Dementia Care Provision: Residential Care Aides' Experiences

by

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B.A., University of Calgary, 1994

M.A., Simon Fraser University, 2006

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SUPERVISORY COMMITTEE

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ABSTRACT

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The purpose of this study was to examine Residential Care Aides' (RCAs) experiences of good quality dementia care provision. Informed by a political economy perspective, I sought to understand how RCAs conceptualize quality dementia care, whether such conceptualizations are reflected in their daily care practice and how the organizational care context impedes or facilitates such care provision. Drawing on a focused ethnographic approach, I utilized in-depth interviews, participant observation and the review of selected documents to contextualize RCAs' experiences within the organizational care environment.

Over a 12-month period, in-depth interviews with 29 staff (21 RCAs, 3 LPNs and 5 managers) and 239 hours of participant observation were conducted in four small-scale dementia units in two nursing homes in British Columbia, Canada. In-depth interviews yielded information-rich data about RCAs' care experiences and their relationships with residents, while participant observation afforded the opportunity to strategically link

RCAs' actions and interactions with what was said, a feature missing from much of the previous research examining staff perceptions of quality dementia care. A select review of facility documents and provincial licensing regulations provided additional insight regarding the relevance of the larger structural context for RCAs' care experiences.

In general, RCAs conceptualized, and exhibited in their daily physical care provision, quality dementia care as that which focused on tangible care outcomes (i.e., keeping residents clean, comfortable, calm and happy), on their care approach (i.e., delivering care in a compassionate, patient and affectionate manner) and was guided by family ideology (i.e., invoking of family metaphors). Inherent in their care provision was a sense of role tension, as they sought to incorporate social interaction with task completion and their co-workers' conflicting expectations. Study findings also illustrated how, in the face of continued disempowerment and organizational constraints, RCAs sought to provide quality dementia care by negotiating their peer and supervisory relationships and selectively breaking formal and informal policies/procedures. Salient to RCAs' experiences of personhood was the limited recognition and appreciation they received from management and the manner in which work-life balance, staffing coverage, human resource management practices and limited information sharing further devalued them and their work.

Study findings draw attention to the importance of: acknowledging the role of structural constraints in the pervasiveness of a task-oriented work culture; attending to (and facilitating) staff personhood; facilitating supportive peer and supervisory relationships and; fostering effective management practices as a means of potentially

improving care quality. As such, the study sheds important light on what RCAs require within their work environments to help facilitate resident well-being, reinforcing the assertion that residents' care conditions are inextricably linked to RCAs' care work conditions.

Keywords: residential care aides, care provision, quality dementia care, person-centred care, personhood, organizational constraints, organizational context

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DEDICATION

This dissertation is dedicated to my late father-in-law, Tony Cooke, whose own life experiences exemplified how hard work, tenacity and an unwavering belief in one's dreams make the journey all the more worthwhile.

CHAPTER 1: INTRODUCTION

1.1 Background

As the number of older adults in Canada continues to increase, there is a concomitant increase in the number of individuals with dementia. By 2038, 1.1 million Canadians will be living with dementia, 68% of whom will be over the age of 80 years (Alzheimer Society of Canada, 2010). While informal, non-institutional care is preferred by most seniors, the reality is that long-term, facility-based care will be required for many more individuals than has previously been the case, especially as the presence of dementia is one of the most likely conditions necessitating admission to a long-term care facility (Canadian Healthcare Association, 2009). Indeed, between 2008 and 2038, the number of long-term care beds occupied by individuals with dementia is projected to more than double from 183,268 to 442,682 (Alzheimer Society of Canada, 2010). Given this increased demand for facility-based residential care, the provision of high quality dementia care has never been more important.

Traditionally, facility-based care for individuals with dementia has been provided within an institutional, medical model characterized by a hierarchically organized, highly scheduled, task-oriented approach that prioritizes physical care (Gnaedinger, 2003; Janes, Sidani, Cott & Rappolt, 2008; McAllister & Silverman, 1999). However, in recent years, there has been a shift towards more individualized, social models (Brooker, 2007; Keating, Fast, Dosman, & Eales, 2001), in which increased emphasis is placed upon the uniqueness of the person with dementia, flexible care routines respectful of residents'

values, preferences and needs, the development of consistent and caring relationships, and an enriched social environment (Brooker, 2007; Talerico, O'Brien, & Swafford, 2003; Edvardsson, Winblad, & Sandman, 2008).

Such models are frequently operationalized in the form of dementia care units, specialized units within long-term care facilities designed specifically for individuals with advanced dementia. Perceived to feature dimensions of care that result in optimal outcomes for individuals with dementia, these units typically include modified physical environments that are small-in-scale (housing fewer than 15 residents per unit) and feature archetypal aspects of home, improved staffing ratios, consistent staffing, specialized staff training and dementia-specific activity training (Chappell & Reid, 2000; Verbeek et al., 2010).

The shift towards such models of care stems largely from the person-centred care philosophy advocated by Kitwood in his writings on dementia and personhood (Brooker, 2004). For Kitwood (1997), the essence of quality dementia care is the enhancement and maintenance of personhood; that is, the recognition, respect and trust engendered when status is bestowed upon one human being, by others, in the context of relationship and social being (p.8). Yet while person-centred care is increasingly viewed as synonymous with good quality dementia care (Brooker, 2004; Edvardsson et al., 2008) its widespread adoption and integration remains elusive (Talerico et al., 2003). As such, further research is required to ascertain the challenges and opportunities surrounding its provision (O'Connor et al., 2007).

In providing the majority of hands-on, day-to-day care for persons with dementia, Residential Care Aides (RCAs; unregulated workers also known as nursing assistants/aides, personal support workers, health care aides) play a pivotal role in shaping the daily life experiences and well-being of persons with dementia. However, situated on the lowest tier in the health-care hierarchy, RCAs are at times afforded as little power, respect or recognition as those for whom they provide care (Innes, 2002; Tellis-Nayak & Tellis-Nayak, 1989). In both Canada and the U.S., 90% of front-line care workers and a significant proportion of management staff are women (Armstrong et al., 2006, in Armstrong & Banerjee, 2009; Dodson & Zincavage, 2007), making care work a highly-gendered experience. RCAs have little formal training and receive minimal remuneration (Tellis-Nayak & Tellis-Nayak, 1989), factors which both reflect and contribute to the widely-held perception of care work as unskilled labour. In addition, while facility managers, administrators and residents are predominantly white, many front-line care workers are from immigrant and visible minority backgrounds (Cohen, 2009; Dodson & Zincavage, 2007). RCAs thus find themselves in a paradoxical position, with considerable practical power and influence over those for whom they care but little formal authority or status (Jaques & Innes, 1998). If we are to improve our understanding of person-centred care approaches, and in turn the quality of dementia care, greater attention must be devoted to examining RCAs' care experiences – their challenges, frustrations, motivations and satisfactions (Jacques & Innes, 1998); this study seeks to do just that.

Initially, this study proposed to examine the influence of both the physical and organizational care environment on quality dementia care provision. However, early analyses highlighted the salience of the organizational environment to RCAs' experience, which focused subsequent data collection (and in turn, this dissertation) on exploring the role of the organizational environment in care provision.

Research examining the experiences of RCAs within dementia care settings remains rare (Innes, 2002); rather, much greater effort and time has been devoted to exploring the experiences of 'professional' care staff (i.e., nurses) (Jacques & Innes, 1998). Such limited attention is potentially due to the low social value ascribed to such work, and few researchers working in this area. Similarly, little, if any, research has been conducted to explore how the organizational care environment (e.g., institutional practices and policies) shapes the nature and manner in which quality dementia care is delivered (Edvardsson et al., 2008; O'Connor et al., 2007).

