethical Considerations

Ethics approval was given by the Provincial Health Research Ethics Board of Alberta (HREB) and operational approval for recruitment of participants and researcher access to the programs, staff, and patient charts was obtained through the AHS Regional Manager of Day Programs, the Director of Home Living programs, AHS Provincial Research Administration and the Northern Alberta Clinical Trials and Research Center.

Best efforts should be made to anticipate ethical considerations at the start of a research study and should be ongoing especially within emergent design studies such as ethnography (Hammersley & Atkinson, 2007). This study presented a minimal risk to the participants. Still, due to the nature of long-term observation and the vulnerability of participants, there were several areas that required careful ethical consideration, including informed consent procedures, confidentiality, the inclusion of people living with dementia, working with family caregivers, entrance and exit strategies, and researcher positioning.

Informed Consent

Informed consent/assent was obtained from participants living with dementia (Appendix K, L, M, N), family participants (Appendix O), key informants (Appendix F) and day program staff/volunteers (Appendix P). In addition, I prepared a parental consent for any minors that are part of the family unit (Appendix Q) but did not encounter any children during the study. Where a person was deemed unable to sign consent legally, a guardian or proxy consent was obtained. As discussed earlier in the participant section, passive consent was obtained from day program participants who were present during observations at the day program. A joint consent -assent protocol (Appendix L) was followed based on work by Batchelor et al (2014) using either a written (Appendix N) or verbal script for assent (Appendix M). Assent was gathered before and during each interaction with the person living with dementia and any day program patients. All participants were given the option for ongoing consent to participate and withdraw throughout the study (Hammersley & Atkinson, 2007). Additionally, the confidentiality of information received and anonymity of information used was ensured to participants during the consent process.

Research with People Living with Dementia

While including people living with dementia in research is important for their perspectives to be heard, it requires sensitive consideration during study planning to ensure safe and ethical participation (Alzheimer's Europe Report, 2011; Hellstrom, 2007; Slaughter et al., 2007). Dresser (1994) points out that previously involvement of people living with dementia in research was limited due to the focus on competence criteria for decision-making. Dresser argues that this resulted in the potential contributions of people living with dementia's thoughts, experience, and emotions being overlooked in clinical research. Often through a desire to protect subjects, the inclusion of people living with dementia in research has been represented through proxy accounts from family caregivers. However, there is now recognition that family caregivers' views may not necessarily represent the person living with dementia (Slaughter et al., 2007). A recent finding by Toot et al. (2013) found significant differences in the concerns and priorities of family caregivers compared to people living with dementia, more so than between professionals and people living with dementia. Addressing the need for just access to participation in research is important and can offer both direct and indirect benefits for people living with dementia (Alzheimer's Europe Report, 2011; Alzheimer Society Canada, 2018), but this also requires ethical sensitivity and methodological considerations through the research process.

In this study, the participants living with dementia were unable to consent to research legally. Assent protocols (Appendix K, L, M) were designed using Slaughter et al.'s (2007) helpful guidelines for assessing assent from people with moderate to severe dementia, which included: creating a sense of comfort and ongoing monitoring of willingness to participate and paying attention to signs of dissent or distress. Verbal consent was sought from guardians to hear more about the study through an initial phone call; then, an initial home visit was arranged if they were interested in participating. At the home visit, study information was reviewed and consent was obtained from the family members first, and then assent was confirmed with the person living with dementia. All participants except for the person living with dementia in

Family 4 attended and were included in the initial information and consent gathering visit. For Family 4, I met first with the family member who was the legal guardian and obtained consent, then had a visit with the person living with dementia where the joint-assent protocol was used (Appendix K). Assent and dissent were communicated verbally or inferred from behavioural cues. The specific issues with cognitive impairment and diurnal variations in orientation and perception for the person living with dementia meant that assent had to be considered situationally. I withdrew several times from observations at Day Program B due to signs that one of the participants living with dementia was not pleased with my presence. In each home visit, I would reintroduce myself, my purpose and the study to obtain assent. Before, during, and after interactions and as part of assent processes, I paid attention to the people living with dementia's communication capability and style, their focus of interest regarding time and place, level of anxiety, and processing capabilities (Hellström, 2007). To ensure I was reading assent cues appropriately with the participants living with dementia, I sought guidance from family and staff regarding preferred interaction preferences. Specific to fieldwork recommendations by Heggestad et al. (20137), I took time for relationship building and consideration of safe contexts, use of language, and preservation of privacy during observation and conversations. Because of my presence across contexts for the person living with dementia, I was careful not to disclose personal information they had shared with me at home unless initiated by the person living with dementia first.

While direct benefit from the study for the people living with dementia in this study is unlikely, there may have been indirect benefits in describing experiences and contributing to further understanding of care. All participants appeared interested in my research and my status as a student. Exit strategies included communicating to the people living with dementia the value of their contributions for the study (Alzheimer's Europe, 2011; Hellstrom, et al., 2007).

Research with Family Caregivers and in Private Spaces of the Home

Families of people living with dementia are known to have higher levels of stress and depression than other forms of caregiving (Gaugler & Zarit, 2001). Recognizing this was important in conducting research in a way that minimized any additional stress on the family caregiver. Additionally, the intrusiveness of observation in the private home was essential to consider. This was managed by having short periods of observation, asking for family preference for scheduling and location within the house, and ongoing permission seeking as well as continuously negotiating consent, and reminding family participants that ending a period of observation and withdrawal from the study was acceptable at any time. Because of the time I was spending with families who have a high risk of being socially isolated, over-attachment to me as a person and health care professional was a likelihood. Exit strategies and boundary maintenance were essential to minimizing the harm resulting from feelings of abandonment upon the termination of the fieldwork. I had ongoing discussions with family members and people living with dementia about the study end date and was intentional in my maintenance of role boundaries during the study. Often families asked me for advice, and when this happened, I was sure to refer them to the appropriate people within their support network who would be able to provide resources and follow-up (e.g. family physician, day program staff, home care case manager). At the end of the study, the family of Participant 3 suggested that I continue to visit the participant for social reasons, so I explained that this was not possible as my role as a researcher required that I complete the visits with the end date of the study.

Entering and Exiting the Field

In any methodology that includes fieldwork, there are tensions in entering and exiting the field (Yanow, 2012). Smith and Atkinson (2017) argue these tensions are more than procedural or ethical issues but are fundamental to the embodied nature of the ethnographic method. Fieldwork requires forming attachments and bonds and this is how one comes to understand the social knowledges being used (Goffman, 1989; Hammersley & Atkinson, 2007). Entering the field required a period of relationship building where I worked to clarify the participants' expectations, negotiated my positioning, and attended to impression management (Hammersley & Atkinson, 2007). Impression management included considering the effect my forms of dress, speech, or demeanour had on participants and the resulting positioning of me within relationships with them (Hammersley & Atkinson, 2007). There were challenges related to the use of multiple sites in trying to anticipate where practices might be followed, as well as consideration of the shifting personal positions, which occurred for me in each site and situation (i.e. home, day program, public spaces, cases of a medical emergency) (Marcus, 1995).

Similarly, exiting the field is a critical part of ethnographic work for the researcher, the participants and the research findings, and therefore requires planning and ongoing negotiation (Goffman, 1989; Smith & Atkinson, 2017). While setting clear boundaries is essential, the reality of the messiness of fieldwork, its social, physical, emotional and cognitive nature, can make exiting more challenging than expected (Smith & Atkinson, 2017). To address these sensitive times of the research process in both an ethical and methodologically informed way, I was overt in my role as the researcher with participants, clear about role expectations and finite quality of the study, provided both verbal and written appreciation for contributions, and promised to share information regarding research dissemination with participants (Hammersley & Atkinson, 2007).

I also reflected on my own feelings about exiting and the tensions I felt and included these within my reflective journal.

Chapter 4

Introducing the People and Places of the Study

This study took place across several sites including homes, day programs and community settings in a mid-sized city region in western Canada. This chapter briefly introduces the study participants living with dementia and their families whom I followed across sites. Their stories are told in much greater depth and detail in subsequent chapters, especially Chapter 6. The study sites – Program A and Program B – are described in some detail here to provide a clear context for the analysis contained in the ensuing chapters.

The People

Participant One: Jan & Louise

Jan is a 90-year-old man who is a lifelong gymnast and writer, his wife Louise is a 65-year-old woman who is an avid hiker and bridge player. Louise works part-time in retail a few days a week. They have one daughter named Helen, who lives in the same city with her husband Sam, and their seven-year-old son Michael. Jan also has five children from his first marriage; one son Geoff lives close by, and the rest are in other cities and provinces. Their home is a two-bedroom condo in a building on the edge of the city, in a mixed business-residential development. At the start of the study, this was a new home and neighborhood for Jan and Louise as eight months prior, they had moved from their previous single-family home of 25 years. Before the start of the study, Jan had been experiencing problems with his short-term memory and problem-solving over the past five years and had been diagnosed with dementia for two years. Jan spends most of his time at home doing puzzles and working on writing a danish translation of his life story. At the start of the study, Jan attended a day program (Program A) once a week for a month.

Participant Two: Wes & Margaret

Wes is a 98-year-old retired telecom engineer, teacher, and musician. Margaret is a 90-year-old woman who previously worked in a science laboratory and has been married to Wes for 66 years. They have three children; one son Rob, who lives in the basement of their home and another son Mike and a daughter Sheryl who live within a 30-minute drive. Wes and Margaret live in a bungalow that has been their home for 60 years. The home is located in a residential area of the city in a neighborhood with houses of similar styles and ages. Wes was diagnosed with dementia eight years ago after Margaret noticed he was having memory problems. Wes has significant short and long-term memory loss and requires assistance with his daily activities of dressing and bathing. He is verbal, often sharing 'one liner' type jokes and still plays the keyboard daily. Wes began using the day program (Program A) eight years ago, and two years ago, Gwen decided to join him there. They both attend the day program three days a week.

Participant Three: Peg

Peg is an 86-year-old woman who was widowed two years prior to the start of the study. She has four children; two sons Ron and Bob that live nearby, a daughter Vicki on the west coast and a son Mike in the US. Peg's home of 50 years is a large two-story split-level house located in an older neighbourhood in a city suburb. Peg lives in the home with a live-in caregiver Gwen. Peg is a petite woman with a dry sense of humour and a fantastic ability for crossword puzzles. Peg began having memory and planning problems about five years before the start of the study. Her family gradually noticed small things, like her misrecognition of people and places and some issues with organizing tasks and routines. At first these memory issues seemed manageable but after the death of her husband, the family became more concerned about Peg's social isolation and safety. Gwen helps Peg with meal preparation, housework, and provides some supervision to Peg with bathing and dressing. She began attending the day program (Program B) two days a week and had been there for almost one year at the start of the study.

Participant Four: Marie & Darren

Marie is a 68-year-old woman who is a former music teacher and basketball coach. Her husband Darren is also 68 years old and is a retired psychologist. They have been married for 40 years and have three children; one daughter (Sarah) who lives in the city, one daughter (Jen) who lives five hours away and one son (Kevin) who lives in another province. They live in a large two-story home in a newer residential area of a suburb. Marie began experiencing memory issues in her early 60's and was diagnosed with early-onset dementia at the age of 64. Marie is a physically active person who enjoys golfing, walking and any sports-like activity. She plays the piano, and the cello at home and is often on the move exploring her environment and collecting small objects as she goes. She has limited verbal ability and communicates with gestures, facial expressions, sounds, and sometimes phrases. She is independent in her dressing and toileting but requires prompting from Darren for changing clothes, showering, and at times she wears several layers of clothing. At the start of the study, Marie attended the day program (Program B) two days a week for one year.

The Places

To familiarize readers with the specificities of each day program that I will be drawing on in the ensuing chapters, I introduce the day programs here by describing their space, typical activities, goals, the people of the program and formal and family care interactions.

Program A

Program A is a seniors' day program that is a mixed type day program, meaning it includes people with cognitive impairment and those without. It is located within a community seniors' centre in an urban setting. A non-profit seniors' care agency operates the program in conjunction with the local health authority. The seniors' centre is situated in a mixed residential/commercial area of the city that has many senior living apartments and assisted living facilities. It is set in a park-like setting overlooking a large man-made pond and walking trails. The facility is a single-level building with three main hallways leading to various activity/meeting rooms, a cafeteria, and a large walk-out deck. The centre holds a variety of recreational, arts, and educational programming. They advertise themselves as a community hub where "people over 55 can drop in and connect with others." Members join the centre for an annual fee of $30 and then can register for programs, lectures or drop into different services or the cafeteria. While located in this centre, there are significant separations between the spaces of the centre and the space of the day program.

The Space of the Program

The day program is in the basement of the centre. The day program is not affiliated with the seniors' centre, instead, it simply rents space. People use the senior centre's main entrance doors for arriving but then are met and escorted by staff down the hall to what is labeled a 'handicapped elevator' to get to the day program space. There is also a long flight of stairs that lead to the basement near the centre's back door, which are usually used by staff and some visitors. The door at the top of these stairs has a few signs telling people that the day program is in session and not to disturb or bring germs into the space (Figure 4.1).

Figure 4.1

Signs of the Entrance Door to Program A

The day program space itself is a large square room and there are windows on one wall that look out to the pond and park and a small deck space. Three rectangular tables with approximately eight chairs at each are located along one side of the room, leaving a wide-open space in the center of the room. Participant artwork, maps, a whiteboard, and shelving units line the walls (see Appendix R for a floor plan). I observed only one occasion where the clients went outside to the deck and that was when two men specifically got up and went to the door and asked, and then insisted, to be allowed out, despite the staff's attempts to convince them otherwise. Staff contained this visit to the deck chairs to five minutes before luring the men back inside for dessert. This program does no outings into the community and the manager explains that they prefer to bring the community in for reasons of privacy, dignity, and in an effort to decrease stress.

The program is open from 930am -3pm Monday to Friday and holds 22 people per day, with most people coming one to two days a week with a few longer-term clients attending three days a week. The program is funded by the non-profit organization, the health authority and people pay $10/day to attend with the rest of the cost of program operations covered by the provincial health insurance plan.

The program manager explains that the staff are all either personal support workers or like her, health care aides. The non-profit operates three day programs in different locations around the city and a caregiver support group. The programs operate in conjunction with the regional health program's Continuing Care division, meaning that they are subject to some of the formal health organization's policies, and intakes are coordinated centrally with the other 13 day programs operated under the health authority.

A Typical Day

On a typical day at Program A, there are four full-time staff present and between 17-22 clients. All activities are done in a group format at either the tables or in the central floor space of the day program. Depending on the activity, the chairs are moved back and forth between the open space and the tables by the staff. The daily schedule of the program is set by the manager each month and includes routine type activities with different themes depending on the season or day. Calendars of activities are sent out to families to inform them of what their family members are doing at the centre and these act as the primary form of communication between home and the day program each month. Each day, the staff rotate responsibilities for leading each activity, assisting with clients' participation, providing refreshments, lunch, and mobilization assistance to the clients.

Most days have the same routine. The staff arrive at 9 am and get ready for the day by checking the schedule and gathering supplies. Clients come between 930 am and 1015 am, dropped off by family or the local public transportation system for seniors and people with disabilities (DATS). Staff arrange themselves to receive the clients with two people upstairs and two down. One staff at the front door greets clients as they arrive and escorts them down the hallway where the other staff takes over and guides them to the elevator. Staff communicate with each other about arrivals through a walkie talkie system. The main entrance of the seniors' centre is a busy place with many people coming and going to different classes. The supervision of the clients is seen as important risk management in that they ensure the clients get to the right place and "do not wander away."

Once the clients arrive downstairs, they are greeted by other staff and coats are hung up and nametags are put on. Clients find their way to their particular spot at one of the tables as the staff bring them a warm drink. "Hello! Coffee with two sugars, right?" is a typical greeting.

The day's events are listed on the whiteboard, usually listing this time frame similar to the one shown below, with the items highlighted in yellow being the activities that change each day:

0930-1030 Client choice

1030-11 Who, what, when?

11-1130 Card bingo

1145-1215 Fun and Fit

1215 Lunch

1-130 Walking club

130-145 Ring toss and curling

145-215 Snack

215-3 Greatest Moments in Sports

3-330 Departure

The first hour is the client choice activity, which translates into people getting settled at their table and colouring, doing a word puzzle, or reading a newspaper while having their warm drink. At one of the tables, a tile rummy game is always set up during this time and facilitated by a staff member. The room is often quiet initially during this first hour. As more people arrive staff begin to facilitate more interaction. At 1030 the more structured activity begins and continues through until lunchtime. Lunchtime takes an hour and is followed by a walking club that takes place within the room, then a game-type activity and snack. Pickup of clients begins between 230 pm and 330 pm, resulting in no hard ending to the day rather a gradual dispersal during the final activity in a similar fashion as their arrival with staff using walkie talkies and escorting people to the front entrance.

Activities are usually quiz-like games or discussions around a particular topic like bugs, tiny homes, or musicals. Games are card-games, bingos, and a variety of chair adapted sports like chair hockey or soccer. Once a week, there is some special activity with an ‘outside’ guest coming in for music, lecture, or demonstration. The activities are often routinized by staff in their rules, use of the room space, and placement of bodies. The clients also take part in maintaining and resisting the program's structure, cueing staff of breaches in the schedule, or the behaviour of others, refusing to participate or challenging rules.

I observe the program on two different days (Wednesdays and Thursdays) following two different clients and note while staffing, activities and routines are exactly the same, the groups differ in their relations to each other and the staff. Staff tell me that Thursdays are the “high cognitive” group, which I find out means that there are less cognitively impaired people in it. There is also a difference over time in the group's makeup on Thursdays as more new people arrive to the program and others leave. Over the nine months I am there Thursday’s group shifts from a gender-balanced group to a predominantly male group (17 men/22 people).

People Attending the Program

A variety of people attend the day program, each with different personalities, backgrounds, interests, and reasons for being there. Most tell me they come because of some kind of change in their lives or bodies that has resulted in social isolation or increased stress on their caregiver: loss of a spouse and a move to a daughter’s house, mobility issues, dementia, hearing impairment. “I come here because it gives my wife a break from me,” Vinny tells me, “and the soup is good.” Helen explains, “I can’t see anymore because of my ‘wet macular,’ so I can’t do much,” and then later on she seeks me out to say, “I don’t know what I’d do if I didn’t come to this program… I’m serious I don’t know what I would do.” Phyllis, a new client, tells me, “My husband died, and my daughter was worried about me.” “My body is good, but my head is gone,” says Bob, a man living with dementia. While at first I had difficulty seeing the individuals present within the group activities and the staff’s practices to make everything standardized, the individuals did emerge; their stories, tastes and personalities came through in relation to the other people, practices, objects of the program sometimes in harmony and at others in conflict – a tension always present and perpetually managed by everyone present. Thus, at times the program participants looked passive and disengaged, perhaps even asleep, and at other times they appeared as a rich community of people tied to the place of the program.

The manager tells me that there is no real process to the placement of people within the days of the program as the “spots” open and are filled as necessary off the waitlist. The programs are usually matched to a client by location and needs. The manager, Sue explains that Program A is a considered a “wellness” type program, which she tells me is related to the type of services they provide: “our goals are always related to physical, social, cognitive, and psychological wellness.” She explains that some of the other programs in the region are more rehabilitation focused and will include occupational therapy and physiotherapy services. The criteria for admission to this program is that people can socialize independently. There is some arrangement of fit between people within the seating arrangements at the tables, and if needed, people will be switched to another day if there seems to be a personal conflict with other group members.

Goals of the Program

The day program’s services are targeted to meet the goals of the client related to four different domains: social, leisure, physical and/or cognitive. Staff and documents of the program reinforce to me that the main purpose is to “prevent decline” and “to maintain” functioning in these areas. While programming is universal and not tailored to the particular client’s needs/goals/likes, the staff track clients in their daily participation. Each day a staff member is assigned to fill out a tracking sheet rating a client’s participation on a three-point scale. Trends in this tracking are monitored by the manager, who looks for signs of decline and then speaks to family or home care to suggest reassessment, increased supports, or changes in attendance schedule. Formal care planning is done in a routine way meeting the requirements of the larger health system policies for person-centered care. This routine includes a review of the functioning of each client on a set time frame (1 month, 6 months and 1 year), a verbal request for input from the client as to whether they would like anything changed and a copy of the care plan sent home to family. Informal care planning is done ‘on the fly’ as the staff observe and respond to client behaviours and requests, the group's relational dynamics, and family requests. Paper charts exist at both the day program and the central office and reflect only the formal care plan charting and unusual events.

Family and Formal Care Interaction with Program

During my observations of the entrance, I notice brief interactions between staff and family at drop off and pick up time, usually family occasionally mentioning a change in pick up time or mode to the staff. The program manager, who was located in an office that was off-site but nearby, has most of the in-depth conversations with family doing the initial intake and fielding any calls with family concerns that would then translate to staff via text messages/phone calls during in-person visits. DATS staff also connect with the day program staff here, checking in with them regarding missing bus passes, walkers or clients that were not home for pick-up. At Christmas time there was a Holiday party held off-site for families and clients of the all four of the non-profit's day programs in the Edmonton region.

Program B

Program B is a day program located in a suburb of the city in a small community hospital's outpatient building. This program runs two 'tracks' of programming, a med-rehab program offering rehabilitative care for older adults with chronic conditions like stroke or heart failure, and a cognitive impairment program for people with dementia. Many spatial and administrative practices work to maintain the divide between these programs, yet staff frequently cite the difficulty in locating some clients within only one of the group designations. Similarly, while I focused most of my observations on the people in the cognitive impairment program, it was impossible not to engage with the whole program.

The Space of the Program

The program is organized within a large space with many different rooms. A large main room is where the med-rehab program takes place and also any combined group activities. The Oak Room is a smaller room where the cognitive impairment day program takes place. There are winding hallways that contain several staff offices, a quiet room with reclining chairs, a 'treatment room' where rehab professionals do their assessments and therapies, and several storage/craft rooms. These hallways form a loop-like path that is typically used for both structured and unstructured 'walks.' There is a small, enclosed courtyard space outside that the program shares with the hospital. Here in this space, the program has several gardening boxes maintained by the clients, and there are a few picnic tables and a small patch of grass next to the parking lot where clients sit and do activities outside (see Appendix S for floor plan).

The staff make use of all of the space of the program and often complain about its limitations. I see them playing lawn bowling along the small strip of grass next to the parking lot. Stored in the many nooks and cranny of the room are plants growing for the plant sale, and in the fall, there are crafts for the Christmas sale stored everywhere. There are field trips out to the community - a bus trip to a greenhouse for a walk and coffee, a bus tour of the local farms, a trip to the mall for Christmas shopping and lunch - all of which require more creative use of space and materials. These outings are exciting for some clients and anxiety-provoking for others. They are certainly labour intensive for staff; barriers seem to come up in these public spaces requiring negotiation and adjustment –buses have no room for wheelchairs and walkers, supervision for bathrooms is a challenge for an all-female staff, and cafés don't appreciate 30 seniors 'loitering' for too long without spending more money. Some outings lead to reactions in clients that extend into the home afterwards. At the same time, staff see these outings as “being part of the community,” a form of inclusion in the wider world.

The program is designed for 18 people in the rehab program and nine in the Oak Room, although it often runs with a higher rehab program census (up to 22). In the last year, the program began offering an extra day of programming to include Mondays and created 20 spots for older people living in the community with chronic conditions requiring “social stimulation.” The program serves the defined geographical area of a small suburban city. An interdisciplinary team of recreational therapists, recreational aides, a registered nurse, a licensed practical nurse, occupational therapist and physical therapist, a unit clerk and a complement of regular volunteers staff the program. Like Program A it is part of the larger health system’s day program service administered under the Continuing Care program. Unlike Program A this program is not affiliated with a non-profit but is related through shared space to the community hospital, bringing particular policies and connections that shape its practices.

Program B costs $10/day per client but also does fundraising initiatives on its own to raise money for events and activities seen as ‘extra’ to the basic service funding. The fundraising events include a spring ‘cakewalk’ and plant sale and a Christmas craft and bake sale. These events involve all of the program clients and staff and families and require months of planning and preparation that are included in the clients' daily activities. The program also holds a client council once a month where members of the med rehab program and some Oak Room participants help make decisions on group outings and resolve any conflicts. Agnes, the manager, tells me that “it works to get client input as to what field trips they should take and usually keeps conflicts to a minimum for about three weeks and then they usually start up again.”

A Typical Day

The program runs from 9 am-3 pm Monday to Friday. Most people attend two days a week. The day begins with clients arriving either by the local seniors' buses or family bringing them into the main room where coffee time occurs at two long tables. Once everyone has arrived, the staff tell the clients, "it is time to go for a walk." This is a routine that is used regularly throughout the day to meet the clients' activity goals and give the staff space to rearrange the furniture supplies for the next activity. The staff have incentivized these walks for the med rehab participants by using a "trek map." The group works together to walk around a certain country like Italy by tracking their steps each day in line with specific destination goals on a map that is on a bulletin board in the hallway. There is a celebration lunch at the end of the 'trip,' and the group chooses another destination. The Oak Room participants are included in the walks' routine and sometimes even tracked as to how many laps they perform a day on a program form. Oak Room clients are invited to the special lunch but not included in the mapping exercise.

During the morning 'walkabout,' clients are guided from the main room through the hallways to the Oak Room, where they will spend most of their time. A set schedule exists of activities created each month by the recreation therapist with input from the staff. Families receive a copy of this schedule as a form of communication about what is going on at the program. The staff refer to the calendar posted at the desk in the Oak Room to guide their day, but it is not posted anywhere for participants. Morning activities include an exercise group, followed by a walk and coffee time, then a cognitive stimulation game such as word-finding, math puzzles, and a group game. Lunch is served in the Oak Room usually unless there is a larger group lunch event (which seems to happen at least monthly). After lunch hour accompanied by music, the group begins a craft activity followed by a snack and then a discussion-reminiscence activity that leads into the pickup time.

Throughout the day, there is ongoing management of little ‘events’ that has to happen here in the Oak Room along with the activities; these events are incidences of unsteady gaits, falls, occasional incontinence, unwelcomed physical contact between clients, ‘collecting’ of objects, verbal or physical conflict between clients and unusual use of food and cutlery that require ongoing monitoring and creative intervention. By lunchtime each day, there are usually a couple of people trying to leave and go home– often getting their jackets on and going to the door- needing to be distracted and soothed.

People Attending the Program

The clients of the Oak Room are a group of eight to nine people each day, all with dementia and a range of memory and verbal capacities. Three women are the regular staff in this room - two recreational aides and a recreational therapist. Most of the team have worked at the program for more than ten years. Staff are all outgoing, and the noise level is high at this program, with many side conversations going on, staff often joking, teasing each other and clients. The clients interact in various ways, sometimes directly through conversation and care for each other or sometimes only as familiar faces helping them orient that they are in the ‘right place’ as they move around the program. Often, I hear the comment “Oh, she/he looks familiar” as I walk the hallways with different people. Clients also seem to join the staff in joking with each other and the staff as well.

Goals of the Program

Staff tell me they see the program as serving two purposes equally - providing respite to families and offering ‘engaging activities’ for older people. Staff tell me they design activities to help people stay engaged and meet any goals they might have for themselves; as one of the staff tells me, "often people with dementia tell me that they can't do anything anymore that they used to do… they lose confidence… I like to see them try new things and succeed and see what they are capable of still." Staff work to tailor the activities to the abilities and interests of the clients. For instance, Peg is a woman who typically scoffs at the idea of crafting, so she is included in helping staff with sorting supplies or preparing material but isn't pushed to participate with the craft. Roy, a former farmer, is engaged with more tool-like tasks such as painting or sanding or pouring cement into moulds. Other activities require more adaption, such as cognitive games and discussion groups for people who have limited verbal ability.

Staff in the Oak Room use a leisure profile to guide most of their approaches to engaging with clients – the staff complete the profile through a family interview about the person living with dementia's life history, tastes, and preferences. There are more formal care plans documented in a chart on admission that include goals for various domains: social, physical, cognitive. The care plans are updated annually and signed by the client. Outside of initial assessments, the staff document little other than significant events like falls or medical crises (fainting, non-responsiveness). Instead, staff discuss ideas and tinker with how to best engage or manage a client in the moment, in brief discussions at the end of the day and during weekly staff meetings.

There is much monitoring here by the nurses and the rehabilitation staff - monthly weights, weekly blood pressures, daily blood sugars, fall risk assessments, and walker assessments. A foot care nurse is brought in monthly to provide foot care/monitoring to those whose families request it.

Family and Formal Care Interaction with the Program

Families have variable contact with the staff. Paper flyers with monthly calendars and special event announcements are sent home with clients, but it is not unusual for staff to find out that family missed seeing these messages. At drop off and pick up times there are often a few family members present in the milieu chatting briefly with staff. Families are invited to the program various events at the program held over the year for fundraising and holiday celebrations. Problems are discussed on the phone with family or assisted living building administrators concerning transportation or attendance issues. Staff communicate health concerns to the family members at pickup or to the home care case manager. Like Program A, home care communication is often one-sided in that the day program initiates it but receives no follow-up communication from home care. Similarly, notification is sent by the program to the client's family doctor about the client being at the program, and occasionally doctor's lab test orders are done at the program, but they are not included in communication back from the doctor's office. Staff tell me they often don't know what is going on outside of the program, and it is up to families to tell them. The program nurse is the key liaison between home care and the family. Intakes come through home care to her, and she triages them for the waiting list based on the caregiver's situation.

Findings

Note for the Reader: Like any written document this dissertation has an infrastructure created through a relation of ideas. This infrastructure sorts and organizes the ideas into discrete yet connected units designed to function in a particular way to deliver the story of this research study. The previous chapters set the groundwork for the study and now in this section the findings are analyzed. These findings are presented in a format of three chapters as well as four "Interludes" where I have included my reflections on the process of the analysis. They are meant to exist in-between the chapters, not in a space-filling sense but as mediators to the analysis. Within these interludes I work through how I am trying to approach the data thus providing some transparency to my analysis. Like interludes in music or theatre composition, they work as part of the larger composition partially connecting and at times doing the work of the analysis.

Interlude 1

Approaching the Analysis: Thinking about Thinking

If we want to think about the messes of
reality at all then we’re going to have to teach ourselves to think, to practise,
to relate, and to know in new ways (Law, 2004, p.2)

Here I sit amid a pandemic – at my desk staring at a blank screen thinking of how I can start this dissertation. I’ve read my data and gone back to my books hoping for a clear beacon of insight to write about, something profound and illuminating to share with others that makes sense of what I observed in the field and in the numerous interviews and artefacts I have analyzed. Of course as part of this quest I have reorganized my home office – sorted all my books and notes, created new shiny folders for the data, read 3 books on ‘how to write a dissertation’ and yet here I sit waiting for the perfect start to emerge. I have been in this exact position many times in the past two months, perched over my keyboard, notes, checklists, and the perfect mug of tea within reach, yet each time I intend to start I seem to either stop myself by deciding to check the data or one of my favourite theorists again (it helps that they continue to publish) but more often than not I am distracted by the inconvenience of other people – my family who are at home with me now as our world has become so condensed, not the original plan for the writing of this masterpiece, but a reality all the same. My colleagues send emails that beep on my computer, my husband comes in to ask questions about a home improvement task he is trying to complete, my son comes in and shares his excitement about his latest tiktok video, my daughter asks to fly a kite that she recently found at one of the only stores open right now, then my parents call to update me on their latest breach of public health advice. So the *work is in pieces, it starts and pauses, stalls and then emerges humming at the back of my mind as I literally fly a kite, take the dog out for walk, or take a impromptu picnic and occasional moments like right now when I have time to sit at the computer. I realize now after 4 years of doctoral work, where I worked valiantly if not successfully to compartmentalize my work, studies, and family life, that the irony is that this is actually the place that this work will come from… and more importantly this is actually what this work is about. This contaminated messy space of people, materials, and ideas moving in relation and against each other all with competing demands. There is no purity here, no ideal, and despite the constant image of what 'should be' I know this 'just is' as it is. And perhaps this is the lesson I wasn't looking for in my doctoral work, into which I entered more in a state of wanting to succeed "despite" my age and caregiving responsibilities. This is life and care entangled and inseparable and there is no solution that will "fix" this way of being, it will continue to ebb and flow, full of partial understandings and no wholes, as I find ways to go on with both, tweaking schedules, roles, objects, adding people or ideas in and stepping away from others.*

This is generally what I saw in the field watching how people living with dementia and their families used day programs as a part of their day to day life. As part of how they "went on", so to speak, with the changes that dementia brought to their lives. This "going on" was not a intentional strategy that could be isolated and purified into a psychological or cognitive construct, such as a coping strategy easily modeled and included in a caregiver education module, but instead was an ongoing practical accomplishment achieved through the relations of many actors including spaces of community, home, objects, people and discourses of care and ageing. The day program was a particular kind of space for each of these families that involved particular practices to fit it into their entangled arrangements of life and care. Like my life and *other's, these arrangements are not pure or solid in consistency or effects, they are fluid and adjusted in little ways by the family, the person with dementia, or other actors. And rather than fixed spaces sealed and separated away from the home, the day programs themselves are entangled, as Anne Marie Mol would say, with other practices of care and life, those of the home, the community, and other formal services. These practices come together in different ways or in what has been called 'modes of syncretism' (Law et al, 2013) that lead to certain goods being achieved.*

While looking back at my proposal I can see some of the work of the progress narrative shaping my somewhat lofty question of "How do day programs work as care in the community for people living with dementia and their families?". I can't help but wonder about what I was thinking at the time, undeniably full of what seemed like original ideas of how research on things like day programs "should be done" and what day programs "should do." While my question was open and broadly suitable for my methodology, I still suspect now that I thought I might actually find some kind of homogeneous answer. Something tangible and innovative for understanding how something like a day program, as a programmatic approach to managing the 'problem' of dementia might work or more likely not work as a universal solution for particular lives. So I try and look at my data and consider some way of smoothing the differences between my case studies to provide some answer that could fit within the normative traditions of my discipline. This thinking exists alongside 4 years of reading otherwise. Strathern, Mol, Pols, Moser, Law, Ceci, Purkis, Tsing, and others have certainly taught me about the partialness, and the heterogeneity, and the assemblages that are often overlooked or buffed out in analysis. My data itself does not lend itself to smoothness, as I try to write case studies that can briefly and richly capture what I have seen in the many hours of observation, people, sites, forms, and *objects involved. So what is it about these practices of purity that seem so appealing yet obviously insufficient? What are the risks in not providing purity in my conclusions from this study?*

After two months in the field I realized that it was not going to be simple to see the relations between home and the day program and the impurity of it all struck me as significant. And perhaps it wasn't that surprising to me that things were non-coherent (I am reminded by Law and others (2013) that this is not the same as incoherent) but that people seemed to still find a way to go on in this mess in such particular ways that worked a bit - reflecting on this early on in my study I knew I did not want to paint yet another picture of a failed system nor one of a hero-type carer that endures despite. So how to talk of this?

There was a sort of boundary evident in the type of care that programs could provide, effects of the logics of routine and containment that seemed to dominate. But these were not coherent and pure, they coexisted with the ones of active engagement, inclusion, and quality of life. As expected, this range of logics did not seem to exist only in the day program itself, they permeated through the larger community, home practices, and care policy discourses.

The gaps between my pre-defined sites of care in the home and program were obvious, yet at the same time I noticed that the day programs did do good things at times and in relation to the spaces of the home and wider community in which people lived - they were at times a rare space of inclusion. And to talk of the programs as one is not to do them justice, it is a product of my 'smoothing' – each program was a particular kind of space enacted through particular socio-material practices, the apparent durability of these practices took work to maintain, they interfered and collaborated with other practices in the family and community life, and at times exposing the local limits of what a life with dementia could be.

What is at stake that will make my intentions to not offer a clear conclusion of what day programs do, worthwhile? While never my intention to use my method to offer solutions, if I don't offer common insights or "take aways" for day program planners and staff, what am I actually doing here? What is my research actually about? Hearing one of my supervisor's voices in my head, I remind myself that it isn't necessarily day programs but rather the ideas of care in the community and how these materialize in solutions like day programs that I am really working with. This is about the possibilities of care for people living with dementia living at home and ways to think about it. As Haraway says "it matters what ideas we use to think other ideas" (2016, p.12). So what ideas to use? Most of my work in this study was seeing and thinking about the ways in which practices of care in the community come together, how they are kept separate, and what the effects might be. As Stengers (2005) points out there is politics at play in how different practices are assembled and how they meet. The goods that result can be enacted through these politics. The challenge in observing day programs within family arrangements of care was to join in the practices as they were, not reducing them for the sake of finding sameness, not to compare the cases or the programs but to use an ecology of practices as a thinking tool (Stengers, 2005), to see the divergence of practices that come to meet between the home, other carers, and the larger communities with which lives are lived and in showing this consider how they might be becoming.

I also have to think of my subject now in light of how the current pandemic shifts what a day program is and how it is valued. Progress narratives are easy when it is more than survival at stake. Seeing the limits of day programs and how they 'should be' did not require much effort during my observations. Working to see them from a less normative stance was constant work for me although the longer I spent in the community the easier it was to see how these programs *became what they were in relation to what everything else in the community wasn't for people living with dementia. Now due to the pandemic and the related social distancing rules, day programs are 'on hold'. I can only assume that now my former participants have only their home-based supports in place and likely even those have been limited. As imperfect as the day programs were, I now can't imagine any of families dealing with the loss of the resource. For while I can certainly say that day programs were not usually enough, they were for sure something and on occasion something good. Is it fair to use the current void of community-based care as part of my analysis? But then how can I not?*

This thinking brings me to the limits of care and how care emerges in conjunction with other practices, managerial, public health or otherwise….shifting not ever stable as evident in my study with the regional health system's shift to new managerial frameworks, new priorities for filling day program spots in a systematic and distributed way and the limits this could bring.

What is easy to see in the data? Space mattered in many ways- care was spatialized and separated from other parts of the arrangements. The space of the program was maintained as separate. The 'spots' of the program were treated as simple spaces to be filled -interchangeable, non-relational, producing a sort of place-lessness to the program. Outside of the program there was also a firmness of boundaries around space that was available in the daily lives of the people in my study and this materialized into much of what the day program was for them. Each family described a shrinking world that they had access to and part of understanding what day program was to them was to understand it in relation to the other spaces available to them. Watching a person entering into the program slowly adjust to the people and find his 'spot' at the right table, with the right people, adjust the activities to his own likes and dislikes, all the while the same was occurring in a variety of ways in his life outside the program – adjustments *being made to spaces he could go, people coming and going, activities shifting in response to the changes that dementia brought as well as those that were anticipated. Bister, Klausner, and Niewöhner, (2016) would say it was in this 'niching' work that the day program became part of, the making of a liveable life. This niching wasn't confined to the families and people living with dementia – the program themselves had to find a way within the larger community in which they lived- quite a difference between my two sites on this- one trying to extend out into the community and one trying to provide a safe haven away.*

It was often difficult to see connections between home and day program specifically and this was perhaps a naive view of mine as a novice researcher in planning my study. I assumed the precise connections would be easy to distill and capture. Instead there was a vagueness to the connections which was telling and often I found myself being seen/used by participants (program staff and families) as a potential conduit between home and family. This wasn't a case of just the program not connecting to the home; there was symmetry to the practices of division work in all the sites to keep home and day program and other services separated. My data can show the practices of how families get enrolled with understanding the day program as a certain type of care, and a certain type of space relied on for certain things and not others. There are examples in my data where the permeability between sites was evident for which work, and rearranging was required for the practices to come together.

Many spatial terms have come to my mind during my time at the day programs – containment, sequestered, bounded, control, exclusion, and the work to maintain these states was easy to see through the processes, documentation, materials, and rules. At the same time this closed off sequestration was not pure and impermeable. It leaked, became porous, at times with intentional effort and at other times without. Connections, community, inclusion were also *present and contaminated the supposed enclosed space. Rarely in isolation would one be more apparent than the other but the conflict between them was often more obvious than the cooperation. How to talk about these states without normative judgement?*

How to think about this?

So what to call this type of space? Container is too pure, too fixed, community too progressive, exclusion too abstract and intentional; needing something that can capture the obvious boundedness that appears yet allow for the fluidity of the edges and the permeability. 'Enclosures' has been suggested by my supervisor as a term that is both a noun and verb (although I am struggling to getting the verb part- seeing only a noun). Interesting history for sure in Stenger's enclosures- she uses them in contrast to the commons and as an example of the costs of capitalistic practices. So, I read Fairlie's (2009) summary about enclosures/commons land rights laws going back to the middle ages while reflecting that weirdly this is not my first farming/agriculture article I've read in my studies. I learn that the enclosure act of England produced a shift from feudal lands, with of common property being shared amongst farmers, to enclosures which were allocated to people privately. This was in line with emerging ideas of individualism. At the time this was seen as the only way to ensure the improvement and maintenance of the land in accordance to the specific needs of the owner. This ethos was carried through capitalism's growth and then launched further with neoliberal rationalities resulting in the 'tragedy of the commons' as sort of taken for granted explanation for why common space can never work. Does this fit with the day programs? Yes, in that they are a form of separated somewhat bounded space for certain types of people, framed as the best space for having the 'capability' to meet the needs of certain people whereas common spaces like senior's centers *and public centers are not. I don't think I can define the other spaces as commons though – they too are a type of enclosure with perhaps commons being the possibility needed.*

Assemblages

I like this term 'Assemblages' and Tsing's (2015) and Stenger's' (2005) use of it within ecological thinking of shifting, fluid entanglements that are world making projects. Tsing's (2015) "polyphonic assemblages" that create harmony and dissonance simultaneously and how contamination works as a form of collaboration within the assemblages, which fits with the idea of practices meeting and the unintentional coordination that develops. But assemblages are a loaded term – many interpretations are possible, and I am not sure I can manage them. Is it possible to use assemblages and avoid having to explain Deleuze? (because my brain is full!) Callon used this rather than network and it would align me into a 'camp' so to speak, requiring me to be clear in describing the lineage of assemblages that I use.

'Arrangements' is simpler and 'practices' are just themselves yet so often confused with practice in nursing…

Why does any of this matter?

How we think of what is helpful and how we go about designing programs and interventions relies a great deal on how we see the "problem" to exist. The limits of how helpful these care in the community supports are for people living with dementia likely lies in how they are conceived of in relation to the problem at hand. How pure of a solution they are anticipated to be, how precise the fit is expected to be, how rigid the rules of use and how relations between supports are structured. Day programs have been posed as a particular solution to how dementia has been conceived as a problem – one of the individuals, one that relies on ideas of care that can be replaced in hours, and on a fixed idea of space. Thinking differently about these *ideas can show the connections, work, and materials present as well as the voids through which people living with dementia and families make ongoing arrangements that work for them to find a way to go on. But to say that these programs help people 'find a way' is likely too vague and misses the real instrumental support that people report from services such as respite and day programs and what they add to these arrangements, what adjustments they require be made, and how gaps are likely to remain.*

There is a strong discourse of solving the 'puzzle' of dementia biomedically that has drifted into the care solutions (Purkis & Ceci, 2014). The ideal of mapping of services has come to the forefront based on purity ideals that the care system should be seamless and universally easy to navigate. This work dominates the solutions being offered and it needs to be unraveled a bit – as Alexis Shotwell (2016) says to be against purity is not to be for harm, sickness, or a kind of suffering. "It is to be against the rhetorical or conceptual attempt to delineate and delimit the world into something separable, disentangled and homogenous" (2016, p.15). While helping people finding their way is not a bad idea, the thinking that this can be standardized, centralized, and stepwise in nature might be. Much of care in the community relies on a 'mode of syncretism' of keeping practices separate and defined (Law, et al., 2013), this results in the smoothing of different practices and does not respect practices for their own work or the ways they may at times include each other (Mol, 2002). Perhaps that is what I need to do in this work, to begin (as I remind myself again; it is a dissertation not my life's work) to show the effects of these different modes of syncretism between the practices of home, day program and the community and the goods that resulted in these lives that I followed. And so with these modest, less than pure goals I begin….

Interlude II

Simple Questions with Complicated Answers

Why don't you write about what a day program is?" suggests my supervisor. "Oh, that's easy" I reply and then confidently set a short time frame to return a good draft of the chapter. I know this will take more than the simple description of the two programs which I observed, but after many readings of Mol's the Body Multiple I am ready for this work… or so I think. Weeding through artefacts of policies, pamphlets, interviews with planners and managers, field notes from over 100 hours of program observations I begin to panic. How to pack this up into a chapter? Can I even answer this apparent trick question? What makes it both desirable and difficult to pack things up and deliver them in succinct statements? Again, resisting smoothing over of the particulars but also needing to provide some kind of scaling so I can give some kind of answer to this question. Tsing's (2015) work on scale in Mushrooms at the End of the World is helpful here - she explains that "we have a problem with scale. A rush of stories cannot be neatly summed up. Its scales do not nest neatly, they draw attention to interrupting geographies and tempos" (p. 38) It is these non-scalable parts that interfere with modern knowledges and the progress narratives that envision universals. Tsing suggests that the non-scalable maybe the point from which theory can begin and may even help us understand more about the scalable. How the scalable is brought together and the work it takes can only be seen from the nonscalable features of the particular or maybe those that perhaps don't fit in easily to others. Approaching the ontological question, I start with Mol's Body Multiple (2002) but am a bit stuck for language. Do I talk about versions, modes of ordering or practices? This is where language is tricky and generally unreliable at capturing the fluidity of the relations that I am trying to represent. Versions seems so defined and stable to me and I feel like it can slide easily into perspectivalism (each version depends on your viewpoint). Modes of ordering is the opposite, *multiple fluid hard to pin down, so much more realistic but may lose readers with no familiarity with the term (of course I am sure I have explained it well somewhere?). Practices seems too general, unable to capture the network of practices within each version/mode of ordering for the day program. Describing the day program multiple seems more difficult than a disease or condition or a fish, likely this is due to the skill of the analyst, but maybe it's not quite as reduced in general terms? People assume more than one thing is going on in day programs even if it is just vaguely defined - don't they? Or is it just a box to put people in?*

After several changes I am temporarily settled on enactments. I struggle to find mutual inclusion in the enactments of the day program – maybe I'm not interpreting it right but there is a ton of interference and occasional collaboration or distribution. Pols (2003) and Moser (2005) reassure me that I can talk of the enactments without having to use inclusion.

Next it is the routines that were in front of my face the whole time while I was in the field that I need to make sense of -so I spend four days analyzing them-a chicken-egg phenomena that drives me mad - finally I find some practice theorists that talk about it in ways that I think I can make sense of. It is these moments of analysis that surprise me how the process of analysis helps me to see data and the relations within it in a new light.

Chapter 5

The Day Program Multiple

Choosing a place to start the analysis of my data is challenging. A problem inherent to studying entangled things. Asdal & Moser (2012) remind me that as a researcher what I decide to include in my analysis is to make a choice about ‘whose version of the world to start from’ (p. 296). This is a political question, there are choices to make, decisions on what to include and what to leave behind. An important responsibility that feminist traditions have brought to light. This study is about relations. Relations that bring into existence people living with dementia, their families, day programs, and their life in the community in particular ways. Working within this tradition using a material semiotic approach demands that I pay attention to all of it and that the day programs are not placed as ‘context’ simply existing on their own and used as an *explanation* for ‘how things are’ but instead are to be *explained* as part of ‘how things are coming to be’ (Asdal & Moser, 2012). This stance is based on ideas of the social world not being a predetermined backdrop to human actors but instead one of ‘worlds in the making’ (Asdal & Moser, 2012). So, for this study day programs are part of this ‘worlds in the making’ for people living with dementia and their families and these worlds are full of materials; people, objects, technologies existing as they do through their particular associations to each other. From here care is not just done *in* a day program but done *with and through* the social material relations of the day program. Taking all of this in mind, to answer the question of how day programs work as care in the community for people living with dementia and their families empirically, an important first question is: What is a day program?

On the surface it is a simple question, which could be answered as it is in much of the research done on day programs, with a sort of summary statement like ‘a day program is a place where people living with dementia can go for some time during the day to do activities and provide their caregivers a break'. Yet when elaborated on, a deeper philosophical question is revealed: how does something like a day program become a 'thing'? This is ontological territory, one in which it is easy to get lost and often easier to avoid. But to avoid consideration of what a day program is and simply go into the rest of my analysis using the taken for granted definition misses the important theoretical stance of material semiotics being used in this study, one that insists that these questions about ontology are important not just philosophically but practically. Within the material semiotic approach ontology is not considered to be 'given in the order of things" (Mol, 2002, p. 6); instead ontologies are multiple, enacted, maintained or erased within specific socio-material practices (Mol, 2002; Law & Lien, 2012). How things come to be is related to how they are done (Mol, 2002). What *is* becomes situated and local (Mol, 2002) and rather than a determining pre-existing order guiding how things happen, there are modes of order*ing* being enacted and enacting the relations and the realities lived through them. These modes of ordering are "specific patterns of ideals, practices, and knowledge" (Pols, 2003, p.321), they are multiple and contingent (Law, 1994). It is through the different relations of the modes of ordering that different realities are enacted. In this chapter my analysis will focus on answering this question of what a day program *is* by showing empirically how day programs come to be something we know as day programs, and how there is in fact multiple enactments of day programs that relate to each other in particular ways that have particular effects. Drawing on Mol's work of the body multiple, in this chapter I will demonstrate how these different enactments are precariously brought together in day to day practices of the program and the effects. I will use policy artefacts, staff and manager accounts from the field notes, data from the key informant interviews, and observations from the two different day programs (Program A and B) to show the respite, social engagement, treatment, safe place, and administrative enactments of the day program and how these ‘hang together’ in some kind of coherent fashion (Mol, 2002). More than a theoretical exercise, this analysis offers an opportunity to open up what a day program is and examine what might be at stake within and between its different enactments.

The Day Program from a Distance

Beginning the exploration from what Cooper and Law (1995) would describe as a ‘distal’ position, likely the most commonly recognized version of a day program is a somewhat generic group of people gathered in an interchangeable space. This version sits in the background of many research articles, while the effects of day programs on the caregivers, service utilization, and the person with dementia are placed front and center. Here, from a distal view, these effects are presented as if they simply exist as part of the day program’s assumed stable existence, situating the day program as a ‘thing’ that doesn’t require further definition and is independent of space or time. This distal version works in useful ways; it travels well and is easily translated elsewhere into things like research articles, policies, health care budgets, or community resource manuals. Such as in the *Dementia Strategy for Canada* (2019) where a shaded text box titled “Respite Care”, mentions day programs in a chapter specific to caregiver supports and resources and includes the following statement:

> Adult day programs can bring respite to caregivers, as they provide an opportunity for the person living with dementia to participate in activities and socialize with others in ways that do not require the usual caregiver to be present (Public Health Agency of Canada, 2019, p. 40)

Here day programs are enacted as a discrete and separate location away from the caregivers, what Whitehead (1920) would call a “simple location”. According to Spoelstra (2016), Whitehead argued that simple locations were simplifications that mistakenly presented things as "universal in time and space" (p.17). Simple locations relate to the previously mentioned distal modes of thinking about organization, where the preconceived thing is stable and predictable (Cooper & Law, 1995). Here in this policy document, how the day program's space is created and maintained, and how this connects to a respite experience requires no explanation. The outcome of respite simply exists on its own through the very essence of a day program.

The Day Program in Policy

In another site, a provincial *Dementia Strategy & Action Plan (2017),* day programs are enacted as respite care that can give caregiver's breaks for self-care. Alongside this is another enactment of day program as a form of social engagement for people living with dementia within the community. A text box that includes a caregiver quote describes this version:

> "If I could describe my wish list, I would ask for 5 days of the adult day program every week because when he is there he is with a group of men, he watches and he knows he is with other men. They say good morning to him; otherwise it is just us in our home" (Government of Alberta, 2017, p. 15).

This social engagement enactment of a day program affords a particular kind of life for people living with dementia, one that is in relation to peers instead of an alternative of being home with no activity or people. But how does this fit with the other versions? The multiple versions of day programs do not exist as dissociated fragments of a whole; instead, they exist in relation to each other 'hanging together' in different ways at different times to create a sort of coherent singularity (Mol, 2002). It is in this 'hanging together' that realities are enacted, and particular lives are lived (Mol, 1999; Moser, 2005). For example, in this site of the dementia action plan document, the two versions of day programs are coordinated in a way that adds the versions to each other without conflict. This coordination is visible in the document's page layout, 'respite' is the heading of the section, bolded and capped, but attention is also given to the social engagement version of the program in the pull-out box using the caregiver quote. Through this coordination, the day program remains one thing, a sort of composite, able to offer both respite to caregivers and social engagement for people living with dementia. This coordination is not a "fait accompli," it is ongoing work (Mol, 2010a). Policies are a form of "distributed doing" that (Gill et al., , 2017, p. 3) that create and are shaped by relations that align things, people, and resources together or apart in different ways (Gill, et al., 2017). Here in the action plan, associations are being made (Moser, 2005); people living with dementia are associated with a single caregiver, the day program is aligned apart from home. These realities enacted by this policy travel, and as they do, the relations sometimes stay the same or shift with new effects.

The 'Mattering' of Day Programs

In discussion with a government health policy planner in charge of planning care in the community for people living with dementia, a new enactment of the programs comes into being, and the coordination changes.

> I see them as a piece of the puzzle when we are talking about the needs, not only of the person living with dementia, but also the caregiver family system around the person. Day programs often have different benefits to both of those groups. We hope they benefit both simultaneously, sometimes they are straight respite and the person with dementia may or may not want to participate but they need to because the care giver needs a break. Ideally in my view, it is that they are also, providing a benefit to the person living with the dementia. That is kind of the

> best fit. I would see day programs as one of a collection of options to provide respite. (Key Informant Interview, February 25, 2019)

In this comment the policy planner includes both of the previous enactments of day programs, but unlike in the policy, the coordination of the two is not as simple; one seems to be more predictable than the other. Respite is assured, but social engagement may be optional. The planner identifies the central problem addressed by day programs is caregiver respite. The manager accounts for a 'best fit' situation where both respite and belonging occur. For the times when it does not, she explains away the importance of the person with dementia's desire for social engagement as sometimes irrelevant if the caregiver needs respite. This is a different coordination of the versions of day program than that seen earlier in the policy practices. Rather than versions existing side by side in harmony, there is a priority given to one over the other. There is some inclusion of social engagement in respite, but this relation is not stable, it may not always be there. Also, another enactment of the day program as a resource is present. This version of the day program is one that can be packaged with other resources and allocated out to people by health care systems, acting like a 'puzzle piece' and connected to other services. Mol (2002) suggests that this kind of attention to multiplicity is an important act or a type of intervention because it can reveal the politics at work. The different versions of day programs do not relate by chance, but rather based on what matters most. Moser (2008) explains that attending to this 'mattering' can help us understand the possibilities for life with dementia that can be lived through things like day programs. This particular coordination of the versions of the day programs is world making for those involved. This account from a person in charge of planning care in the community for people living with dementia reflects how from a planning perspective day programs are positioned and how they position others. The day program is primarily for caregivers and secondarily for people living with dementia's participation. The day program is part of a "collection of options." The coordination of these enactments has effects. Subjectivities are created: particular types of people with particular roles and needs come into being, some needs deemed essential and some not. Relationships are formed between day programs and other 'options' and the problem of dementia; day programs are a discrete unit of a collection of resources meant to solve a particular type of 'puzzle': respite. While local, these relations can travel. The practical consequences of these relationships and subjectivities are evident in a different discussion, this time with a day program manager about how it is not always easy to manage the day program being different things for different people.

> Manager: One hard thing that we all struggle with… [is] clients who are nearing the end of our ability to manage them and what is that end and you know…what is to justify and knowing how difficult it is for the caregiver and not wanting to deliver that bad news….and that is a tough one…just that…there does come a point where they are sleeping all the time…. often, I think right now we have someone who does a lot of "do we still bring them….do we not bring them" … ...and yeah sometimes what is the goal of the program? Is it truly just respite for the caregiver, so it really doesn't matter if they are engaged if they are with us, or do we all want them to be engaged and when they can no longer engage, is then that a discharge point?
>
> Interviewer: right
>
> Manager: or if their bowel incontinence gets to be too much, which in the past has been an issue as we only have so much staff time to do it (Key Informant Interview, January 28, 2019).

It is evident that in the day to day practices of the day program the “simple location” version of the day program is not so simple; there are relations at play between the needs of the people attending, the staff, and the supplies available. Through these relations, the day program is something for some people and perhaps not for others; there is sometimes competition between the enactments of the program as respite and as social engagement. This competition has effects in defining the limits of the program, but they are not always clear. This creates certain kinds of relations between staff, the family, and the person with dementia. Staff must justify the delivery of bad news; they must decide what is too much to handle (sleeping all the time or incontinence). Within these relations both the limits and possibilities for the program are created.

Care and Day Program Enactments through Practices of the Routine

In term of limits and possibilities, care at the program is complicated because, like the rest of the program, care is not a simple essence exuded by the program’s existence, but an ongoing accomplishment achieved through different enactments of the program. What care is and what it can be within the day program varies as it does not exist in isolation from other practices and their logics, but rather is in continuous relations, competing, complementing, and or interfering. A typical activity at day program A gives an excellent example of this.

> A cell phone ringer tone goes off from the staff table and the staff tells the group that it is time for card bingo. Cards are dealt out to each member and paper plates are placed in the middle of each table. I note that the staff are standing beside the tables (there is no room at the table) telling the clients to put their cards down on the table and sort them into suits. I stand near Jan and he tells me that he never plays cards, so he doesn’t know what the suits are. I explain the suits to him, and we organize his cards. The

> man next to him seems to be sleeping again so I tell him I will sort his cards for him. He wakes up as the game begins. This game is done by the staff in the center of the room calling a card from an oversized deck of cards and holding it up to the group - the clients are to check if they have the card and if they do discard it onto one of the plates. The first person with no cards left is to call BINGO! The game begins, and I notice Jan is following along well and so is the man who was sleeping. Occasionally they don't notice a card that they have, and the staff quickly tells them that they have it and they need to put it on the plate. Jan puts a card of the wrong suit on the plate and staff tells him quickly "no that's the wrong suit." After this correction he checks with me each time he picks up a card and asks, "is this the right one?" I confirm for him and he then discards it or keeps it. Occasionally, the caller mentions that she is holding up the card for them to see but she is about 20 ft away from us and often holds the card for only a few seconds before going on to the next-it is a fast-paced game. For the next round I help deal the cards, this time the man who was sleeping at the table is awake and he sort his cards in his hand holding them as if he were playing a card game – I notice this and assume it's his preference, staff notices and says "No, Terry you have to put them on the table so we can help you" he does this and the staff come over and sorts his cards. We begin another game (playing three rounds of this)…it is interesting to me during this game how I seem to develop the need to ensure the right cards are picked by the clients and begin to correct them even though I start with the idea that it really doesn't matter and that people may take time to sort, I get the impression somehow that the rules are important and there seems to be a pace that needs to be kept. (Field notes, May 16, 2019)

In this activity, the version of the day program as social engagement is present, but this game is not just an opportunity for socializing; while it has the appearance of that kind of performance, something else is going on. The activity is a highly structured one in pace and rules. It is a card game, but it is also an activity structured to be played (and even won) while asleep or without knowing anything about cards. It is a routine, and like most routines, it requires work to maintain and is accomplished through a range of actors and materials across time (Feldman, Pentland, D'Adderio, & Lazaric, 2016). Events happen in a particular order and pace; timing buzzers mark the beginning and end, cards are dealt, sorted, then played, and prizes are awarded. Staff circulate around the tables, intent on monitoring the player's hands, ensuring rules are followed. In this routine of the game there is a need for sameness, despite the wide range of different individuals using the program. Perhaps sameness isn't the desire but instead an effect of this routine that serves some purpose. Terry can't hold his cards because if he does staff are unable to supervise and guide him. The game's routine also holds together certain relations for staff and clients and enacts the care possible; that of supervision and guidance. Roles are established, those that are the guides and those who need guiding. The practices of routine are everywhere in the program's day to day activities and in the communications home to the family. Easy to say this resembles some of Goffman's total institutions, but to stop there on an explanation without explaining would ignore the need for symmetry in the analysis (Law, 1994). Further tracing of this routine is needed (Asdal & Moser, 2012) and consideration of what makes it seem stable (Latour & Woolgar, 1986).

Listening to staff accounts of the routine and what they are trying to achieve through it reveals more of the logics at play in this enactment of the day program. In discussion with two managers, Lisa and Karen, from program A, the routine is described as a key aspect of what the program offers to both the people living with dementia and their families.

> Lisa: ours is very routine based, so when they come, the staff greet them at the door….
>
> Karen: Structured….
>
> Lisa: …. They bring them downstairs, help them get their coats, have coffee. It is very routine; it is very structured. They don't to…there is no risk of them getting lost, you know…. the families know that we are going to meet them right at the door and at the end of the day we are going to bring them up for the families. Whereas if they are coming into a program upstairs, they do have to be able to do that independently. So there is that risk of somebody potentially….
>
> Karen: safety….
>
> Lisa:…..exiting the building unsafely, you know, it would really just depend on their ability and whether they could participate in those activities so we try to adapt our programs so that everybody can be a part of the program and we have the facilitators and the staff there to kind of lead those activities and help those people who need a little bit more assistance. Whereas if they were just doing a crafting program upstairs [in the senior's centre], they would not have that potential one to one guidance.
>
> (Key Informant Interview, February 20, 2020)

The Manager Lisa describes the need for this routine to facilitate social participation of everyone who attends in a safe, predictable way; the routine affords the space in which social engagement can occur and through this respite happens. So it seems the routine acts as a coordinating mechanism (Jarzbowski, Lê, & Feldman, 2012) for the enactment of the day program as a safe predictable place, as social engagement, and as respite. While this term "mechanism" can indicate a stable quality, the routine is actually an ongoing relational accomplishment between people and materials that work to align these interdependent activities of the day program (Jarzbowski, et al., 2012). Staff and patients work to maintain an order, tables, chairs, and the space of the program is used to reinforce the routine. A shared understanding of what happens at the program, predictability, and accountability for daily events is what justifies the routine (Okhuysen & Bechky, 2009). According to the managers, accountability for this safe, predictable place reassures caregivers, and responds to a homogeneous version of who is attending the program: people 'at risk' or in need of support despite their specific situations. While the routine works to coordinate the different enactments, the relations between these enactments are precarious. Sometimes the enactments are supportive of each other but sometimes an interference occurs between them. For instance, social engagement fades away quickly during the card game with the focus on following the rules. I see Jan, a newer member of the program, go from "playing a game" to worrying about making a mistake. In particular, the universalizing approach to risk management of the safe predictable place enactment can interfere with people's engagement with the activities as seen one afternoon during a mini-putt golfing game.

> One man Raj, who is new, comes up to the mini-putt game and staff try to get him to line up at the designated spot but he walks past to the little green felt that is laid out in front of the hole and staff tell him to come back that he has to "start at the line." He ignores them and bends down to smooth out the felt "the green is uneven" he says back to the staff, "you can't putt well on a bad break." He comes back to the line and takes his turn. After he is finished, he stands to the side to watch the next person and the staff tell him he should take his seat "but I want to watch… I like golf" he says. "Ok but you are going to

> have to go for your turn at the other end soon," replies the staff pointing to a bean bag toss station set up at the other end of the row of chairs. Raj stands still beside the golf game watching other people play for a few turns and then is called down by staff to the other end. (Field notes, August 8, 2019)

Vinny is a man who tells me on our first meeting that he wishes he could play more active sports at the program as he misses that kind of activity, explaining that "my brain is going but I am still in great physical shape." One day, during a game of chair soccer, the staff work to constrain Vinny's physical exertion of being the goalie.

> Vinny is intense in his efforts as a goalie – with very long legs he stretches himself in his chair and can reach far into the "field" to get the ball and he tries to do this often. Staff tell him not to and he doesn't listen. Eventually staff stand behind him holding his shoulders saying he might fall and needs to stay seated. "I won't fall" he says. Staff stays there standing behind him for the rest of the game occasionally holding his shoulders towards the chair as he reaches his foot out for the ball. (Field notes, June 20, 2019)

In these scenarios safety and supervision of the day program seems to override individuals with preferences and freedom. Both Vinny and Raj are people with passions for particular sports, both of which are being offered at the program but their participation in these activities is undermined by the dominance of the risk management practices present. The safe, predictable place enactment requires homogeneity of a group, and the members have to work hard to emerge as individuals breaching the rules and are sometimes literally held back by staff who are situated as monitors and rule enforcers. At other times the safe predictable place can fade to the background and social engagement seems to take precedence with staff tinkering to accommodate the different ways people might participate in an activity.

At Program B the craft activities are scheduled in the afternoon and contain specific projects, usually quite complex in nature, but staff accommodate individual capacities ‘on the fly’, allowing for the social engagement component to emerge.

> One of the staff (Sara) says “we are going to start a craft” and shows the table the instructions she has on paper. A sample of the final product is on it (a turtle made of a shell and sea glass on a sandy canvas) is out on the table. Sara reads through the instructions to the group quickly emphasizing the instructions to “go with the flow” directing this in a dramatic way towards Peg at our table, who I already know is not a fan of crafts. Peg laughs and says, “Oh yeah the flow!” After this instruction it seems that the next task is to get the women to choose a size of canvas and a background color. This takes several minutes and involves much second guessing. Everyone begins to paint their canvas, surprisingly even Peg. I work with Marie who is interested and quite able to do the tasks but needs frequent focusing. She frequently puts paint brush down and goes back to sorting the shells and several times, I notice her getting up with some in her hand and going to her jacket, apparently putting shells away that she wants to keep... Next to us is Nora who is slowly painting the canvas a dark blue telling me it is like the ocean in Norway where she is from. I notice that each of the women at our table work at their own pace and staff support only some of them with the planning of the shells and situating the supplies needed. I do the same with Marie who seems to be a moving target when it comes to deciding on what she wants to do with the shells, I try to carefully balance my directions to focus her with letting her have choice and final say in what is created. It seems to be important here that the work is hers and not mine. Agnes the staff has told me “it should be their work not ours.” I notice the pace of each person is different and the

> supports offered by the staff flex to meet their pace for the activity. Marie finishes fast and must be occupied between steps, Nora spends the entire time painting her "Norwegian sea" and then it is put away to be finished another day. (Field notes, July 11, 2019)

In this activity the routine is present in the schedule for the day and the timing of the activity. The routine supports staff being prepared with the materials needed but otherwise it is not as obvious - there is no pace being kept. And while there is a plan and sequence to the activity, it is adjusted as we go; for Marie to sort the shells and change the design many times, for Nora to paint the blue sea. Some of the members don't participate at all and instead color or sit watching or talking with the others. So here the social engagement comes to the foreground and the routine of the safe predictable place enactments exerts less of a homogenizing effect while still structuring materials and time.

The Day Program as a Safe Enclosure

This day program as has other practices, other than the routine and risk management that enact relations in a particular way between people and materials of the program. There are spatial effects of this version of the program as well. Providing a sort of safe enclosure for people to be supervised in requires practices that demarcate the space in a particular kind of way so that the inside and outside of the program seem obvious. This boundary between the program and outside materializes in forming relations and separations between objects, space, and people. Objects are arranged to communicate the boundary of "in and out" at the program. A sign on the door of the day program A says, "Day Program in Progress Do Not Enter" and a sensor alarm that rings when I come to the bottom of the stairs. Program B has locked doors supervised by a unit clerk.

Staff have key cards; clients do not. There is a doorbell for visitors to use. A sign on the main door states “Caution Elopement Risk- Do Not Leave Door Open.”

Program A’s co-location in a public senior’s activity center is deceiving, as much work goes on to maintain the separateness of the day program from that place. Over nine months at program B there are almost no interactions noted between the day program clients and the people upstairs.

> I ask about the upstairs facilities like the library and the cafeteria and if they ever go to those spaces and the two staff shake their heads “no that is separate from this program.” Kara the casual staff says “yes, it’s a really nice senior centre but… I think it’s more for… independent people.” (Field notes, May 16, 2019)

Here the social engagement version of the program is marked off and confined spatially by the version of day program as a safe predictable place. As Mol (2010) describes, coordination between different enactments is not with out frictions, there are tensions, and “gaps must be bridged” (p. 264) through ongoing negotiation by the staff, patients, materials of the program. These negotiations end up enacting the realities experienced by people through the program; for the most part at the day program social engagement can happen but only in a safe predictable place.

The Day Program as Treatment

There is another enactment of the program that both interferes and collaborates with the enactments of the safe predictable place, respite, and social engagement day program and that is day program as treatment. The echoes of the rehabilitative origins of day programs seem loudest when listening to staff discuss their goals for the program's activities and the care planning processes. The manager from Program A explains the goals for care planning:

> So with a person with dementia the goals are always going to involve cognitive needs – we want to prevent decline and try to maintain their cognitive skills… the goals are always to maintain. If someone has a walker, we want to maintain their mobility. (Field notes, May 23, 2019)

The Manager tells me that they base the programming around "the five areas of wellness": social, physical, leisure, cognitive, and emotional. As she explains how these areas are addressed, she speaks of the program as a form of physiological intervention.

> You know, the social aspect of you know, being with people, getting out, being able to be immersed in conversation amongst their own peers….that alone can help kind of target you know things like depression, social isolation, and just be able to get them out of the house. The physical aspect, you know, really working on that mobility, so whether it be increasing muscle ability, maintaining balance, or increasing balance. So we have exercise programs, we do some type of physical game every day with the clients….so just really target as some of the clients come with a cane or a walker….or some type of mobility aide. So encouraging the use of those. Cognitive kind of looks like trivia and mind games and kind of challenging them to use areas of the brain that might not get used. And whether that is to maintain brain function or to maybe help increase as well. And then the emotional as [the other manager] kind of stated, really that reminiscing … things that they were able to remember, things about the past. Music is a huge one, it targets a whole different area of the brain and so that one is really important too. (Field notes, May 23, 2019)

From this account it appears that the routine of activities is not just about providing a safe, predictable place for reliable respite and social engagement. The routine also works to ensure that therapeutic activities are delivered, ones that can ‘target’, ‘challenge’, ‘increase or maintain’. The routine ensures accountability through its documentation and assignment of responsibilities. This is reflected in both programs' care planning documents that focus on goals that can be monitored and intervened with. During a care planning session at program A the team of 4 staff members and the manager sit around a table for a case review where they discuss a client’s “goals and progress.”

> Manager: “so how is Ken doing?”
>
> The staff sit quietly for a minute, then one of them says: Good
>
> Manager “Ok what does Ken like to do?
>
> A short pause, then another staff says: “he likes the tile rummy”
>
> Manager “oh I should say his goals are cognitive and social.”
>
> Another pause, then another staff says “and the word games in the morning…”
>
> The Manager writes on the care plan form, “Ken is a pleasure to have at the program. He enjoys tile rummy and word games”
>
> Manager: “no changes in mobility?”
>
> Staff: “no”
>
> Manager (checking off the sheet):“Any concerns? bathroom? Meds?”
>
> Staff: (in unison): “No”
>
> The chart is then passed around the table and each staff initial the sheet and next person’s name is called…The team goes through 13 charts over an hour. (Field notes, October 16, 2019)

While listening to the different reviews, I hear the types of things that the staff consider as indicators of concern, which are mainly related to not participating in activities or arrival/departure time issues. There is a non-specificity to the review of clients that I have met, they are hard to 'see' in any details of the conversation. Later in the meeting after the formal care plans are completed, I observe the team discussing a few specific concerns for patients unrelated to the care plan.

> One woman has recently lost her sister and is observed by the staff as being sad and more withdrawn, apparently using a walker now and has reported being scared of falling. Staff tell of an interaction today where the woman apologized for needing help off of toilet and told her of a recent incident at her lodge where she was stuck on the toilet for 20 minutes unable to get up and that she rang the bell only to have EMS arrive to help her off which caused her great embarrassment. Manager and the staff talk about possible supports such as a raised toilet seat that might help eliminate the problem here… The Manager talks about her plan to call the woman and reassure her and maybe go visit her at home to check in with her…
>
> Another man's family has informed the manager that his ride home on the seniors' bus is 1.5 hours and when he arrived, he was locked out of his residence for 30 minutes (a senior's apartment building that locks its doors at rush hour times due to fear of people walking by getting in). The Manager tells us she plans to call the senior bus coordinator and the senior's apartment.
>
> A new member of the group is not staying for full days and complaining about the food. This is a person who has attended in the past. Staff talk about her complaints re: her sandwich and the manager coaches them to "just smile and make it their fault or blame me." They talk about what activities she does like and identify scrabble and talk about potential scrabble partners that might work with her or if a day change may result in

> better matches with other clients. The Manager tells the group "I have told her it's ok if she wants to leave early." During this conversation the staff appear animated and engaged in conversation, there is ongoing exchange of ideas and observations, patient's narratives are upheld as part of the solutions. (Field notes, October 16, 2019)

Here in this meeting, the versions of the day program as treatment and as social engagement are not made into a coherent singularity, they don't fit well together and are kept separate allowing for both to exist in a way that works. Within this distribution, care and accountability get enacted differently in accordance with the different modes of ordering. The treatment version of the day program is present first in the meeting, enacting the goals, interventions, and measures that the formal care plans and monitoring forms require. In this version the space of the program is discrete, what is measured is what occurs at the program or in direct articulation to it (early or late arrivals or pick-ups). Here the patients are assessed on predefined outcomes with simple yes or no indicators. Staff are positioned in a reporting role and the manager as the record keeper. Jerak-Zuiderent (2015) points out that these care plans act as types of accountability devices that have come to represent a generalized indescribable ideal of 'good care' within health care systems. Similar to Jerak-Zuiderent study of long-term care, the day programs situatedness within a healthcare system focused on treatment and cure leaves little room for the narrative work required for program staff to talk of people who are experiencing progression of a non-curable disorder or even the inevitable decline of ageing bodies. Within this version of the day program it takes great work for staff to account for that which fits within the "standards of good care for health and well-being" (Jerak-Zuiderent, 2015).

Later in this same meeting, the day program as social engagement is enacted, shifting the dynamics of the conversation as staff engage with tinkering practices as they work to create solutions for particular client situations and preferences. Within this version, the space of the day program expands to include the outside places like client's homes and transportation services. The program's activities become more tailored to the person's interests as a device for social engagement rather than a measure of functioning seen previously in the meeting. Even the program's day becomes flexible in hours that can shift, unlike the safe, predictable program where there are discrete beginning and endings of the day. In this version, accountability and care are interrelated as staff work to account for meaningful care for particular individuals (Jerak-Zuiderent, 2015).

When Day Programs Clash

The realities enacted by the treatment versions of the day program are not always easy to coordinate or distribute with the other versions, and clashes can occur as seen in the observation of the daily cognitive stimulation activities at program B. Cognitive stimulation is an 'evidence based' form of treatment for people with mild to moderate dementia (Rai et al., 2018). This intervention involves activities that stimulate cognition, such as "reminiscence of childhood, current affairs, and word games that consist of a combination of group activities, discussion, and individual-based tasks" (Allward et al., 2020, p.497). These activities are a common feature of day programs (Anderson et al., 2013) and both programs I observed used them daily. Staff at program B explain to me they use activities from a cognitive stimulation program called "Brain Quest." Staff tell me that they initially tried to implement the whole program but now only use a few of the worksheets because it was too difficult for most of their patients. My first experience of assisting with 'brain game' time revealed a mix of participation by the different clients and much tinkering required by staff to keep people 'on task'.