In order to address the above-noted gaps, this study utilized a focused ethnographic approach to explore RCAs' experiences to better understand how the organizational environment facilitates or impedes quality dementia care provision. In contrast to the traditional ethnographic approach with its focus on social groups, social institutions and social events, focused ethnography is more concerned with actions, interactions and social situations (Knoblauch, 2005). As such, it is ideal for analyzing the structures and patterns of interactions between RCAs, residents with dementia and the organizational care context. A focused ethnographic approach acknowledges the relevance of the broader social context, yet gives voice to individual experience, which is

important given the relative absence of RCAs' voices within the research literature. Key questions guiding my inquiry included:

1. What do RCAs perceive to constitute good quality dementia care?

2. To what extent do the everyday care practices of RCAs reflect their perceptions of good quality dementia care?

3. How does the organizational environment (e.g., staffing practices, policies and procedures, care routines) of the care facility impede or facilitate good quality dementia care?

1.2 Dissertation Overview

This dissertation features seven chapters. In this first chapter, I have provided a brief background to the study, and introduced the methodology and key questions guiding the study. Chapter 2 provides an overview of the literature relevant to the topic of inquiry, including person-centred care, personhood, staff perceptions of quality care and the potential influence of the organizational care environment and the socio-political context on person-centred care provision. In Chapter 3, I discuss the theoretical perspective informing this study, political economy, and explain the study's methodology, including the purpose and utility of focused ethnography. I describe where, from whom and how the data were gathered, the analytic technique and the steps I took to ensure scientific rigour.

In following the University of Victoria's format for a publication-based dissertation, Chapters 4, 5 and 6 present the study's key findings; each chapter is a stand-alone manuscript to be submitted for future publication. Chapter 4 explores RCAs' conceptualizations of quality dementia care. It highlights the role tensions

experienced by RCAs and how, for them, quality dementia care entailed focusing on tangible care outcomes and their care approach and was guided by family ideology. In Chapter 5, I examine RCAs 'care in spite of', drawing attention to RCAs' experiences of disempowerment and how in valuing and negotiating co-worker relationships and selectively breaking procedures they sought to provide quality dementia care in the face of such disempowerment. In Chapter 6, I explore RCAs' experiences of personhood and illustrate the role of management-staff relations and person-centred workplace policies and practices in such experiences. Lastly, in Chapter 7, I highlight the key insights and implications (both practice and research) emerging from the research, along with the study's strengths and limitations.

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CHAPTER 2: REVIEW OF SELECTED LITERATURE

This chapter begins with a brief overview of two opposing approaches to dementia care provision – the traditional biomedical model and the more recent person-centred care approach. Within the section on person-centred care, I draw on Kitwood's work to examine the notion of personhood, a concept considered central to the provision of quality dementia care, and its applicability to RCAs, who provide the bulk of that care. I then turn to the literature examining staff perceptions of quality dementia care and the potential influence of the organizational care environment and the socio-political context on person-centred care provision.

2.1 Biomedical Model of Dementia Care

Within many long-term care facilities, the biomedical perspective dominates the way in which residents are viewed, care is provided and institutional priorities shaped (McLean, 2007). Dementia is considered pathological, an abnormal condition of cognitive impairment that results in the characterization of both the individual and their behaviour as diseased (Lyman, 1989; McLean, 2007), in turn shaping the attitudes of others towards them (Estes & Binney, 1989). Clinical symptoms, 'deviant' behaviours and subjective states are thus viewed solely as artifacts of the disease process, the influence of the social and environmental context ignored (Lyman, 1989; McLean, 2007). Under the biomedical model, attention is directed towards bodily hygiene and physical maintenance (i.e., 'bed and body' work; Gubrium, 1997), such that resources are allocated towards the meeting of basic physical needs as opposed to optimizing quality

of life (McLean, 2007; Ronch, 2004). Residents are treated according to their diagnostic or functional status, with funding and staffing determined in relation to such status. Staff are hierarchically organized, highly scheduled and oriented towards clinical tasks and documentation (Gnaedinger, 2003; Diamond, 1995). In the presence of a top-down management structure, in which power and influence are centered at the apex, front-line staff are viewed simply as interchangeable cogs in a wheel, turning out a quota of standardized care procedures on each shift (Ronch, 2004).

Continued reliance on the biomedical model neglects the social construction of dementia and the impact of the treatment context (e.g., the care facility) and relationships with care providers on disease progression (Lyman, 1989). The end result is a dependency-oriented, safety/need-based model of facility-based care that minimizes attention to residents' emotional and social needs, and the establishment and maintenance of personhood (Ronch, 2004; Edvardsson et al., 2008; Beattie, 1998; Kitwood, 1997b).

It is thus of little surprise that Goffman's (1961) characterization of nursing homes as 'total institutions' can still be seen to apply today (e.g., Diamond, 1995; Briller & Calkins, 2000; McAllister & Silverman, 1999; Lopez, 2006a). Within a total institution, all aspects of life are conducted in one place under a single authority; daily activities (e.g., eating, sleeping and socializing) are carried out at the same time, in the immediate company of others, according to a schedule developed and imposed by institutional authorities; and, all activities are rationally organized to *fulfill the official aims of the institution, as opposed to the needs of the residents* (Goffman, 1961) (italics added). A

clear division exists between staff and residents, such that two different social and cultural worlds develop, with 'points of official contact but little mutual penetration' (Goffman, 1961, p.9). Upon entry into a total institution, a resident's sense of self is systematically affronted and curtailed as continuity with past roles, routines and possessions is severed. Residents become objectified as they are shaped, coded and worked on within the 'administrative machinery of the establishment' during which previous bases of self-identification are ignored (Goffman, 1961, p.16).

Research indicates that behaviours supporting autonomy or self-determination (e.g., choosing one's own food or clothing, moving freely throughout the home) continue to be actively discouraged (McAllister & Silverman, 1999). Staff are expected to move efficiently between residents performing tasks (e.g., toileting, bathing, positioning), rather than remaining with one resident to visit or socialize. Consequently, social interactions with residents are often infrequent and fleeting, with conversations rarely extending beyond a few minutes (Coughlan & Ward, 2007; Lopez, 2006b; McAllister & Silverman, 1999).

Interestingly, Goffman (1961) notes that total institutions present themselves to the public as rational organizations consciously designed to produce officially avowed and approved ends (p.74). Given the pervasiveness of the biomedical model, it would appear that the nursing home draws legitimacy by situating itself as a repository of medical personnel and practices, emphasizing the meeting of residents' basic physical and medical needs to the detriment of their psychosocial needs.

2.2 Person-Centred Dementia Care

Rallying against the dominant biomedical view of dementia, Kitwood (1997b) advocated for a more humanistic 'person-centred' approach to dementia care, in which personal experiences of well-being and self-worth are acknowledged. Indeed, his writings on dementia and personhood constitute much of the foundation on which person-centred care is based (Brooker, 2004).

2.2.1 Personhood

Examining the concept of personhood entails asking the question 'Who or what is a person?'; the underlying implication being that those excluded from such a definition (i.e., non-persons) are treated differently than those who are included (Baldwin et al. 2007). For individuals with dementia, terms such as 'Alzheimer victims', the 'demented', 'elderly mentally infirm' and 'mentally fragile' devalue the person (Kitwood, 1997b), labelling them as different and potentially deviant (Innes, 2002). As Christine Bryden, an individual with early-onset dementia, writes:

> *"Please don't call us 'dementing' – we are still people separate from our disease, we just have a disease of the brain. If I had cancer, you wouldn't refer to me as 'cancerous' would you?" (*2005, in Brooker, 2004, p.97*).*

It can thus be argued that our frame of reference needs to shift from that of (potentially non-) 'person with DEMENTIA' to 'PERSON with dementia' (Kitwood, 1997b).

In Western society, to be a person is to be conscious of thought, to possess autonomy, rationality and continuity of memory (Kitwood, 1997b; Brooker, 2007); in other words, 'I think, therefore I am'. The implication for individuals with dementia is 'if

I do not think, then I am not' (Post, 2000, p.247), thus fostering the deep-seated cultural assumption regarding the loss of selfhood for all persons with advanced dementia (Kontos & Naglie, 2007). In terms of care provision, viewing individuals with dementia as non-persons potentially precludes providers and politicians from concerning themselves with optimizing residents' quality of life (i.e., attending to residents' emotional and social needs) and the distribution of resources to enhance such quality (Innes, 2002; Kitwood, 1997a). The individual becomes objectified, with care reduced to basic physical tasks and procedures (McLean, 2007).