> A work sheet is given out with a list of words and different questions that are to be used to eliminate them and reveal a secret message. We start with the first instruction, a few people at my table get right to work and seem to be following directions, Harry is looking at the sheet but says “I don’t know what to do” I go over it with him helping him find all the words beginning with the letter ‘P’ to cross out. I notice Fred sitting next to him is not doing anything. Harry offers his sheet to him saying “here you can copy me.” Fred laughs and tells me he can’t see anything on the page. I notice he is wearing glasses, so I ask if he has macular degeneration and he says “yes”. “So, you can’t see this page?” I ask and he says “yes.” I don’t know what to do to help him and I have 3 other people to assist at the table, so I move on to the next person’s sheet. The rest of the time I go from person to person trying to get them to complete the task. It is difficult work as each person is going at a different pace and one man is simply crossing out every word. I am relieved when it is over as it seems to be ‘a mess’ by the end of the game and only Nora has reached the secret message. I ask her as I am picking up her sheet if she likes word games and she shakes her head “no” then smiles. (Field notes, July 17, 2019)

Each day this brain game activity would come up with a new task - sometimes math, sometimes memory or spelling related. Each time the group would splinter into individuals with their unique interests and challenges of memory, motor, and sensory deficits. It seems that the social engagement and the treatment versions of the day program come to direct conflict in these sessions. When I ask one of the staff why they continue to do these activities, she acknowledges the challenges for some of the patients and that the less verbal people withdraw. But she tells me some do enjoy it and that often people think that people living with dementia don’t have any goals “like Peg, who perhaps may have wanted to keep her word skills as long as possible, which is a goal that those games can help with.” The staff member accounts for the treatment version not as a generalized outcome measure but specifies it for a particular person’s desires, translating it into a form of patient-centered care. In these ‘brain game’ sessions, the treatment version of the day program is distributed, it is only for some of the people, others are not included. This treatment enactment of the day program structured particular relations between everyone present. Staff would work in relation to each person’s capacities and try to make it into a game-like activity, but only so much could be done to support some of the people with the tasks. Staff would argue with each other over the answers or methods required for the task. Patients would support each other sharing solutions or encouragement; at other times, patients without the required vision or speech capacities would simply withdraw. The effects of these relations could be far reaching at times. For example, Mike, a patient with aphasia would leave the Oak Room each day just before brain teaser time. He would go and sit in the med-rehab side of the program for the rest of the day. On the med rehab side, his cognitive impairment was more pronounced than other participants, so the staff did not push him on any cognitive stimulation tasks. A few months later, this became a problem when the med-rehab program became too full of patients and asked the Oak Room to take him back for the full day. One day staff attempted to have a conversation with Mike and his wife at pick-up time about the fact he was spending most of his time out of the Oak Room. The conversation quickly escalated, and Mike became angry and agitated at staff. In response to this his wife became angry at him telling him “he better behave or he would get kicked out.” Staff then were focused on repairing their relationship with Mike and reassuring both that he would not be kicked out. An obvious interference of treatment with social engagement and respite enactments of the program.

The Day Program as an Accessible Resource

Up until now, the day program is established as an ongoing relational achievement between multiple enactments, all with different ideas and values around what a program should 'be', the safe predictable place, social engagement, respite, and treatment. The scope of actors and materials involved in supporting each of these enactments and their coordination or distribution is becoming evident from the few scenarios shared. But the day program as a resource only touched on earlier is also often present. This version is present in many accountability practices of the programs, and staff frequently would refer to the waiting list and the "spots' of the program. It came to light quite significantly during a conversation with the manager where she told me about recent changes to a new waitlist management system: a solution created to standardize the access to the program so that everyone coming in will have one day/week rather than the current two days/week that are offered.

> Manager: the concept of bringing in people initially one day a week rather than two, just to see how they will do…only giving them a second day if they really need it rather than assuming everyone needs a second day…. we can service more people which is a great benefit…. right?
>
> Interviewer: Yeah.
>
> Manager: and hopefully still serve the ones on a second day when we need to, but…. yeah….it will be…. but because you will have different people each day, you might have a little bit less community built between the clients. Because if one person comes Tuesday/Thursday and then we have someone who only come on Tuesday, that Thursday will look different for them….so that part will be interesting….especially for dementia

> because I don't know if they can say everybody's name, but I think they certainly have probably familiarity with people.
>
> Interviewer: Yeah, yeah….
>
> Manager: And it might be a little harder on staff, and to me if anything is harder on staff, it somehow affects the clients a little. (Key Informant Interview, January 28, 2020)

In this response, the relations and materiality of several enactments of a day program are evident. The endpoints of these enactments are at times compatible, helping people living with dementia feel included *and* having families get a break. But it seems there is another endpoint present that isn't always as compatible. Day programs don't exist in a vacuum, and for the health system, the day program is enacted as a resource that can be allocated, quantified, and translated into 'spaces' in an administrative database. Within this enactment, an ideal of 'fair access' orders the practices of program. If the program is for the caregivers to get a break, it needs to be accessible, but to be an accessible resource, more caregivers need to be served, yet this enactment clashes with other enactments and sometimes needs have to be compromised. This clash becomes more apparent when the day program manager brings the new admission policy to the staff meeting.

> Manager: we have 24 people on the main room waitlist and
> 27 for the Oak Room…this is a huge waitlist and with those numbers for the Oak room it may mean some of those people may never get into the program which is sad...
> We may need to see about changing our processes so that initially people are accepted for 1/week and then add extra days as appropriate.
>
> Mary (RN): some people have been moved off the waitlist by referring them to a dementia specific day program for the Saturday program where there is room …but the

big issue is that the senior's bus doesn't serve these sites. The bus serves a few main spots in the city but not these, so transportation is a problem.

The Manager suggests the staff needs to consider that perhaps there are people in the program that don't really need their services and could be discharged. For instance, those that live in assisted living setting with in-house recreation programs. Staff discuss what recreational programming is offered at one of these assisted living facilities and the issue with the staff there not gathering people with cognitive impairment to come to the activities, people have to be independent in coming.

Sara (recreational aide): There is no difference than living in a home as far as activities, but you don't qualify for respite services there and there is something about leaving the building to go out to a program"

Lori (recreational aide): "it's a better program in that they get more attention"

Mary (RN): this is just proof that we need more programs and that this is the best way to take care of our seniors especially to have nursing/OT/PT in the house not travelling around home to home which costs more money.

Manager: Yes, I agree but until more money arrives and new programs magically created, we have to do something…

Yvonne (Recreation Aide): maybe having 1 day a week is ok for some poor attenders because they maybe then they will come for their one day.

Manager: We have to deal with the holding of spots too. two weeks in hospital then you are put back onto the waiting list and can be an urgent readmit when you get out.

Sara (Recreation aide): But how do we do an urgent readmit if we fill their spot?

> Agnes (Recreation Therapist): it is hard for us to set limits with the family and tell them they have to wait for the next spot to open up. We are emotionally attached, and we know how much they need it. So, a formal written policy may help us do this better or if we can draw in (Manager) to have these hard conversations.
>
> The Manager then tells the staff that the other program managers from the region are meeting in December and she has asked all programs to consider what the implications of this change would be so they can plan.
>
> The staff begin to brainstorm some of the implications such as calendar changes, crafts will take longer to complete. Agnes the recreation therapist mentions that in the Oak Room they will just choose fewer things to do so it can work out…events like the Harvest Dinner or summer BBQ will be affected "everyone won't always get everything." (Field notes, October 9, 2019)

Mol's work on ontological politics is useful here. Here in this staff meeting, there are different realities of the day program coming together and what is at stake is how and when certain realities come to matter most. Here the day program as a resource of highly sought after 'spaces' of care is front and center and at odds with the day program as respite, or day program as treatment or social engagement that provides a chance for people living with dementia to 'get out' from home and be attended to and 'stimulated'. The walls of the program are less solid now with obvious relations from the outside seeping through. The bus routes, assisted living facilities programs, in-home respite policies, limited government funding, seem to actively constitute what the program can be in this meeting. Within all these relations regular attendance is becoming most important. There is no room for illness or vacations by the clients as the program is accountable for not just who is using their "spaces" but how. The solutions of a waitlist are creating new relations between the staff and the clients and the manager. There are managerial practices at work here shaping how the problem is conceived, how the staff have a role to play in the solution, and staff and clients are being enrolled in the managerial strategy to be responsible for the proper use of the day program through the formalized waitlist policy (Callon, 1984; Purkis, 2001). The world making effects of this are apparent, the enactment of the program as a resource requires it to be an interchangeable space with slots to be filled. This shifts the identities of the people using the program. There are 'types' of users now - those that are good attenders and those that are not. Families' requests are shifting into demands that can be directed to the manager. Activities will shift to allow for the lack of continuity, emotional connections with family will be mediated by more explicit rules, and the manager will have the job of "hard conversations." As Law (1994) points out, the relations between the modes of orderings at the meeting and what is coming to matter most tell a political story about values and their limits. Everyone won't always get everything.

The Day Program Multiple and Precarious

Three months later at a staff meeting the manager updates the staff about the latest plan for the waitlist system. This is a new computerized referral management system that will manage intakes, the program is called 'Pathways'. It will take referrals from home care and match profiles to open spots and then send information of the 'top 5' referrals matched to the program when a spot is open. This means that the nurse will no longer have a "fat file" of paper-based referrals sitting in a waiting list pile and that the program will only get a referral when a spot is open and the person is ready to start.

The Manager emphasizes how this will save time and “only send you people who are ready to start.” Staff comment that this is often a problem, that people often aren’t ready to start when a spot opens, and it can take weeks to figure this out.

She also mentions that this is a modern information system unlike ‘meditech’ (current system used by home care) so it is easy to use and will integrate with CareNet (another system wide information system being gradually implemented across the health region).

She explains that it will decide who comes to the program and prioritize referrals with people coming from hospital and those with high caregiver needs first. Part of the change to the intake process is also that each person will be given only one day for the first month to see how they fit with the program and then they will be waitlisted for the second day.

Manager: “It’s less paper for sure but a change is a change…so it will take some getting used to.”

Staff ask if the program will be able to manage deciding which area the person is going to (referring to both the med rehab and cognitive impairment programs)

Manager: “for wellness it will make no difference for Mondays” (Mondays are a day for socially isolated seniors, the other days are for people needing physical rehabilitation or with cognitive impairment)

Mary (Nurse): “dementia doesn’t really matter unless less there’s a lot of medical needs”

Agnes (Recreational Therapist): “I think it may be helpful that the decision making about days is done by the program because it can be so hard to respond to the different needs of the families so if it’s just decided on, it will be easier to follow.” (Field notes, January 15, 2020)

Here in this meeting the roles of staff and the purpose of the program begin to shift again, revealing their impermanence. The roles of the staff in triaging referrals are being relocated to the computer's priority system. But there is new work for the staff in learning to use the software. The relations with the other services are shifting too, the day program has been relocated from home care to transitional living; therefore, patients transitioning from hospital will be the priority rather than those at home. Patients' reasons for attending have become medical categories and some like dementia "don't make a difference" to the smooth running of the system. Here, the version of day program as respite and social engagement is fading quite a bit as it seems need for the program may be determined on the patient's spatial location rather than caregiver or patient needs. Requirements for the patients to be 'ready to start' seems to excite the staff but what this will mean to people on the waitlist remains to be seen. All of this information is delivered to staff through enrolling them in the efficiencies that will occur with less paper, more modern integrative systems, and patients who are 'matched' and 'ready', centering these factors as the problem that needs to be solved. Within the administrative version of the day program this all makes sense. The politics reveal a certain normative stance to the 'fair' allocation of the day program as a resource being most important over the other versions. The effect is one of possibilities for access, and at the same time, the possibilities of what will be accessed are becoming limited.

The last excerpt comes from a meeting at the end of my study. Over the nine months that I was at the program, I felt the ground shifting beneath my feet in each of these waitlist meetings, wondering how the program would continue to exist as I knew it within this new administrative system. During these meetings, it was difficult to recognize the program as I had come to see it through all its varied enactments. Language changed, patients and families seem to recede, replaced by managerial processes. Pols (2003) describes this kind of interference as a dissonant one where no merging of values or knowledge between enactments seem to take place. The day program as a resource seems to trump all. Interesting to me in this experience was that going into the field, I expected to find multiplicity but was surprised by the instability of the enactments. How quickly they could shift, and each day in the field I could often find myself wondering what happened. Several times in my field notes I have written, "something strange is going on here." I had assumed stability of the relations between enactments and forgot about the precarity of them. Cooper & Law (1995) explain that seeing this precarity is the privilege of proximal thinking where what is captured is "always partial and precarious" (p.239). Attending to this precarity is important as Tsing (2015) reminds us it is more the rule than the exception of our current times, and despite this, lives continue in ways that don't always match up to ideals of progress. So, the day program goes on, and lives are lived through its different enactments and because the relations are precarious, changes happen, not always for the better.

This day program multiple is a different entity than that commonly found in most day program research. While this chapter began with the ontological question of what a day program is, it ends here with an understanding that the day program exists in multiple versions, precariously coordinated in an ongoing way sometimes together, apart, or in dissonance. That the day program is not a fixed, stable thing can seem precarious and uncertain, difficult to pin down in text, yet it also opens up possibilities and opportunities to take note when the multiple enactments hang together well and when they don't (Tsing, 2015). Attention to the politics of the relations underlying these different coordinations, their enactments and effects, realties made and remade can help us evaluate the values at stake. Taking forward this recognition of the practical, multiple, and precarious nature of what a day program is will be important in the next chapters, looking at how the day programs work for people living with dementia and their families and their particular fluid arrangements of care and home.

Interlude III

Thinking with Arrangements

The next chapter is about showing the arrangements of care that existed for each participant and how the day program was a part of these. It is about introducing the day program and home as worldmaking practices that extend beyond the walls to the life of the family and person living with dementia. 'Connections' was a term I used earlier in my work, but I am not fond of the plug and socket type image that the term evokes. The relations are messier, unstable, and partial, terms that in relation to an electrical connection sound dangerous. So how to show the nuances of these connections, their precarity, as part of what can both enable and constrain possibilities? I also want to empirically show care in the community as practices, taking place within arrangements that come together in various ways as a form of interference with typical ideas of programs as units of care that can be added in a total sum approach.

So, what to pull from the data? The relations between formal care solutions and families, the ongoing tinkering, the maintenance work involved and limits that are met. Arrangement thinking is not just about the care but also the analysis. Lopez Gomez (2015) offers helpful ideas about using arrangements as a sort of sensitizing tool for ethnographic analysis. This is the thing about ethnography that was hard to understand from the books; the methodology is embodied in such an encompassing way throughout the research process. The work is an ongoing situating of the units of analyses within a set of relations, drawing focus to certain activities, objects, people, doings, sayings, and "most importantly the organizings of these" (Schatzi just said this on twitter), and then care-ful piecing together of the data to tell a story to show something. Arrangements are not just what I find but also what I looked at and now what I try to do in my analysis. Arranging the stories of the data to show the relations between the day program and home/family care practices that shift over time and space. Being care-ful in the arrangements of *this chapter's organization of ideas because, unlike care practices, text is more stabilized, etched… by putting things together I create and eliminate relations, potential comparisons come out, others are made invisible.*

Arranging Work

This study involved a lot of arranging work, 'arranging to study arrangements' could be a section title. Ongoing arranging of papers, objects, space, processes, people, and ideas was needed for this research to happen. Arranging of permissions and access with the formal health system's layers of approval processes, meeting with program staff and volunteers, filling out forms, using research approval systems, then the recruitment at support groups, caregiver agencies, and finally with the families themselves. I had to arrange myself in the field get a system of notebooks that worked, find a place to write jot notes, figure out the spaces of the home/programs and my positioning with the staff and families. Finding childcare, arranging teaching schedules, and student meetings was also required. That was just on my behalf, my arrangements triggered other people's arranging work. My supervisors responded to emails and voicemails. Managers pulled together meetings or carved out space in existing agendas, staff put up posters, sent home information sheets, tracked opt-out letters, answered family questions, found a place for me to sit, figured out things I could do and some things I could not. Families and caregivers chose times to meet me that worked best with their daily lives, sometimes taking time off work, and travelling to meet with me for the consent process, playing telephone tag, making me tea when I arrived. People living with dementia also made arrangements. They adjusted for the sometimes familiar or not so familiar face that would arrive in different spaces of their lives every few weeks, responding to this person who seemed to know things about them that may or may not have connected directly to their setting at the time. They fit me into their *conversations and activities. The other day program participants would also make room for my presence, offering me a chair, telling me a story, or asking me about my study progress. This arranging was ongoing and worked to accommodate the research study into the existing relations of both my participants' lives and my own.*

Researcher as Part of Care Arrangements

For some families, the research practices of the study were brought into their care arrangements. My positioning between the day program and the home made me a useful bridge and I noticed I was often called upon for this work. I also noticed that I was used as a trusted opinion for families over time. Louise liked to bounce ideas off me about random things like what to pack for a trip to Mexico. Peg's son Mike called me when concerned about his mom's decline. These moments scared me; they didn't feel right- they were very familiar to me as a nurse, but they confused me as a researcher. Reflecting now I see I was being pulled into the arrangement and, despite not believing in a world where a researcher doesn't affect a field, I had never thought of research as a part of care. I was very grateful for reading Rudge and Allen before starting the study, as these moments were useful information for my study; they told me to pay attention to how I was being positioned and what this can tell us about the social. Helpful as this was, I still feel like it is almost too general to just think about what was going on in the social. It left me with an impression of passive observation of these positions rather than an embodied feeling. In Netherlands, at the STS summer school in the summer of 2019, I met Bernd Kraeftner, a physician who researched care practices with people in vegetative states. Bernd is a researcher who doesn't shy away from the affective component of research and instead tries to capture it in art, film, and invention. His reading for the seminar was "The Body That We Care For" by Vinciane Despret, which was such a moving article about what worlds we create by the *methods we use as researchers and how these matter. This made me think about how being a care-ful researcher matters especially when research becomes a part of the care arrangements. During his session, I had a revelation that I had been doubting myself as a researcher in these moments of being brought into arrangements, and would always think that if I was sociologist rather than a nurse, I'd be better able to study it and just notice the positioning. He argued the opposite, that what I was studying and how I was experiencing these moments was because of making connections, not in the resisting of them. Being care-ful is not being reserved and uninvolved but instead as Vinciane Despret (2004) says, it is articulating oneself with the worlds one is studying, which "means to make an effort to become interested, to immerse oneself in the multitude of problems presented"(p.131).*

Arrangements of Writing

I write this part of the dissertation during a pandemic where everyone's arrangements are being redefined - our relations with people, space, governments, materials, are in a massive flux. An uprising against systemic racism has flickered or ignited in some places. Standing back and intellectualizing for moments is a more comfortable position than the existential angst of being within it. I see subject positions shifting – children, youth, women, older people, heroes, and bastards all becoming something and someone else, practices of gatherings, greetings, potlucks, childcare, and work rearranged with risk. Science, knowledge, community, and the economy questioned, valorized, and enrolled. Precarity seems new, but it was always there, hiding in relations that seemed durable and unquestionable, established by practices that enabled certain subjectivities, power differentials, and values to be naturalized.

Chapter 6

Case studies –Arrangements of Care

Starting with a Story of Arranging

I received my first voice mail from a person interested in knowing more about my study while I was on vacation in California with my daughter. I delay the day's planned excursion to Disneyland and sequester myself in the hotel bathroom away from the noisy television and a potential tantrum and call the woman back immediately. She tells me her name is Louise and her husband Jan recently started attending day program A. She tells me "I wanted to find him a place for exercise… he used to be a gymnast, but he has memory problems so the club where he used to belong wasn't working anymore." We discuss the study a bit, and she tells me it would be good if I could come to their home and tell Jan about the study as she says "I am interested but I want to be sure Jan is ok with it, as it really is going to involve him too." We pick a day and time in the following week for me to visit and I get the address. I come out of the bathroom, elated that my study may actually happen and quickly shift back into 'Disney mode.'

I arrive at the home the following week to meet with both Jan and Louise. They welcome me in, Louise has just returned home from her job, she tells me she is later than usual as she must take the bus due to a broken wrist from a fall a few weeks ago. Jan has been home all day alone, working on translating his life story from English to Danish. Louise offers me a seat in the living room near Jan and says she will make tea. The papers of the consents come out and I begin to explain the study, Jan follows along but then begins to tell me a story about his book. The consent process starts and stops as I listen and then try to shift to conversation back to the consent form. This is an intricate dance, I am interested in the stories he tells, I want to convey both engagement with him and my role as a competent ethical researcher. The first story is interesting: a short history of Denmark as a conquering nation. I shift the topic to Iceland, once a

Danish Conquest, where I know about another study on day programs and then to this study. After several rounds with us shifting leads, the waltz between the consent form and his stories has been a slow and choppy one. My consent form seems to be endless. Jan is attending to the information but also expanding at times into his own life story and I worry if perhaps both of our goals can be met. I wonder out loud if perhaps the consent should be left for him to read over. Louise who has remained quiet until then, sipping her tea and listening to us, says "No if you leave it, it will be forgotten; better to go through it all now." So, we continue, and Louise joins in asking specific questions to Jan keeping him on track with the form. Faster than I expected, the consent content is finished and signed. Jan now picks up the large white binder sitting on the coffee table and says, "Now I can show you my book."

What is going on here? A researcher is coming into the lives of the participants, meeting the practices that shape it. Summed up quickly as a 'process of gathering informed consent' brings the consent form and researcher's rational, logical goals forward. Chairs, tea, storytelling, bus schedules, a book, Iceland, Vikings, coaching, and dancing are all invisible. There are multiple goals here. Informed consent is one; relationship building is another. Louise has a goal of making this a joint decision between Jan and her. I also have a goal to say, "I am a researcher with a 'real' participant." There are limits on how all of this can happen together. Through tick boxes and signatures the consent form demands attention; through enthusiastic description and a twinkling eye, the storyteller demands attention. Louise indicates that Jan's memory may limit the staying power of the consent information and so through careful adjustments and failed attempts, the right combination of information, listening, guidance, the research study enters into the lives of the participants and we are enrolled into relation with each other. Thinking of it this way requires attention to different things than merely the outcome. It requires a view of relations and materialities present that are not set or stable but rather fluidly and temporarily arranged. Not immediately configured with certainty, but rather tinkered with, adjusted as we go. Allies are brought in to help reinforce the consent's stepwise detailed agenda, the storyteller makes allowances for interruptions to the tempo of his narrative. Bodies are positioned in relation to each other centering Jan as the object of interest, close to the researcher, his book is placed so that it is easily referred to, cups of tea are added bridging the formality of a researcher's visit with the rituals of an afternoon at home. All of these come to be into relation with each other as an arrangement that works and takes work to maintain. Effects from this travel and shape us in relation to each other in the visits to come, although because the actors and the materials change, the arrangement is never exactly the same.

It is these arrangements of care and life that were the focus for my observations in the field and now for the analysis. This chapter draws on the data from the four participants: Jan, Wes, Marie, Peg, and their families. Using the specificity of the arrangements that I observed between home and the day program, I will introduce the people living with dementia and their families through case studies. In these case studies I will show how the day program fit as a part of this arrangement and the possibilities and limits of care that were realized. Since a flipbook type animation is not an accepted dissertation format, I will try to overcome the limits of text in capturing the temporal nature of the coordination of arrangements (Gan & Tsing, 2018) by using a series-type arrangement of stories. Beginning with Jan and Louise, a family in the early stages of attending a day program through the first year, I will show the tinkering and flux of the fit of the program within the other family arrangements worked out to sustain a life with dementia. Then the stories of Wes and Margaret, who are the longest users of a day program in my study, will show a seemingly precarious life made durable within an arrangement of multiple elements.

Marie and Darren demonstrate the arranging work of inclusion and how the program's care practices help to sustain a person recognizable to their carer. Finally, Peg and her family's stories will show another set of family arrangement with a day program that both enables, and at other times limits, the possibilities of enacting good care for a person with dementia living alone.

Jan and Louise

Jan and Louise are a couple who have been married for 25 years. Jan is 90 and Louise is 66 years old. Jan is a lifetime writer, gardener, and gymnast. Louise is a hiker, traveller, and reader. Louise tells of their previous shared social interests of folk dancing and travelling that have dwindled in the past few years with Jan's memory problems. Louise tells me that dementia has affected Jan's short-term memory and "processing." He is independent with his activities of daily living and still does most of his own meal preparation. Louise says that lately she has become concerned about ways Jan uses utensils and kitchen equipment and gives an example of him using an ice cream scoop for oatmeal. Jan tells me the "only thing I am good at is forgetting!" and feels that he has good days and bad days. Jan attends Program A once a week on Thursdays, and has a respite worker Margo who comes in for three hours on Wednesdays. Louise works part-time a few days a week.

Fitting in the Program

Program A is a 20-minute drive away from their home. Louise, who works part-time in another part of the city, organizes her work schedule to drive Jan to the program most days and then has Jan use the senior transportation service to get home. The transportation service requires pre-booking but only takes reservations two days in advance. Jan doesn't feel he can manage this task as the phone has become overwhelming for him, so Louise makes the booking. Sometimes this works, and other times it doesn't. Louise adds it to her 'to do' list that has been getting longer since Jan's memory problems started. It seems pickup times are not consistent, so if the day's assigned pickup time will be early, she has to call the day program manager to let the staff know. The manager then acts to mediate this with the transportation system, telling them that they need to change the time.

Fitting in at the Program

I ask Jan in our initial visit what his early impressions of the day program are. Jan tells me he is impressed by how the program "manages to take care of so many different people at the program." He tells me he likes some of the activities, like the exercise group, but finds other times boring. He is frustrated by the fact that people don't circulate in the room but stay in their one seat all the time. "I change my spot every time," he tells me.

Knowing the Program

In an early visit, Louise tells me that "it isn't the relationship that I was promised" as she has had no communication from the program in two months. "I thought I would hear more about how he was doing there." On most of my visits, I am the intermediary between the day program and the home. Louise only hears generalized accounts from Jan, such as that they had a good day but he isn't sure what he does there. One day I ask her if she has seen the space of the day program, and she tells me, "no, because the staff have told me it is better to just drop him at the door and leave." In my visits, if I ask Jan questions about specific people and activities at the program, he will then tell stories about them.

In this early stage of Jan's participation in the program, both Jan and Louise make adjustments. The logistics of transportation booking have to be accounted for in the weekly 'to do' list. Jan must navigate the program's routine in a way that fits with his tastes. Louise navigates the unknown of the program and has to rely on Jan's vague reports. When I ask her what she could do about her dissatisfaction with the program communication, she tells me "Oh I could likely call someone, but that would be one more thing that would likely get dropped down on the list of things to do.” When Louise does hear of Jan doing a new activity, she considers how to extend it into the home, despite its odd fit with Jan’s typical tastes. Louise often speaks of not knowing what she ‘should’ be doing for Jan. “There is no teacher here,” she tells me one day. The addition of the day program to the family care arrangements seems to act as a sort of expert authority. While vague to her, she draws on ideas from the program for what care/activities are ‘right’ to do with Jan. But there is conflict in the goals of the day program and home practices within the arrangement, and these often became apparent to me as I moved between home and the program.

The nature of respite as a pure space away is maintained by the program practices but denies the potential messiness of what respite practices might include beyond time away (Law et al., 2013). Like ‘Vegas Rules,’ what happens at the program seems to stay at the program, facilitated by minimal communication between the program staff and Louise, as well as Jan’s memory loss. Present here is the homogenizing idea of Jan as a person needing supervision and guidance, and Louise as simply a caregiver who needs space away from him. This ‘simple location’ of respite works against Louise’s desire to share ideas, learn, know what Jan is doing there, as well as their existence as a couple with shared experiences. While Louise finds relief that Jan is ‘doing something’ with others, she finds the vagueness of what is happening there frustrating. This effect comes into conflict with the logics of the couple’s other arrangements of care, where they are striving to find a way to attend to Jan’s preferences and activity levels.

Slow Entanglements

After three months, the program seems to have become more of a part of the weekly routine – it is written on the whiteboard that Jan and Louise use as a reminder of things to do and for important numbers. The number for the transportation system is listed there for Louise to call each Tuesday. She has this listed in her personal calendar as well. Jan eventually settles into his own ‘spot’ at a table at the program with people he seems to enjoy talking to, and he stays there. Louise eventually calls the manager to ask about communication and receives a monthly calendar of activities and a report by mail that she tells me said “something about him doing well there.”

Despite the establishment of the program within their lives, there remains a generalized quality to their reports on the effects. Louise tells me, “I think some things are good, but I still don’t feel that we have all the pieces of care that we need.” When I ask her what she feels is missing, she tells me that “we are missing a regular connecting physical thing for Jan” and that she wants “to make sure someone is able to listen to his stories.” She tells me she often comes home from work and finds Jan hasn’t left the house all day, he tells her that he does his stretches, but she isn’t sure that this actually happens. On the other hand, Jan tells me that he feels his “time is too regulated.” They agree that he could be going out for more walks, but the neighbourhood remains unfamiliar to him and he worries about falling. I ask if the respite worker who comes Wednesday would be able to do this with him, and Jan tells me that when she came this week, he was ready to go for a walk outside, but the worker wanted to stay in and work on the puzzle. Louise says the computer has also been a major source of frustration for both of them “it is a great stimulation for Jan but it also something that makes him sit for too long and then when there is a problem it becomes a big frustration for him and then as a consequence, me.” She tells me that while her daughter is helpful in troubleshooting the glitches in the computer over the phone, she doesn’t want to impose too much on her daughter’s time. “But what do you do? We are still living,” she says.

Finding a balance in the arrangements of care within their new living space continues for Jan and Louise, and the day program is just one part of this. The supports needed are not general, what kind, how much and when matter to both Jan and Louise in different ways. So, there is tension in the ongoing negotiation of this between each other and with the other people involved like respite workers and family. While the day program is often held separate from home, there is some integration between the sites that has happened. Communications have changed, booking routines have come into the materials of the home, as well as some new effects such as Jan feeling "too scheduled."

Arranging Generic Resources

After six months of Jan attending the day program, there is a family meeting with the home care case manager Michele. Within the local arrangements of the formal health system, home care is the allocator of day program 'spots' and other respite and support care for people living with dementia at home. Jan, Louise, and I sit at the dining room table with Michele.

> Michele places a binder and a few resource guides in front of her, opening up the binder to what looks like a chart she begins the meeting by explaining its purpose: "So today is our annual review meeting where we talk about resources that are set up and if any more are needed… it is the way we renew services for the next year."
>
> Louise: Yes, I feel like I have set up a lot of things this year, but everything takes so much time.
>
> Michele: Yes, day program took quite a while to be arranged, like six to eight months, I think… and now I hear that the average wait time for day programs is one year.
>
> Louise: Oh so six months wasn't that bad, I guess…
>
> Michele: How are things going?

Louise: Well, it’s hard because as I focused on the move and helping Jan adjust, I also am adjusting to the new place, and with his short-term memory problems, it is hard to connect… I have no connections, and I often wonder where am I living, like what kind of space is this for me? I can’t be here alone with him for very long; I go crazy in my head… but I don’t have a sense of if it’s ok to leave him or not… I do leave him… and he has the program, but I like to work and see my friends too.

Michele: Have you been using any other of the supports we talked about through the Alzheimer Society?

Louise: We did go to a meeting together back in May, but I haven’t really embraced that yet as a support… it was fine, but we were busy in June, and then the July one was cancelled, and I suppose there is one coming up this month… I wish they would send reminders of these things because if it’s not right in front of me, I forget about it with all the other things going on… so many appointments.

Michele: Has Jan been for a geriatric assessment yet?

Louise: Oh, he is due for some cognitive tests this month, I think… but no, we have only seen Dr. C, his family doctor.

Michele: Dr. C would need to do a referral to the Geriatric Assessment Clinic. They would do an assessment and then send a report to home care to help guide us in making referrals they think are needed and whether there is a need for any increased services.

Louise: Yes, I know. Dr. C said he feels he can handle this level of things now with the cognitive tests and stuff… I know it’s good to be proactive, but you can also feel like you are pushing. And we seem to be doing ok. I think Jan has come into himself in the new space; he is adjusting to the new routines since the move.

> After the meeting, as we walk to our cars in the parking lot, Michele tells me that she is often limited in offering resources to families because “when you offer services you have to realize that at some point you might have to take them away… and that there is paperwork approval processes tied to anything more than the ‘standard’ hours of respite.” (Field notes, August 12, 2019)

Arrangements are happening here in the meeting. People are arranged into roles in relation to each other. Limits are being set on needs and possibilities. Louise, who has told me her plan for the meeting is to try and get more flexible and personalized resources for Jan, begins the meeting by explaining her feelings of isolation and changing identity, perhaps as a way of accounting for need or perhaps in not understanding her position in the meeting as a carer of Jan. The case manager quickly calls her into the role of caregiver, which the home care supports are provided in relation to. The case manager enters the family’s arrangement but remains in relation to the larger formal system arrangements of her role. Somehow, what Louise describes as daily angst is translated into a need for monthly caregiver support groups at the Alzheimer society and more formalized testing of Jan’s capabilities. These resources seem to be the specialized support available for the case manager to allocate beyond generalized respite care options. While not unempathetic in her approach to Louise, the case manager's responsiveness is limited by processes that involve other gatekeepers to determine more specialized needs. The distributed approval process limits the case manager’s freedom to tinker with resources to a narrow scope of risk management resources and a maximum number of respite hours she is free to allocate. Despite being in more of a supportive type role with the family, the dominance of the reenablement model of home care permeates the case manager’s role within the arrangement with this family (Bødker, Langstrup, & Christensen, 2019; Ceci & Purkis, 2011). This home care agenda for certain types of caregiver supports arranges both Jan and Louise into certain subject positions. Louise is the caregiver, and Jan is the care receiver. Jan is active a few times in the meeting, asserting what he can still do for himself, but the discussion shifts him into the conversation's background more than I have seen in other home visits. The limits and possibilities created by these subject positions, and the coordination of the resources with the family practices become apparent as they discuss options for getting Jan help with the computer and his writing.

> Louise: We've talked with Holly about how much Jan likes to work on his book and the translation but that the computer can be a big problem for him, and I can't be the 'help desk.' It would be nice to have someone who had the skills to help him with the computer when it doesn't work. My daughter and son-in-law have been helpful, but they can't be on call all the time.
>
> Michele: Well, that is something that your respite worker can do while she is here if she has the skills.
>
> Louise: Can she?
>
> Michele: Yes, respite is for you guys and whatever needs you have – *you* guide that time.
>
> Louise: Well, often I am not here to see Margo when she comes, so I don't always get to tell her what to do, and I'm not sure Jan feels comfortable doing that either. I think it's a bit like having a visitor.
>
> Michele: I can put it into the care plan so that it becomes part of the list of tasks for the respite worker, some of them need that structured guidance as to what they can do.
>
> We talk a bit about a possible source of people who might volunteer to help Jan with his writing and computer time. Michele explains that volunteers are hard to find. She can

> request more respite with the contracted agency and for it to be someone with computer skills, but Louise isn't sure she wants more respite. I ask if there is a volunteer resource center in Edmonton and she is unsure, but that home care relies on volunteers from Continuing Care.
>
> Michele: I can add services in. Would you like more respite hours?
>
> Louise: No, I don't think it's more hours that I need.
>
> Michele: Yeah, I can add more services but I'm not sure that's what you need… you need resource finding. The recreation therapist may be the answer to that, I will ask her and she will either tell me some ideas and I'll tell you, or she will say to do a formal referral to her and then she will come out and do a consult with you.
>
> Louise: That would be good.
>
> The discussion turns to the issue of Jan running out of supplies for his breakfasts and how his memory at times interferes with planning for groceries. This issue causes much conflict between Jan and Louise. Louise asks the case manager whether the respite worker could help Jan with grocery shopping, and Michele says she will try and put it in the care plan but that often respite workers are not comfortable with anything involving money. (Field notes, August 12, 2019)

Here, in this part of the meeting, it again seems that fitting specific needs within the formal services categories for support is quite difficult. The respite care is offered as a solution, framed by the case manager as wholly based on "client choice," yet it seems limited in meeting the specific needs of Jan's interest in working on translating his book. The home as a non-clinical space where guests are welcomed and hosted and not managed is a problem for the family in their negotiation of specific respite care activities. This leads both Louise and the case manager to consider how it may not be a number of hours needed but more related to specifying the activities and tasks required of the respite worker. There is tension in whose responsibility it is to do this, and Louise pushes back the work to the case manager. Resources for Louise are not only a form of support, there is a cost-benefit quality to them for her- they require work, and as she assumes more responsibilities around the home, she actively works to limit the time spent on arranging. Jan's daily living supports are minimal, he could use help doing his groceries, but this is not part of the predefined home care supports, which are based more on physical care needs than cognitive ones. The assumption by both the case manager and I is that Louise will adjust this to be her task, but she refuses this, explaining to us that they have always managed their own breakfast and lunch provisions. The case manager decides to try to translate the interests and supports into tasks for the respite worker and uses the care plan as a technology to interfere in this relationship between the respite worker and the family more formally. The case manager also translates some of the specifics of the request into something that is in fact, not respite at all but resource finding. This translation overcomes the limits of her ability to tinker with the care plan and add more hours by displacing the responsibility to another expert.

In this meeting, the day program exists as a scarce resource that the family was lucky to get into, but it is otherwise invisible to the discussion. Within the total sum approach that drives much of the service allocation model of home care, the day program, like the in-home respite, sits as a fixed homogenous block of time in a list of resources being totaled. The day program is maintained apart from the formal system that allocates it. On the chart the nurse can see that Jan attends once a week on Thursdays but otherwise knows nothing about what the attendance entails for the family nor what the benefits are. Here the day program acts to distribute the responsibility of some of the care provision away from the home care agency who acts only to connect people to the resource but not integrate it within the care that needs to be “managed.” While not unappreciated for being ‘someplace for Jan to go to,’ the generic quality of the day program and its boundedness lie outside of the specific arrangements in Jan and Louise's day-to-day life, and as such unmet needs continue to exist.

Materials of the Arrangements

Despite the program's limitations to joining in the other practices of the home, over time, there is gradual fitting in that occurs with work from Jan and Louise, the people at the program and in relation to gradual shifts in the other spaces of Jan’s life. Tracing the work of Jan’s book shows how materials of the arrangement are part of what helps hold things together.

Jan began writing his life story 40 years ago and decided to record them together in a book for future generations of his family. The book is called ‘Bedstefar,’ which is Danish for Grandfather. It is approximately 600 pages of text with occasional pictures covering Jan and his family’s life from birth until now (as Jan tells me it is not yet done as he is still writing). The pages sit within a white three ring binder, and he has made copies on USB sticks for his family. The book is a central part of Jan’s day to day life as he either reads it or works on translating it into Danish most days. In every visit, I notice the book is visible on the coffee table, referred to, sometimes read out loud for interest or to clarify information that Jan can’t remember. Louise describes the book as a point of connection for them as a couple, and she tries to find time to read it with him a few times a week. She also tries to organize others in relation to Jan around the book, looking for ways that Jan can tell his stories. The book enables other relations such as that of the extended family drawn in to help with the computer.

At the program, I notice the book is not mentioned in any of the chart forms, and staff are not aware of its existence until I mention it to them. After a month of observing Jan at the program and home, I begin to recognize the stories from the book at home and how they materialize within his relationships at the program. Jan shares stories with other members emplacing him in relation to others' stories and common interests of writing.

Over the early summer, new people join the program, and other people leave and with this, the dynamic of the room changes. Thursdays at the program become known for the loud and gregarious group of men who attend. At Jan’s table, the group of people become more familiar to each other through their love of storytelling. In August, a man named Vinny joins the Thursday group, and he is a storyteller who speaks multiple languages and tells everyone about his “bad head” from dementia. Vinny brings in several books that he has self-published, and Jan tells him of his own writing. Bob also comes in around the same time, a former politician and local historian, he tells magical stories of the ‘olden days’ when much of the city was farmland. These tales engage everyone at the table and always end in belly laughs. I see Jan frequently arranging himself to sit with these mates throughout the day's activities, sharing stories with them.

A sort of familiarity and cohesion develops between these group members that does not rely on remembering each other’s names or specific stories. These participants and their arrangement at the table create a place of telling. In this place there is freedom for Jan; stories can be retold without the correction or interruption that I see at home, where repeating stories is less tolerated.

This group of storytellers go through the program's daily routine, at times complying with scheduled activities and at other times resisting and telling their stories instead. Staff begin to act differently to them over time – still insistent on the routine, but also seeming to step back on the rules for total conformity. Jan has taken to doing his dance steps at walking time and now several people are doing fancy dance steps like Jan.

In the fall, a volunteer has been found by home care, a woman with computer skills who is also a writer. Nancy comes on Tuesday mornings and helps Jan set up his computer – troubleshooting any problems that have developed. Jan is pleased with this addition to the arrangement, and he tells me that "Nancy is also an immigrant to Canada with a fascinating story."

When I visit Jan at home in the fall, I notice that he can't recognize people from the program by name, but if I tell a bit of their story, it immediately triggers recognition for him. Louise remains vague in knowing the details of events at the program outside of the monthly schedule. She continues to try and extend any activities Jan mentions from the program into their home. "I am thinking of getting a newspaper subscription," she tells me, "because I think he does that at the program." One day when Jan and I are telling her about the storytellers Jan sits with, Louise asks me if it would be appropriate for her to ask if Jan could bring in some of his book. I tell her that a man at the program brought in his fiddle and played for the group, so it seems possible. Jan agrees, and Louise tells me she will call the manager and ask. Jan brings in a short excerpt of his book and reads it to the group.

Ongoing Adjustments

In the early winter, the arrangements change again. The volunteer Nancy quits as she finds paid work. The respite worker Margo still only works on puzzles, but Jan decides to walk in the hallways instead of outside. Louise considers several community exercise programs from resource books that the case manager leaves her, but finds the fixed schedule is more than either of them want to commit to, so she considers doing stretches as a couple a few evenings a week at home. Jan nods and says that "if you get too scheduled, you can lose the individual." They host a dinner party and plan a game night with the family. Louise tries another Alzheimer support group meeting but finds it overwhelming to hear what might lie ahead, so she takes to calling one of the support workers there for one on one discussion instead. She tells concerns of what's next haunt her and equates this feeling to "skating on a rink with no boards." But despite this feeling, she tells me that as she sat down to write a Christmas letter to friends and family, she was proud to see how much Jan and she have done this year. "We are in a different world, but we are still living."

After Christmas, the computer crashes, and Louise decides it will need to be replaced. Jan seems to be focused more on reading his story than writing the translation. Louise tells me that she is worried about their condo building neighbours' tolerance of Jan, as he mistakenly went into the wrong apartment during one of his walks. Within this gradual shift of the apartment space's inclusiveness within the care arrangements, the day program emerges as a safe and welcoming place that knows Jan and tolerates his condition. They decide to add a second day starting in February. Louise explains to me:

> The people that work there are friendly, and they care… It is a long winter to be stuck inside and here in the building they aren't very tolerant, there is judgement from others and that is hard, I mean I moved here because I thought it would be better but maybe I didn't move far enough… it makes me happy that Jan has that other space to go where it is ok. (Field notes, February 17, 2020)

Louise tells me that adding a second day would be a good idea as she sees "a difference" in him since he has been going to the program. "He can't tell me what he does there, but I can see it in his posture and expression that it is good for him that he is doing something and not just sitting and (she gestures a curled in posture)."

So, the arrangements shift slowly over time; new resources and people come in both at home and at the day program changing the nature of those spaces for Jan and Louise. Jan, Louise, and the case manager all tinker with the parts of the arrangements with some successes and some failures. Through the care enacted by these arrangements, both possibilities and limits have been set for how Jan and Louise can be sustained. Withing these arrangements Jan, as a writer, is harder to maintain, but Jan as a storyteller remains. Louise's sense of anxiety has gone down, she seems less tied to knowing what's next or what's right to do, but she has also taken on more responsibility for care. New definitions of space have emerged for both Louise and Jan; these shape where Louise can be present and how, where Jan can belong, and where he is 'safe.' The day program's place within the arrangements shifts over this time. Still bounded in its connections with the home and home care, Jan and Louise have worked it into their goals for Jan to be 'doing something' and have balanced this with his desire not to be overscheduled. While still somewhat homogenous for Louise, for Jan, there are connections made, he has inserted his story into the routines and relationships there, and as other spaces become less familiar or predictable, the day program begins to emerge as a familiar, safe place. This arrangement is not perfect or complete, but that would be an unrealistic goal with a greater risk for failure (Winance, 2010). A 'good enough' fit seems reasonable for now; it will require ongoing work, as it will continue to shift as the people and supports will come to be different things through their relations to each other.

Wes and Margaret

Wes and Margaret have been married for 66 years. Wes is a 98-year-old retired telecom engineer and teacher who has dementia. Margaret is a 90-year-old woman who has some physical health issues of her own and is the primary caregiver for Wes. Wes was diagnosed with dementia eight years ago after Margaret noticed he was having memory problems. The day program came into their arrangements early on after Wes's diagnosis, and its role in the arrangement has gradually shifted over the years in response to both Wes and Margaret's needs.

There is a certain haphazardness to my home visits with Wes and Margaret, and it takes me some time to realize that despite the apparent precarity of their lives, there is also durability made possible through their arrangement's ability to distribute care and define areas where they have control over their lives. Margaret has neck problems that cause her to sit with her head down most of the time, only lifting it to talk. This often gave me the feeling that perhaps she had nodded off during the interviews only to be surprised by a quick toss-up of her head and some thoughtful comments. Wes is a cheerful man with a long mane of white hair and beard who is usually humming to himself or saying funny one-liner statements about his age or state of being on "permanent vacation." His short-term memory is quite impaired, so visits with them were interspersed with Wes frequently asking me who I was and whom I worked for, followed by a few pleasant comments about my university and then a few moments later, the cycle would repeat. Between these interchanges, Margaret was serious in answering my study questions and seemed intent after the second visit that she hoped I had my answer. Both seemed to tire quickly in the interviews, so home visits were shorter than my other participants. In contrast to these impressions, Margaret told me of making meals, washing dishes, reading newspapers, and choosing recipes for dinner time; Wes smiled and cracked jokes and spoke of playing his keyboard.

Family Arrangements

A key preference that guides Margaret in the arranging work for her and Wes is that she does not like having too many people in her home. She tells me, "Home care always asks me, 'is there anything else we can do to help you stay at home?' and I tell them no. I don't want anything else and anymore people coming into the house!" Despite this preference, she tells me that home care supports have gradually increased over time, initially just to help Wes with baths once a week and then later on with his morning care on the days of the program, and then even more in the past few years for his daily morning and evening care. Margaret also receives a bath once a week. Although Margaret voices no complaints, she laughs as she describes home care as "the people who come and tell you to get your pajamas on while you are eating supper." Margaret tells me that they go to church on Sunday and that this is possible because a volunteer from the church offered to drive them.

Because of this desire to limit outsiders in the home, family are an important part of how care is distributed within their arrangements. Wes and Margaret have three children whom all live in the same city. Their son Rob, aged 66, has lived with them in the basement for three years and helps with groceries and general house upkeep. Rob's twin brother Mike helps with household maintenance and repairs, and their daughter Sheryl, aged 68, does regular fridge cleaning and brings a meal over on Sundays. Over the years, 'the kids' have done many adaptions to the house to help accommodate Wes and Margaret's changing needs. Wooden railings line the walls down the home's hallways, installed after Wes broke his hip years ago and left in place because they seemed helpful. Both Wes and Margaret use these, and the carefully placed furniture, to help them get around. During one of my visits Mike, their son installs a 'walk-in' tub in the bathroom to address the fact that Wes insists on taking baths in the tub, and home care feels this is a risk for falls.

While Margaret tells me the support from her family is helpful, family member support practices are not always coordinated in their goals. There is often some conflict between the two sons' impressions of what is most important, which can escalate into arguments. During one home visit, I observed Mike and Rob arguing as to Rob’s role in the house. Mike expressed his view of the substandard work Rob does at upkeeping the house and argued for the need for a more ‘professional level’ care. During this loud argument, I notice Margaret and Wes quietly sitting and listening. Margaret interjected once saying, “Rob does plenty, and it’s fine.” She then tells me later about listening to her sons argue that “it’s hard, but once Mike just gets out of here, it’s fine.” She also tries to manage the amount of work allocated to the family. She tells me that the one thing she feels is not working for them right now is the laundry situation. The washing machine is in the basement, and so the journey down the stairs is a lot for Margaret to do, but she doesn’t like having to ask Rob to do it all the time, so she is considering relocating the machine upstairs.

Family practices are key parts of the care arrangements for Wes and Margaret that exist in relation to the materialities of home and day to day life. While family members are generally oriented to the same goal of sustaining both Wes and Margaret at home, different ideals sometimes interfere with each other and create new work for the arrangement, managing and tolerating conflict. This is not surprising to anyone that is part of a family, but it does contrast sharply with the ideal of family as a cohesive stable unit that guides much of the ageing in place policies and home care practices (Allen, 2012; Fine & Glendinning, 2005). This ideal version of family makes it difficult to account for friction, change or capacities of the members within an arrangement. Wes and Margaret’s arrangements show how family members come into the arrangement in relation to each other and the other practices of the arrangement. For instance, they work with the house and its materials to enact an accessible environment for Margaret and Wes. Within these relations, roles are established, explosions of conflict occur, sometimes goals and roles are adjusted, and the arrangement continues.

The Evolving Role of the Day Program within Care Arrangements

After Wes's diagnosis, Margaret tells me she hasn't wanted to leave him alone because "he requires attention," which the day program initially provided. "It gave me a break from being the one attending to him from 9:15-3 a couple days a week." She tells me that initially, she would often use the time to run errands and go to her medical appointments. As time went on, Margaret's mobility became more limited, and she redistributed some errand work to family members, so she found herself spending more and more time alone at home with nothing to do. Three years ago, her daughter felt that her mom was very socially isolated and not doing much on the days that Wes was at the program, so she encouraged Margaret to consider joining the program as well. They both now attend together Monday, Wednesday, and Fridays. When I ask Margaret what she likes about the program for both her and Wes, she tells me, "we play a lot of games there, we sit with at the same table with six other people and drink coffee, play gin rummy tiles, and then we exercise." She says that the people are friendly for the most part, "some are good conversationalists," and that everyone wears a nametag, so it is easy to remember peoples' names.

At Program A they sit at the same table but often not next to each other, and I note that staff do most of the care of Wes and Margaret separately. Wes chooses his own lunch and sits away from Margaret during the main space activities. He does seem to be aware of Margaret, though and will refer to her if someone asks him a question or asks where she is when she is in the bathroom. Margaret responds to Wes when he asks for clarification of his life history.

Researcher: What type of work did you do Wes?

Wes: Hmmm I don't know what I did… I think I was a high school teacher or something.

Margaret: You worked in telecom for years Wes, and then you taught at post-secondary.

Wes: Oh right! that's what I did. (Field notes, September 18, 2019)

In the chart, the care plans for Wes document an appreciation of his interest in music and inclusion of him as the musician for the sing-along time. The staff tells me his goals are under the cognitive and social domains of the wellness model the program uses. Wes participates in the rummy tiles game with the help of the staff, the exercise group and usually watches others do crafts. He seems confused by some discussion if pictures aren't used or prompts aren't given, which they often are not. At time he also takes naps during some of the activities. On the other hand, he is the in-house musician who plays the organ by ear for lively sing-along sessions. He cracks his familiar jokes, usually asking staff how old he is and then proclaiming, "Huh? 98? that is old!" He routinely groans about standing up and then does a countdown ritual to rock himself out of the chair, and each time the other clients laugh and roll their eyes at him saying, "Oh Wes."

Rob, their son, tells me that if it were not for the day program, he would "lose his mind." He has a deep appreciation for the service but also sees the limits of what is offered there. "I think they (the programs) could be more," he tells me without being able to describe the specifics of what 'more' would look like. He tells me that the majority of day program contact with the family is between the staff and Margaret. "For the most part, Mom's ahead of the game, and I'm just the back catcher… and sometimes not that good of a back catcher." He explains that likely the only reason "we would call Sue (the manager) is if they weren't coming to the program."

Rob reports he wishes there were more outings for his Mom and more music for them both, and then adds, "but maybe that is a family thing that we should be doing more for you." He tells me that his mom doesn't have the contact with friends that she used to have since mobility issues have made it harder to walk around the neighbourhood and see people.

While not perfect, this is an arrangement that works for Margaret and Wes right now. This arrangement between home and the day program practices seems stable and mundane, but many pieces work together to support it in the background. Merely getting to the program three days a week requires the coordination of several different actors, and these relations enact the day program as it exists for Wes and Margaret. On these days, a home care aide comes at 8:30 am and assists Wes with getting out of bed and dressed. Margaret does her own care, then the seniors' bus picks them up at 9:30 am and takes them to the program. When I ask if I can observe this time and Margaret says quickly, "I don't think that would work." Rob tells me that most mornings go smoothly with "things going sideways only two or three times a year." When I ask what 'sideways' looks like, he tells me, "just when things don't go as planned, things come up that you don't expect." The senior bus driver comes to their door at 9:30 am and escorts them to the bus with their walkers, drops them at the program, and then picks them up at the end of the day and brings them home. Margaret tells me she uses a prepared meal service on day program days to have supper quickly ready when they return.

Multiple practices are hanging together, Margaret and Wes's life together, the family support practices, the day program, the transportation service, a volunteer driver, a church congregation, and home care. Through this care infrastructure, there is both a sort of precarity and durability present. There are cracks and less than ideal circumstances evident in the clutter, the family conflict, and the confined isolated space of their lives. Yet it is somehow enough for Margaret to say she is good and for Wes to say, "no complaints." This arrangement is about care, and there are allowances within it for the ongoing adjustments required over time. In the background, the practices of the program, DATS, and home care monitor and connect to keep things running as smoothly as they can in conjunction with a family who adjusts the materials of the home and reallocates the tasks around the changes that dementia and ageing have brought. The possibilities created through this care infrastructure occur around the limits of what types of help home care has to offer, Margaret's boundaries of letting others into her home and the opportunities available for Wes and Margaret's inclusion within the larger community.

Marie and Darren

Marie and Darren are both in their late 60s and live in a large home in a suburban neighbourhood. Marie, a former junior high teacher, soccer coach, and musician, is a tall woman with an athletic build. Marie was diagnosed with dementia five years ago, soon after she retired from teaching. They have three children, one of whom (Sarah) lives nearby. Darren says Marie began having subtle problems with her memory in her early 60s, but there were other stressors in the family, including a terminally ill granddaughter, which seemed like reasonable causes for these problems at the time. It was during a trip overseas seven years ago that the significance of Marie's memory problems became apparent. Darren noticed she could not use the travel guide or maps as she could not remember what she was looking for. After this trip, Darren reported his concerns to the family doctor, who arranged for neuropsychological testing, and two years later, Marie was diagnosed with dementia.

Darren tells me that up until the past year, Marie was "fairly functional in the sense that she was having some trouble expressing herself with words, but she was able to go for walks and bike rides by herself without getting lost." A year and half ago, Marie had a serious accident while riding her bike, resulting in a broken pelvis and elbow. She required surgery and hospitalization and had an arduous recovery from this. Several months after the accident, the family noted that Marie's language problems had progressed and were now both receptive and expressive. At that time, Darren had no supports in place for him or Marie other than his adult children and his sister and brother-in-law, who lived away for part of the year. Despite a previously active social life, it did not fit within the new arrangements required for attending to Marie: “I have good friends, but they are more activity-oriented good friends, so when Marie became…when it became more difficult to leave her… we didn’t have those activities. They faded away… and only occasionally we will get together for supper and stuff….” (Family interview, October 23, 2019)

Over time, Darren became overwhelmed and isolated: “I was starting to feel like a prisoner in my own house.” His children were worried about his stress levels and told him he needed to get support, which eventually led them to the day program.

> First of all, my daughter heard about day programs and encouraged me to look into stuff. I found that I was so busy with Marie and just trying to… as a result of the accident a year ago. So, I just… between fatigue and busyness, I just never got around to it. So Sarah was the initiator, and she got in touch somehow with the social worker, Jackie… and she was the one that made arrangements and told her about these day programs and made arrangements for us to get into first the one at Jamestown [a small town 20 minutes away from their city], because there were no openings… then an opening came up and then we got into Program A. (Family interview, October 23, 2019)

Marie started attending the day program one day a week, in a town about 20 minutes away from their home. Initially, Darren was skeptical of how the day program would work for Marie due to her being much younger than the rest of the participants. When she was transferred to the program closer to her home, staff added an extra day and rearranged her days of attendance to “match” Marie with the group that would be a “better fit.”

Recently, home care connected Darren with an “enhanced respite” pilot program that provides in-home respite workers 17 hours a week. They are also enrolled in a weekly program at the local recreation center for people living with dementia and their partners. Outside of these times, Darren tells me that he and Marie go out to retail spaces to "look around," go for coffee, and once a week, they go out for wings at a pub - a tradition he says they have done since their teaching days. At home, Marie likes to "putz around" with her things; she has collections of many small items in her room all arranged on shelves, she washes dishes and watches television.

Arranging for Inclusion

As a younger person with dementia with limited language capacities and occasionally intrusive behaviours, Marie exposes interesting aspects about the care infrastructures of the program and the arranging work required for her inclusion. Star and Strauss (1999) emphasize the power that infrastructural relations have in creating both a network of connections and spaces in between. Marie seems to land in the spaces in between who the program is designed for, and this results in much arranging work by Darren and the day program staff. Adjustments must be made for someone outside of norms of age, behaviour, and language capacity for the program.

Darren adjusts the drop-off time to be about 30 minutes later than the program start time so that when Marie comes in, it is an exercise activity. He tells me he does this as he feels it is harder to get her to stay if she walks into the big room and "sees a bunch of older people sitting around drinking coffee." Darren also has a routine for drop-off that settles Marie into the Oak Room.

> Marie arrives with her husband and goes immediately into the Oak Room, and he tries to get her to hang up her coats and some of the sweaters she is wearing (she seems to have three sweaters on today). She is not interested but instead checks her 'craft box.'
>
> Darren: Come, let me hang this up… you will be too hot.
>
> Marie finally agrees and takes off two of her sweaters.

Darren (to Marie): Ok, I'll be back.

Marie: Where are you going?

Darren Physio … for my neck (rubbing the back of his neck).

Marie: Oh ok (giving Darren a kiss). (Field notes, October 9, 2019)

Marie is often a challenge for staff to contain at the program. In her chart, her care plan from admission lists a variety of assessed behavioural and cognitive concerns related to poor judgement, a risk for wandering, as well as a potential for aggression and disinhibition. Her "assessed needs" are related to "limited social interaction, engagement, leisure activity deficits, and participation barriers." The interventions listed are related to monitoring, redirecting, reinforcing, cueing, and maximizing participation and facilitating engagement. There is one handwritten note in the assessment that "she doesn't like the word 'no.'" Marie's touchiness can be problematic for others and herself as it sometimes results in conflict. A few incidents of altercations between Marie and other clients are documented in the chart. While the formal care plan's tic box format appears non-specific for Marie, in day-to-day practice it is obvious that the staff have developed multiple specific approaches to managing Marie in the room. Through arranging materials and people, staff work to try to protect Marie from the other clients' responses and the other clients from her.

Managing Marie's moods is a matter of careful arrangement that involves staff, clients, the space, and materials of the program. Marie will be angry at one of the staff (or the resident researcher) on any given day. She is powerful in her disregard and communicates it clearly through body language and gestures.

> Marie and I work on the shell craft for an hour. She seems to like her final product, and as I finish gluing the last shell, she picks it up exclaims, "Oh look!" holding it up,

> showing it to everyone at the same time. At this point, I notice she has folded up the printed instructions to the craft and slipped them into her coat pocket. I ask if she needs these, and she says yes and moves away from me quickly. Staff Gina tells me, "be careful she gets mad quick." (Field notes, July 11, 2019)

Staff physically distance themselves from Marie when they are the target of her frustration. They rearrange which table they are at, and other staff take over interacting with her. Other clients often try to intervene in response to this.

> During a brain teaser game, I sit with five women looking at pictures of birds and matching them with other cards that have names on them. I have placed ten large photos on the table, and the group discusses which bird is which. Marie is quietly watching the others discuss and then stands up, takes the photos off the table, and carries them toward her cubby box. "Oh, darn we can't play the game without those Marie," I say to her casually, not wanting to reprimand her. She continues and puts the cards in the box. Staff Deb goes over to her and says, "can we have those back, Marie?" "No!" says Marie. Staff Megan comes over quickly to our table with a replacement stack of photos and we continue the activity. Marie sits down at the table again but is now sneering at me. "Ooh, she's mad at you," says one of the women at the table chuckling. Marie begins to mumble angrily and use hand gestures to indicate I am talking too much (which is likely true). Sonja a woman sitting close to Marie, "Oh don't do that… she's a nice lady." She then distracts Marie by asking her about her arm. I quickly trade spots with staff Deb at the other table. (Field notes, October 2, 2019)

Policing Marie's collecting is not easy work for the staff as she reacts with anger when she is redirected or told not to do something.

> Clients are colouring mandalas at one table. Marie is taking the markers as she finishes each section and putting them in her pocket. At snack time, Staff Gina tries to take them out of her back pocket, and Marie turns around quickly and says “NO! I’m mad” and storms off out of the room and down the hallway. Gina watches her walk away and then says to me, “I just don’t want them to end up in the washing machine at her house.” A few minutes later, Marie returns to the room and joins the group at a table. (Field notes, November 13, 2019)

The staff also enlist Darren in managing this behaviour each day at pick-up time.

> Marie comes over to Darren with today’s shell craft creation and shows it to him along with some of the many shells in her pocket- her husband looks at staff, who quietly say to him that she has taken quite a few shells and the instructions for the craft. Megan, a staff sitting near me while I observe this interaction tells me that “he is really good at bringing things back to us if she takes them.” Darren says to Marie that she doesn’t need to take all the shells home and together they lay them out on the table – Staff Deb tells her to pick her favourite three. She picks up two and then leaves the room smiling. Darren says quietly to the staff, “I’ll get the other stuff back to you next week when I do the laundry.” Megan says to Darren as he is leaving, “Marie was so good at a game we played earlier in the day with paddles… if she wasn’t there, we wouldn’t be able to complete the game.” Darren smiles and says, “Oh good! ” Megan tells me after Darren leaves that she tries to tell Darren something positive about Marie each day because she does have a lot of behaviours that make her challenging at times, and they don’t want him to think Marie is a problem all the time. (Field notes, July 11, 2019)

Accommodating Marie's differences requires ongoing tinkering by staff, family, and other clients. Staff try a variety of strategies to manage her collecting behaviours and moods. The program's space is also brought into use, providing Marie with some freedom to leave when she is frustrated by the limits set by staff. There is no exit from the program for Marie, but the program's hallway offers her a looping walk as a place to 'get away.' The secured yet separate space of the hallways also provides a space within staff's relationship with Marie for both de-escalation and her agency, she can take action and 'leave' their presence and staff do not have to chase her out of the room or try to contain her through verbal de-escalation techniques.

Arranging a Home Visit

The arrangement for fitting Marie into services and space also takes place at home, where Darren manages Marie and her interactions with objects and materials of the house, as well as with any people coming in. Arranging a home visit for me reveals the work and materials involved with this making of home (Pasveer, Synnes & Moser, 2020). Darren first tells me he can only talk to me when Marie is at the program as she does not like to hear him discussing her. Later, he decides that if I can include Marie in the visit, it will be ok. We choose a day after I am at the program so I can gauge how Marie feels about me with the plan to abort the mission if she is mad at me that day. We discuss how I will enter the home and include her without making her suspicious. We decide that bringing coffee might be a good entry point for my visit as Marie loves coffee. Darren tells me to mention that I am a university student as he feels this will appeal to her as a former teacher and alumni. During the visit, I follow Darren's lead and sit with him as Marie wanders around the house, sorting her many things into drawers and boxes that she has distributed around the house. Eventually, Marie comes and sits with us to drink the coffee. She then takes me through her home, showing me objects and telling me about them with short words and gestures. She takes me into her bedroom where I see the remnants of the day program activities; colouring pages are posted on the doors, crafts and baubles are placed on her bedside table; the monthly schedule is up on the wall. There are also pictures of Marie throughout her life posted on the wall, or in frames that she has organized on shelves. I see the significance of the physical objects as mediators for her conversation with others, and in this place, her collecting habits seem to mean something more than an uncontrolled behaviour. While Marie shows me her various keepsakes, Darren crawls down under the bed, explaining he is taking this opportunity to look for a missing boot and an iPad. Here in this house is an arrangement of things that enact a comfortable and familiar place for Marie, a home, a product of Darren and Marie's arrangement work. As Ceci, Moser and Pols (2020) point out, making home, and care can lead to a home that is made more for one partner than the other. While Darren has his own spaces in the house, the work of arranging home through things, people, and affects around Marie is ongoing for him.

Arranging for Respite

Darren tells me that finding a 'match' between Marie and the in-home respite is the most challenging aspect of formal care for him, and the limits of this service and the work involved make the day program more appreciated within his arrangement. He finds the in-home respite helpful and was excited to have time for himself to exercise, attend to household management duties without distraction and occasionally go to a concert or sporting event.

> They come and basically do whatever I ask them to do, but it's mostly just to be with Marie and keep her company and maybe do some fun stuff. So, Marie loves to walk, so a ton of it has been walking and going for walks and sometimes going to places…trying to do activities with her. (Family interview, October 23, 2019)

But it is not as simple as telling respite workers what to do; figuring out how to engage Marie with the respite worker is work that Darren has to do.

> That is becoming a bit of a challenge, and I don't know if it is more of a challenge because Marie is not connecting with this person or what… It seems like there is always this, and I think a lot of it is just because of who my wife is… there is this added stress of trying to make sure she is happy and that the three hours or the four hours or whatever are fun. And it is not going to be like pulling teeth.
>
> Researcher: So that is your responsibility. Is that what you are saying? Trying to plan…. or the worry about?
>
> Darren: Oh yeah… the worry… I carry the worry. When she is at the day program, she is always happy, and when I come, sometimes I have to go find her, and she is chatting with people. Sometimes she is standing at the right at the door (laughs). But anyway, but I know she is ok, that she is amused and that there have enough variety and activity that she has a good time. After about the first month, I never really had to do much to try to convince her to go. (Family interview, October 23, 2019)

For Darren, care for Marie is about sustaining her as a person with interests and activities consistent with her history. Darren values people who know how to interact with Marie and credits the staff and leadership at the day program for having a particular "passion" for working with people living with dementia. He compares this to the respite workers he sees as having varying investment levels in their work with Marie. An issue for Darren is that his respite hours are split between two contract agencies, each with different staffing practices. One agency can provide the same person for each shift, and the other sends a new person each time. After three months, Darren tells me he is ready to forfeit the hours from one agency instead of dealing with the stress and work of managing the various workers.

Darren also tells me he is considering placement for Marie as his children and others have said to him that it is “time,” but for now, he says it is more about him “not being ready.” A barrier for him is that he has difficulty seeing Marie away from the familiarity of her home and things. The options available also require discrete choices based on models of dementia in which Marie doesn’t fit. While Marie is physically able to enjoy the activities of an assisted living setting and the day program, she may wander away. Based on the classifications of care levels for continuing care, she would require a locked memory care unit that excludes her from community services like the day program. As he tells me this, I wonder how Marie’s arrangements of space and objects would work in a long-term care setting.

Peg

Peg is an 86-year-old woman who describes herself as a “Saskatchewan farm girl,” an “old nurse,” and a mom to four children. Peg is a petite woman with a very dry sense of humour. She lives in a house that she has lived in for 50 years in a suburban neighbourhood. Two of her sons Ron and Bob, live locally. Her daughter Vicki lives on the west coast, and her son Mike lives in the US. Peg began attending Program B a year ago, about six months after the death of her husband. Peg and her family's arrangements for care required adjusting after the loss of her partner and her progressive decline in functioning. Although Peg had memory problems while her husband was still alive, they become more evident for the family after his death. Initially, the primary concern was providing her social interaction opportunities, but eventually more supervision and physical care were required. The day program is an integral part of the family’s care arrangements offering possibilities for Peg to be in relation to a place, and people, yet as demands change and arrangements shift, the day program and its relations limit the care achievable for Peg.

After the death of Peg's husband, the family initially thought regular home care visits "just to check in on her" might be enough to sustain her. After four months or so, it became apparent that Peg lacked opportunities for socialization. Peg was aware of her memory issues and felt embarrassed by them, so she had stopped going to her weekly bridge club. The family reported that she just seemed to sit and stare out her window all the time. One of the sons, Ron, tells me they considered moving her into assisted living but felt that if she was going to sit and stare out a window, she should stare out at *her* tree and a street that she knew, so the day program seemed like the best option for her.

So initially the day program emerged for Peg's children as a type of social outing for Peg, a form of reassurance for the family that she wasn't "just sitting around" all the time. It was a way for her to stay at home, a place that had many familiar attachments for her. Getting into the day program took several months, and during that time, the family became more concerned about Peg's day-to-day functioning. At that time, the home care aide came in once a day for 15 minutes to check in on her and make sure her meds were taken. While still independent with dressing and making meals, they worried about potential risks related to her forgetfulness and being alone.

As a result of this concern about her safety, the family hired a live-in caregiver named Gwen and waited for the day program to have an opening. Hiring Gwen was made feasible for the family because some of the costs were covered by a program offered by home care for self-managed care. In this program, home care allocates the funds for approved services in a block amount directly to the family, who then manage their own employees. Within this model, a case manager is still provided and is intended to help with resource finding and service level approval.

Ron, one of Peg's sons, tells me that the presence of someone in the home for more time appealed to the family more so than the daily short visits by home care.

> Ron: I would say, to begin with, it was more for us than for mom. She was like, "I can take care of myself, thank you very much." But if someone is here and somebody stays here, and Gwen stays here…. if something happens at night…and so this was something on our minds…. You know…is just if somebody falls… mom falls or whatever… So, ummm, I guess to sell it to mom, was, and even now… Gwen is here to assist mom if she needs assistance, not to carry her around... .right…. It is just to help if she needs help. So yeah…. that makes us feel a heck of a lot better. (Family interview, August 15, 2019)

With the loss of a family member, the family begins to shift the arrangements. They accommodate, by providing for Peg's and by association, their own well-being; relations and roles shift between the actors. Home care, which was a significant part of the care arrangements during Peg's husband's heart failure, begins to fade in significance for Peg's needs. The effects of her dementia are social, and the medical orientation of home care services does little to address this in a meaningful way for the family. While the family tells me that Peg was the key caregiver for her husband, after his death her position shifted as she was identified as one in need of care. In this positioning, Peg becomes the one arranged for, but she is not entirely passive in this process; she makes decisions that must be overturned, requires convincing, adjusts to new faces in her home and cares for her family by addressing their worries. The house's role as an actor in the arrangement also shifts with the other actors. While previously the house was a sort of accessible container of medical equipment and treatments to support Peg's husband, it now becomes an important material form of Peg's subjectivity to her family. The house and the family together enact a place that acts to ground who Peg is, and who and what she is connected to.

Within these arrangements, the house also shifts to be a place with certain risks in relation to Peg being alone. No one might hear Peg fall. Through these relations of actors and practices, a live-in caregiver and a day program emerge as affording the best possibilities of care and are added to the arrangement.

At the start of this study, Peg had been attending the day program two days a week and has had her live-in caregiver (Gwen) for almost a year. Gwen works most days 10 am to 7 pm, helping with meal prep, going on outings, and housekeeping. On days of the day program, she works a split shift, helping with morning preparation from 8 am-10 am and then after day program 3 pm-7 pm. Peg takes the seniors' bus to and from the program, prescheduled for regular pickups by the program. I ask the family if the day program has met the social needs they were trying to address, and they tell me "sort of."

> Ron: No… but it helps.
>
> Researcher: It helps…
>
> Ron: Because it is two days a week, it is Wednesday and Friday.
>
> Researcher: Right.
>
> Ron: If mom could go, you know, every day and she quite enjoyed it every day to do that…. then we would be happy to do that…
>
> Researcher: Right….
>
> Ron: Right… so she goes Wednesdays and Fridays and so Saturday, Sunday, Monday, Tuesday…. So, this is why we are sort of "filling it in." (Family interview, August 15, 2019)

For Peg and her family, the day program comes into a shifting arrangement of care, working to try and sustain Peg in her home and as a social person. For the family, the day program helps structure the social outings of the week. At home, Gwen's work, besides cleaning, making meals, and general supervision, helps to fill in the time on non-program days with activities like local walks or outings to the mall or grocery store. Through these arrangements, certain realities are made possible. Peg has a place she belongs. She is a recognizable person to her family as her continuity as a socially active person is maintained, and she is at home with her 'stuff' in a neighbourhood she has lived in for 50 years. While the program and its relations are an anchor for part of the week, other pieces of care are spread out to support the other times. The family feels there is too much time open without structure, and they juggle what to do with these open spaces in the schedule. There are weekends when Gwen needs days off, so Bob stops by on Saturday and Ron on Sunday. They also ask Gwen to work overtime sometimes when they are busy on the weekend, but she finds this tiring and likes to visit her daughter more regularly. Ron and Bob need vacation time with their own families, so Mike will come in for a month-long visit. Vicki who lives in another province is dealing with her own health problems, so she does most of her care by phone, talking to her mom in the evening, or calling doctors.

Arrangements at the Program

The day program practices come into relation to the other home and formal system practices in different ways, most of the time working together for similar goals with a few points of conflict or compromise.

At Program B, Peg sits and chats with her other table mates. Despite memory loss, she can still maintain the social niceties of a general conversation. A former crossword puzzler, she is the reigning Oak Room champion of word games. She frequently jokes with the staff making remarks about the activity or her skills, and the staff joke back. Peg is known here as having a dry sense of humour, and she engages with most of the activities on her terms.

> Megan (staff) introduces the activity by asking people if they ever went berry picking in the summer and several people tell us about their experiences of berry picking when they were younger, including Peg telling us about the farm. The cheesecakes we are making will have berries on them. Megan asks Peg, “what job do you want to do for the recipe?” and Peg smiling, says “none.” Megan smiles and responds, “well, with that bad attitude, we might not give you any cheesecake,” and they chuckle together. (Field notes, July 17, 2019)

The staff seem familiar with Peg’s family and history; they have a five-page social leisure tool as part of her chart, completed on her admission via a family interview. It details Peg’s interests, her childhood, work, and family history. The staff draw on this information to personalize activities for Peg. One of the staff Gina frequently teases Peg about “really being a cowgirl on the mechanical horse outside Zellers.” Peg laughs and scoffs at this and then tells stories of her favourite horse Sparky. Staff Megan tries to think of ways to match Peg with a volunteer job in December that involves horses. The nurses at the program talk to her about being a nurse, referring to old doctors they know she remembers from her working days. They ask her about her kids using their names and respect the fact that she has never liked crafts and offer her crosswords or sorting tasks to help others during craft time. The staff tell me that the life and leisure profile help them understand “so much more about clients than the clients themselves are likely able to tell [them].”

Peg’s program chart outlines a care plan, breaking down Peg’s needs into “domains” to be maintained through the program. Also documented by the staff are cognitive tests, gait assessments, monthly weights, and blood pressures. The chart also includes a letter sent to Peg’s family doctor when she started the program. It is a form letter explaining that Peg is now attending the program and that if there are any medical changes or needs, the doctor may want to let them know.

The monitoring practices of the day program complement but do not always connect to the home practices. At home Peg is weighed every three days as Mike (Peg's son) told Gwen during his last visit that Peg is eating too much rice and has gained ten pounds over the past eight months. Gwen tells me she is tracking her weights in a logbook to show Mike on his next visit. Peg listens to this conversation and then says, "what's that?" "Mike puts us on a diet," Gwen explains. "Oh really? Hmm…" Peg says smirking. I asked Gwen if she knew that the day program weighs Peg monthly and wondered if there was any communication from them about weight. "No" Gwen says, "not to me, but they maybe tell Bob." So, the work of maintaining Peg is distributed across the arrangement, but this is not done efficiently and tells of the quality of coordination between practices.

Following a Fall

At the end of the summer, I am at the program when I notice Peg wincing as she stands, I ask her if she is sore somewhere. "Oh, I have this old bruise on my knee" she tells me. This bruise hasn't come up before, so I ask her how old it is, and she tells me it happened when she fell on the sidewalk. We are having this discussion on our way out of the Oak Room, and I see staff listening to her and making eye contact with me. They come over to us and ask her if she fell recently, and Peg says, "Oh no, it was a while ago." We continue to walk down the hall, and she limps a bit on her one leg. "Yes, I fell when Gwen and I were walking outside," she tells me. "Gwen fell too." When we come back to the room from doing our 'lap' around the hallway, Marcia the LPN is there with Staff Deb.

Marcia and Deb: Peg we need to take a look at that knee of yours.

> Peg: Oh why?
>
> Marcia: I heard you might have had a fall.
>
> Peg (looking at Deb and me): I feel like you may have heard some stories from someone about me. (Field notes, September 4, 2019)

The following week I am at the program and see Peg is still unsteady in her gait.

> Peg gets up to go for a walk, and she tips to the left side catching herself on the table and then leaning on other pieces of furniture as she makes her way to the door. Gina, a staff member, is walking past her and says, "Peg, you do have this cane here you can use if you want," and points to a cane hanging on one of the coat hooks. "Oh no," Peg says, "I don't follow the rules for the elderly," as she walks by and into the hallway, grabbing the railing. I look back at Gina and Deb. "Oh yeah, she's bad," says Deb shaking her head, "we had her assessed for a walker last week by physio, and I had a major issue with the assessment because they say she is fine, low risk, and it's only because of how they do that test, it's focused, so she doesn't have to be distracted by anything else going on…but in here she's always distracted. (Field notes, September 11, 2019)

I look at her chart and see the LPN Marcia has documented the bruise in the chart using clear descriptive language of color, size, and location. Different assessments have also been done by the physical and occupational therapist. The occupational therapist has also done some cognitive testing, the first since her admission a year ago. In the chart, there seems to be no trace of where these assessments travel to but are instead seem a form of day program accountability.