Kitwood (1997b) challenged such assumptions by conceptualizing personhood in relational terms, defining it as the recognition, respect and trust engendered when status is bestowed upon one human being, by others, in the context of relationship and social being (p.8). Personhood is not the 'property' of the individual, but rather a status that can only be provided or assured in the context of a mutually recognizing, respecting and trusting relationship (Kitwood & Bredin, 1992). Embracing the notion that each person has absolute value, Kitwood (1997b) argued that there exists an obligation to treat our fellow beings with respect, to view them as ends, as opposed to means to some other end. As such, he believed respect for the personhood of front-line care staff to be as critical as for those with dementia. As with persons with dementia, attending to staff personhood entails acknowledging and valuing RCAs' worth as unique individuals, conveying recognition, respect and trust in the context of relationship (Brooker, 2007; Kitwood, 1997b).

One of the key criticisms of Kitwood's conceptualization of personhood is that it tends to be applied within the context of an individual's immediate environment. The danger with such a narrow, relational focus is that responsibility for the treatment and well-being of persons with dementia in care rests solely with the RCA; what the RCA needs to be able to facilitate such well-being is given much less consideration. While RCAs' interpersonal communication skills influence the quality of their interactions with residents, broader contextual factors such as staffing levels, workload, organizational priorities, commodification of care and ageist attitudes also potentially play a key role (Baldwin & Capstick, 2007).

2.2.2 Defining Person-Centred Dementia Care

In the last two decades, the concept of person-centred care has become increasingly popular, such that it is commonly considered synonymous with good quality dementia care (Brooker, 2004; Edvardsson et al., 2008). However, in spite of the frequent references to person-centred care within both the literature and practice, consensus has yet to be achieved on its definition (Edvardsson et al., 2008; Talerico et al., 2003; Packer, 2000). This is likely due to the fact that person-centred care is as much a philosophical approach as a practice-based framework. While some individuals perceive it to be a value base or a phenomenological perspective, others interpret it to mean individualized care or view it as a set of caregiving techniques (Brooker, 2004). Key components of person-centred care include the development of consistent, supportive relationships, respect for individual values, preferences and needs, knowledge of the individual's biography, respecting freedom of choice, maximizing

individual potential and a focus on remaining abilities (Kitwood, 1997b; Edvardsson et al., 2008; Talerico et al., 2003).

Acknowledging that person-centred care is best represented as a composite term, Brooker (2004) provides a contemporary definition that outlines four essential elements: valuing people with dementia and those who care for them; treating people as individuals; looking at the world from the perspective of the person with dementia; and a positive social environment. Neither element is considered superior over another; rather all the elements are believed equally important.

As outlined in the above discussion on personhood, valuing individuals with dementia entails viewing them as persons, as relational and historical beings worthy of respect, whose needs and rights are not dissimilar from the rest of us (Kitwood, 1997a; 1997b). In emphasizing the value of all persons, person-centred care also acknowledges the personhood of direct care staff (Kitwood, 1995). Typically, however, RCAs are afforded as little status and value as those for whom they provide care. For example, nurses working in facility-based long-term care generally receive lower wages and fewer benefits than those in acute or paediatric care settings (Armstrong & Banerjee, 2009; Brooker, 2007). Many of the RCAs have little formal training and receive minimal remuneration, reflecting the (false) belief that the work requires little in the way of skill (Lustbader, 2001; Zimmerman et al., 2005).

The gendered nature of care work, in combination with the high proportion of workers from ethnic minorities, also likely contributes to the low social value ascribed to such work (Innes, 2002; Armstrong & Banerjee, 2009). The danger is that without

explicit recognition of the value of both individuals with dementia and their care providers in government policy, national and provincial frameworks, and care organizations (e.g., value statements, policies and procedures), the pervading status quo will erode any attempt at person-centred care (Brooker, 2004). However, viewing person-centred care solely as a value base may result in a series of empty platitudes with no practical application (Brooker, 2007); i.e., facilities may 'talk the talk' but be unclear as to how to 'walk the walk'.

It is the last component in Brooker's definition of person-centred care, a positive social environment, which encompasses the centrality and promotion of relationships. It is here that Kitwood's notion of personhood is particularly relevant, its development and maintenance to be facilitated through the course of day-to-day interactions. In a study of care quality in Ontario nursing homes, Coughlan and Ward (2007) interviewed 18 residents, both with and without cognitive impairment. Each of the residents spoke of how their life was given meaning by relationships and the connection of relationships to their feelings of self-worth and identity. While all relationships (those with family, friends, other residents and staff) were deemed important, it was their relationships with staff that were most central to their discussions of quality of care and quality of life within the facility.

The centrality of relationship to care quality has led Nolan and colleagues (2002) to propose the 'Senses Framework', a relationship-centred approach to dementia care practice that outlines six prerequisites for good relationships within the care context – a sense of security, continuity, belonging, purpose, achievement and significance (Ryan,

Nolan, Reid & Enderby, 2008) (see Table 1 for more detail). The underlying premise of their approach is that good care is only delivered when the 'senses' are experienced by individuals with dementia *and* their caregivers.

Table 1: Six Prerequisites for Good Relationships within the Care Context

Prerequisite/ Sense	For the Individual with Dementia	For the Staff Caregiver
Security	Attention to essential physiological & psychological needs To feel safe & free from threat, harm pain & discomfort To receive competent & sensitive care	To feel free from physical threat, rebuke or censure To have secure conditions of employment To have emotional demands of work acknowledged & to work within a supportive culture
Continuity	Recognition & value of personal biography Use of knowledge of the past to contextualize present & future Consistent care delivered within established relationships by known people	Exposure to good role models & care environments Expectations & care standards communicated clearly & consistently
Belonging	Opportunities to maintain &/or form meaningful and reciprocal relationships, to feel part of a group (as desired)	To feel part of a team with a recognized & valued contribution To belong to a peer group
Purpose	Opportunities to engage in meaningful activity to facilitate constructive passage of time To exercise discretionary choice	To have a sense of therapeutic direction & a clear set of goals to which to aspire
Achievement	Opportunities to meet meaningful & valued goals & to feel satisfied with one's efforts To make a recognized & valued contribution	To be able to provide good care To feel satisfied with one's efforts To use full range of skills & abilities
Significance	To feel recognized & valued as a person of worth, that one's actions & existence matter	To feel that care practice is valued & important, that one's work and efforts matter

Source: Ryan et al. (2008)

Dewing (2008) suggests that the Senses Framework potentially offers a detailed structure for practice application, a key advantage given the difficulties in operationally defining person-centred care and the absence of a 'how-to' manual regarding its implementation and delivery (Edvardsson et al., 2008; Packer, 2000). However, the framework does little to address the influence of wider contextual aspects (e.g., policies, institutional culture) on care practices.

Much of the published work on person-centred care tends to be conceptual or anecdotal (Edvardsson et al., 2008); the few empirical studies have primarily focused on resident outcome measures such as agitation, neuropsychiatric symptoms and psychotropic medication use (Chenoweth et al., 2009; Fossey et al., 2006). Little is known about how formal care providers conceptualize and experience person-centred (i.e., good quality) dementia care. Similarly, little published research identifies the pre-requisites for person-centred care in different settings, explores how the philosophical approach is incorporated into practice or ascertains how organizational structures can promote or obstruct person-centeredness (Edvardsson et al., 2008; Epp, 2003). The next few sections of this chapter focus on staff perceptions of quality dementia care and the potential of the organizational care environment and socio-political context to influence its provision.