A couple of weeks later, I am at the house, and Gwen tells me that Lindsay the home care case manager was there last week for a visit. I ask what happened in the visit

> Gwen: It was only 15 minutes. She just asked us some questions and looked around.

Researcher: What did she ask about?

Gwen: Oh it was about falls… everyone knows about the fall… day program knows too.

Peg: What fall?

Gwen: You remember the one where I fell, and you helped me, and then you fell.

Peg: Hmmm…

Researcher: And then I noticed you limping at the program and asked you about it, and then the nurse had to check out your knee.

Gwen: And now everyone knows. (Field notes, Sept 17, 2019)

Here a fall travels from home to the program to home care and back to the home. As it travels through the arrangements, its nature changes and positions us to Peg in a particular way- people who are telling stories about her, and those stories are travelling. Starting as an accident when Peg helps her caregiver get up, this event is investigated for risk and a possible indicator of a cognitive status change. Through assessment tools at the program, home care is notified, and they come out to the home to do a fall risk assessment. All these practices organized themselves around Peg as a patient, a potential risk to manage.

There is what could be called 'continuity of care' going on, in that care about Peg is travelling across the arrangements of actors involved. But there is an almost clumsy quality in this continuity that leaves it somewhat incomplete. Certain actors are more connected within this care infrastructure than others, and this has effects. Despite common goals, connections made between actors are not always the most efficient at addressing the issue at hand, telling of boundaries between parts of the arrangement and the organizing going on to maintain these. The report of the fall comes from Peg and is translated quickly into risk management schemes of formal care. The story from Peg is vague, and given her dementia, her account is deemed unreliable. Staff accounts are also given little credit and fall risk assessment tool's results are declared most valid. The family is thought of and eventually reached but not included in the early chain of reaction. Accountability practices of documentation and reporting to formal care providers are all that is required before the event is passed to another provider. There is no feedback involved in the arrangement; despite initiating the investigation, the day program is left out of the rest of the evaluation. The staff tell me it is usually only one-way communication between them and home care. As this fall travels, relations between actors are changed, this arrangement positions me as a monitor to Peg, and eventually, Gwen is too. The tools and procedures of fall-risk assessment and what is not captured on them position the recreation staff to the rehabilitation staff. Materials like walkers and canes come forth into Peg's relations to the day program staff, giving opportunity for conflict. The home care nurse is triggered to surveil the home for unknown risks. Gwen tells me she thought she had mentioned it to Bob, but it seemed mundane at the time. Yet when the family hears of a fall at home through a formal agency with little day-to-day contact, the fall becomes more than a simple accident. Gwen becomes monitored through these relations, her accountability for Peg's safety is reinforced by the family and in response to this, new practices emerge, shifting relations between her and Peg. Gwen tells me a few weeks later that she is not just writing down weights; now she also writes down everything that happens in the day in the logbook.

> Gwen: I have a little book I use, and I write everything down in it- naps, food that Peg eats, walks we take… Then I can show Mike when he comes, and I don't have to talk I can just show him.
>
> Peg: What are you writing notes about?
>
> Gwen: You… what you eat, what you do… the kids like to know what's going on.

Peg: (shaking her head side to side) Hmmm. (Field notes, September 17, 2019)

Changing Status and the Limits of Arrangements

Autumn comes, and I see Peg at the program weekly and home monthly. Peg's gait continues to be unsteady. She frequently tips sideways when she is standing up from a chair. She continues to refuse a walker or cane. The staff also notice her becoming less active in games and more irritable with them at times. They tell me, "She is really going downhill with her memory." The staff use this comment often with each other to account for changes they see in someone's participation in the program activities. Part of the treatment version of the program, there seems to be an inevitable point when treatment is no longer working to maintain people; at that point there nothing to do.

At home, Peg's family have noted some of the changes in Peg's functioning too and have decided that they need to have more help. They hire a regular weekend person to cover Gwen's days off. Thanksgiving comes, and Mike comes back from the US for a three-week stay. He calls me during his last week to ask if I know anything about medications that might help stop his mom's decline in functioning.

> He says he has noticed this trip back that she is getting much worse with her memory and seems to be more suspicious and irritable in conversations. "I know you know about dementia, and I know that the memory decline is part of the deal… but I wanted to ask, are there any medications that might help her?" "Do you mean with her memory?" I ask. "Well yeah, but more so the irritability… something that would make her calmer and happier like an anxiety pill," he explains. I am intrigued by this question and wonder how it seemed to land with me rather than anyone else in the care arrangement. I ask Mike what he sees with Peg, and he tells me she has been forgetful about conversations or

> events, and then when reminded, she is suspicious that someone is trying to trick her or make things up. Mike says it's usually Gwen who has to deal with it, but since he has been home for the week, he has found it difficult to dance around conversations without her arguing with him. I ask if he has asked the day program or the family physician about this, and he says no. He tells me that he did drop his mom off on Friday at the program and said hi to the "ladies" but didn't mention it to them. I tell him I have seen a decline in his mom's memory over the past two months and that she has seemed quite tired and unsteady and that this could be part of her dementia but that it would not be a bad idea to have her seen for a check-up by her family doctor to make sure she doesn't have anything else affecting her health (I am specifically thinking of delirium when I say this to him). He agrees and says that he thinks he will have Bob or Ron set up an appointment with the family doctor for his mom. (Field notes, October 14, 2019)

I find it very interesting that I too, have been worrying about Peg's decline and wanting a quick fix. Drawing on my previous nursing experiences, I find myself assessing Peg's neurological status, trying to link a reason for her obvious decline. While I am used to working with people with significant dementia and enjoy making connections with them, I am attached to keeping Peg as the Peg I met four months ago. I want to tinker, to 'right the ship,' so to speak, so I begin stepping around the arrangements. The previous fall investigation has outlined the separations between parts of the arrangements, and I work to reinforce connections that I am not sure exist.

Two weeks later, after being at the day program in the afternoon, I can't help but worry about Peg. She has been increasingly confused, and one afternoon at the program, I notice her using the bathroom every 20 minutes. During craft time, I notice her distracted by a few coloured sprinkles on the floor. She is not her usual self. The staff and I discussed the changes, and again they ask if I can let the family know this because they could arrange for a urine test to be done there. Again, I wonder what it is about my role with Peg that makes the team think it is easier for me to access family than them. I tell them that it would be best if they did their typical practice. They tell me this would involve letting the nurse know and have her follow-up. This practice reflects a particular unspoken classification of communication roles at the program; the recreation staff can call family about transportation or absences, but the nurse deals with health-related issues. I know the nurse is only part-time, so she will not get to this matter until Monday. I feel torn as to my role as a researcher but also have a previous practice of diagnosing delirium, so I fear for what might happen to Peg if it continues untreated. I have visions of Peg in the emergency room and an inpatient unit, often a place of ‘no exit’ for people with dementia. I decide to call her son Ron and tell him about my concerns and let him know that the day program can arrange to collect a urine sample there if the doctor orders it. Ron says he is appreciative of the call because he has been worried about his mom’s most recent rapid decline, and while he hasn’t heard anything from Gwen as far as urine frequency, “she is not a nurse, so she may not know what to look for.” He says he would be glad to have the day program talk to the family doctor and collect the urine sample. I call the program and leave a message for Staff Deb that the family agrees with their urinalysis plan.

A week later, I am back at the program; Staff Deb tells me she has got my message about the urinalysis and the family wanting to have it done but tells me that she needed to call the family to call the doctor, who then faxed the requisition into the program on Tuesday. She tells me they have the cup in the bathroom now and need to try and get the sample from her but haven’t done so yet.

Back in the Oak Room, the group is getting ready to do some baking for the craft sale. I see Peg heading towards the bathroom and mention it to the staff in the room, but they are busy getting supplies ready. I then tell Peg and show her the cup and the wipe to use to get a midstream. She comes out a few minutes later saying, “well this is embarrassing but I missed.” I tell her it’s ok we can figure something out. I go to the clean supply room and grab a new specimen cup and run into Mary, the nurse there. I tell her that Peg missed the last cup, “yeah it’s so hard to get a sample from people with dementia… sometimes I call home care and ask them if they can do a straight catheter, but then that’s a lot for someone to handle. …” I mention that it seems that even using a ‘hat’ (collector device) would be a good thing to try first. She agrees and shows me where they are on the storage cart (a weirdly well-stocked hospital storage cart). I bring it back into the Oak Room, where sure enough, Peg is getting up to use the bathroom again. I set it up for her and tell her to try again without the cup- she agrees. She comes out and tells me that “it worked.” Staff Deb is back in the room now and says, “oh, thanks for getting that for her. It could take us a long time.” I package up the specimen into the bag with the requisition and then ask the staff where I put it – no one seems to know. “Bring it to Mary the nurse,” the staff tells me. I walk through the hallways looking for the nurse. I ask the unit clerk, who tells me, “I think there is a fridge somewhere for those.”

I wander the hallways of the program with the urine specimen, looking for the fridge. I walk into room after room noticing the abundance of craft materials that fill most of the space. This search tells me a lot about this place. Despite what seems like somewhat familiar institutional supplies, roles, and forms, the actual practices are much different than what I have experienced in other healthcare settings. It also makes me

> wonder why it is that I keep assuming these day programs are a sort of health care setting- is it just me, or is it the practices of the healthcare organization that surround the program giving it that façade? Why the nurses, rehab practitioners, monthly weights, fall assessments, medical equipment carts, blood pressures and cognitive screens but not urines? There are practices not included or kept out of the day program that limits or set a boundary of what it can do from a health perspective; bodies but not leaky bodies… I finally run into Mary, the nurse who was "in the treatment room with a patient" (hmmm… those seem like healthcare terms). She shows me the fridge in the utility room tucked in between the staff coat rack and some Christmas crafts. (Field notes, November 13, 2019)

A week later, I check in with the nurse and recreation staff to see if she had heard anything about Peg's urinalysis.

> Deb says no but that they often only hear what the family decides to tell them, and usually, it would be only if they needed a medication delivered at the program that they would hear any health updates. "I wish they would tell us more" she says. The nurse says she hasn't heard, but she will check on the electronic health record and see, she tells me she can see the urine test was positive for bacteria: " I assume she would have been put on an antibiotic." (Field notes, November 20, 2019)

The family continues to try and fill in the extra days with other activities finding a short-term program for people with dementia at the local recreation center but find little else suitable for what they feel Peg's needs are. Often Gwen and Peg take an uber or a bus to the mall and sit in the food court for hours, people watching and eating Peg's favourite Chinese food. They add in a second caregiver to cover the weekends.

At home, Gwen tells me that she is finding Peg is hard to deal with sometimes as she changes her mind often and argues with her. Gwen asks me what to do about changing tastes in food and managing the forgetting of preferences. She tells me that Peg will suddenly change her mind and not eat certain foods saying she doesn't like them. Gwen ends up arguing with her to convince her that she *actually* does like them. I tell her that maybe convincing Peg she likes something won't work, and she could give Peg choices closer to mealtime or maybe have a backup plan B meal ready just in case, something easy like a sandwich. While offering this advice, I wonder again about how I am being used as a resource for this arrangement and what this might tell me about what is missing.

After Christmas, the family tells me Peg got very confused on Boxing Day, taking lots of naps, and they noted she was going to the bathroom frequently, so they took her into the doctors who diagnosed her with a urinary tract infection and started her on antibiotics. "Her second round of antibiotics?" I ask them, "No, she wasn't on antibiotics before this," they tell me, "we never heard anything about the last urine sample done at the program."

I am frustrated by this event. I feel somewhat responsible for entering into the coordination of getting the urine, hoping to help act as a mediator on the limitations of the arrangement's separations. Instead, it seems that the way practices are held apart in this arrangement is quite durable. Something more than one person's intentions may be able to shift. The distance between the practices in this arrangement becomes even more apparent when Peg's daughter comes to stay with her for a month over December and brings new relations to the arrangement.

Peg's daughter Vicki tells me that it has been hard to see the decline in her mom over the past year. I ask what she thinks might help right now, and she tells me that they need bedtime care, and they need more day program days to help structure the week because she can't go "just anywhere." Those other spaces are not designed for people with dementia. Vicki also tells me she is very concerned about the lack of bedtime care.

Vicki: I think proper bedtime care is needed. This going to bed with a nightie pulled over your day clothes is not right. She should be put to bed with a change out of her clothes into a nice flannel nightie with socks on her feet and her dentures out. And made sure that she is tucked under nice warm covers not laying on top of them.

Researcher: So right now, there is no one helping with the bedtime routine?

Vicki: No, Gwen is done at 7pm, so it would mean changing her hours to later… now mom is alone after 7, and with the dark, we notice that she often thinks it is bedtime earlier than usual. Rick calls between 7 and 8 to try and keep her up and check in and then she puts herself to bed by 8…. I just think that if she got proper bedtime care she might sleep better, and that might be important down the line.

She then asks if I have any information on sundowning, and I ask if this is an issue for Peg as I have not heard this before. Vicki tells me there have been major issues with her mom being very confused in the evening for several months, that she and her brothers have been trying to manage this through phone calls.

Vicki: You should hear her on the phone some evenings, she doesn't recognize where she is, and I have to ground her and describe the room and the layout of the house to remind her and convince her. I tell her to look out the window and see the neighbours' houses and remind her of who lived there, I mean used to live there, she's been in this house for 50 years so she remembers the old neighbours who have moved away but I use those names and describe all that she can see in the window so she can believe it is her house.

> Later away from Peg, as I am getting ready to leave, we have a conversation near the front door of the home:
>
> Vicki: I'm just so angry about what this disease has done to her… It's like I have a toddler again. I mean my brothers are great, but they don't go in and check her in the bathroom and see what's she's doing in there, so they don't see her having little accidents.
>
> Researcher: Oh is she having some incontinence?
>
> Vicki: Yes occasionally she is, I think it's that when she notices that she has to go she has to go NOW! so sometimes she's wearing wet underwear.
>
> Researcher: Do you think she could wear a pad just to keep her dry?
>
> Vicki: I think she would but then she would have to remember to change it and I don't think that would happen and I'm not sure Gwen will know to check and change it… it is just if this is slower onset dementia then I don't want to imagine regular onset and I just wish we had started the medication sooner. (Field notes, January 9, 2019)

The arrangement seems to be breaking down, and new needs must be addressed. Between the family and formal care providers, there are competing normativities at play regarding what Peg needs. This competition affects which needs of Peg's come to the forefront and how care is arranged for Peg. Vicki organizes many of her concerns for her Mom around the trajectory of dementia. She worries about the disease progression that seems to be a given to her and stopping or reversing this trajectory seems to be prioritized over the tinkering required to address Peg's current needs. She talks of UV light treatments and better medications. Her place in the arrangement also gives her access to information on Peg that also lead to different goals than her brothers. Perhaps because of gender roles, she also sees her mom's body more than her brothers do and can consider this part of the care required for Peg. Mike also worries about the trajectory and thinks of physical wellness related to her diet and activity level. Each time he comes home, he finds an exercise program for Peg to try. First, it is a yoga class for seniors that accommodates caregivers and then it is a specific exercise class for people with dementia and their caregivers. These classes add something to the arrangement oriented towards the ideals of physical wellness. Still, they also create other work for the arrangement, preparation, planning transportation is required, and often a one-hour class consumes three hours of time which interferes with other care practice priorities of the arrangement of providing a spread of supervised hours in the home. Ron and Bob are focused on maintaining Peg's social wellbeing, and initially, this was related to the materialities of home. Bob tells me now that Peg's attachment to the home is becoming less relevant to the arrangements as "she often doesn't seem to recognize it as her home anymore." This change in relations to the house shifts the ideals for care initially in place, as now keeping mom safe is more important than keeping mom safe at home. Other actors in the arrangement have other normativities that interfere, such as home care's goal of distributive justice in allocating care. Maintaining sustainable resources for everyone within a seemingly increasingly limited fiscal environment means limiting what can be done in any particular case. The day program operating under this service's allocation rules cannot expand days or hours of service. Peg is 'at the max' of two days a week anything more would be 'unsustainable' for the system.

A few weeks later, in a phone conversation, Peg's son Ron tells me that they have had to increase the hours of live-in caregiver to ensure there are 12 hours/day seven days a week covered. This increase in hours was decided after a month of him sleeping on the couch at night on weekends. He tells me the issue is the self-managed home care program calculates the reimbursement for the live-in care only on minutes allocated for specific home care-related tasks such as med administration, bath, or meal preparation, not general supervision. Within this formula, Peg receives only four hours of care a day that is reimbursable, so the family pays $7000.00 out of pocket/month for the two caregivers. He tells me that this cost is unsustainable, and because his mom often doesn't recognize the house as her home, they think it is time to look for a 'placement' for her. He tells me that home care has arranged a placement coordinator to come and assess Peg.

At the program, I ask Deb if she had heard from Peg's family, and she says no. I tell her and the nurse about how the family concerns about Peg was having sundowning symptoms, incontinence, and about her urinary tract infection. "I never thought to check as I just thought the doctor who ordered the test would close the loop," says the nurse. Deb looking worried, says, "this is the part that is frustrating sometimes as we don't have a good picture of what's going on - like it would be good to know if she's tired cause maybe she's been up or not feeling well." She then says

> It's like George [another Oak Room client], he's not coming back now, and you know how he was so irritable in December, and we thought it was one of us he was mad at before Christmas, and it turns out he had a urinary tract infection and became delirious before they figured it out. He ended up in the hospital and then became aggressive, so now he can't go back to his placement. I feel guilty. He was not himself, and I did call his sister and ask her if she had noticed any changes, but she told me, "he's just stubborn." (Filed notes, January 15, 2019)

It seems Peg's experience of delirium is not unusual, and the day program staff are frustrated by their limited ability to be part of the management of it. Despite having several monitoring practices in place at the program, this work's relevance seems disconnected from the potential needs of the people attending. These practices are structured through things like checklists, job descriptions, and chart forms, much of which have been inherited from rehabilitative day program traditions that preceded the maintenance care of people with dementia. These tools structure what is almost a façade of 'treatment' - one that lacks support and connections to be able to be implemented in full. On top of this, there are significant boundaries maintained around family doctors' clinics and home care, and despite some of the work the day program does to try and connect with these services, there seems to be only one-way communication out. The limits of the day program's ability to respond and repair within Peg's arrangement occur through the relations of the materials such as the family information sheets ordered around attendance rules, the roles of the staff categorized as either related to recreation or health care but not both, its exclusion from other formal system practices of communication. This is not to argue that the day program should be organized around physical health intervention as perhaps the ability to be both a social space and a healthcare facility is contradictory, and it would be unrealistic to think it could be everything for everyone. But what is clear is, in this case, the increasingly popular portrayal of day programs as an intermediary within 'care at home' arrangements is unsuccessful for Peg once she has a physical concern. What is interesting, if not frustrating, for me to observe is that this failure happens despite many individual actors being concerned about Peg. Here it is evident that care is indeed complicated; it is more than an affective notion or specific tasks, it is material, and it does rely on socio-material relations.

In my last visit Peg at her home, she sits in her favourite chair at the window. She is seeming tired and quiet, wrapped in a fuzzy blanket. She has only a few jokes for me that day but lets me look at a photo album with her. Meanwhile, Gwen asks me for advice on where she might find her next job.

Interlude IV

Configurations

Arrangements and the configurations that do things is what I am thinking about and living. I write this this chapter in the midst of a pandemic where ideas of safe spaces have shifted, and my world is smaller and more crowded. I am working from home (interesting how that statement assumes home and work are naturally separate). Like other family caregivers, the community supports we have relied on for distributing some of my daughter's care have somehow evaporated over night, a silent victim of the coronavirus. Leaving me wondering if they were ever really 'here.' My daughter's day program that she was to transition to from high school is closed and will be until social settings are able to reopen. So, I rebuild the house of cards that is our care arrangements and work from home while providing her supervision. After a few episodes of Annie attempting her skills at house painting, my quiet upstairs office space is no longer my retreat for writing binges. Instead, I write in the middle of the kitchen/great room where I can attend to my daughter's needs (translation: catch her doing things she shouldn't). Here I write to a consistent background noise of children's TV cartoons and Annie's favourite 80's dance hits. I arrange my day in slots of time on a calendar. The time translation from paper to life never seems to work out, but at least I am given a temporary impression that all I have to do is possible, if only on paper. I arrange the furniture to see more from my occasional glances up; I use materials to entice my daughter away from the television and iPad if only for a few moments break from the noise. I show her how to patch and paint the walls properly, engaging her in a new hobby that seems productive and safe in these conditions. My husband comes home between shifts at work and takes Annie out for rides in the car. Through shifting arrangements, we make a home, office and DIY activity center coexist at least partially. In this configuration, my writing is in spurts, interrupted and disjointed. At the same time, I learn to teach online *which is like learning to teach again. Despite the familiar content I am puzzled on how to deliver it in an asynchronous way, how to connect, relate – questioning what it is I am actually teaching.*

This is not a pity party, there is something about what I am writing about that connects to this chaos (not random chaos but the fluid patterned kind- think Jeff Goldblum in Jurassic Park 1). This is the ways in which sociotechnical arrangements enable and constrain possibility, and in which versions of life materialize precarious and temporary (my hopeful emphasis on temporary!).

So far, the day program is multiple and specific to different family arrangements. Interesting but not enough to answer the research question, more is needed, another vantage point of analysis to show more specifically the effects. In the way of Robert Cooper, I need more to help move 'beyond' (Spolestra, 2016), to continue to undo conceptions of day programs as stable bounded entities. Not dismissing the distal view of day programs but demonstrating what is revealed within a proximal one. Using a framing of day programs as a health technology allows for analysis of the socio-material configurations of arrangements and their effects. This framing will draw on ideas of technology in practice, users/scripts, and installations of technology, as well as Cooper and Law's (1995) proximal approach to organizings. Each of the cases allows for an illustration of the specificity of configurations and effects observed. Interestingly structuring this chapter has been a significant challenge in trying to account for each case and make some kind of statement about them together – the point is that the configurations differ, and as such, the effects do as well, but this diversity is hard to manage. I want a thread that ties through it all, and each time I think I find one it ends up being less stable than I thought. Fraying to the point I fear it won't hold. Again, I am looking for a whole in the partials- (Thank God Chris made me read Strathern's Partial Connections (2004)!). Like

Cooper and Law's ideas of how part/whole relations and contact points are partial and intermittent helps me think about this chapter's case studies. So unstable in more ways than one, I move into the analysis again.

Chapter 7

The Configuring Effects of Day Program as a Health Technology

For both individuals and formal providers, strategies to provide care are designed based on representations of what 'could be.' Within these strategies, particular ideas of care are made manifest and work to both organize and produce relations between materially distinct elements (Law & Mol, 1995). Care at home for people with dementia, and as a result, the strategies to support it, come from particular ideas of individuals, community, care, dementia, and space. These are not just ideas existing only in the heads of family or health and social care planners. They are material and held "in-tension" with each other through organizing activities like strategies (Cooper & Law, 1995, p. 245). These 'intentions' often materialize as interventions in the form of health technologies. Health technologies extend beyond traditional medical devices to "include physical objects, procedures, social interventions, and health care systems" (Timmermans & Kaufman, 2020, p. 584), all of which involve strategies "developed to solve a health problem and improve quality of life" (WHO, n.d.). Health technologies such as day programs are expected to produce societal transformations in their ability to question or establish new social relationships and stabilize certain orderings of everyday life according to their particular rationales (Schillmeier & Domenech, 2010).

The Material Semiotics of Technologies in Practice

Most of the time, health technologies are studied only from an optimistic view of anticipated rather than actual outcomes, or from a model of simple cause and effect (Timmermans & Kaufman, 2020; Winner, 2014). These approaches leave their rationales ignored and their full range of effects unexamined (Timmermans & Kaufman, 2020). Science and Technology Studies (STS) and material semiotics complicate, and in effect broaden, our understandings of health technologies with their attention to the iterative processes of how health technologies both configure and are configured through practices of everyday life. Moving beyond technical determinism and social essentialism of technology, material-semiotic framings of 'technology-in-practice' situate what health technologies do and how they work in heterogeneous relations to other people, things, and spaces as an open empirical question (Timmermans & Berg, 2003). Using this 'technology-in-practice' approach to analyze how day programs work for people with dementia and their families helps extend current static and isolated conceptualizations of day programs. Rather than considering either day programs or families and people living with dementia as pre-existing entities that come together and affect each other, we can envision them all as emerging through their relational materiality. As a health technology, day programs, families and people living with dementia are some of the many elements present in a story of how to care for people living with dementia in the community. These elements come together to recursively organize a day program's practices, practices that in turn help maintain material differences between the elements. The material effects of this configure relations of people and space within family arrangements and the day programs themselves.

Through a 'technology-in-practice' approach, if we want to understand how day programs work, what is produced by these configurations between day programs and specific family care arrangements matters. López -Gomez (2015) offers arrangements as a useful ecological and symmetrical tool for showing the diversity and precarity of how lives are configured and practiced in relation with health technologies. In his study on telecare services for older adults, López-Gomez found the effects of reconfiguring arrangements are often overlooked when new forms of care are added into already existing routines. These effects included new subjectivities, forms of agency and relations with space. Callon (2008) offers additional ideas on arrangements, as he explains that configurations with technology can act as 'agencements' to make particular kinds of actions and ways of being an 'individual subject' possible. The template of who an individual ‘is’ can be built into technologies in a way that affects the configuration of the arrangement and distributes agency in particular ways (Callon, 2008).

Along with the agency that configurations enact are the subjectivities that are made possible. Moser (2003) emphasizes the importance of attending to how arrangements enact agency and the different subject positions and the versions of life that they make possible. Moser (2006) describes subjectivities as the "locations of knowing or consciousness that are made possible within relations, practices and collectives" which people move between (p. 385). In effect, these positions establish how a person is recognized by others and themselves as an 'I' (Thygesen & Moser, 2010 p. 130). Along with these configurations of agency and subject positions, arrangements with technologies also have placemaking effects, as demonstrated in Langstrup's (2013) study of chronic care infrastructure. In her study she shows how health technologies define spaces in particular ways that in turn shape the relations made possible. This occurred through extensions of practices that travelled from clinic to home or because of the defined subject positions and agency enacted.

It is important to emphasize that from a 'technology-in-practice' viewpoint, these effects are not technology centred with users positioned as merely passive recipients. Instead, through recursive relations within these configurations, both people and the technologies are defined. These arrangements are also not static but tentative and fluid, resulting in different effects from certain entanglements over time (Gan & Tsing, 2018). In a life with dementia at home over time, the day program comes into family care arrangements in specific ways, enacting the possibilities and limits for care. In each of the participants' lives, the day program entered into arrangements, facilitating, and limiting relations in different ways. Taking the theoretical framings into account, in this chapter, I will use my data from observations, interviews and documents to analyze the various configurations of family arrangements created with day programs and their socio-material effects.

Day Program as a Material Force of Classification

It is not realistic to say that health technologies are "super actors" determining all interactions (Timmermans & Berg, 2003, p. 104). Instead, there is a reciprocal dynamic present between users and technology that results in certain types of configurations formed. From a 'technology-in-practice' approach, what a technology is can be defined by examining what it does. For example, in the case of Jan and Louise the day program emerges in relation to practices in the home and in the community and it does things within these relations that define it.

Louise tells me that they decided to move into an apartment in a new neighbourhood due to the increasing challenge of maintaining their home with Jan's memory problems. At the same time, after becoming lost one day in the city, Jan had stopped driving. With this move and the change in driving, a change in routines occurred. Louise noted that Jan was often 'just sitting' on their couch all day. This lack of activity and the increasing issues with memory concerned her, and she also felt she had "to pull more people in" to help her and Jan adjust to the changes. Jan and she both agreed that maintaining his regular exercise routine would be good for him, but this now required some support. A series of community care referrals through family doctors, fall prevention clinics, and frail elderly clinics led to the assignment of a home care case manager, three hours a week of in-home respite and placement on the waiting list for one day a week of the day program.

Louise finds the day program while implementing several solutions to address the changes Jan's dementia has brought. The new neighbourhood is unfamiliar and offers limited walking space. Routines have changed with the move and the new arrangements. The usual cues for household activities are missing, Jan is on the couch more, and they are in a smaller space, so his inactivity is more visible to Louise. On top of this, other spaces of the community have shifted in relation to Jan: the gymnastic club is not considered a suitable place for someone with memory problems, places that require a car to get to have become unreachable. By moving to a home that can accommodate ‘ageing in place’, new materials, people, and spaces have come into being and require a reorganization of existing relations to find a way for them to fit.

The day program as a health technology sits in relation to the larger care infrastructure understood as 'care in the community.' This care infrastructure is the sort of 'tracks' of background relations that ‘care in the community’ runs on (Star, 1999). Most of this infrastructure involves invisible work of classification standards, and structured networks of communication that work to divide expertise, responsibility and the spatialization of care in taken-for-granted ways (Langstrup, 2013). Timmermans and Kaufman (2020) explain that established health technologies often go unnoticed as they become ingrained within 'systems' of care, creating infrastructural paths of ‘what comes next.’ Formal system practices organize people, materials, and space into discrete service-based units, each with specific need-based criteria that build on each other, forming a sort of stepwise path to institutional care. Historically, day programs' position on this path has been varied. While initially conceived as an intervention to prevent institutional care, they are more recently positioned as part of the transition to institutional care.

Within administrative logics, the sequencing of low to high-intensity services makes sense, but within the ‘forms of life’ that it creates, other effects are made possible. Through this established path-making, the formal health system translates a solution like an exercise program generated by Jan and Louise based on a lifetime of interest into a need for certain services: respite care. So, while a place for a gymnast to do gymnastics doesn't logically translate into forms of respite care, there is something about Jan's dementia that makes this reasonable. Jan's dementia legitimizes this request for a leisure activity by translating it into a health-related concern, one that can fit within classifications of need to be addressed by the formal system rather than the general community. Day programs sit within formal system processes as a potential intervention for certain needs: respite, social engagement, and 'structure.' For the formal system, dementia is a problem of care sustainability, whether that be for families or health systems. This problematization of dementia makes the day program, a specific technology of respite and structured activity, a good 'match' for Jan and Louise. Bowker and Star (1999) explain that classification systems always have a 'material force’ generating material effects on those categorized. Within this translation of Jan's need for exercise, the space of care and arguably life, paths are defined for Jan; paths bounded to the home or other controlled spaces deemed appropriate for someone with dementia. With this ‘material force’ other places in the community, such as the local recreation center located five kilometers from Jan and Louise's home, or the seniors’ activity center in which the day program is located are made invisible. Thus, through its participation in the classification practices of care infrastructure, the day program works to bring Jan and Louise into relation with other people and places, producing particular material ways of living within their community.

Jan, who is a lifelong gymnast and writer, joins the day program once a week. The program is located in the basement of a seniors' activity center, which is full of activity rooms and has many older people coming and going to diverse programming. On the door to the day program 'do not disturb' signs demarcate the space as separate from the rest of the center. Day program staff meet people at the center's main door and escort them to an elevator that takes them down to the day program room. The room is organized with three tables aligned near a whiteboard that displays a daily schedule of events. People take their seats and move only when told by staff or when they need to use the bathroom. Jan, who according to Louise, "never plays games" spends the day at the table playing card games, making small crafts, listening to fun fact type discussions, participating in adapted forms of chair-based exercise and walking in circles within the space of the room at a designated time.

Jan is a person with interests and capacities, and he enters a day program with a specific design that materializes in the program's practices. Like any technology, the space of day programs is designed with a particular relation between its users in mind (Akrich, 1992). At Program A there is a highly structured routine that works to contain individual needs and interests. The routine is striking in its dominance and, as discussed in Chapter 5 doesn't seem to leave room for the oft promoted goal of social engagement. Technologies like day programs are not fixed in their design or implementation, but as Winner (2014) points out, transformations for technology are often only variations on old patterns that are recursive and, much of the time, limit the actual innovation achieved. Day programs were not originally designed for people with dementia; in fact, this population was often considered inappropriate for the day programs' rehabilitative goals. Over the late 20th century, these sequestered spaces' role gradually evolved from a transitional hospital service to supporting care at home. This evolution of use emerged through strategies that organized material differences between home and institutional care, and between caregivers and people living with dementia, to tell a particular 'story' of care. This story included distinct roles for those giving and receiving care, and through these relations, respite as a specific form of care emerged, one that would be effective at relieving caregiver strain and sustaining people outside of longer-term institutional care. Fundamental to this form of care was a material form of physical distancing required between an identified care ‘giver’ and care ‘receiver.’ The pre-existing day program spaces offered a sort of ready-made template that could support this idea of this care for people living with dementia and their families. The goals of rehabilitation already present within these programs worked to shape the expectations of what could be done in these spaces. So, while new ideas of quality of life for people living with dementia extend beyond the caregiver's psychological status, the material distinctions of space and care are embedded in the design of day program. Ultimately this design works in relation to specific arrangements to shape the practices and subject positions available for people using them.

Dividing Spaces and Relations

Louise tells me in an early visit that "it isn't the relationship that I was promised" as she has had no communication from the program in two months. "I thought I would hear more about how he was doing there." Eventual communication from the program to Louise is a single page calendar with a list of scheduled activities sent in the mail. When starting the program, the staff tell her that it is easier to drop Jan off at the door rather than enter the program space. Objects such as alarms and signs used at the day program signify it as a separate space closed to outsiders. These practices of physical separation extend to the type of information that is considered relevant for staff to share with families. When I ask the staff members at Program A what kind of information they would communicate to the family outside of the monthly schedule, they identify circumstances of falls, physical illness, attendance issues, or if there was concern about appropriate clothing or missing equipment such as a walker. These guidelines for communication are an effect of the script built into the day program design and ultimately its practices, where the patterns of traditional family caregiving are sustained, including home as a separate private space, care as a set of tasks and established roles of care givers and recipients. These communication practices of Program A position Louise as separate from Jan, a caregiver needing space and Jan as someone to be supervised.

> During one afternoon at the program, there is a visit from a mobile zoo. We see and touch frogs, turtles, a ferret, a bunny, a hairless guinea pig, a large snake, and several parrots. I see Jan sitting with the large snake around his shoulders, telling the others about a trip to Costa Rica. There is much conversation and laughing in this session - I notice that no one is asleep or on the designated 'nap chairs.'
>
> At the end of the day, I walk with Jan to the upstairs exit and see Louise waiting for him. We greet each other and discuss the upcoming home visit. Jan is smiling at her, and Louise asks how the day was. "Very interesting," he says. I wait for him to continue, but he doesn't say anything. I wait for the staff sitting next to us to say something about the day, but they don't, so I tell Louise that today we had a zoo into visit and that Jan had a snake on him. Louise laughs and tells us a story of another snake they saw in Costa Rica. (Field notes, July 11, 2019)

There is evidence here of a certain type of configuration happening between Jan and Louise, and that of Jan and his environment, which tells us something of the rationale embedded in this day program's design. Ideas of caregiving and space are evident. The staff communication practices work to organize Louise in relation to the program and to Jan. Their relationship becomes one based on demands, not mutual experience. Louise is the care giver, and Jan the care receiver. Within this relation, previously shared journeys with snakes are clearly not relevant.

Health technologies enact configurations of how an individual is conceived and how they act for themselves. This agency is configured within the sociotechnical arrangement (Callon, 2008). Callon's ideas on configurations can be helpful here. Callon identifies that often social policies are based on approaches to sociotechnical arrangements that are themselves based on ideas of either prosthesis or habilitation. These different modes guide the distribution of agency across the arrangement (or as Callon would prefer "agencement"). Callon explains that within a prosthesis configuration, individual agency is embedded in material devices and procedures designed around the idea of an individual who has a barrier or deficit that needs repair. The arrangements are configured to restore access to all resources by enacting a disciplined version of agency that helps to conform the person to norms of expected activity. With Program A and Jan's family arrangements, agency is enacted within a configuration of prosthesis. Jan is centred as a person with dementia who has deficits that require support from space, materials and people in a way that enables him to participate in a 'normal' way within a community space. Within this disciplined agency, Jan is extended in his abilities but also made to conform to universal ideas of what he should and can do. In line with active ageing discourses, Jan can go out of the home and be 'active' and social with others, but because of his dementia, a defined space and close supervision by staff need to make this happen. While prosthesis approaches can be helpful and necessary, they often ignore the webs of relations and attachments in which people exist, creating asymmetries and mismatches between people served and those designing the services (Callon, 2008; Peine & Moors, 2015).

For Jan and Louise, the arrangements of their home and life are kept separate from those at the program. While Louise values a specific kind of care for Jan, one that connects with his interests and keeps him interactive with the world, the care she experiences is vaguer, and often, the details remain unknown. Jan's interests from home, his book, puzzles, and plants are invisible at the program. In fact, his athletic ability and independence at home are erased and replaced with a subject position of 'being at risk.' He is defined as the deficit, and the barriers to his inclusion in the community do not get addressed. López-Gomez (2019) argues that no matter how useful a technology is, the ongoing care and maintenance of the arrangements of daily life are affected in a variety of ways when new services are added in. There is a sort of violence inherent in the omission of this from design and evaluation work on technologies (López-Gomez, 2019). In Jan and Louise's case, the care at the day program begins as a vague, generic space where Jan does some structured activity away from Louise. It is not enough for them, and Louise looks for other resources to add to their arrangement that are more specific to Jan's needs.

Configuring Prosthesis and Habilitation

Wes started using the program when he was diagnosed with dementia, and several years later, Margaret decided to join him there as she no longer needed 'time away' from Wes and wanted more social interaction for herself. At the program, they sit at the table together. Wes is called on to play the piano for sing-a-longs, and Margaret enthusiastically attempts every craft presented while Wes sits back and watches or takes short naps in his chair.

Using Callon's (2008) ideas again, the same day program comes into relation with a different family arrangement, and other types of configurations emerge over time. Like Jan, the program began as a prosthetic type arrangement for Wes, extending his ability to participate in the community away from Margaret's supervision. This arrangement aligned with the other services that worked to extend and repair Wes's cognitive abilities so he could get dressed, bathe, and move around the house. These services were not designed for Wes particularly, but were instead scripted by providers with an idea of what a universal form of an older adult male should do in daily life and what a caregiver like Margaret needs to cope. But over time, a different orientation to Margaret and Wes evolved, and a configuration of both habilitation and prosthesis has come about. Callon explains that habilitation focuses on rearranging the world to allow for the network of relations necessary for an individual to act. This approach assumes an interactive view of an individual, in that they exist in relation to the world and have capacity for productive interactions with it.

Holding Things Together

My first impression of Wes and Margaret was one of precarity. On my first visit, as I stood on the doorstep for five minutes after ringing the doorbell, hearing a voice and bumping sounds coming closer to the door, I noticed the red peeling paint of the front door, worn stucco and crumbling concrete of the front step, yet a freshly cut lawn. Wes and Margaret seemed physically unstable as they lurched around their house, holding on to furniture and railings as they went. I felt like I might need to 'catch' them at any moment, but they appeared nonplussed by their travels around the home, moving with a sort of haphazard yet loosely choreographed tempo. They tell me they have walkers that they leave outside on the driveway as these are too difficult to bring up the three stairs into the home. This pragmatic idea makes sense to me as I cannot imagine either of them even using stairs, let alone with a walker. The home is cluttered with memorabilia, food items and papers laying on most surfaces. There is a disorganized quality to the home visits, with one of them usually being in bed when I arrive, requiring a long waiting time on the doorstep, or sitting alone in the front room hearing sounds from elsewhere in the house.

> At the program, I note Margaret and Wes arrive usually looking a bit dishevelled. Margaret's shoes are worn and have pieces of the sole hanging off the side, their walkers are often wet, or the wheels are covered in mud from the front path or from being left outside. To see them only as they enter the program, one would think that they have come in from a storm. But to see them at the table 30 minutes later sipping their coffee and playing rummy tile, they appear less threadbare and more present, perhaps propped up by their surroundings – the coffee, the card game, the other people. (Field notes, September 11, 2019)

Opposing prosthesis's take on individuals needing specific compensatory mechanisms to act in a defined way, habilitation draws on interactive ideas of agency. Within networks that are flexible and accommodating, with the right interactive type of supports, people can come to be self-managing 'agents.' While an initial impression of Wes and Margaret is one of precarity, there is a sort of durability enacted within the material supports of the day program, enabling their interaction with each other and the world. Within this configuration, Wes and Margaret are not passive agents but interact with the technologies like walkers, railings, home care, and day programs in ways that work for them and ways that stabilize their arrangement. These configurations of habilitation and prosthesis are not mutually exclusive (Callon, 2008), and there are aspects of both present within the day program's configurations of Wes and Margaret's arrangements. There remains a disciplinary script of activities and use of space at the program, but also an acknowledgement of Wes as a product of a network of social and material relations requiring attention. The home care plan for Wes prescribes both times and a pace for baths and dressing each day, but it also notes his preference for tub baths over a bath chair and the family's waiver of the perceived risk of this choice. Wes is acknowledged as having memory problems that need compensation, and he is also seen to exist in relation to his attachments.

Enacting the Individual Agent

> After lunch, it is ‘sing-along’ time and Wes is the guest organ player – he gets up out of his chair with a rocking motion - "one, two, three, oof!" - and shuffles with his walker over to the organ. A staff member hands out songbooks. Another staff stands with Wes at the organ and asks him to start with 'Roll out the Barrel'. Wes hums a bar of the song to himself then begins playing by ear. The group sings along smiling. After the first song is over, the staff asks the group, "what should we sing next?" One of the women in the group shouts enthusiastically, "When the saints!" and Wes begins playing that song.
>
> In his care plan at the program, the manager notes Wes's numerous needs for assistance and stimulation as well as a note: "We love when Wes plays the organ for sing-along, he makes us smile and is always full of joy. It's a pleasure having Wes at the program.″ (Field notes, September 18, 2019)

While sing-a-long time is only held once a week, it is in these moments at the program that Wes is enacted in this web of relations that recognize his attachments and his needs for support as an ‘individual’ who can take action and play an active role within a social setting.

Normalizing Technologies and their Limitations

As Moser (2005) notes, this idea of active agency is both a common feature and a bug of normalizing orderings that guide interventions for people with disabilities. From the policy level to the practice level, there is a promotion of supports that can enact a person living with dementia in these presumed 'normal’ active ways. This ‘ideal’ of active/normal agency is evident in these excerpts from interviews with policy makers and day program managers, who each describe activity and engagement as central goals in programming for people living with dementia:

> Program A Co-Manager: They can't go to a seniors' center or a more independent setting on their own anymore… those who would really benefit from getting out and it's not at the point where they need to have services in the home, because they don't want to feel that they are being babysat, but going out and being something bigger really helps them. (Key Informant Interview February 20, 2020)
>
> Program A Co-Manager: It just provides something that is hard to make tangible, but she is out making friends and having a good time and actually has something to talk to about when her family calls and says, "How are you doing today? How did your day go?" (Key Informant Interview, February 20, 2020)
>
> Policy person: Can we help you to be a person with dementia that … live[s] in purpose, to still not just be, but to live well in the community? (Key Informant Interview, February 25, 2019)
>
> Program B manager: I think our role is to help clients meet their goals to help them maintain their independence well ensuring a safe and positive environment. (Key Informant Interview, January 28, 2019)

These statements reflect the types of subject positions that formal health planners seek to maintain and account for through the day programs: an independent and engaged senior with dementia. Moser (2005) explains this "order of the normal" (p.668) is in fact, limiting for people with disability in that it promotes the norm of a subject who is self-contained and centred, and ignores the actual distributed nature of agency as an achievement of many things working together. Through this normalizing view, the web of supports needed for Wes to achieve ‘normal’ activity in fact limits him from accessing other spaces. Here the person who needs supports for independence is positioned in opposition to an apparently singular individual who is independent. This positioning is evident in the rationale of the Program A manager explaining why people in the program are not integrated into the more general seniors’ centre activities: "Whereas if they are coming into a program upstairs [in the general community seniors’ centre], they would have to be able to do that independently" (Interview, February 20, 2019). Through this positioning of independence in the normalizing discourse a divide is enacted between the perceived safe inside and risky outside of the program. As discussed in Chapter 5 much of the organizings of the program are related to maintaining this division (Cooper & Law 1995).

Tinkering and Durability

> One morning at the program drop off time, Wes is helped off the bus by the driver. As Wes hums a song to himself, the driver grabs his walker and sets it up for him, then guides Wes to the front door of the seniors’ center. He then returns to help Margaret. The driver escorts them into the entrance where the staff is waiting.
>
> Driver: (to the staff waiting at the door) They have a subscription pass, right?
>
> Staff: Yes.
>
> Driver: I thought so, but they didn't have them today.
>
> Staff: Oh, I will call and make sure it's up to date, and maybe the son can put the pass on their walkers. (Field notes, September 11, 2019)

In Wes's chart, communication logs track concerns about times when staff noted his clothing was inappropriate for the weather, he was missing his walker, had bruises on his face from a suspected fall, or arrived late. When I ask the manager what would have happened in these cases, she says, "Oh, I just get in touch with the family to make sure everything is ok, and if it sounds like there are issues of needing more supports, I may call home care to ask for them."

From a distal perspective, a day program is a defined bounded space. In attending to Wes's attachments, the 'seams' of the day program become less tightly adhered and the partial contact points emerge between his home, Margaret, and other formal services. The lost bus pass causes a potential breakdown of the network, which then makes visible some of the bus driver and day program staff's ongoing organizing work that allow for Wes and Margaret's simple transitions between spaces of the home and the program. Again, like with Jan, the day program as technology no longer stands alone but exists within this larger care infrastructure. The program sits in relation to the other services of transportation and home care. These relations are contingent and temporary (Cooper & Law, 1995) and similar to Margaret's shoes, it seems that it could all fall apart, but it doesn't. There are cracks and less than ideal circumstances evident in the clutter, the dirty walkers, family conflict, and the confined isolated space of their lives. There is not a set path of connection that is solid and predictable, but instead, much of the care that the day program provides is that of tiny adjustments and monitoring of Wes and Margaret, their equipment, their shoes, which requires the ongoing relations between the program and the bus drivers and home care. All of this facilitates Wes and Margaret's ability to have a 'social outing' three days a week together, a shift from the program's previously defined script of merely being a respite space. This arrangement is about care, and the relations within it make room for tinkering. In small ongoing ways, the day program accounts for Margaret and Wes, they are seen, monitored and their interests are occasionally engaged. Within these arrangements, the day program offers something to both Wes and Margaret - moments of enjoyment, social contact, space away from home together but still apart enough for Margaret to share some of the attention to Wes with others.

Some Selves

> It is snack time at Program B, and a younger-looking woman I had initially thought was a volunteer is sitting beside me. She is talking fairly often, using spurts of words that sound like phrases but don't seem to connect to a consistent theme. While talking, she uses her hands and arms to make big gestures. At times, I can guess the topic through her gesturing and comment back – each time, she smiles, nods, and says something more. She moves around frequently in her chair, reaching out and touching other people's hands, the cups on the table or turning to look at the fish tank. She takes off her glasses and holds them up to mine, and I see that we have the same shaped frame. She laughs when I say this and then turns back to the fish, gesturing and says some words unrelated to fish or glasses, then turns around and smiles at me. (Field notes, June 12, 2019)

The staff introduce her to me as Marie, a former teacher and a sports fan, a golfer, and a musician. They base this introduction on a tool they use called a Life & Leisure tool that they complete with the family on admission. It details Marie's interests, her childhood, work, and family history. The staff tell me that this social leisure profile helps them understand "so much more about patients than the patients themselves are likely able to tell [them]." A staff member Megan tells me she recognizes that other people's viewpoints are not a whole picture of someone, but sometimes the only information they have access to for some clients with dementia. She says the team uses this information to help give people focus when "they lose the thread." The staff can then give relevant biographical hints or prompts in the reminiscence or brain teaser games.

Marie's identities become crystallized through the life and leisure tool despite the rapid progression of the change dementia brings to her experience of her world. This stabilization occurs according to the normalization script of what she should be doing and creates conflict for staff in acknowledging and accommodating Marie as she is now. Beyond being just a matter of staff awareness of tailoring care, the scripted activities of the day program and its placemaking effects have material effects on the way staff can attend to Marie's tastes and interests. Rather than meeting the tactile sensory desires that her body seems to want to explore, she is shaped to partake in 'normal' behaviour: sit at a chair and sip coffee with others. At Program B, staff work to tinker and adjust the environment and materials around her, disciplining her body's restlessness, desire for touch and short attention span to maintain her in the expected behavioural norms. Sometimes they are successful and other times, they are not.

These adjustments are not benign, and they have effects on Marie's subjectivities. As Driessen and Ibanez-Martin (2020) found in their study of food provision for people with dementia in long-term care, this way of attending to difference is common as staff try to find ways to tailor care to the person's unique tastes but within the limited repertoires of doing this, individuals get enacted differently. This maintenance is not just a philosophical stance towards Marie's personhood but rather an ongoing "practical concern" (Driessen & Ibáñez Martín, 2020, p. 255). In day-to-day practice, it is evident that the staff have developed multiple approaches to managing Marie in the room, and it varies at times as to whether she is being habilitated or disciplined. Most of the time, the staff focus their time trying to engage Marie with the things they know she likes from 'before' like sports and games, and attempt to support her into participating during the rest of the time where activities are too complex or require verbal skills.

> During a complex activity, I work with Marie, who is interested and quite able to do the task but needs frequent focusing. Despite all her movement, Marie finishes the canvas first, and we move to the next step of letting it dry while choosing shells. As we work, there is chatter, and staff tell me about Marie being a former teacher, and I ask her where and she tells me, and staff tell me about her talents at sports and music. I ask Marie what instrument she played, and she makes gestures that seem to indicate a cello, which I guess, and she agrees. (Field notes, July 11, 2019)

Here I work to adjust the activity to Marie's abilities, and her biography serves as grounding from which I enact her as a person within the activity. Based on what the staff tell me, I envision Marie not as the person in front of me but as someone who has lots of experience in class projects, instructions, and groups. Marie accepts some of my help and ignores other parts. She is enabled and interactive within the habilitative arrangement of objects, support people and her attachments to roles, objects are recognized. The activity requires I focus my attention on Marie as I tinker and redirect, and at times, it involves compromise by Marie, especially once I am in charge of the hot glue gun, but it is feasible and accommodates some of what Star (1990) would describe as the multiple selves of Marie.

'Other' Users

There is often no accommodation for Marie's lack of verbal skills and short attention span at cognitive stimulation time.

> She sits quietly at the table with a pencil doing what I assume she thinks she should be doing trying to write on the worksheet; she becomes quieter and responds irritably with any offers of help, eventually standing up abruptly and storming out of the room. (Fieldnotes, September 4, 2019)

The staff often talk of the work of managing Marie as this work stands out as exceptional. It seems it is not just her behaviours and moods but also her younger age and physical strength. Marie's mismatch with the activities and space reveals the program's disciplinary design for a different type of user with dementia than Marie. Through the disciplining design of the day program, some versions of Marie are excluded, and the day program's standardizing technology is made obvious. The program stabilizes Marie as a subject into a few of her selves: the former teacher and the jock, but other selves, including Marie's current embodiment of dementia as a younger person, is excluded. There are positive and negative effects from this. The program's socio-material arrangements connect to the broader arrangements of Marie's life to ensure continuity, and in effect, an extension is made between home and community that is not an easy achievement (Moser & Law, 1999). For Darren, her husband, this arrangement creates a sense of trust because he can see continuity in the Marie that he knows, a woman with likes and dislikes that are consistent. He tells me he trusts the staff and sees them as being very capable in their work due to their knowledge of Marie. He tells me that this is not the case with other services he uses through home care who do not seem to acknowledge her attachments or previous identities.

Working with Standard Scripts

On the other hand, Star (1990) explains that while standards often are seen to create an order, they can create 'monsters' of those who do not fit within the standards. This exclusion is an exertion of power and through it much of Marie's agency is distributed away from her (Moser, 2003). But this technology is not wholly deterministic of Marie, and at times she can resist the selves the script places her in. Much of this resistance generates a sort of ongoing dance between staff and Marie as they respond to the scripts of the program.

> Marie has finished her Christmas tree craft for the craft sale, and the staff quickly takes it to put into the Christmas sale box before she puts it into her cubby box. Staff give her a handful of the baubles. Marie grins widely and exclaims, "oh wow!" quickly putting them into her pockets. (Fieldnotes, November 6, 2019)

Arranging materials and people requires work to protect Marie from the other patients' responses and the other patients from her. The staff strategically position her at certain tables or chairs next to people they know will not react negatively. They watch other patients' items if Marie is close by and quickly put them away. But Marie is agile and moves quickly and often. A cubby box system is used in one corner of the room to store people's craft projects. Each box is labelled with the patients' first names. Staff direct Marie to her box and away from the others throughout the day. The downside to this cubby box system is Marie also likes to collect objects and take them home, and this cubby box serves as a perfect ‘stash site.’ This adds a role of stealth policing of the box for the staff as they take opportunities throughout the day to look in the box when Marie is not in the room or is distracted, and they remove any objects that are not hers. Later in the study, they tell me they have decided to take away her box as they feel she spends too much time looking in it.

The staff also enrol Darren in the work of fitting Marie into the script of the program. He drops her off later than the morning coffee time as he knows she may balk at staying at that kind of activity, bringing her for exercise time instead. Marie herself works to connect to an environment not designed for her cognitive and physical abilities. She responds to redirection to "take it easy" with her 'slapshots' during chair hockey, and despite not being crafty, she takes up colouring mandalas as this is a regular activity offered.

This issue of fit between the day program and Marie is not surprising as the limitations of day programs for people with responsive behaviours of dementia have been explored well with limited solutions proposed (Femia et al., 2007; Leblanc, 2010; Mävall & Malmberg, 2007; Vandepitte, et al., 2016). So while these responsive behaviours often stimulate the need for more supports, the supports offered are not designed for users with these behaviours. Oudshoorn, Neven, and Stienstra (2016) explain that the need for diversity is challenging for gerontechnologies as they often rely on pervasive fourth age viewpoints of older people being frail and passive. In addition, the popular distal view of day programs has difficulty capturing the socio-material networks involved in accommodating differences in behaviour and emotion, so the awareness of what work is involved and what is useful is limited. This work of accommodating operates in the background and becomes visible only when things go wrong (Star, 1999).

While the activities seem to ‘design out’ Marie (Oudshoorn, et al., 2016), the staff use particular objects of the room as a prosthesis for interaction for Marie. These materials enable interactions and commonalities that are difficult for her to express verbally.

> One day while trying to help Marie with an intricate craft, she stops participating and gets up from the table. She takes the baby doll out of the little high-chair that sits tucked in next to the fish tank. She is 'oohing' and 'ahhing' at the doll and showing it to the other women at the table, saying, isn't this nice? Agnes and I comment on how lifelike it is. She brings the doll over to Peg, who smiles and says, "Oh, what a nice baby." Marie hands her the doll, and Peg takes it and holds it close like an infant, rocking it gently and leaning her head close to its head, saying "oh so sweet" smiling and then handing it back to Marie. (Fieldnotes, September 4, 2019)

Another time I come into the room and

> Marie is standing at her table and turns when I come in and smiles, gesturing to me to look at the small squirrel toy she has – “look see it's cute!” she says – this toy is motorized so when Marie touches its head, it sits up or crunches over while making noises. With each movement, Marie laughs and says, "Oh!" I tell her I am not a fan of rodents, and she says "yes" and picks it up and holds it on my shoulder, laughing. I cringe and say, "ooh!" She puts it back on the table and shows it to another woman. (Fieldnotes, June 26, 2019)

The staff tell me these objects have come in over time to the program as it has adjusted to the increased number of people attending with more significant effects of dementia. Again, homogenous ideas of the person with dementia have guided the acquisitions of these objects. Oudshoorn et al. (2016) argue that a sort of design infantilization can occur through these child-like technologies and yet here they do work to create connection and respond to Marie's capacities leaving the question of which Marie should be attended to?

Interestingly Marie presents the biggest challenge to my research both in data collection and in the analysis. In the field, I am drawn to her immediately, as I am used to working in an institutional setting with people with dementia who communicate, and act like her. The apparent mismatch of the routines of the day program and she are striking to me. Because of her quick mood shifts, the fieldwork was challenging with Marie. While I was used to managing this as a nurse, new ethical concerns emerged for me as a researcher- when someone tells you to take a flying leap, it is pretty apparent their assent is no longer valid. So, while my initial interactions with Marie were positive, in the fall I dye my hair, and it seems she no longer finds me familiar or perhaps thinks I am someone else (sounds rational), and she becomes hot and cold to me. So, *I dance between engaging with her and backing off when her mood and physical cues told me I was intruding. Home visits were limited because of this, and careful arrangements had to be made to see her at home. An amazing opportunity for me to see her in her home space, but it definitely felt on the edge of imposition for both her and Darren, so I did only one. As I analyze the data, I notice a difference from the other cases. There is less data than other participants, and it is predominantly from observation at the program. I also have predominantly Darren and the staff's accounts of Marie rather than her own accounts. I pull my hair out while trying to make a symmetrical analysis, and after an afternoon of writing about her lack of fit with the program scripts, I hear myself muttering: "Oh god, why did I recruit her?"... So, it seems Marie doesn't fit here within the research practices either. What script is it that I am following that makes this so? Why did home visiting feel like such an imposition? I live with someone very much like Marie, and as a caregiver, I have a less than delicate impression of my life, yet Darren seemed like someone to protect from the stress of the research process and Marie too. Maybe that makes me an ethical researcher, but perhaps it is more complicated. Maybe framed through REB guidelines for vulnerable people, application processes and ethics sections of my proposal, I am naturalizing the non-fit of people like Marie and Darren to be a part of dementia research or at least this kind of research. Once again, the devil is in the data, the things that makes this challenging to analyze can actually tell me a lot about the larger orderings at play.*

Home-Making

Understanding home as a ‘making' or a "shifting arrangements of people, things, and places and affects" (Pasveer et al., 2020 p. 11) allows for an exploration of how the installation of a day program into the home might work. Dementia, like other conditions, demands accommodations for care within the arrangements of home (Ceci et al., 2020). Often with limited supports, the arranging work of maintaining home with care can become too difficult. Within the substitution-oriented supports for caregivers, there are few opportunities to create space in the arrangements that make a home. The accommodations for care are more than psychological; they are material in that they include real objects, spaces, and affects. Darren tells me before finding the day program, he felt "like a prisoner in his own home." He tells me he had no space and no uninterrupted time at home, and that Marie's habits of collecting and organizing "stuff" meant that he often couldn't find things, or if he did begin to look through drawers or attempt to do her laundry, she would get angry. With the addition of the day program, his home's nature shifted from a place Darren felt trapped into a place of order and comfort. For Marie, the space away at the program allows for the maintenance of routines that make the home familiar. When Marie is gone, Darren can find the laundry and objects that she hides without conflict, he can complete his banking and emails without interruption from Marie, and he can leave home freely to exercise and see friends. I observe Marie at home one day, and I am struck by her comfort there. When I arrive, she is in her office "organizing her drawers," something Darren tells me she often does as "she likes to tinker around." Marie emerges from her office and takes me on a tour of her house, showing me objects and pictures. She has difficulty expressing who or what these items are, but her attachment to them is obvious, and she gestures and makes sound effects to shape my guessing, and Darren fills in the blanks. She stops on the way up to her bedroom to play the piano and her cello for me. She shows me mandalas that she has coloured at the program, which are now posted on different doors. Her room is a collection of hundreds of tiny objects collected and arranged by her. As I pick them up, she makes exclamatory sounds and then smiles, takes them from me and places them back into the ‘spot.’ Darren tells me I am fortunate to see the room as Marie often lets no one enter, including him. As we later sit talking in the family room, Marie gets up and shows me the sunset through the window and then moves to the kitchen and starts washing dishes. She is at ease here in this habilitative arrangement. There is a freedom to her movements in this space unlike those more restricted ones at the day program. Marie's arrangements of things and her attachments to the spaces, sunsets and tasks of the home seem to shape her into someone who is not passive or requiring discipline but rather someone interactive with her world, someone with agency. This is not simply the notion of home but a socio-material arrangement of care, Marie, her things, place, and Darren. The program installs not into the home as a noun but the home as a verb (Pasveer, Synnes, & Moser, 2020). This making of home and care takes ongoing work to accomplish, and for now, the day program affords the space needed for this to be done. Darren tells me he sees her comfort at home, and this is what stops him from acting on the formal care provider's suggestion to 'place' Marie in a long-term care facility. This isn't a stable installation; the arrangement is precarious and requires ongoing attention and care. If care needs shift, the arrangements will need to move too, and they may not be maintainable within this space with these people and things.

Configuring Passages

In the case of Peg, the advantage of seeing the shifting configurations over time is most apparent. When I first meet Peg, the effect of the day program arrangement's ability to enact an active subject is obvious.

Peg begins the program shortly after her husband dies, and the family looks for a way to keep her home and socially engaged. Her sons tell me their biggest concern was her isolation and seeing her "just sitting in her chair."

> Ron: So, I think that was what it was, so just to get her out, and the social aspect. You know, people your age and your experiences and get you out doing something… you

> know, you… you are a social person you know, you like to be chatty, and, and she is a lot of fun and….
>
> Bob: Yes, just the social element is… you got to get out of the house and not be sitting there every day…right? (Family Interview, August 15, 2019)

Peg begins attending the day program in the main room with the med-rehab track of the program and the staff immediately notice her memory issues are a bit too severe for the scripts of 'full participation,' so she is transferred to the Oak Room, which is for people with moderate cognitive impairment. In the Oak Room, Peg is engaged with cognitive stimulation activities and socializing. She is verbal, intelligent, and physically active, essentially the trifecta of abilities required for the program activities. Her relaxed, friendly relations with the staff and other group members are obvious.

> At the end of the activity, the program nurse comes in with a piece of paper and approaches Peg saying, "Hi Peg. I need to get you to sign your care plan." Peg looks up, confused "my what?" The nurse explains, "it's the plan we use to say what it is we are doing for you here, and you sign it to say that you agree with our plan." Peg looks at the form and says "oh, ok." The nurse asks her, "do you like coming here?" Peg smirks and looks at the staff sitting next to her "yes, I do," and then the staff says in a dry tone, "say that with enthusiasm Peg" and they both laugh. Peg signs the form. (Fieldnotes, July 11, 2019)

For the family, these relations and humorous interactions are familiar to them as who their mother has been and is one of the first things they tell me about the program. Her son Ron says,

> She gets out with people, there is a couple of old ladies, and my brother says that she is as smart as a whip out there… they take jabs at each other and… mom usually wins those arguments I think… with what is her name? [refers to staff member at day program] (Family Interview, August 15, 2019)

I ask Peg about what she likes about the program she tells me:

> Just the fellowship of other people … I think that is probably what it is. Because I don't really feel that I am one of them…. well I guess I am. I can't explain it. I belong there, but I don't, I don't belong there. Does that make a lot of sense? (Fieldnotes, August 15, 2019)

Through these arrangements, certain realities are made possible. Peg has a place she belongs to. She is a recognizable person to her family as the socially active person she has always been. While her former attachments have dwindled with the loss of her husband and her changes in memory, the day program works to stabilize her into a new network of attachments. She is situated at the small tables in relation to other patients, their commonalities encouraged, and opportunities for engagement structured through rituals like morning coffee, game activities, and meals. Besides positioning Peg as an active person with dementia, the program care practices also work to define her as a care receiver not giver, revealing the prescriptions of care that are built into the program. This is a sort of morality built into the program, prescribing the roles of staff and clients and their capabilities (Akrich & Latour, 1992). But Akrich and Latour (1992) also point out that scripts of technologies are not deterministic; they may be inscribed but can be de-inscripted by the actor's resistance.

> During a reminiscence discussion, the staff calls on Alice to answer a question about a favourite birthday, but another patient, Susan answers instead. Staff Gina says, "wait, it's

> not your turn; it's Alice's turn." At this point, Peg speaks up and says to Staff Gina sharply, "Don't yell at my friend!"
>
> Gina tells me at lunch that Peg is always trying to "nurse other patients." I joke that old nurses never stop working, and she laughs and says, "yeah, and when I tell her to stop babying the other patients, she bites my head off!" (Fieldnotes, October 16, 2019)

Interestingly, it is this identity of 'an old nurse" that is often drawn on by staff in their reminiscing conversations with Peg, and it is the one outlined in the life leisure tool. Yet when Peg enacts this self of hers, she is redirected. Peg resists, and conflict ensues. Through resistance to the one-way caring script, Peg maintains her identity as an 'old nurse' and a person who cares for others.

Defining Spaces

Day Program B builds a local community of the participants that includes activities beyond the program's walls and activities that draw family into the program. Through these family teas, bake sales, and visits during pick up and drop off, the family's attachments to the place and the people of the program solidify the program's relations within the family arrangements. As Peg changes in her day-to-day functioning and potential risks emerge, the family uses the program as a sort of anchor. They build other supports around it, finding other pieces of care to spread out and support the times away from the program. Like Marie and Darren, the day program works within an arrangement that makes home possible for Peg. A live-in caregiver is added, and her hours adjusted around the day program days. The day program's template also acts as a guide to the family as they look for activities similar to the day program on the other days of the week. A yoga class is attempted with great disdain from Peg, then an exercise class is trialed along with weekly trips to the mall with her caregiver. Her daughter tells me later on that finding other activities has been difficult.

> ‘The week is kind of unbalanced with Monday and Tuesday having nothing to do… so I wish the day program was on Mondays too.” I ask if Peg has ever gone to anything at the local seniors’ center and she says, “I don’t’ think so… but do they have anything for people with dementia there?”
>
> Barb says that she would love to get her mom involved with something else but reiterates again that “there are few places for people with dementia.” I ask if that is necessary for Peg and she says that it’s just that with programs geared for dementia, like the day program “they know what they are getting.” (Fieldnotes, January 9, 2019)

So again, the classifying technology of the day program works to define Peg as a socially active person and a person with dementia who requires a certain kind of space where the inconveniences of her condition can be accommodated. Similar to Wes’s case, the profiling of supported types of independence available through the day program reinforces the idea that ‘true independence’ is required elsewhere.

Bad Passages

Despite the program’s relational connections to the family, there is still a sort of division established in what the program can be used for by the families. This division is not obvious in the common portrayal of the program being a support to families, so I only begin to notice it as I travel between the established boundaries of the program and the home.

> I tell Mike and Bob that I have seen Peg at the day program exercise and note that she is quite engaged during those sessions. Mike says, “since you see her there can you tell us what she is like there… like how she’s functioning in those exercises?” I am somewhat

> surprised by this question because I have seen Mike drop-off and pick up his mom from the program and talk with staff whom all seem to know him. I ask if he has asked this question to the staff, and he says that it tends to be more general conversation about the daily activities. (Fieldnotes, July 16, 2019)

It seems that somehow while the family appreciates the program's social activities and relations, they don't seem to think of the staff as a source of feedback or information on the health or functioning of Peg. A few months later, staff at the program notice Peg has a limping gait, and she tells us about a fall at home.

> Gina, a staff member, comes over to me and asks me if I know Peg's family, and if I have contact with them, I confirm that I do. Gina wants to know if I can let them know about the fall. She tells me the bruise on Peg's knee is obviously fresh. I tell her that because I am researching the connections between home and the day program, I need to see what they typically do with this kind of information. She tells me that she charted her assessment of the bruise and requested an assessment from the physical therapist at the program. She says she will call the home care case manager who then can decide what the next steps are, such as talking to the family or suggesting a home safety evaluation. (Fieldnotes, September 4, 2019)

It seems I am a quick connection to home, revealing the more indirect and convoluted path that is usually taken through home care to the family, and may indicate sanctioned topics of family communication for recreation staff versus others in the arrangement. It is apparent here that the technology of the day program is situated within a care infrastructure. As seen in Jan's case, this infrastructure leads to the formalization of paths and an established sequence of how services can connect. Recognizing this positioning allows for a different account of when ‘things go wrong’ beyond one centred on staff actions, instead, despite intentions, the design and relational connections of a technology can determine its limits (Poland et al., 2005). This infrastructure divides responsibilities, while home care uses the day program as a respite solution, the day program must feedback any medical concerns to home care. So while the program does its own practices of monitoring Peg and her body and has access to material forms of connection such as fax machines, voicemails and electronic health records, the local practices travel slowly and only at certain thresholds to other areas of the care infrastructure. The effect of this is an invisible boundary between inside and outside the program that the staff commonly feel frustrated with. Staff tell me they wish they knew more about changes at home as they recognize their impact on the program. The recreation therapist tells me “this is the part that is frustrating sometimes as we don’t have a good picture of what’s going on, like it would be good to know if she’s tired cause maybe she’s been up or not feeling well.” The staff work to overcome the boundaries but the scripts and positioning of the day program in relation to the care infrastructure create obstacles for them.

> I ask the recreational therapist how she thinks the program sets up families to know about when and what to share…. She says “Well, when they come for their first day, we tell the family to let us know about any changes in attendance and we give them this sheet of paper.” I look at the information sheet and see that it primarily talks of attendance rules and does not actually include any information about when to call and point this out to her and she takes a closer look and says “you are right it doesn’t.” (Fieldnotes, January 15, 2019)

In the program chart, there are copies of letters sent to Peg’s family physician and home care, a sort of relational extension made from the day program as an attempt to connect or insert into the web of care services around Peg. Staff tell me despite these letters, they rarely receive information from home care or the family doctor: “it’s really only one-way.”

For Peg, the positioning of the program within the care infrastructure, and the mediated connections between home and the program that result, has some serious effects. Several months into the study, Peg becomes more confused and unsteady, a delirium becomes evident. The staff work to connect with the family doctor and family, but the material communication paths are clunky, and the feedback loops are not predictable. Several phone calls are made, and voice mails are left and finally a urine sample is collected at the program and sent to the lab. There it is processed, and results are sent to the ordering physician’s office and placed in Peg’s chart. The nurse at the program can see the results on the electronic health record and assumes the doctor has prescribed treatment but because the typical trigger for the test was not an office visit, the results are not communicated to the family. As such, the delirium continues on, and Peg’s functioning continues to decline. Later during a holiday gathering, the family notes her declining condition seems to be more than dementia, and she is brought to the doctor for another urine test and then finally, a diagnosis of an infection is made, and treatment started.

Moser and Law’s (1999) ideas of good and bad passages come to mind in this situation. Moser and Law point out that the character of the materials that enable ‘passages’ between heterogeneous networks enacts people's dis/ability. Good passages are about the ability to move easily between specificities, and bad passages lead to “awkward displacements” that impair or stop the movement (Moser & Law, p. 205). The day program and its related care infrastructure create both good and bad passages for Peg as she attempts to move with a continuous biography between her home, the community, and the program. At times the program joins its socio-material networks with those of the home arrangements and the community bus to enable Peg to spend a day out sipping coffee, playing crosswords, and bingo with people she feels connected. Other days Peg moves from home to the program, and her subjectivities are not supported, she is limited in who she can be and what she can do. It's perhaps not a terrible passage, but it is not as good. Much of the time, the arrangements that support her in these passages remain invisible and are difficult to account for. Yet with the changes in Peg's body, with her urinary tract infection and delirium, her specificities change, and the configured arrangements aren't enough to accommodate her physically or cognitively. A certain helplessness emerges, and gaps appear between the care she needs and the care that is available. "She's really going downhill fast," the staff tell me. Discussion begins at home and the program about "placement." This unfortunate circumstance reveals the day program's limits for adjustment to certain specificities and the inscribed normativities that are invisibly present in the program. Peg's cognitive and physical changes shift her out of standard specificities inscribed in the program. The program's limited connections to the care infrastructure make the adjustments needed to enable a smoother passage difficult.

Conclusion

While day programs have emerged as a health technology aimed at improving quality of life and sustaining care at home, the predominant view of them being bounded spaces of respite has not led to much innovation in their design. From this proximal analysis of the configurations observed in the four different family arrangements, it seems apparent that day programs, like other health technologies, have a range of specific and local effects. Using a proximal approach also reveals many intentions at work within the organizing, inherited ideas of rehabilitation, normalizing discourses of independence, and a narrow range of subjectivities available to both patients and families. The programs configuring effects on agency varied within the specific arrangements, at times working as prothesis, and at others habilitation. Common in all the cases was the normalizing scripts for certain types of users that had effects on people's relations to others, agency, and definition of space. Rose and Blume (2003) explain that the configuration of users is dependent on policy environments that narrowly prescribe who needs what services. As Oudshoorn et al.,(2016) point out, ideas of "crisis accounts of ageing" underlie many gerontechnologies. Unfortunately, with this framing, diversity is a difficult concept, and within generic solutions like day programs, specific users and context are designed out of the technology (Oudshoorn, et al., 2016). The day programs relations within the larger care infrastructure both enable certain parts of its classifying and standardizing technology and limit its ability to accommodate specificity not already inscribed. So as Moser and Law (1999) would say, this leads to good passages and bad passages. At times the participants living with dementia were engaged, recognized, maintained, and accommodated, and at others, they are excluded and neglected. Important here is that generic solutions do not have generic effects, and it is through the specificity of the sociotechnical arrangements configured with day programs that versions of life with dementia are made possible.

Chapter 8

Care in the Community: Partial Connections

In this final chapter, I gather the threads of my previous analyses to return to my beginning question of ‘care’ in the community for people living with dementia and the role that day programs may play in this, but in a new way. As mentioned in the introduction, much of this dissertation was informed by Moser’s (2006) observation that if you want to understand what something is, ask "what it is made to be and how it emerges" (p. 376). Previous chapters have explored how the day programs came to be within specific family arrangements, how various versions of the day program come together or stay apart, and how they are configuring and configured in everyday sociomaterial arrangements for people living with dementia and their families. But as Law (2004), as well as many others, has argued, descriptions are also always ways of writing and re-writing the world, and there are many stories that might be told about the same situation. This is a process that Harbers (2005) describes as re-scription, and in my analysis I have worked to re-scribe day programs as a technology, a part of care infrastructure, a contested space enacted through multiple practices and competing modes of ordering, and as an actor within sociomaterial arrangements of care.

This re-scription is more than a theoretical exercise; it is a political move (Harbers, 2005) accomplished through a material-semiotic strategy intended to unravel the tensions present between the multiple orderings of care in the community through which different versions of life with dementia are made possible. The political work here is not a case of bringing two sides together in some sort of ‘zero-sum game’ for justification or legitimation (Harbers, 2005), but rather one of creating complexity (Mol & Mesman, 1996) and opening up possible worlds (Harbers, 2005). This opening up does not lead to grand solutions, but it does work to denaturalize ideas of what a day program is and how it works, and to show the conditions of possibility enacted through it. Puig de la Bellacasa (2011) describes this opening up as a way of generating care for taken for granted or “neglected things;” an etho-political move designed to create accounts that generate care as a form of intervention in “ethical and politically demanding issues” (p.94). The shift of day programs from their status as unquestioned ‘simple locations’ of containment (or ‘matters of fact’) into contested spaces, as well as a configuring health technology in practice and an actor within socio-material arrangements, can draw attention and concern to them. This opens opportunities for consideration and care about what is at stake in how they exist, as matters of care. This is an important move, as it is from this positioning of day programs as matters of care that a speculative commitment to how things might be different can occur (Puig de la Bellacasa, 2011). Embracing this stance, this final chapter is not a conclusion; rather, it is meant to be yet another point of departure, a location from which to speculate about how day programs might connect, for better or for worse, to the broader politics of care in the community. To do so I will tell a few more stories, re-scribing the day program within these politics of care in the community, drawing on ideas of infrastructure and cosmopolitics as ways of thinking that open up understandings of care in the community in order to make a case for the places this work may travel to.