2.3 Staff Perceptions of Dementia Care Provision

Research examining the experiences and perspectives of RCAs within dementia care settings, who provide up to 90% of the hands-on, day-to-day care remains limited

(Eaton, 2000; Innes, 2002; Jacques & Innes, 1998). This is potentially due in part to the continued low status and value ascribed to RCAs and their work (Innes, 2002), and few researchers working in this area. The similarity between care providers and care recipients with dementia, through their marginalization, is reflected in the little power, respect or recognition afforded to either group (Innes, 2002; Tellis-Nayak & Tellis-Nayak, 1989).

It is imperative that the experiences and perspectives of RCAs be better understood and represented in the research literature, for without it, the agency of front-line staff may only be further denied and prevailing (mistaken) assumptions about care work perpetuated. To improve our understanding of person-centred care approaches in the hopes of enhancing care quality, we must pay close attention to the world of the care aide, to examine what it is like to provide care to individuals with dementia – the difficulties, frustrations, motivations, and satisfactions (Jacques & Innes, 1998). While the world of the care aide has been explored in a number of ethnographies (e.g., Diamond, 1995; Foner, 1994; Gass, 2004; Henderson & Vesperi, 1995; Lopez, 2006b; Savishinsky, 1991), none have focused specifically on dementia care settings. As Jacques and Innes (1998) note, greater examination is required of the structure of dementia care provision and the paradoxical position in which RCAs find themselves – with enormous practical power and influence, yet little formal authority or status.

To date, only a handful of qualitative studies have explored staff perceptions of what constitutes good or person-centred care for individuals with dementia (Chung,

2013; Edvardsson, Fetherstonhaugh & Nay, 2010; Ericson, Hellstrom, Lundh & Nolan, 2001; Kalis, Schermer, & van Delden, 2005; Zingmark Sandman & Norberg, 2002) , how they construe their daily care provision (Colomer & de Vries, 2014; Stockwell-Smith, Jones & Moyle, 2011), and their experiences in small group-home settings (van Zadelhoff, Verbeek, Widdershoven, van Rossum & Abma, 2011). No studies have specifically examined RCAs' perceptions of the influence of the organizational environment on their ability to provide quality dementia care.

The themes emerging from research examining predominantly professional staff perceptions of what constitutes good quality or person-centred dementia care reflect those of studies exploring residents' subjective experiences of care (e.g., Aggarwal et al., 2003; Clare et al., 2008; Harmer & Orell, 2008). For example, notions of residents' worth and rights permeated interviews with nurses in a newly-opened Swedish Special Care Unit (Zingmark et al., 2002). Emphasis was placed on respecting dignity and striving to preserve residents' sense of self, accepting residents' way of being (i.e., of the way they spoke and acted), encouraging a sense of belonging (i.e., bringing residents' pasts into the present context), providing opportunities for meaningful occupation and promoting a sense of power and control in residents (i.e., facilitating autonomy around activities of daily living). Similar themes were noted by Kalis and colleagues (2005), in their interviews with professional staff (i.e., ward heads and activity staff) from five nursing homes in the Netherlands; i.e., autonomy and freedom (of choice and movement), relationships and social networks (i.e., connecting with the world outside

the home, attention, understanding and empathy), warmth, safety and familiarity, feelings of well-being and stimulating activities.

Given that RCAs provide the bulk of the hands-on care, it is somewhat surprising that both the above studies chose to interview only professional staff; however, the rationale provided by Kalis et al. (2005) is telling. They note that the heads of the ward were selected due to their overview of daily care practice and "because they are, owing to their educational background, assumed to be the most capable of reflection on care practices" (p.32). Such a comment illustrates the commonly-held (mis)perceptions of care aides. Are RCAs really less capable of reflecting on their care practice or is it that they have never been encouraged or given the opportunity to do so? Similarly, Kalis and colleagues (2005) chose the co-ordinators of ward activities because their role (of organizing leisure activities) is "explicitly concerned with improving the well-being of residents" (p.32). While this may be the case, it can be argued that it is the RCAs who, by virtue of the time spent with residents, have a major role to play in enhancing residents' well-being.

In addition, the aforementioned studies did not include observations to determine the extent to which staff perceptions of good quality care were reflected in their care practice. Although ward coordinators may articulate person-centred values with regards to what constitutes a 'good life' for individuals with dementia, it is unclear to what extent (or how) they or their front-line staff incorporate such values in their daily interactions with residents.

In an exploration of staff perceptions regarding their ability to manage behaviour and care needs of individuals with dementia, Stockwell-Smith and colleagues (2011), found that the examples of personal and peer practice reported by personal care workers bore little resemblance to the person-centred philosophy espoused by management. Person-centred care was not a term with which workers were familiar, nor a philosophy that (based upon their conversations) they applied in their care practice (Stockwell-Smith et al., 2011). While workers considered their interactions with residents enjoyable, they primarily defined their role as a sequence of allocated tasks to be completed. Little attention was devoted to residents' individual needs or engaging residents in conversation, which Stockwell-Smith and colleagues suggest was attributable, in part, to standardized care practices.

The tendency of RCAs to describe good care in traditional task-oriented ways has been noted in several other studies (Chung, 2013; Colomer & de Vries, 2014; Talbot & Brewer, 2015), in which RCAs emphasized the importance of resident cleanliness, comfort and happiness. Yet the fact that RCAs also focused on the importance of conducting care in an affectionate, kind, patient and flexible manner highlights the implicitness of the humanistic philosophy of respect, a central tenet of person-centred care, in their care approach (Colomer & de Vries, 2014).

Although not specific to individuals with dementia, nurses and nurses' aides in a Swedish study found it difficult to articulate what constituted a good caring encounter, choosing instead to describe what they considered poor practice (e.g., talking over residents' heads, performing care in a routine manner, neglecting residents and their

personal needs, objectifying residents) (Wadensten, Engholm, Fahlström, & Hägglund, 2009). Participants also had difficulty concretely describing how they might realize good encounters with residents in their care. Such a finding reinforces the importance of attending to RCAs' experiences and the obstacles within the care environment that potentially inhibit the provision of person-centred encounters. For example, Lopez (2006b) reported how administrators in one facility gave written disciplinary notice to RCAs found socializing with (as opposed to 'working on') residents. The supervisor explicitly stated, "…they [staff] are being paid to work, not to sit around and gossip. There's always something that needs to be done." (p.145). Such a view contrasts sharply with that of a supervisor in a small-house dementia care facility in Australia, who stated:

> *If, when I come into the unit in the morning I see all the beds made, and the residents all dressed, I am concerned. But, if I see that not everything has been done, and that staff members are eating breakfast and joking with the residents, I know everything is fine.* (Cohen-Mansfield & Bester, 2006, p.541)

In conceptualizing RCAs' work in this manner, the Australian supervisor helps create the space within which relationships between staff and resident are permitted to develop and flourish.

Exploring RCAs' perceptions of care quality entails clarifying the assumption that the way in which RCAs think about care and/or residents guides the manner in which they deliver care. Anderson and colleagues (2005) found that RCAs utilized two 'mental models' – 'the Golden Rule' and 'mother wit' to interpret care situations and determine the relevant action. The 'Golden Rule' steered aides towards treating residents as they themselves would want to be treated, while 'mother wit' drew on RCAs' experiences as

mothers, guiding them towards treating residents as they would their own children. The use of such models, however, potentially impedes the provision of person-centred care. Focusing on one's own preferences and desires (i.e., 'what I would want done for me') could preclude RCAs from learning (and acting upon) residents' individual preferences, while likening care duties to those of a mother or child-care worker may serve to infantilize (and thus depersonalize) residents (Anderson et al., 2005).

Similarly, Fisher and Wallhagen (2008) identified three dominant ways in which RCAs perceived nursing home residents – as fictive kin, as a commodity, and as an autonomous person. Care practices of aides who viewed residents as fictive kin highlighted the emotional connection between themselves and the residents, and tended to be highly-attentive, protective and respectful. In contrast, the practices of those who framed residents as a commodity tended to objectify residents. Considerable effort was devoted to ensuring residents were well-groomed and dressed, such that they could be deemed 'lounge-quality' (p.30). The care practices of RCAs who construed residents as autonomous persons appear to have the greatest resemblance to person-centred care. Aides adopting this approach highlighted their reciprocal relationships with residents, and the independence, choice and autonomy they sought to offer them.