Day Programs as/in Infrastructure

In the field, I was usually spatially located in day programs and homes which, as discussed in Chapters 5 and 6, were generally maintained and treated as discrete bounded settings. Because I positioned myself theoretically to trace relations of the person living with dementia, the edges of these spaces were less discrete for me, with many relations extending between home, day programs and other community infrastructure becoming visible. It was the relations of people, sidewalks, buses, and walkers that afforded people’s transport to and from the program. It was the social materiality of the spaces of home, neighbourhoods, and broader community that participants and day program navigated in their daily life. During my time with Jan, Peg, Wes, Marie, and their families, I heard about how they, their families and care providers worked to negotiate access to various community places on the days they weren’t attending the day program. For example, Jan and his respite worker withdrew from doing puzzles in his apartment building’s common room in response to community feedback about who was allowed to do the community puzzle in that place (it had become apparent that respite workers were not). I spent four hours sitting with Peg and her caregiver Gwen at a nearby mall, people watching from the food court, a place Gwen described as one of the only locations outside of the home where they could “just sit.” I heard Darren describe how the local retail stores' staff knew him and Marie by name as this was a place they could go and easily walk around. I heard Wes’s son wish that there was somewhere with music to take his parents. In observing and hearing about these different sites, what became striking was how these other spaces and places of my participants' lives worked to define the day program as a certain type of place. Massey (1991) considers space and place as social and material constructs that are interconnected (Sergot & Saives, 2017). Space is a product of relations and place is a particular point of their intersection or meeting (Massey, 1991). These relations that produce space can facilitate both the movement and confinement of actors (Murdoch, 2006). Infrastructural relations and their inherent normativities route people to particular relational intersections and exclude them from others (Massey, 1994; Ivanova, Wallenburg & Bal, 2020). This has place making effects not only within the localized place but also through what Ivanova and colleagues (2020) refer to as place by proxy, that is, when effects of one place take action to shape other places elsewhere. As discussed in Chapter 5, a version of day programs often enacted through its practices is that of a safe place, one that provides supervision and predictability. Beyond a safe place, day programs were often one of the few accessible spaces in the city where people living with dementia could be in relation to others outside of their family, and this worked distally to define what other places might be suitable for people living dementia.

While I have previously situated day programs within care infrastructure, I now consider these programs in the context of the larger infrastructures of the cities where they were located.

Infrastructural Normativities

Work started by Susan Leigh Star in the 1990s has led to an ecological understanding of infrastructure as something more than the materials and structures that other things run on (Star & Ruhleder, 1996). Her work revealed the invisible work, interstices, and precarity of infrastructure, and she and others have since re-visioned infrastructure as a set of practices and relations that structure and enact our world. No longer a simple backdrop, Simone (2015) for example, explains the ways infrastructure produces people and lives as it provides specific possibilities for acting and interacting, and with this comes “specific trajectories of impact” (p.375). This force and effect of infrastructure organizes people’s lives in particular ways (Berlant, 2016; Simone, 2015), determining “who can circulate easily and who should stay put” (Rodgers & O’Neill, 2012, p. 402). This force is also placemaking in its effects as it works to shapes spaces that emplace people and materials into particular locations (Langstrup, 2013). Through infrastructural positioning, people figure out what they think about themselves, what they think they can do and where they belong (Duff, 2012; Simone, 2015). Within infrastructure normativities are constituted that enable (or constrain) particular forms of sociality and life to flourish. These normativities are not stable or preestablished norms but rather the fluid, emergent values enacted through the relations of infrastructure, which then materially guide actors in responsive actions towards what matters most. In this study, powerful normativities present within the infrastructures of formal care and the broader urban environment of the people living with dementia and their families seemed to limit their navigation of the world. These normativities worked through infrastructure to sort people living with dementia to a particular type of social space. Frictions were often seen between the multiple logics of the larger community and people living with dementia and their families, and these frictions also affected the day programs' relations with the larger community. Interestingly though, while the programs themselves were often posed as a sort of solution for social inclusion, they often found themselves dealing with the forces of infrastructure and related effects of social exclusion. The friction points for both families and day programs that seemed most obvious were the public spaces, and this made for incredibly small worlds that people living with dementia, their families and program staff could access. Evident in these points of friction were "the obligations and reciprocities" (Bister et al., 2016, p. 188) produced between the day program practices and those of the public spaces. To talk of these varied, ongoing, and specific negotiations in a homogenous way is misleading however, as the negotiations were specific for each participant and setting, yet connection and containment seemed to be commonly competing values. This resulted in conflicts in how to connect and at the same time contain the person living with dementia in relation to their broader world. As I will show in the following sections, the day programs worked out these conflicting values in different ways with different effects.

Cosmopolitics

Stengers (2005) uses cosmopolitics to account for the contingent, specific, and material nature of politics by directing our attention to the effects of practices coming into presence with each other. From this ecological stance, cosmopolitics is not just a matter of different people or things coming together under a singular logic, but rather attention is directed to negotiations of multiple “ways of being human" (Bister et al., , 2016; Farias & Blok, 2016, p. 9). Cosmopolitics is a way to think about how people come to live together and the types of relations that can be negotiated (Stengers, 2005). Such negotiations are rarely made by consensus, but instead, relation-building occurs in a partial and uncertain way – with the terms of relation-building themselves always at stake (Bister et al., 2016). Describing two instances of friction between a day program and the broader community shows a range of shifting and unsettled normativities, where valuing of containment and connection were enacted while, at the same time, being continually negotiated. Using cosmopolitics as a way to surface the community infrastructure in which day programs are embedded (Star, 1999), these examples show the different goods that are worked for through day program practices and their effects. In both of the following stories, each program finds itself in relation to the broader community and within the space of this relation is obligated towards its own practices (Stengers, 2005) of routine, safety and social participation, while negotiating these values in relation to broader community demands for predictable behaviour and independence. Threaded through these stories are boundaries that show shifting normativities – what can and cannot be accommodated?

In and Out of Community (i): Partial Containment

> I arrive at Program A to find the parking lot full and the streets full of cars – I note a sign that tells me that overload parking is available at a nearby church. I find parking a few blocks away and walk to the seniors’ center. It is apparently the day for the "Older, Bolder, Better" Seniors Fair. There is a large van parked outside the entrance with a sign saying it is a mobile bookstore. As I enter, I see it is packed with people, and as I walk down the hall towards the day program entrance, I see numerous tables with raffles,

prizes, and pamphlets everywhere. I notice residential, private home care, legal, and wellness companies make up the majority of the exhibitors.

I come down to the day program and enter the room to see the group at their tables in their usual discussion activity for this time of day. I sit at table 3 where Jan is sitting and hear the discussion is about tarantulas as pets (I look at the whiteboard and see Unusual Pets is the activity and say out loud that every time I have come to the program, I have learned about a new insect). There is one staff Joan sitting at the table, and she has the iPad but is busy typing into it; she explains to me, "we are having problems with Wi-Fi ... it's slow because of all the people upstairs." While we wait for her to find the webpage, I ask if anyone saw the bookstore on wheels at the front when they came in today. The room is noisy today. The radio is on as usual in the background, and there is a stomping sound coming from overhead which one of the staff explains is from the line dancing going on. Every so often, a voice comes on over the PA system announcing what must be upcoming sessions for the fair: "7 tips for wills session starting in 2 minutes" or "Don’t forget to bid on the silent auction items in room 3." At one-point Fern a woman sitting next to me, says irritably, “Oh, just be quiet up there!... I can hardly hear anything!” I notice that there are five staff here today (one more than is typical) and ask about this number – one of the staff tells me that it is because of the fair – they don’t want to lose track of anyone in the hallway during arrival or departure time so need the extra staff to walk with the people down the hallway. They also need someone to go and get the lunch from as the kitchen is too busy serving lunch for the fair. (Fieldnotes, June 6, 2019)

Here, as discussed in previous chapters, the day program exists in a bounded form, and much work of the program practices is centred on this work of maintaining an inside and outside.

On a day like this one, the divide seems striking and ironic to me. Jan, for example, has come to the program in an effort to ‘join’ into the community, yet he sits sequestered in the basement below an event celebrating his community’s cohort of ‘older’ people. Considering the competing values at stake here through these infrastructural relations, Star (1990) would ask, “Cui bono?” or who benefits? (p. 43). This question is not designed to situate blame but to consider the relational effects of infrastructural arrangements that, while designed to include some, also always exclude others (Timmermans, 2015). The day program works to create a community of connections between the people who attend the program while separating them from the perhaps messier, less structured interactions of the senior center. The practices of separation are placemaking in their effects, establishing belonging in one place and not the other. On a day like today, those belonging to the defined space of the day program are excluded from the activities of the fair upstairs, even while those activities seep into program space and routines – Wi-Fi is compromised, more staff are required. The containment of the program in the basement of the seniors’ centre allows for a defined space for the program, one structured through lease agreements, building codes, and health system regulations. This separation of space also requires the staff to choose how to interact with the seniors’ centre, and today specifically, the fair. They can join in or keep things as usual. The safe environment version of the program seems to take priority over a version valuing social participation as the risks of “losing someone” in the crowds seem too great. The manager also tells me that this insulated private nature of the program is appreciated by some members who now feel different in their negotiations with the world due to their conditions of dementia or Parkinson’s disease. “They are not who they used to be” the manager tells me.

But there is more going on here than can be captured in a vocabulary of 'containment.' The day program attempts to go on as usual, but of course, the boundaries of the program are permeable, and the partial connections achieved are not entirely welcome - noise seeps in, meals change, and practices adjust. Extra staff are brought in to ensure things can run smoothly given what is seen as the perceived obstacle of the seniors' fair. Here we can see the normativities as enacted in program practices. That is, rather than preset from the outside (this is good, and this is bad) they emerge in practice as the staff strive towards doing good care (Pols, 2015). So good care is not something preset from the beginning, instead there are multiple goods that could be accomplished. On a day like this one, with the practices of the seniors' centre and the day program coming together, there are multiple goods possible: inclusion, entertainment, predictability, and safety. The staff take action in their practices that show which goods are to be strived for, tinkered with, and evaluated – and which bads are to be avoided (Pols, 2015). The valuing of these goods is done in and through the practices of the day program - the schedule, the work assignment checklists, the room, the staffing ratio policies, and more - in negotiation with the practices upstairs, mediating noise, busy hallways and kitchens. The effect is the valuing of practices of routine and predictability, and this has specific effects. While for some, this effect of protection and predictability works to arrange what Moser and Law (1999) describe as good passages, but for Jan, it is less clear. As described in Chapter 7, good passages reflect the ease of movement between material specificities when possibilities enacted by specific materialities and the relations among these are carefully attended to. For Jan, who seeks community, the space of his belonging to a community is narrowed by the program. How the program is being done and the valuing enacted in this practice work in some ways to constrain him. It is important, however, to recognize that these cosmopolitics, in the sense of how relations are distributed, are not fixed and as time goes on and other shifts happen, the effects change. Later in the study, the program appears to offer Jan a safe extension to an enclosed space that no longer seems so constraining – the specificities have changed. This emerges as Jan's world gradually shrinks in his home setting where the navigation of his neighbourhood and the common spaces of his building seem to enact 'bad passages,' insofar as expectations of a normative independence are enforced, reducing his 'degrees of freedom' (Bister et al., 2016). By the end of the study, Jan's wife Louise tells me that for Jan, the day program has become one of few public settings "where it is ok" to have dementia. At that point, this contained space of predictable routine offers a sort of good passage, one that facilitates both Jan's connection and containment in a world outside his apartment.

In and Out of Community (ii): Partial Connections

Unlike Program A, Program B does an outing every few months. These outings take place in the community and involve visits to common landmarks, cultural and seasonal events. Of note, the money used for these outings is not from the health system's funding but instead comes from the program fundraising through sales of crafts, baking, and plants throughout the year. The staff coordinate two days for each outing to include as many people as possible. There is much to plan for as the outings are a step away from the familiar routine for both staff and clients. I arrive at Program B one morning in the fall in time for the monthly activity planning meeting.

> The program staff sit around a long table drinking coffee and discussing upcoming special events at the program. On the agenda is the plan for a Christmas Shopping outing to the shopping mall that will happen in early December. The recreation director explains to me this is a traditional outing the program does that relates to typical Christmas

preparation routines and offers an opportunity for some people at the program to do some shopping for their family. Staff discuss logistics of the planning: they will have lunch at a restaurant in the mall (one of the staff is family member of the owner, so they have got a deal set up where they can preorder meals). The staff discuss the cost and decide that the program can cover the meal, and drinks and tip should be covered if each person bring $5. There is some discussion of relocating people to different days that week who won't go on the outing.

Staff M: Might be only 4 out of 10 from the Tuesday group and Tom is a crapshoot.

Staff K: Yeah and we might have issues with Hank pocketing things and then. Katherine… watch her she might scream; she misses out on everything maybe she'll recognize being in a store?

Staff G: And Marie is another one that might be pocketing stuff.

Staff M: I can talk to Darren and see what she is like in stores.

They continue listing potential patients that might not be able to go or the adaptions they might need. I can hear through the discussion that this outing is a big change for many of the people in med rehab and the Oak Room, and staff have concerns about how they will handle the anxiety.

Staff M: Some of them will be so afraid they will be hanging on to us.

Staff J: No not Mike … too traumatic for him.

Staff K: If we prepare Bob, he might be ok.

Staff V: Well, we will know when we go to family and tell them what we are doing they may say 'that's a terrible idea!'

> Staff K: Do we have any men working those days? I'm worried about how we will handle the toileting.
>
> The discussion then turns to the fact that there is no male staff available and ways they might use the gender-neutral/family bathrooms, and how easy it is to find them in the mall. Staff express concern over their uncertainty about if some of their clients will be able to wait for the time needed to get to those bathrooms and the alternative fear of "losing them in the men's bathroom." (Fieldnotes, October 30, 2019)

The staff's planning reveals some of the perceived risks of leaving the space of the program, anticipated breaches in behaviour and norms and plans for their containment - people might get anxious, and they might shoplift, become incontinent or get lost. Despite these risks, the staff justify these outings as important ways for clients to participate in and connect to their community. In this meeting who people are is being re-defined in relation to the new space of the mall and restaurant. Behaviours and preferences that are taken for granted at the program become potentially more problematic within the public space. With this in mind, the program staff work to simultaneously plan for connection to the community, while building in structure as a form of containment for the clients to be able to be in these unfamiliar settings. Their planning enacts connection - they will preorder meals, preplan bathroom maps, find a male volunteer. Also revealed in the frictions of this conversation is the difficulty of fitting into the infrastructure of the mall, reminding us, as Star (1999) observes, "one person's infrastructure is another's topic or difficulty" (p. 380). The things like transportation, the mall, the restaurant are all infrastructural elements taken for granted as accessible spaces of the 'community,' yet for the people at the program, these mundane practices are hurdles that need to be negotiated. For some, it seems these spaces are non-negotiable, and they will be left behind.

The actual outing is a whirlwind mall tour of three hours that feels like eight. We stroll the mall in small groups. Peg and Marie try on hats, sip coffee, talk to strangers and have lunch. Complications occur with transportation, mall bathrooms, restaurants and buses that struggle to accommodate people, wheelchairs, and walkers. Staff tell me these hiccups are not unusual, “it is always an adventure!” The next day I hear the staff at the front desk discussing the event, who they think liked it and who did not. They identify an issue with not everyone bringing the money to cover the tip. They discuss how tired some of the people were by the time they got back to the program. The recreation director tells them, “Katherine’s husband called this morning and said never take her on another field trip she was so out of sorts last night that he said he got no sleep.” The staff discuss if it is worth the trouble, “maybe we should just put them in a bus and drive around town for sightseeing rather than getting them out?....maybe it is too much?”

Using cosmopolitics to consider what is going on here reveals the day program practices coming into relation with the practices of the larger public context, but connections are partial and precarious. The day program is obligated to its own practices of social engagement and connecting people with their larger community. Public spaces have expectations of independence, mobility, and accepted ways of socializing with strangers, which requires different practices of containment as the day program staff work to support the people living with dementia to conform to the norms of expected activity. It is not just the logics of the program that structures the interactions between people living with dementia and their ecology, instead the lives of the program are lived within a larger urban assemblage (Bister et al., 2016). This mall, restaurant, bathrooms, and buses are more than simple infrastructural backdrops for life but rather key actors that come into relation with the world making-arrangements for the people at the program and the staff.

What Goods?

These stories show a valuing, and an arranging for, the accomplishment of a range of possible goods and the avoidance of certain bads, or what could be described as a valuing-in-practice. That is, day program practices show, and actively enact, what is understood to be of value and sought after, and what should be avoided in efforts to figure out how to be in 'community' – a normative valuation or valuing that opens ideas of 'good' and 'bad' beyond specific 'moral' concerns (Pols, 2015). Both stories also show the work involved to, however precariously, manage connection and containment necessitated in practices of making relations to a broader community. This is not easy work, and there are different goods being sought after and bads to be avoided, as the programs come into relation with their ecology. Program A takes a containment approach to spatially separate the program from the seniors' fair. Contained local connection within a safe, predictable routine is sought by Program A, and for Jan this means he will sit at table #3 with his tablemates and have conversations about spiders, a good lunch, and some time for games. A day that could seem familiar to him from other days at the program. He will then go home, and despite perhaps not leaving his apartment building again, Louise will know he has been 'out to the community' this week. Program B navigates the demands of public space in a different way, bringing people together in a contained space away from home as well as finding ways to get 'outside' in a different but still partial connection to the community. The spaces of the outside are not easy to navigate, there are different practices of interaction and materials required. Staff and clients of the program work together between the practices of the program and the public spaces of the mall and restaurant to make the outing as smooth as possible. Marie and Peg will have similar days to Jan at their program but occasionally will go out to new places, see new people and be seen, all while being grounded by familiar relations and eased through processes that will make this outing as predictable and safe as possible. They will return home, and possibly (if communications connect), their family will know they went Christmas shopping and out for lunch. The outings have other effects at Program B as money is required to fund these outings, and this means more connection (and work) by the program in making of goods to sell, coordinating family teas and raffles. Peg and Marie’s families will hear of the bake, plant, and craft sales. Peg’s son Rick will feel obligated to buy a cake and raffle tickets. Peg’s daughter will attend a fundraising tea. Staff will argue about plans for outings, and adventures will continue to happen.

This analysis works to show the cosmopolitics of the broader ecology of practices that day programs exist within. Here in this partial, contingent coming together of different practices, ongoing negotiations and obligations are enacted, resulting in different goods and bads being valued in practice. This is not a comparison of the goodness of practices but rather of the multiple goods and bads that are enacted in practices. These are not goods that are fixed, based solely on day program missions or mandates or intentions of staff. These goods are political effects of how the normativities present within practices coming together are being worked out. Here goods are partial, uncertain, and specific. Mol (2010) suggests if we want to find ways for good care to happen, we need to pay attention to these specific places of friction and how competing values intervene with each other. These values don’t just come within the walls of the program but include those of the larger infrastructure as well. From this stance, we can better understand the tensions between the values at stake and tinker (Mol, 2010) towards the goods that matter most.

Situating the Findings and Their Limits

In health and social care policy, day programs are positioned as a contained version of the community operating as a satellite of the health care system. Within this positioning, their situatedness within the larger urban assemblages is often not attended to. As a result, the limitations and possibilities of day programs and their role in working out a life with dementia in the community that is bearable are neglected. It is this space of neglect between home, day program, and the community that I would like to open up as a matter of care (Puig de la Bellacasa, 2011). In this writing, or specifically in my re-scriptions of day program practices and their relations with people living with dementia, I have worked to draw attention to and be concerned about the limits defined within/between these spaces and their effects (Lopez et al., , 2010). It is this interference, rather than solutions, that an ethnography like this one can offer. Through de-scription and re-scription of these spaces, relations have been revealed and concepts denaturalized - this is the political potential of ethnographic work (Harbers, 2005; Law 2009b; Winthereik & Verran, 2012). My analysis offers a proximal view, one that is attentive to the partialness and precarity of the local relations under study. More time in the field, different sites, different participants, a more experienced researcher would change the specifics of these stories but not the socio-materiality of the relations revealed through this attention to the proximal and the precarious. In other words, different people and different settings would still exist in socio-material arrangements that are world-making. This unravelling of day programs for people living with dementia is an intervention of sorts working to unbracket the practicalities and politics involved and show how practices of care in the community have material effects. Returning to Whitehead's (1920) ideas of simple location discussed in Chapter 5 which reminds us that how we conceive of space and its discreteness has effects on what we can come to know about it. From a simple location perspective, "each bit of matter is individually independent… fully describable, apart from any reference to any other portion of matter" (Santos & Sia, 2007 p. 91). Considering day programs as 'simple location' belies the contested nature of the space and makes invisible the cosmopolitics - the interdependencies and their effects on subject positions, space, and agency. These effects work to enact both people living with dementia and their families, the spaces they can exist in and what they can do and be. These findings have implications for nursing, policy and health system planners and future research.

Implications for Practice and Education

Day programs are staffed with interdisciplinary teams, including practitioners from recreational therapy, rehabilitation medicine, nursing, social work, and personal care workers. These teams, their administrators, policy makers and the general public have various ideas of what people living with dementia and their families need and what day programs might be for. Alongside these ideas, day programs as a health technology are historically loaded with scripts of ideas about people living with dementia, home, and community. The stories from this study demonstrate the effects of these ideas and the ways in which they materialize, become coordinated, clash or are held apart in practices. The goal would not be to create a single version of the day program but rather consider what different goodnesses are we are trying to accomplish and if the work taking place to maintain certain organizings upholds this. For example, if program planners and staff agree that day programs are meant to provide a place of belonging for the social engagement of people living with dementia, the practices of allocating this care need to consider the effects of distributing a place-less universal ‘spot.’ Trade-offs are made between social engagement and the even distribution of day program service days, and the effects of the trade-off requires recognition and attention to about what matters most.

The findings of the study implicate those on the margins of day programs as well, such as nurses in home care who act as gatekeepers for the programs, determining eligibility, and allocating the resource. Understanding the day program multiple complicates it beyond a placeless resource (Poland et al., 2005), or a ‘spot’ be simply filled, allocated and never monitored. Using a ‘plug and play’ approach to installing health technologies, that is, one where a resource is added to an arrangement without consideration or evaluation of the configuring effects has the potential for ‘bad passages’ (Moser & Law, 1999), where arrangements don’t support people's way through the world. Solutions like day programs are not innocent and inherently good; instead, they exist in relation and have effects, and these effects change over time and within different arrangements. These configurations are local, specific, and temporal. As such, the scope and frequency of evaluation practices that account for potential effects may need to account for this fluidity and the variability of configurations and effects that might be made possible. Student practitioners should be made sensitive to the material nature of care and support resources like day programs, how effects travel, their precarity and what this might mean to our assessment and evaluation of them.

Implications for Policy and Health System Planners

Barry (2001) reminds us that “politics does not just circulate just through the flow of ideologies or rationalities of government but through diagrams, instruments and practices” (p. 151). A question for health system planning is what and who day programs are actually for? This question, of course, implicates the larger moral questions of cosmopolitics to ask what is at stake and what we are willing to negotiate in order to live together? If day programs are indeed a necessary container for people living with dementia living in the community, a more intentional connection to the broader infrastructures they articulate with is needed. Moving beyond program walls to evaluate effects as they travel may enhance the goodnesses of care that can be offered and bring to light the “space in between” (Star, 1995, p. 31). This broadened scope might help account for the challenges that staff at day programs consistently deal with in their attempts to provide good care within truncated networks. Using Callon's (2008) ideas of habilitation and prothesis (as discussed in Chapter 7), it seems that day programs could have the ability to act as a habilitative resource, a sociotechnical arrangement that works to bridge access to the community for people living with dementia. This is not the same as being a prosthetic-type extension to the community. Habilitation requires recognizing the person's network of attachments and working to maintain and repair links, and perhaps most importantly, working at rearranging the world to accommodate the assumed interactive agency of people living with dementia and their families.

Ideas of social health and rights for the inclusion of people living with dementia are fairly new (Dröes et al., 2017; Vernooij-Dassen & Jeon, 2016), and how these might be enacted in everyday life seems yet to be determined. There has been promising recent work on lived-place and neighbourhood experiences of people living with dementia and their families (Keady, 2012; Li, Keady & Ward, 2021; Ward et al., 2018), as well as work on dementia and social exclusion (Biggs et al., 2019; Odzakovic et al., 2021; Walsh et al., 2020). That said, it might be some time before efforts like the dementia-friendly community initiatives shift from considering the environment in a way that artificially divides the social from the material (Ward et al., 2018) to understanding social inclusion as a precarious socio-material accomplishment of community infrastructure and technologies. This research could extend ideas of citizenship within the dementia-friendly community initiative from one of the individual rights to one of relational citizenship. This type of citizenship recognizes that social spaces are shaped through interactions and that differences are negotiated and accommodated within social and material relationships (Pols, 2016).

Implications for Future Research

The design of this study was an intentional attempt to take practices (and the social) seriously, something often overlooked or smoothed out within nursing research (Ceci et al.,, 2017; Purkis & Ceci, 2016). The study's findings point to a variety of effects of day programs and open up potential areas for future research to conceptualize day program services as contested spaces within care infrastructure. In regard to community care research these findings also support the value of a practice perspective for considering the effects of interventions in our evaluation of health care services. As Mol (2006) has argued, separating interventions from the daily lives in which they are enacted does little to improve care and the ways we might work to make it better. Day program and other forms of care in the community research could benefit from more attention to the particularity of what works and how, with the hope that good ideas can travel (Mol, 2006). Future research based on this study's findings might also extend both day program and dementia-friendly community initiatives to consider the material, recursive nature of social life and the inherent infrastructural complications that are world-making for people living with dementia (Harvey et al.,, 2017). This type of work would echo Pols (2016) call for more empirical work attending to the materials and values that hold social spaces together for people to live with one another, especially those requiring new or different forms of interacting like people living with dementia.

Staying with the Trouble

Dementia is not a new trouble for society (Andrews, 2017), but it seems to tell us a lot about who we are. Perhaps it is as Gronemeyer (2017) explains, that we seem to "have a society that no longer knows how to proceed" in regard to dementia (p. 26). This lack of direction sounds worse than it is, as progress narratives are often overhyped. Though it may be time we acknowledge in our care and research practices the limits of care within the rather fragmented infrastructures in which people living with dementia live. Donna Haraway (2016) calls us to think about how we might better live in a troubling world. She asks that we consider ways to commit to making less stark calls for drastic changes or just giving up, and instead ‘stay with the trouble.’ That is look for changes and efforts that are more partial and modest in how we might get on together. ‘Staying with the trouble’ of care in the community for people living with dementia requires thinking differently about care, programs, home, and community. It means we need to rethink what problems we are actually addressing and what our solutions might be doing. It asks us to acknowledge the gaps and margins of care infrastructure and the effects of lives lived within these spaces being more the rule than the exception. Solutions like day programs are for now both limited and enabled by these infrastructures and staying with this trouble means considering how they offer a space of new potential collaborations from which to emerge differently (Haraway, 2016; Tsing, 2015). This requires that we attend to the goods that come within these small spaces of belonging and moments of recognition. Equally important is thinking of the “spaces between” (Star, 1995, p.32) within the gaps, voids, and margins of care and asking how it could be otherwise. As all the participants in this study showed me repeatedly, this requires stepping away from pure solutions and looking for possibilities that might assemble from the less than perfect, fragile, local relations where we find ourselves.

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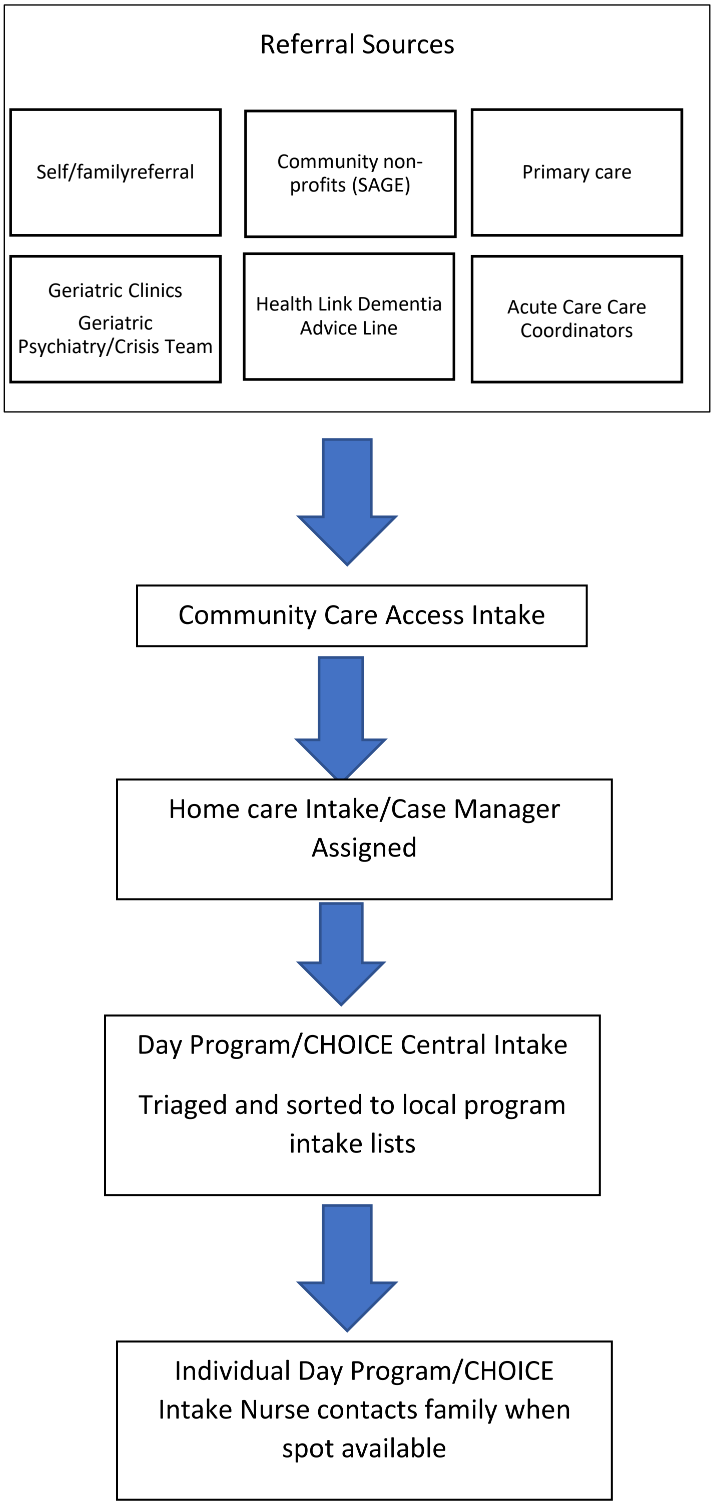
Appendix A

Referral Pathway for People with Dementia Accessing Day Programs in Edmonton Zone



Appendix B

Recruitment Poster/Flyer

Understanding How Day Programs Work as Care in the Community for People with Dementia and their Families

Are you interested in being part of a study about how day programs work for families and people with dementia living at home?

We are looking for:

- **People with a family member 65 years or older with dementia who is currently attending or will soon start an Adult Day Program at the Sturgeon Hospital or the Eldercare DayBreak Program.**

What is required of you in the study:

- **This study involves a family interview and ongoing observation of everyday family life and at the day program for short periods of time 2-4 times a month for up to 9 months.**

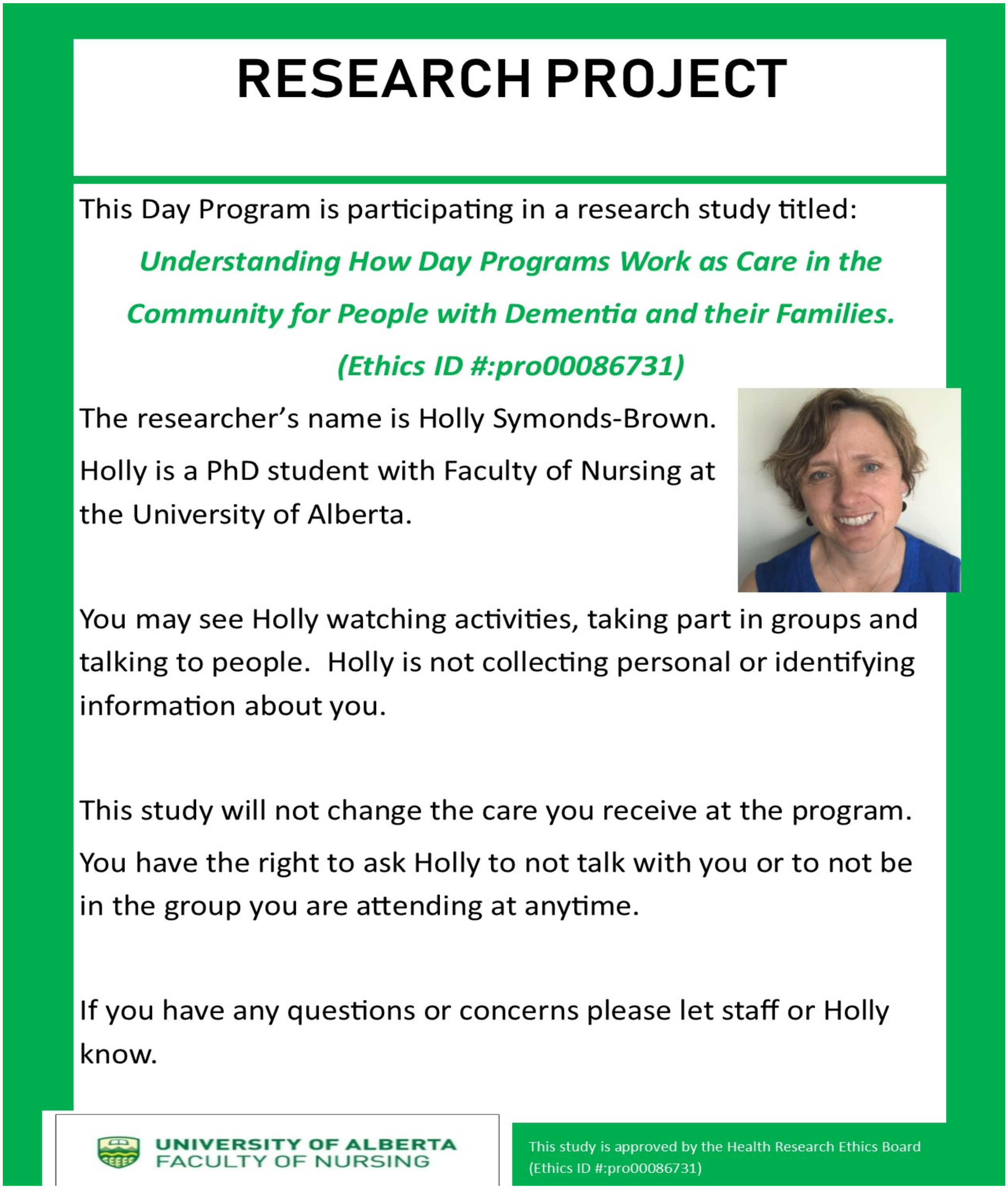
For more information please contact :
Holly Symonds-Brown at 780-492-8911 or hsymonds@ualberta.ca

UNIVERSITY OF ALBERTA
FACULTY OF NURSING

This study has been approved by
Health Research Ethics Board
U of A Ethics ID # pro00086731

Appendix C

Passive Consent Poster for use in Day Program Milieu



RESEARCH PROJECT

This Day Program is participating in a research study titled:

Understanding How Day Programs Work as Care in the Community for People with Dementia and their Families.

(Ethics ID #:pro00086731)

The researcher's name is Holly Symonds-Brown.

Holly is a PhD student with Faculty of Nursing at the University of Alberta.

You may see Holly watching activities, taking part in groups and talking to people. Holly is not collecting personal or identifying information about you.

This study will not change the care you receive at the program.

You have the right to ask Holly to not talk with you or to not be in the group you are attending at anytime.

If you have any questions or concerns please let staff or Holly know.

UNIVERSITY OF ALBERTA
FACULTY OF NURSING

This study is approved by the Health Research Ethics Board (Ethics ID #:pro00086731)

Appendix D

Opt-out Letter for Other Day program Participants

Dear Day Program Member and Family,
My name is Holly Symonds-Brown, and I am a PhD student with the Faculty of Nursing at the University of Alberta. I writing to let you know that I am currently doing a research study titled: Understanding How Day Programs Work as Care in the Community for People with Dementia and their Families. (Approved by U of A Health Research Ethics Board ID #: pro0008673).
*You may have already received a letter, but I have added information to ensure it is easy to understand.

WHAT IS THIS RESEARCH STUDY ABOUT?

I am doing this research study to understand more about how day programs work for people with dementia and their families. I hope this will help us learn more about the ways day programs are helpful to people with dementia and their families as well as ways they may be improved. To do this I am following a few people, who have agreed to be in the study, at home and during their time at the day program.

WHY AM I RECEIVING THIS LETTER?

You are receiving this letter because one of my study participants attends the same day program on the same day that you or your family member attends. This means I may sometimes be visiting the day program and because I am a researcher, I need to inform you about my presence at the program and what I will be doing there.

WHAT WILL THE RESEARCHER BE DOING AT THE DAY PROGRAM?

In order to understand day programs, I will be present at the day program a few times a month observing what goes on there (type of activities or interactions that take place between my study participants, other people at the program, staff and the space/materials of the program).

I will observe and take part in regular program activities and observe and/or join in on naturally occurring conversations with people at the day program a few hours a month for up to 9 months. I will act similar to a volunteer at the program.

WHAT INFORMATION WILL RESEARCHER BE COLLECTING?

Each day after being at the program, I will write notes describing the types of things I observed, related to my study participant, which could include activities that you as a group member are a part of (such as games or crafts) or general topics of conversation that I heard or participated in. No identifying information of day program clients (such as your name or your specific biographic details) will be included in my notes.

I will have no access to your personal information (other than your first name) or health record.

ARE THERE ANY RISKS TO ME?

This study has no risk to you other than possible confusion related to a new person being at the program.

In order to decrease this confusion I will be sure to introduce myself to the group and my role as a researcher each time I attend. I will have a nametag on identifying me as a researcher. There is also a poster up at the day program with my picture on it reminding people that I am a researcher.

If at anytime my presence seems to upset someone, I will leave the activity.

WHAT ARE MY OPTIONS FOR BEING INVOLVED?

You can either OPT IN or OPT-OUT of being included in the observations and interactions at the day program.

If you "OPT IN" it means:

- I may interact with you (greet you, engage in conversations) and possibly include observations of activities you are a part of at the day program in my notes.
- You will still have the right to ask me not to talk with you or be in the group/activity you are attending at any time (for example, if you are tired, not interested in new people or prefer being left alone).

If you "OPT-OUT" it means:

- I will not talk to you while I am at the program or include you in any observation notes I make of the program at any time.

HOW WILL THIS AFFECT MY CARE AT THE PROGRAM?

The presence of the researcher will not change the care you receive at the program.

Whether you OPT IN or OUT will not change the care you receive at the program.

HOW DO I OPT IN OR OUT?

To "OPT OUT" : please complete the last page of this form and bring it back to the program by ___________.

To "OPT -IN" : Do nothing. If I do not receive anything from you or a family member by __________I will assume it is ok for me to be present and to talk to you.

If later on you decide that you prefer to OPT OUT, you can always notify me (780-248-1692) or the manager at Eldercare: Krista Mulberry: 780-434-4747 ext. 106

Appendix E

Key Informant Email Recruitment Script

Subject Line: Understanding How Day Programs work for People with Dementia and their Families Research Study

Hello,

I am a PhD Student with the Faculty of Nursing at the University of Alberta. I am conducting a research study titled: Understanding How Day Programs Work as Care in The Community for People with Dementia and Their Families. This study has been approved by the Health Research Ethics Board (U of A Ethics ID# pro00086731).I am recruiting people who have professional experience related to coordinating care in the community for people with dementia and their families. I have received your name as a possible participant. Involvement in the study would include an interview that would last about 60 minutes and could be scheduled at a time and location of your choice. If you would like to know more about this study please see the attached information sheet and feel free to contact me by email.

Thank-you,
Holly Symonds-Brown
University of Alberta, Faculty of Nursing

Appendix F

Key Informant Information and Consent

PARTICIPANT CONSENT FORM

Title of Study: Understanding How Day Programs work as Care in The Community for People with Dementia and their Families. (U of A Ethics ID #: Pro00086731)

Principal Investigator: Dr. Christine Ceci 780-492-8911

Co-investigators: Holly Symonds-Brown MSN RN (graduate student) & Dr. Wendy Duggleby 780-492-6764

Why am I being asked to take part in this research study?
You are being asked to be in this study because you are considered to have expert knowledge related to the coordination of formal care of people with dementia living at home.

This study is focused on the ways in which day programs work to provide care for people with dementia and their families living at home.

Before you decide about being in the study, a researcher will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer.

You will be given a copy of this information sheet for your records.

What is the reason for doing the study?
This study is interested in finding out more about the ways in which day programs work for people with dementia and their families living at home. It is part of the work of one of the researchers (Holly Symonds-Brown) who is a graduate student.

What will I be asked to do?
You will be asked to participate in an interview with the researcher.

Interview questions will focus on how of day programs are used by the formal health system for people with dementia and their families.

This interview will take up to one hour and will be scheduled at a time and place that is convenient to you. Interviews will be audiotaped and transcribed afterwards to assist with the analysis.

What are the risks and discomforts?
There is minimal risk involved with your participation in this study.

Possible discomfort may include feeling anxious in discussing your views on day programs, strain in work relationships or be concerned about job security because of participation in the study.

It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?
You may feel reward in contributing to research and sharing your expertise on people with dementia and their families, but it is not likely you will get any direct benefit from being in this research study.

Do I have to take part in the study?
Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect your employment.

During the interview you do not have to answer any questions of the researcher that you are not comfortable with and you can request that the audio recording be turned off at any time or that your responses to the interview be removed at any time during the interview.

During the study, if there are parts of the interview that you later decide you do not want to be included in the study, you can notify the researcher and they will exclude this information.

If you decide that you do not want to participate any further, you can withdraw up to 30 days after the interview by phoning or emailing the Principal Investigator and have all information collected from you during your participation removed from the study.

Will my information be kept private?
All information in the interview will be kept confidential. The interview will be recorded and transcribed into a text document. We will do everything we can to ensure this document is kept private including storing it on a password protected encrypted computer.

Unless you direct the researcher otherwise, your name will not be attached to any data collected and a pseudonym will be used instead. Identifying information at to your specific place of work will not be attached but your role may be included (e.g. manager or coordinator).

Sometimes, by law, we may have to release your information with your name, so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

After the study is done, we will still need to securely store data that was collected as part of the study. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study.

What if I have questions?

If you have any questions about the research now or later, please contact Holly Symonds-Brown at hsymonds@ualberta.ca or one of her supervisors:
Dr. Christine Ceci 780-492-8911 & Dr. Wendy Duggleby 780-492-6764

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT

Title of Study: *Understanding How Day Programs work as Care in The Community for People with Dementia and their Families*

Principal Investigator(s): Dr. Christine Ceci **Phone Number(s):** 780-492-8911

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your position at the day program.	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records?	☐	☐

Who explained this study to you?
____

I agree to take part in this study:

Signature of Research Participant
____

(Printed Name) ____

Date:______________________________

Signature of Witness
____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix G

Observation Guide

Participant observation will be used. All aspects of observation are subject to ongoing negotiation, and participants will be able to end or refuse a visit or observation of an activity at any time. The observer will be sensitive of perceived issues of intrusion or discomfort on the part of all participants and clarify consent to observe if participants seem uncomfortable. The level of participation by observer in activities will depend on setting and ongoing permission by gatekeepers, people with dementia and their families. Participants can identify activities that they would like to keep private from observation at the start of the study or can request this at any time during the study.

These general questions that will guide field observations:

- Who/what are involved with the practices (people and things)?
- How do they relate to one another?
- What are the things that matter in this practice?
- How do they matter?
- What are the associations?
- What are the problems?
- What are the solutions?
- What is the role of technologies and tools?
- What are the actors trying to accomplish in their everyday activities?
- How do actors account for what they are doing?

Appendix H

Key Informant Interview Guide

- Explain nature research project and review information sheet and consent form with participant
- Ask for permission to record interview and explain that information will be transcribed and anonymized.

Questions

Can you tell me about your role in connection to day programs for people with dementia and their families?

How do you see currently day program's fit within 'care in the community' for people with dementia and their families?

What do you perceive to be the benefits or challenges of day programs?

What other services or agencies does your role with people dementia and their families interact with?

How do these interactions or relationships happen? What makes them work well what gets in the way of them?

Is there anything I haven't asked that you think would be important to understanding how day programs work to deliver care in the community for people with dementia and their families?

Appendix I

Initial Family Meeting Interview Guide

- Explain nature research project and review information sheet and consent form with participant
- Ask for permission to record interview and explain that information will be transcribed and anonymized.

Questions

To begin, can you tell me about who is part of your family supports? Are there any other people or relatives that you consider important to supporting your day to day life?

Can you tell me about when and how your family member with dementia started using the day program?

How does the day program work for you as a family? How do you see it working for the person with dementia? What does a typical day look like when using the program and when not?

Are there any challenges of using the day program?

What other health or community services or people does your family use for support and care of the person with dementia? Do these services connect to the services you receive from the day program at all?

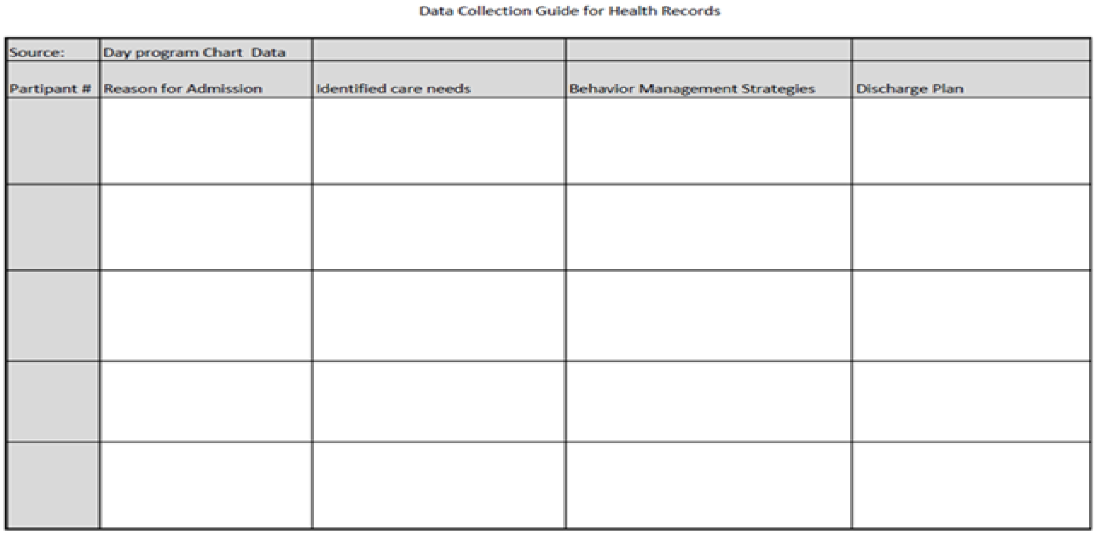
Is there anything I haven't asked that you think would be important to understanding how day programs work for your family and family member with dementia?

Appendix J

Data Collection Guide for Health Records

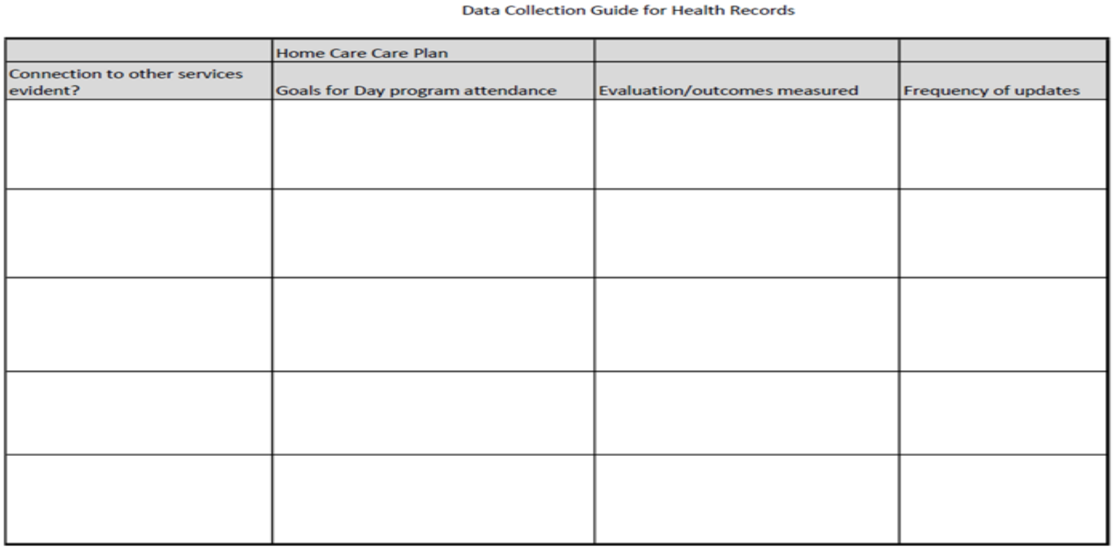
Data sources: Day Program based chart forms: admission, discharge form, behavior tracking and behavior management plan

Home Living day program care plan and communications between day program and case manager on Meditech (extracted by DIMR) and.



Data Collection Guide for Health Records

Source:	Day program Chart Data			
Partipant #	Reason for Admission	Identified care needs	Behavior Management Strategies	Discharge Plan



Data Collection Guide for Health Records

	Home Care Care Plan		
Connection to other services evident?	Goals for Day program attendance	Evaluation/outcomes measured	Frequency of updates

Appendix K

Participant with Dementia or Guardian Consent

PARTICIPANT CONSENT FORM

Title of Study: Understanding How Day Programs Work as Care in the Community for People with Dementia and their Families (U of A Ethics ID#:pro00086731)

Principal Investigator: Dr. Christine Ceci 780-492-8911

Co-investigators: Holly Symonds-Brown MSN RN (graduate student) & Dr. Wendy Duggleby 780-492-6764

Please note in reading this information and consent form as a guardian: “you” should be read as “you or your loved one”

Why am I being asked to take part in this research study?
You are being asked to be in this study because you are attending a day program.

This study is focused on the ways in which day programs work to provide care for people with dementia and their families living at home.

Before you decide about being in the study a researcher will go over this form with you.

You are encouraged to ask questions if you feel anything needs to be made clearer.

You will be given a copy of this information sheet for your records.

What is the reason for doing the study?
This study is interested in finding out more about the ways in which day programs work for people with dementia and their families.

This is part of the work of one of the researchers who is a graduate student (Holly Symonds-Brown).

What will I be asked to do?
You will be asked to allow the researcher to observe you and your family at home, during social activities, or other appointments and at the day program.

1) The study will begin with researcher meeting with you and your family to interview you about your experience with the day program. This interview will take about 60 minutes and will be audiotaped and transcribed. You can ask for

the audio recorder to be stopped at any time. All information in the interview will be kept confidential and names will not be attached to the data.

2) The study will then involve the researcher spending time with you and your family as you go about your normal activities at home and at the day program and other related health services. You are not required to do anything outside of your normal activities. The researcher will basically 'hang out' with you, have conversations, and watch activities. The visits will take place 2-4 times per month over a period of about 9 months, unless you stop using the day program sooner. The length of time for each visit at home will vary and will be based on your family's preferred time and place. Visits will be planned for 1-3 hours but may be shorter if at any time you prefer them to be finished sooner. Visits to the day program may last 1-8 hours.

Some of the following events would be the type of activities the researcher would like to be able to observe:
- morning preparation time for day program at home
- different time periods at the day program
- time spent after the day program at home
- days off the day program
- other home or community-based activities

While these are examples of activities the researcher is interested in, the decision of what activities are observed, where and when the observations take place is up to you
and your family and can be changed by you at any time during the study.

3) You will also be asked to allow the researcher to access health records related to your participation in the day program such as day program admission and discharge papers and day program related care plans that may be kept by the day program or home care. Information from these records will be used to understand the ways day programs use data about people with dementia and their families to plan care.

What are the risks and discomforts?
There is minimal risk involved with your participation in this study. Possible discomfort may include feeling upset or confused when talking about your experiences or feeling that your privacy is intruded on by an observer being in your home or during day to day activities.

If you are feeling upset tired or confused the researcher will stop observing/interviewing and staff or family assistance will be requested.

It is not possible to know all the risks that may happen in a study, but the researchers have taken steps to minimize any known risks to a study participant.

What are the benefits to me?

You may feel reward in contributing to research and through sharing your experiences with someone else, however you may not get any direct benefit from being in this research study.

Do I have to take part in the study?

Being in this study is your choice, as well as how long you decide to remain in the study.

If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the care or services that you are entitled to.

During observations and interviews you do not have to answer any questions from the researcher that you are not comfortable with. You can also decide what parts of daily life or locations in your home you would like to be observed in. If there are any parts of your daily life that you would like to keep private, you will be able to tell the researcher ahead of time or tell the researcher to leave at any point where you feel like not being observed.

At any point in the study if there are conversations or events that you later decide you do not want to be included in the study, you can notify the researcher and they will exclude this information.

If you decide that you do not want to participate any further, you will be given the choice to withdraw and have no further information collected or you can decide that all the information collected from you and your family will be destroyed and not used in the study.

Once the study is completed the researcher will be unable to remove your information.

Will my information be kept private?

During the study we will be collecting data about you through observation, interviews, and health record review. Your name will not be attached to the information and a pseudonym will be used instead.

We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher’s office or be published by the researchers. Information will be stored on a password protected computer.

Sometimes, by law, we may have to release your information with your name, so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.
If any abuse of you is observed at the day program the researcher is required by law to report it to the Protection of People in Care Office for further investigation.

If any abuse is witnessed in the home the researcher is required to report it to the appropriate agency for further investigation.

The investigator may need to look at your personal health records or at those kept by other health care providers that you may have seen in the past (i.e. home care nurse) that are related to your care at the day program. Any personal health information that we get from these records will be only what is needed for the study.

During research studies it is important that the data we get is correct. For this reason, your health data, including your name, may be looked at by people from:

University of Alberta and the Health Research Ethics Board

By signing this consent form you are saying it is okay for the researcher to collect, use and disclose information about you from your personal health records as described above.

After the study is done, we will still need to securely store your health data that was collected as part of the study. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study.

If you leave the study, we will not collect new health information about you, but we may need to keep the data that we have already collected.

What if I have questions?

If you have any questions about the research now or later, please contact Holly Symonds-Brown at hsymonds@ualberta.ca or one of her supervisors: Dr. Christine Ceci 780-497-8911 & Dr. Wendy Duggleby 780-492-6764

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT

Title of Study: Understanding How Day Programs work as Care in The Community for People with Dementia and their Families (U of A Ethics ID#:pro00086731)

Principal Investigator: Dr. Christine Ceci **Phone Number(s):** 780-492-8911

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your future medical care or without penalty	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records, including personally identifiable health information?	☐	☐

Who explained this study to you? ____

I agree to take part in this study Yes No

Signature ____

Printed Name____

For Guardians:
I agree to allow my family member __________________________ to take part in this study.
(Name of Family Member)

I have the legal authority to give this consent. Yes No
Signature of Guardian
____

(Printed Name)
____

Date: ______________________________

Signature of Witness
____

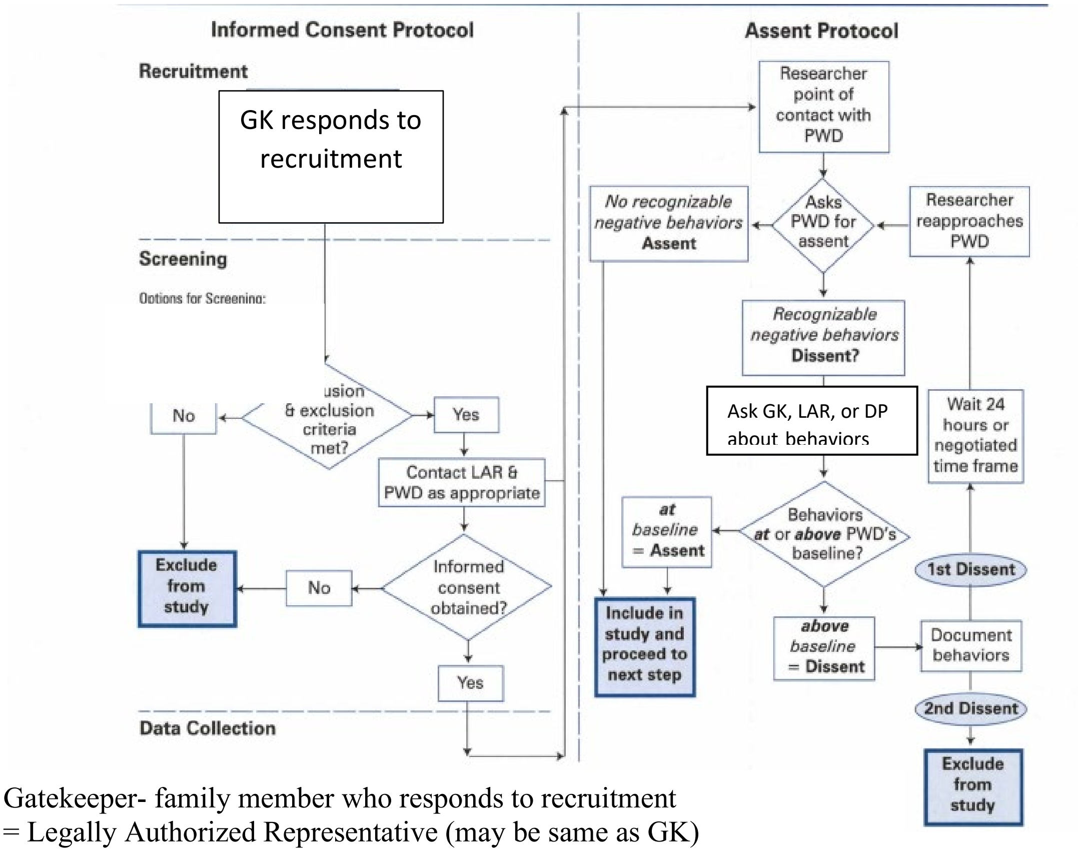
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.
Signature of Investigator or Designee _________________________________
Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix L

Procedure for Joint Consent -Assent

The protocol for joint consent/assent from Batchelor-Aselage et al, (2014) will be followed.
Assent information will be provided by either written or verbal means based on family and or staff's perception of the participant's comprehension of written materials. If this is not known written information will be provided first.
Indicators of Assent or Dissent
Assent will be assessed through both verbal and behavioral indicators. Assessment will be based on the individual's specific capacities for verbal language expression and baseline behavioral patterns as described by family members or staff at day program. Assent will be indicted by verbal expression or behaviors that indicate a willingness to go along with study procedures.
Dissent will be assessed in an ongoing basis and may be expressed by the person with dementia in either a verbal or behavioral manner. Indicators of dissent will be negative verbal expressions and or onset of negative behaviors above baseline. In the case of a person with dementia with a baseline of negative behaviors input from family and staff will be sought if indicators of dissent are suspected, the person will be approached again at a different time to confirm dissent.



GK= Gatekeeper- family member who responds to recruitment
LAR = Legally Authorized Representative (may be same as GK)
PWD = Participant with dementia
DP= Day program Staff

Batchelor-Aselage, M., Amella, E., Zapka, J., Mueller, M., & Beck, C. (2014). Research with Dementia Patients in the Nursing Home Setting: A Protocol for Informed Consent and Assent. *IRB: Ethics & Human Research, (2),* 14.

Appendix M

Verbal Assent Script for Participants with Dementia

Study Title: Understanding How Day Programs Work as Care in the Community for People with Dementia and Their Families (U of A Ethics ID#: pro00086731).

Principal Investigator(s):	Christine Ceci PhD	Phone Number: 780-492-8911
Co-investigators:	Wendy Duggleby PhD	Phone Number: 780-492-6764
	Holly Symonds-Brown (student)	

Hello Mr/Mrs._______. Introduce self by name and position as a PhD student with Faculty of Nursing at University of Alberta- ask if you can speak with them (have small talk for a few minutes to build rapport.)

I am conducting a study about day programs for people who have issues with their memory and their families. I am interested in seeing how the day program works for people with dementia and so I would be spending time with you at home at the day program just observing what everyday life looks like there, what makes it good and what makes it difficult.

This would mean you would see me a few times a week for a few hours at home and at the day program for about 9 months. I would also talk to you and your family about how things are going. You and your family can decide when I can spend time with you, where and during what activities. If there are activities or places at home that you want to keep private you can tell me now or any time later. I would look at the chart that they keep here at the day program and at home care about you to see how the staff plan care for you and communicate to other people like your family or the home care nurse.

All the information I get by watching, talking to you and your family and reading the chart information will be kept private.

Being part of the study might help with making day programs and care at home better. You might get confused about who I am when you see me, but I will remind you when I come and if you don't feel like seeing me that day you can tell me to go away and come back another day or never.

If you don't want to be part of the study you can say no now or later and nothing will change at home or at the day program.

Does that make sense? Do you have any questions?

Appendix N

Written Assent Form for Participants with Dementia

Participant Assent Form

Title of Study: Understanding How Day Programs Work as Care in the Community for People with Dementia and their Families. (Ethics ID #: pro00086731)

Principal Investigator(s):	Christine Ceci PhD	Phone Number: 780-492-8911
Co-investigators:	Wendy Duggleby PhD	Phone Number: 780-492-6764
	Holly Symonds-Brown (student)	

We want to tell you about a research study we are doing. A research study is a way to learn more about something. We would like to find out more about how day programs work for people with memory problems who live at home. You are being asked to join the study because you have dementia (memory problems) and you come to the day program.

If you agree to join this study, you will be asked to let the researcher observe your everyday life at home, on outings, and at the day program. This would mean the researcher will 'hang out' with you for a few hours each week a few times a month. The researcher may also spend a couple whole days at the day program with you. You and your family can decide where, when and how long the researcher is observing for. You can tell the researcher what's ok to observe and what you would like to keep private. You can do this ahead of time or at any time you feel like you want the observation to stop.

You will also be asked to be part of an interview where the researcher will ask you about what's being going on for you and how you use the day program and other services in the community. That interview will be audio recorded and you can ask to have the recording stopped at anytime The researcher will also look at some of the information in your health record at the day program and with home care. The researcher will be collecting information about how care at the day program is planned for you, what information they use when you start or and what other health or social care agencies they share this with.

You might like showing me how the day program works for you, but you may also feel strange having the researcher hang out with you or sometimes you might forget who they are and get worried when you see someone new at your house, but they will be sure to introduce themselves and remind you why they are there. If you feel uncomfortable having the researcher around or are feeling tired you can always ask them to leave.

We do not know if being in this study will help you.

This study will help us learn more about day programs and community care for people with dementia

The information collected about you during this study will be kept safely locked up. Nobody will know it except the people doing the research. The researchers will not tell your friends or anyone else.

You do not have to join this study. It is up to you. You can say okay now and change your mind later. All you have to do is tell us you want to stop. No one will be mad at you if you don't want to be in the study or if you join the study and change your mind later and stop.

Before you say yes or no to being in this study, we will answer any questions you have. If you join the study, you can ask questions at any time. Just tell the researcher that you have a question.

If you have any questions about this study, please feel free to contact Holly Symonds-Brown at 780492-8911 or by email at hsymonds@ualberta.ca

☐ Yes, I will be in this research study. ☐ No, I don't want to do this.

~~Participant's Name~~ ~~Signature~~ ~~Date~~

Person obtaining Assent Signature Date

Appendix O

Family Member Consent

PARTICIPANT CONSENT FORM

Title of Study: Understanding How Day Programs work as Care in The Community for People with Dementia and their Families. (U of A Ethics ID #: Pro00086731)

Principal Investigator: Dr. Christine Ceci 780-492-8911

Co-investigators: Holly Symonds-Brown MSN RN (graduate student) & Dr. Wendy Duggleby 780-492-6764

Why am I being asked to take part in this research study?

You are being asked to be in this study because you have a family member with dementia who is attending a day program.

This study is focused on the ways in which day programs work to provide care for people with dementia and their families living at home.

Before you decide about being in the study a researcher will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer.

You will be given a copy of this information sheet for your records.

What is the reason for doing the study?

This study is interested in finding out more about the ways in which day programs work for people with dementia and their families.

This study is part of the work of one of the researchers who is a graduate student (Holly Symonds-Brown).

What will I be asked to do?

You will be asked to allow the researcher to observe you and your family at home, during social activities, or other appointments and at the day program.

1)The study will begin with an interview with you lasting approximately 60 minutes. You can choose where and when this interview takes place and who is present. The interview will last about 60 minutes and will include questions related to your experience with having a person with dementia in your family using the day program and how this affects your day to day life. The interview will be audiotaped and transcribed. You can request that the audio recorder be shut off at any time during the interview. All information in the interview will be kept confidential and names will not be attached to the data.

2) The study will then involve the researcher spending time with you and your family as you go about your normal activities at home and at the day program and other related health services. You are not required to do anything outside of your normal activities. The researcher will basically ‘hang out’ with you, have conversations, and watch activities. The visits will take place 2-4 times/month over a period of approximately 9 months unless you or your family member stops using the day program sooner. The length of time for each visit at home will vary and will be based on your family’s preferred time and place. Visits will be planned for 1-3 hours but may be shorter if at any time you prefer them to be finished sooner.

Some of the following events would be the type of activities the researcher would like to be able to observe:
- morning preparation time for day program at home
- different time periods at the day program
- time spent after the day program at home
- days off the day program
- other home or community-based activities

While these are examples of activities the researcher is interested in, the decision of what activities are observed, where and when the observations take place is up to you and your family and can be changed by you at any time during the study.

What are the risks and discomforts?
There is minimal risk involved with your participation in this study.

Possible discomfort may include feelings upset when talking about your experiences, or feeling that your privacy is intruded on by an observer being in your home or during day to day activities.

It is not possible to know all the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?
This study may help to other people in the future through increasing what we know about of day programs and ways they might be helpful or unhelpful for people with dementia and their families.

There may be a feeling of reward in contributing to research or of relief through sharing your experiences with someone else however, you may not get any direct benefit from being in this research study.

Do I have to take part in the study?

Being in this study is your choice, as well as how long you decide to remain in the study. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the care or services that you are entitled to.

During observations or the initial interview, you do not have to answer any questions from the researcher that you are not comfortable with. You can also decide what parts of daily life or locations in your home you would like to be observed in. If there are any parts of your daily life that you would not like to keep private, you will be able to tell the researcher ahead of time or tell the researcher to leave at any point where you feel like not being observed.
At any point in the study if there are conversations or events that you later decide you do not want to be included in the study, you can notify the researcher and they will exclude this information.

If you decide that you do not want to participate any further, you will be given the choice to withdraw and have no further information collected or you can decide that all the information collected from you and your family will be destroyed and not used in the study.

Once the study is completed the researcher will be unable to remove your information.

Will my information be kept private?
During the study we will be collecting data about you through observations and interviews.

We will do everything we can to make sure that this data is kept private. Information will be stored on a password protected computer. No information relating to this study that includes your name will be released outside of the researcher's office or published by the researchers.

Sometimes, by law, we may have to release your information with your name, so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

If the researcher witnesses abuse of anyone she is required to report this to the appropriate agency for further investigation and support resources.

After the study is done, we will still need to securely store research data that was collected as part of the study. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study.

What if I have questions?
If you have any questions about the research now or later, please contact Holly Symonds-Brown at hsymonds@ualberta.ca or one of her supervisors: Dr. Christine Ceci 780-497-8911 & Dr. Wendy Duggleby 780-492-6764

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT

Title of Study: Understanding How Day Programs work as Care in The Community for People with Dementia and their Families. (U of A Ethics ID #: Pro 00086731)

Principal Investigator(s): Dr. Christine Ceci Phone Number(s): 780-492-8911

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your access to the day program or with any medical care.	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records?	☐	☐

Who explained this study to you?
____

I agree to take part in this study:

Signature of Research Participant
____

(Printed Name) ____

Date: ______________________________

Signature of Witness
____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix P

Day Program Staff/Volunteer Consent

CONSENT FORM

Title of Study: Understanding How Day Programs Work as Care in the Community for People with Dementia and their Families. (U of A Ethics ID #: Pro 00086731)

Principal Investigator: Dr. Christine Ceci 780-497-8911

Co-Investigators: Holly Symonds-Brown MSN RN (graduate student) & Dr. Wendy Duggleby 780-492-6764

Why am I being asked to take part in this research study?
You are being asked to be in this study because you are a staff or volunteer of a day program.

This study is focused on the ways in which day programs work to provide care for people with dementia and their families living at home.

Before you decide about being in the study, a researcher will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer.

You will be given a copy of this information sheet for your records.

What is the reason for doing the study?
This study is interested in finding out more about the ways in which day programs work for people with dementia and their families living at home.

It is part of the work of one of the researchers who is a graduate student (Holly Symonds-Brown).

What will I be asked to do?
You will be asked to allow the researcher to observe you in everyday activities related to patient care at the day program. These observations will take place 4-6 times/month over a period of about 9 months. Observation periods may last between 1-8 hours at a time.

You are not required to do anything outside of your normal activities. The researcher will basically ‘hang out’ at the day program, have conversations, participate in and watch activities.

What are the risks and discomforts?

There is minimal risk involved with your participation in this study.

Possible discomfort may include feeling uncomfortable in discussing your activities with the researcher or feeling that your privacy is intruded on with an observer being present during day program activities.

It is not possible to know all the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?
You may not get any direct benefit from being in this research study.

This study may help to other people in the future through increasing what we know about day programs and ways they might be helpful or unhelpful for people with dementia and their families.

Do I have to take part in the study?
Being in this study is your choice, as well as how long you decide to remain in the study. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect your position at the day program.

During observations you do not have to answer any questions of the researcher that you are not comfortable with and can request to be excluded from observations at any time.

At any point in the study if there are conversations or events that you later decide you do not want to be included in the study, you can notify the researcher and they will exclude this information.

If you decide that you do not want to participate any further, you will be given the choice to either withdraw and have no further information collected from you or you can withdraw and have all information collected from you during your participation removed from the study.

Once the study is completed the researcher will be unable to remove your information.

Will my information be kept private?
During the study we will be collecting data through observation and conversations. Your employer will not have any access to the observation notes.

We will do everything we can to make sure that this data is kept private. Information will be stored on a password protected computer.
Your name will not be attached to any data collected and a pseudonym will be used instead.
Sometimes, by law, we may have to release your information with your name, so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

If the researcher witnesses abuse of a patient at the day program they are required by law to report this under the Protection of Person's in Care Act for further investigation.

After the study is done, we will still need to securely store data that was collected as part of the study. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study.

What if I have questions?

If you have any questions about the research now or later, please contact Holly Symonds-Brown at hsymonds@ualberta.ca or one of her supervisors: Dr. Christine Ceci 780-497-8911 & Dr. Wendy Duggleby 780-492-6764

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT

Title of Study: Understanding How Day Programs Work as Care in The Community for People with Dementia and their Families. (U of A Ethics ID #: Pro00086731)

Principal Investigator(s): Dr. Christine Ceci **phone number:** 780-497-8911

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your position at the day program.	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records	☐	☐

Who explained this study to you?

I agree to take part in this study:

Signature of Research Participant

(Printed Name)

Date: ______________________________

Signature of Witness

____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix Q

Minor Participant Assent Form

Title of Study: Understanding How Day Programs Work as Care in the Community for People with Dementia and their Families. (Ethics ID #: pro00086731)

Principal Investigator(s):	Christine Ceci PhD	Phone Number: 780-492-8911
Co-investigators:	Wendy Duggleby PhD	Phone Number: 780-492-6764
	Holly Symonds-Brown (student)	

We want to tell you about a research study we are doing. A research study is a way to learn more about something. We would like to find out more about how day programs work for people with memory problems who live at home. You are being asked to join the study because you have a family member dementia (memory problems) who uses a day program.

If you agree to join this study, you will be asked to let the researcher observe you in your everyday life with your family member with dementia at home, on outings, and at the day program. This means the researcher will 'hang out' with your family for a few hours each week a few times a month. You and your family can decide where, when and how long the researcher is observing for. You could also be asked to be part of an interview where the researcher will ask you about what's being going on for you and how the day program and other services in the community helps your family. That interview will be audio recorded and you can ask to have the recording stopped at any time during the interview.

You may also feel strange having the researcher hang out with your family at home. If you feel uncomfortable having the researcher around or are feeling tired you can always ask them to leave.

We do not know if being in this study will help you.

This study will help us learn more about how day programs help people with dementia and their families.

The information collected about you during this study will be kept safely locked up. Nobody will know it except the people doing the research. The researchers will not tell your friends or anyone else.

You do not have to join this study. It is up to you. You can say okay now and change your mind later. All you have to do is tell us you want to stop. No one will be mad at you if you don't want to be in the study or if you join the study and change your mind later and stop.

Before you say yes or no to being in this study, we will answer any questions you have. If you join the study, you can ask questions at any time. Just tell the researcher that you have a question.

If you have any questions about this study, please feel free to contact Holly Symonds-Brown at 780-492-8911 or by email at hsymonds@ualberta.ca

☐ Yes, I will be in this research study. ☐ No, I don't want to do this.

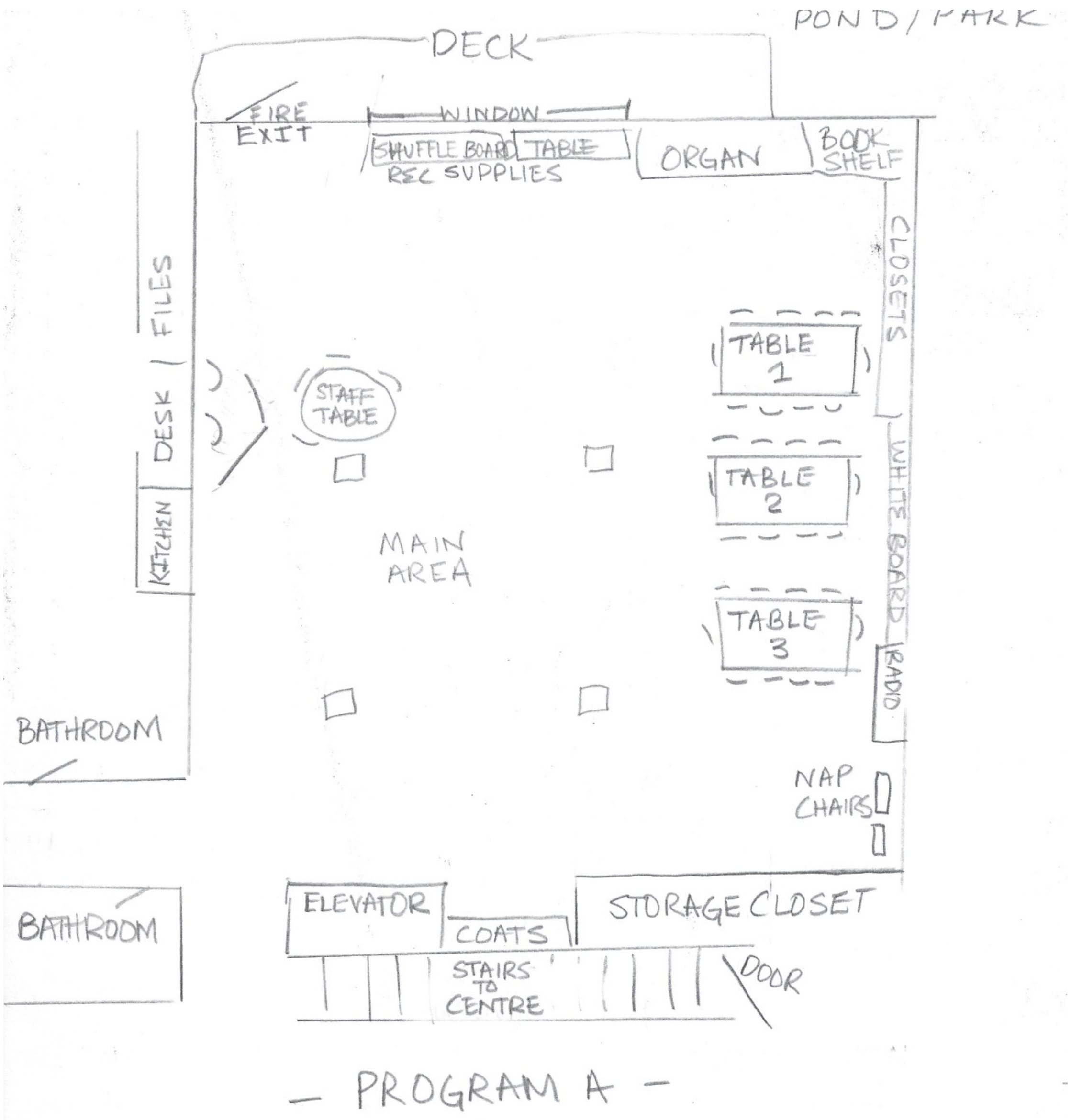
~~Participant's Name~~ ______________ ~~Signature~~ ______________ ~~Date~~ ______________

______________ ______________ ______________

Person obtaining Assent Signature Date

Appendix R

Program A Floor Plan



Appendix S

Program B Floor Plan