Further research is required to better understand the perspectives and experiences of RCAs; a group whom, to date, has been afforded little status or recognition in practice or research settings. As subjective experience can be seen to be socially constructed within both an individual's immediate environment and a broader

societal context (O'Connor et al., 2007), attention must also be directed towards exploring how the organizational context (e.g., institutional practices and policies) shapes the provision of quality dementia care. As one front-line care worker articulated,

> *There's plenty of information… that tells us what we should be doing. I really need something or somebody to show me how to achieve all these things in my current working environment.* (Packer, 2000, p.21.)

Subsequently, the following section examines features within the organizational environment with the potential to influence person-centred care provision, including staffing practices, organizational routines and policies, and person-centred workplace practices.

2.4 The Organizational Care Environment and its Potential for Influencing Person-Centred Care Provision

2.4.1 Staffing Levels

Much has been written about the relationship between staffing levels and care quality; however, the majority of studies have focused on the association between staffing levels and nursing home deficiency citations or functional resident outcomes (e.g., Bostick, 2004; Harrington, Zimmerman, Karon, Robinson, & Beutel, 2000; Moseley & Jones, 2003), the results of which are mixed (Castle & Engberg, 2008). While less attention has been paid to how staffing levels influence the provision of person-centred dementia care, care staff frequently identify inadequate staffing as an obstacle to such

care (Banerjee, Daly, Armstrong, Szebehely, Armstrong, & Lafrance, 2012; Bowers, Esmond, & Jacobson, 2000; Curry, Porter, Michalski, & Gruman, 2000; Lopez, 2006a).

Comparative research between Canada and Scandinavia revealed that despite similar resident populations (in terms of age, gender, and disability), 60% of Canadian front-line care workers experienced having too much to do all or most of the time, versus 40% of Scandinavian workers (Banerjee et al., 2012). Similarly, Canadian workers were responsible for almost twice as many residents as Scandinavian workers, a factor which likely contributed to their feelings of being constantly rushed. Working short-staffed (i.e., when absent staff are not replaced) may have also been a contributing factor; short-staffing was a daily experience for 44% of Canadian staff, compared with 12-23% of Scandinavian staff, a practice which some Canadian staff linked to cost-saving measures by the organization. Consequently, while Canadian care workers emphasized the importance of relational care in supporting residents' needs, heavy workloads precluded the provision of such care (Banerjee et al., 2012).

Similar findings have been reported in the U.S. Lopez (2006a) found that despite above-average staffing levels, RCAs were unable to complete their assigned care tasks in the allotted time without deviating from official care rules and procedures. RCAs assigned to residents with higher care needs had less than 15 minutes with each resident to conduct the morning care routine, which resulted in care shortcuts (e.g., using incontinence pads on residents instead of taking them to the toilet).

Bowers and colleagues (2000) observed that, when working short-staffed, RCAs tended to bundle care tasks so as to accomplish several tasks with only one visit to a

resident's room. Such a tendency not only eliminated any variation in care procedures (i.e., individualized care) but also minimized the opportunity for residents to demonstrate reciprocity (e.g., chatting with staff about their lives). As in Lopez's (2006a) study, working short-staffed made it almost impossible for RCAs to complete their work without cutting corners. As it was the more visible outcomes of their work upon which they were evaluated, RCAs cut corners in ways that were less visible to their supervisors (e.g., leaving a resident to lie in a urine-soaked bed versus leaving dirty linen on the hallway floor) (Bowers et al., 2000). Notably, the establishment of relationships appeared to mitigate the impact of short-staffing; when working with residents with whom they had developed a relationship, staff reported cutting corners in ways least detrimental to the residents. The danger, however, was that staff who did not know the residents found it easier to cut corners in a potentially more harmful manner (Bowers et al., 2000).

Inadequate staffing can also take a physical and psychological toll on staff. RCAs in Bower et al.'s (2000) study reported that trying to complete care tasks for a greater number of residents in the same amount of time was physically exhausting and made it increasingly difficult to come (or continue) to work under such circumstances. Although staff viewed their relationships with residents as an important source of job satisfaction, the negative influence of working short-staffed on such relationships led to a sharp decrease in such satisfaction (Bowers et al., 2000). The moral distress arising from RCAs' continued inability to provide residents with the care to which they believe residents are entitled is palpable in the following comment:

> *It really makes me feel personally bad when I know in my heart how somebody should be cared for, how you know that you would like to receive care yourself, how you believe that your family members should receive care… when you are in that situation giving care to the residents and you know there's no way you can approach what you feel you should be doing, that is a very disappointing thing. You know you're letting the residents down and yourself down.* (Banerjee et al., 2012, p.396)

However, alleviating the time pressures experienced by staff may not necessarily lead to the provision of more person-centred care. While the majority of RCAs in a recent study (Talbot & Brewer, 2015) felt that their workloads and daily routines left little time for interacting with residents, several of their RCA colleagues indicated that there was time to spend with residents but that the tendency was for RCAs to sit and chat with their colleagues instead. Similarly, for some aides, when additional time was available, it was spent completing tasks rather than interacting with residents. RCAs attributed such tendencies to their being assigned 'extra' tasks when the units were quiet (Talbot & Brewer, 2015). Further research is warranted to identify additional organizational/structural features potentially leading RCAs to privilege task-oriented procedures over person-centred interaction.

2.4.2 Staff Assignment

Consistent assignment of staff to the same group of residents on the majority of shifts is currently advocated as best practice by a number of national organizations in the U.S. (Centers for Medicaid and Medicare, state Quality Improvement Organizations) (Rahman, Straker, & Manning, 2009). Viewed as superior to the more traditional practice of rotating staff, it offers an opportunity for staff to become increasingly

familiar with residents (e.g., their biography, abilities, care needs, and preferences) thus facilitating the development of relationship. However, the potential for consistent staff assignment to enhance and maintain personhood and person-centred care may be influenced by the degree to which staff are consistently assigned and staff workloads. For example, research by Burgio and colleagues (2004) found that within the nursing homes reporting consistent assignment, residents received care from their primary aide only 50% of the time. While this rate was twice that of the homes reporting rotating assignment, one questions the extent to which it would foster the continued development of relationship. Similarly, in Lopez's (2006a) study, RCAs were permanently assigned to residents, yet the varying care needs of residents led to widely different workloads for staff, which affected both their quality of work life and quality of care for residents.

2.4.3 Organizational Policies and Routines

The manner in which facility policies (be they explicit or implicit) and routines shape the nature of care delivery may also influence the degree to which personhood is enhanced and maintained. For example, flexibility in daily work and task scheduling has the potential to promote both resident and staff autonomy (Cohen-Mansfield, & Bester, 2006). Care staff in a study by Hicks-Moore (2012) spoke of the contradictions that arose between the policies extolled by management and their experiences on the front-lines. Management instructed staff to consider residents' individual needs, emphasizing the 24-hour nature of the facility and the flexibility that arises from carrying out prescribed care routines over a 24-hour day (versus an 8-hour shift). In theory, this is a

valid point – facilities are staffed 24/7 so, for example, if a resident is tired and sleeps late, their bath time could occur on a later shift. However, the emphasis on task completion was so entrenched within the facility that participating staff reported being frequently chastised by their peers and RN supervisors if prescribed resident routines within a particular 8-hour shift were not completed (Hicks-Moore, 2012).

Highly structured routines and protocol, considered essential to the 'smooth operation' of the facility, may also limit choice and flexibility for residents and staff (Kontos et al., 2009; Hicks-Moore, 2012). In discussing the practice of allowing RCAs to bring residents to the dining room whenever residents awaken, a supervisor in Kontos et al.'s (2009) study remarks:

> *If breakfast is late and dietary starts late, then the clean-up doesn't happen on time. The laundry doesn't get done on time to get back up for the next meal… it's a domino effect…. And I know it sounds silly but when you're looking at the time factor and the shifts, it's what you have to work with so we could never have PSWs bringing residents in whenever they want.* (p.124)

The quote offers a textbook example of Goffman's (1961) notion of a total institution in which activities are rationally organized to fulfill the official aims of the institution, rather than the individual needs of the residents. Routines are so firmly entrenched that change seems entirely implausible, particularly in the face of structural constraints related to human and financial resources. The above example also highlights the interconnectedness of the organizational and physical environment. A small-house model of care, with its multi-tasking staff, is perhaps less likely to experience the above

issue than a larger, more traditional care setting in which staff (and departments) have clearly demarcated role boundaries.

2.4.4 Person-Centred Workplace Practices

A number of researchers highlight the link between the personhood of staff and residents, believing that if staff experience limited participation in care planning and decision making, and restrictive rules and regulations, residents will encounter a similar fate (Thomas, 1996; Ronch, 2004; Eaton, 2000; Lopez, 2006a). Indeed, Thomas (1996) asserts that residents will never have more autonomy or self-respect than that which facility management grant their employees (p.70).

Central to the notion of person-centred care is the building of authentic relationships; if RCAs are to practice integrity, nurturing and authentic communication in their daily encounters with residents, then such principles should be reflected in the interactions between the organization and the RCAs (Brooker, 2007). However, in addition to inadequate staffing levels, heavy workloads and highly regimented routines, RCAs regularly experience little decision-making autonomy (regarding care routines or ward management issues) and limited opportunity for communication with either their colleagues or supervisors (Caspar & O'Rourke, 2008; DeForge et al., 2011; Kontos et al., 2009; Talbot & Brewer, 2015). Less than a quarter of Canadian care workers in Banerjee et al.'s (2012) study indicated an ability to affect the planning of each day's work, and only 22% reported having enough time to discuss difficulties in their work with their colleagues, compared with 45% and 54%, respectively, of Scandinavian workers.

When asked to identify the features they believe would improve their work environment, RCAs routinely respond with smaller staffing ratios (e.g., 4 to 6 residents/RCA versus the more common 10-12; Holmberg et al., 2013), better wages and benefits, greater work flexibility, involvement in work-related decisions and improved work relationships (e.g., better communication, increased supervisory respect and support, improved collegial support) (Bishop et al., 2008; Castle, Degenholtz & Rosen, 2006; Kemper et al., 2008; Parson, Simmons, Penn & Furlongh, 2003). Such factors are intimately linked to the quality of care provision (Eaton, 2000); for example, structural empowerment (i.e., access to support, resources, information, opportunities for increased knowledge and skills, and formal and informal power) has been found to be significantly associated with RCAs' provision of individualized care (Caspar & O'Rourke, 2008). Similarly, involving RCAs in decisions regarding staffing, care services, menu planning, and care standards has been found to be strongly related to families' perceptions of care quality (Hamann, 2014). Not surprisingly, empowering RCAs proved more important than empowering nurses (RNs/LPNs) as a means for improving care quality. Hamann (2014) suggests that including RCAs in such decision-making offers them an opportunity to advocate for decisions that facilitate greater consideration of relational care dimensions.

Meaningfully engaging RCAs in decision-making and care planning may also be facilitated through the use of empowered work teams (Yeatts & Cready, 2007). RCAs who were involved in management decisions pertaining to their work, and who met weekly to review residents' health conditions, new residents and their care needs, and

any issues of concern to the aides, experienced greater empowerment, autonomy and competency than RCAs in nursing homes with more traditional hierarchical management approaches. RCAs also became more aware of resident health conditions and were more likely to share information regarding the needs, uniqueness and preferences of residents. According to family members, RCAs were significantly more likely to listen, talk and care for the residents, and offer greater choice regarding when residents ate or bathed following the implementation of the work teams (Yeatts & Cready, 2007).

It is important to note, however, that in the above study RCAs' job satisfaction was diminished if team meetings detracted from their ability to complete their direct care duties (e.g., held at inopportune times), if opportunities for decision-making involvement were not routinely provided, or if management failed to routinely respond to the minutes of the RCAs' team meetings (Yeatts & Cready, 2007). Such a finding highlights the importance of ensuring appropriate organizational and management conditions are in place to support the work teams.

While few studies have specifically focused on staff personhood within the context of person-centred workplace practices, those that have underscore the key role of managers and workplace culture in facilitating care quality. Research exploring the experiences of caring and being cared for with paid nursing home staff (including RCAs) illustrated the importance of their own humanity being valued and acknowledged, of feeling connected to something larger than oneself, of knowing (individuals and situations) and being known, and of teamwork (Sikma, 2006). Organizational

characteristics, such as the provision of adequate staffing, equipment and supplies, a sense of trust (i.e., to do one's job with the freedom to make mistakes), and the ability to access the requisite information to carry out their work (via open communication with colleagues and supervisors), were not only viewed as essential to workers' capacity to care, but also to their sense of being cared for. With their personhood recognized and their own needs met, staff felt better equipped to care for their residents, thus reducing the potential for poor care/treatment of residents (Sikma, 2006).

The continued devaluation of RCAs' personhood has also been found to contribute to the ongoing issue of staff turnover. In a study by Bowers and colleagues (2003) dissonance between management rhetoric (i.e., 'we value you and your expertise') and messages embedded in organizational policies and practices (e.g., around staffing, absenteeism, orientation and compensation) led to RCAs feeling professionally and personally dismissed. RCAs experienced a general devaluation of their work, the skill and expertise they brought to their jobs overlooked and the effect of their work on residents' quality of care ignored, and a disparaging of their integrity, intelligence and commitment. Similarly, RCAs felt their managers and supervisors failed to distinguish between them on the basis of their skill and expertise, or their honesty, intelligence and commitment. For example, when unfamiliar, temporary staff were brought in to address staff shortages, RCAs perceived that management viewed all aides as interchangeable, thus dismissing their intimate knowledge of residents and its role in facilitating care provision. RCAs also encountered hallway interactions in which management would walk by without acknowledging their social greetings, leaving RCAs

feeling invisible (Bowers et al., 2003). Such practices repeatedly discounted RCAs' experiences as both workers and human beings.

Cognizant of the potential role of managers in developing person-centred workplaces, Tellis-Nayak (2007) studied the relationship between the quality of RCAs' managers and work environments, and RCA engagement (i.e., satisfaction, loyalty, commitment). Not surprisingly, RCAs' engagement deepened when managers cared about them and listened to them; that is, when managers assisted in times of job stress, created safe workplaces, ensured provision of adequate equipment/supplies and offered training to assist with difficult residents and families. Significant correlations between RCAs' ratings of management and workplace quality and families' ratings of residents' quality of life, quality of care and quality of service, underscored the association between person-centred workplaces and resident quality of life.

The importance of attending to the personhood of staff and its potential for influencing care is also highlighted in research by Scott-Cawiezell and colleagues (2005) who, in examining the link between working conditions and nursing home performance found that staff in facilities with high performance scores more frequently mentioned feeling involved, empowered and appreciated. In contrast, staff in lower scoring facilities felt underappreciated and unheard, received little communication about their roles or expectations and experienced a lack of cohesion or teamwork. Such findings are not surprising given that leadership teams in high scoring homes saw staff as their greatest asset, and provided recognition, reward and ongoing appreciation for staff members' efforts, while managers in low scoring homes indicated that staff were their

greatest concern, focusing on what they perceived to be staff members' lack of work ethic (Scott-Cawiezell et al., 2005).

Nolan et al. (2002) argue that good dementia care occurs only when the 'senses' (of security, continuity, belonging, purpose, achievement, and significance) are also experienced by front-line staff. The literature reviewed in this section illustrates how key features of the organizational environment (e.g., staffing practices, organizational policies and procedures, person-centred workplace practices) may impede the meeting of these senses. For example, minimal decision-making autonomy and care planning input potentially limits the ability of RCAs to feel part of a team with a recognized and valued contribution (i.e., a sense of belonging), or to feel that their care practice is valued and important, that their work and efforts matter (i.e., a sense of significance). Similarly, working short-staffed appears to limit care RCAs' ability to provide good care, and to feel satisfied with one's efforts (i.e., a sense of achievement), or to have the emotional demands of their work acknowledged (i.e., a sense of security).

While my research focuses on the influence of the organizational care environment on the provision of quality dementia care, it is recognized that such care does not occur in a vacuum. RCAs are not impervious to misguided notions about individuals with dementia as non-rational, non-autonomous persons or to the low social value ascribed to their work, just as care facilities are not impervious to the economic and political agendas and priorities of the surrounding social world (Baldwin & Capstick, 2007). In the same way that residents and staff are subject to the influence of the facility environment in which they live and work, so too are facilities influenced by the

larger regulatory and socio-political environment in which they are situated. The following section thus explores the potential of the broader socio-political context to influence person-centred care provision.

2.5 The Socio-Political Context and its Potential for Influencing Person-Centred Care Provision

In British Columbia, facility-based long-term care is licensed and regulated under the *Community Care and Assisted Living Act.* Within the *Act,* the *Residential Care Regulation* outlines a series of minimum requirements to which facility operators must abide. It details general physical standards (e.g., temperature, lighting, maintenance), and those specific to bedrooms, bathrooms, common areas and work areas, as well as staffing (e.g., character and skill, coverage) and care requirements (e.g., food service and nutrition, medication administration, restraint use, incident reporting).

In terms of staffing, the regulations are somewhat vague, noting that staff must simply be 'of good character' with the personality, ability and temperament necessary to manage or work with persons in care, and the training, experience and skills necessary to carry out duties assigned to them. Similarly, the regulations stop short of dictating specific staffing levels, noting only that employees on duty be sufficient in numbers, training and experience and organized in an appropriate pattern to meet residents' needs and assist with activities of daily living (i.e., eating, mobility, dressing, grooming, bathing and personal hygiene) in a manner 'consistent with residents' health, safety and dignity' (Government of BC, 2009). It therefore falls to regional health authorities to determine appropriate staffing levels. Consequently, considerable

variation exists across the province, with factors such as residents' care level and facilities' for-profit/not-for-profit status (McGregor et al., 2005), and a disparity in per-diem funding levels (Hospital Employees Union, 2009) also playing a role.

In contrast, the regulations detail, with considerable specificity, the state in which furnishings should be kept, the amount of useable floor space for bedrooms and lounge areas, the number of washbasins, bathtubs and toilets (relative to the number of residents), menu/nutrition planning and mealtimes. There is considerable emphasis on documentation, with regards to both resident care plans and facility policies and procedures. Yet, care plan requirements focus on medications, behavioural interventions, oral health care, nutrition, fall prevention and recreation/leisure. There is no mention of addressing resident independence, autonomy, choice or continuity of self.

Similarly, the regulations simply note that written policies and procedures should exist to guide 'staff in all matters relating to the care and supervision of persons in care'. Greater attention appears devoted to outlining the need for written policies and procedures regarding risk assessment, fall prevention, staff orientation and continuing education, complaint/dispute resolution, nutrition and medication monitoring, restraint use and appropriate record keeping. With little specificity detailing *how* resident care and supervision be conducted (e.g., in a person-centred manner), the meeting of residents' emotional and social needs again appears subsumed by the focus on physical aspects of care.

Research conducted by both Kontos et al. (2010) and DeForge et al. (2011) with front-line care staff (i.e., Personal Support Workers; PSWs) in Ontario care facilities reveal how the broader legislative context potentially shapes staff members' relationships with residents and curtails their ability to provide quality dementia care. Staff narratives highlighted the pervasiveness of a culture of compliance (to the standards outlined in the 2007 Ontario Long-Term Care Act), and the resultant sense of surveillance it created for front-line (and supervisory) staff (DeForge et al., 2011, p.121). The increased emphasis on documentation (of fluid and nutritional intake, toileting etc.) left staff feeling overwhelmed and that their priorities were inappropriately directed towards paperwork, as opposed to the residents. The danger, as Diamond (1986) observed, is that care becomes transformed into discrete, quantifiable and measurable tasks, with only the physical aspects of care monitored and documented. The social relations and emotional labour (integral components of person-centred care) are thus rendered invisible.

PSWs expressed concern over the increased standardization of care – a one-size-fits-all approach brought about by the legislation – that limited their ability to individualize care and thus discounted the insights gained from their daily interactions with residents (DeForge et al., 2011; Kontos et al., 2010). For example, staff in Kontos et al.'s (2010) study spoke of how the potential for food handling violations precluded flexible wake times for residents. If residents were to miss the initial 8 a.m. breakfast sitting, they would be served 'leftovers' that were subject to strict regulations (e.g., kept in the refrigerator, labelled, covered, to be reheated to a certain temperature), and as

dietary staff were on their own tight schedule, care staff would thus have to serve the food. This again highlights the influence of facility routines, and the clear demarcation of role boundaries associated with more traditional models of care, on care provision.

Interestingly, staff in both studies selectively challenged the rules, engaging in rule breaking or developing workarounds as a means of bypassing standardized care regulations (DeForge et al., 2011; Kontos et al., 2010). However, in contrast to previous work by Lopez (2006a) which found rule breaking to be routinized and to negatively influence care quality, rule breaking carried out by the PSWs was contextualized, a strategy to individualize care because of the presence of structural/political conditions that otherwise constrained their ability to do so (Kontos et al., 2010). Importantly, DeForge et al. (2011) and Kontos et al. (2010) emphasize that while workarounds offer an immediate, short-term solution to such structural conditions, their covert nature precludes change at either the institutional or provincial level.

2.6 Summary of Reviewed Literature

It is evident from the literature reviewed in the preceding sections that a series of gaps exist within the field of facility-based dementia care research, particularly with regards to RCAs' perceptions of care provision and the manner in which the organizational and socio-political care context shapes the nature of quality dementia care provision. Themes emerging from research examining professional staff perceptions of what constitutes good quality or person-centred dementia care dovetail with those identified by residents' as important to their care experience (e.g., respecting

dignity, striving to preserve residents' sense of self, autonomy and freedom, encouraging a sense of belonging, providing opportunities for meaningful occupation) (Kalis et al., 2005; Zingmark et al., 2002). Such studies, however, have primarily been conducted with supervisory staff and activity or social workers, as opposed to RCAs, and to date, none have examined the extent to which espoused perceptions are reflected in daily care practices.

Research examining the organizational care context illustrates the potential of inadequate or short-staffing (Banerjee et al., 2012; Bowers et al., 2000; Lopez, 2006a), staff assignment (Burgio et al., 2004), highly structured routines and protocol (Kontos et al., 2009; Hicks-Moore, 2012), limited participation in decision-making and care planning (Caspar & O'Rourke, 2008; DeForge et al., 2011; Kontos et al., 2009), and non-person-centred workplace practices to influence person-centred care. Similarly, the socio-political context has the potential to shape RCAs' relationships with residents and their ability to provide quality dementia care (DeForge et al., 2011; Kontos et al., 2010).

In order to address the above-noted gaps in facility-based dementia care research, this study explored the role of the organizational environment in the provision of quality dementia care. Key questions guiding the inquiry included:

1. What do RCAs perceive to constitute good quality dementia care?

2. To what extent do the everyday care practices of RCAs reflect their perceptions of good quality dementia care?

3. How does the organizational environment (e.g., staffing practices, policies and procedures, care routines) of the care facility impede or facilitate good quality dementia care?

In the following chapter, I describe the research process in greater detail including the theoretical perspective, methods and strategies employed, the study settings and sample characteristics, the analytic technique and the steps taken to ensure scientific rigour.

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CHAPTER 3: RESEARCH DESIGN

In this study, I sought to explore the experiences of residential care aides (RCAs) within the dementia care environment to better understand how they conceptualize quality dementia care, whether such conceptualizations are reflected in their daily care practice, and how the organizational care environment facilitates or impedes such care provision. To do so I required a theoretical perspective and method of inquiry that allowed me to comprehensively contextualize individuals' experience within the organizational environment. Hence, I utilized an ethnographic methodology, in particular, focused ethnography, which was informed by a political economy perspective.

This chapter outlines the research methods that guided this study. I begin by discussing the theoretical perspective, political economy, and the method of inquiry, focused ethnography. Following this, I describe the process for gathering data, including negotiating access and entry to the study sites, participant recruitment and data collection methods (i.e., participant observation, in-depth interviews and document review). I then discuss the data management and analytic techniques and strategies for establishing the scientific rigour of the study, concluding with a review of the ethical considerations related to the study.

3.1 Theoretical Perspective: Political Economy of Aging

At its core, ethnography is aimed at the study of social context, of the links between the micro and macro and of everyday interaction and wider socio-cultural

influences (Savage, 1994). Given that I sought to better understand the context of dementia care provision, a political economy of aging perspective potentially offered a useful lens through which to view my data. This perspective emphasizes the implications of political, economic and social relations for older adults and society's treatment of them (Estes, 1999) and, as such, is sensitive to the connections between the societal (i.e., macro-level), organizational (i.e., meso-level) and individual (i.e., micro-level) dimensions of aging (Estes, 2001). It explicitly acknowledges how structural influences, such as social relations and societal institutions (e.g., political and economic systems, ideology, gender, race, class), shape the meaning and experience of old age and the distribution of resources; that is, how individuals are defined and treated through the reproduction of prevailing power arrangements and inequalities (Estes, 1999; Estes, Biggs & Phillipson, 2003a). It thus draws attention to the processes that lead to empowerment and control for some, yet create dependency and powerlessness for others (Phillipson, 2006). A central dynamic is the contradiction between the social needs of individuals and how the organization of work (e.g., capitalist modes of production) and state actions around them, interact and affect these social needs (Estes, 1999).

Estes (2001) has developed a multi-level analytical framework of the political economy of aging that highlights the inter-relations between structural forces and individual experience. It positions the individual (public/citizen) at the centre of several multi-directional relationships between post-industrial capital, the state and the sex/gender system (that give rise to the medical-industrial complex and the aging

enterprise), which are in turn situated within the (oppressive) context of gender, class, race and age; all of which are nested within the dominant ideology and belief system of the political/economic regime (Estes, 2001). Of particular relevance to the current study is the framework's inclusion of the medical-industrial complex and the aging enterprise, which draws attention to health and long-term care policy as products of the relations between the state, capital and the sex/gender system (e.g., market-driven reforms and restructuring, commodification, privatization, medicalization). These aspects, along with the role of ideology and the systems of gender and class were particularly helpful in informing how I thought about my data. As Daly (2013) notes, much of the empirical and practice literature on care work is frequently situated at the micro-level, described and analyzed in terms of relationship (or lack thereof) between the care worker and care recipient. Drawing on a political economy perspective brings into focus the importance of the meso- (organizational) level, within which everyday care practice is enacted, and the broader socio-political context.

Within the neo-liberalist ideology that characterizes Canada's current political economy, market and business sectors are believed to be able to administer health and social programs more efficiently than politicians and bureaucrats (Estes, Wallace, Linkins & Binney, 2001). This has resulted in a determined push to substitute free market forces and private profits for the public mechanisms of the welfare state (Williams et al., 2001). As facility-based care is not an insured service under the Canada Health Act, increased opportunities are available for private, multi-national corporations to enter the sector. As a result, decisions regarding care provision are potentially made further

afield, with less concern for how care is provided than at what economic cost (Armstrong & Banerjee, 2009). Indeed, recent years have seen the increasing privatization of care provision, evident by the increasing number and influence of for-profit providers and the declining proportion of public providers, along with increased competition, in which market share and the bottom line dominate concerns of both profit and non-profit providers (Armstrong & Banerjee, 2009; Close & Estes, 1994). At the organizational level, such ideology is evident in labour restructuring; for example, diploma-trained Licensed Practice Nurses (LPNs), who have less clinical preparation than RNs (and are paid lower wages), are replacing degree-trained RNs as the source of licensed nursing staff in facility-based care (CIHI, 2004). With the priorities and provision of health services guided by a value system based on money and economics, there is little room for the humanistic values associated with the maintenance of personhood and person-centred care.

Neo-liberal restructuring reinforces and legitimizes the structural inequalities, ideologies, assumptions and practices that devalue and naturalize care (Campbell, 2013). Care work, at a rudimentary level, appears similar to work in the home, carried out primarily by women without formal training and understood as routine, manual, simple labour (Armstrong, 2013). As Innes and Surr (2001) note, '"perceptions of care work are intimately tied to notions of women's work traditionally carried out within the private sphere for little or no pay and with little perceived benefit to wider society and the public arena of work" (p.267). As such, the lower wage patterns associated with

such work appear to reflect a message of maternal self-sacrifice (Dodson & Zincavage, 2007).

Within a free market ideology, the value system and structural arrangements that influence the degree to which a particular group of individuals (e.g., older adults) is valued, is rooted in economics (Estes, Biggs & Phillipson, 2003b). In our productivity-focused society, aging individuals, especially those in nursing homes, are viewed as different, apart from and less than other members of society (Ronch, 2004). Believed to have little productive capacity, they are seen as a burden, their deservingness of health and social care determined solely by their current productivity (Estes et al., 2003b; Innes, 2002). Such a view permits a subtle rationalization of financial resources allocated towards older adults and their care (Ronch, 2004).

Perceived as a market opportunity, an entire 'aging enterprise' of programs, organizations, providers and industries has sprung up to serve older adults (Estes, 1993). In this manner, aging has been commodified, the needs of older adults processed and treated as something to be exchanged for money (Estes et al., 2001). As one of the fundamentals of a capitalist system is the expansion of markets for existing or new products, services for older adults (e.g., nursing home care) are embraced for their revenue-generating potential (Estes et al., 2001). The notion of nursing home care as something to be advertised, bought and sold is aptly captured in Diamond's (1995) well-known ethnography of nursing home care in the US. Such commodification entails the moulding of everyday care work into the language of business, concerned with profit margins, cost-accountability and the bottom line (Diamond, 1986). With a continual

focus on cost-containment, productivity and efficiency of service delivery, the emphasis is on care staff working faster, more efficiently and cheaper, which leaves little room for promoting resident well-being (Eaton, 2000; Tellis-Nayak & Tellis-Nayak, 1989).

Commodification redefines the social relationships inherent within care work; care is transformed into discrete, quantifiable and measureable tasks, a process which objectifies both residents and staff (Diamond, 1986). The resident becomes an object upon which care is performed (i.e., care 'done to' as opposed to 'done with'), while the caregiver, viewed as unskilled and replaceable, becomes the vehicle by which care is produced and profit exchanged (McLean, 2006; Lustbader, 2001). The relationship and commitment of caregivers to residents as persons thus becomes obscured as the fulfillment of human needs and the maintenance of personhood (of both residents and staff) are subsumed within the search for increased profit (McLean, 2006; Diamond, 1986; Armstrong & Banerjee, 2009).

By continuing to situate analyses of care provision at the micro-level, the blame for poor care remains primarily leveled at the RCAs. However, as widespread uptake of more individualized, social models of care remains limited, attention must also be focused on the larger structural features that potentially perpetuate the continued provision of traditional, custodial-based care. As such, adopting a political economy perspective helps draw attention to the larger socio-political context and its role in the organization and provision of quality dementia care.

3.2 Method of Inquiry: Focused Ethnography

Ethnography has its roots within the field of anthropology, its initial characterization that of prolonged immersion in a small and remote community, and the subsequent production of a supposed authoritative and unbiased account of the beliefs and practices of the group under study (Savage, 2006). Over time ethnography has experienced considerable diversification as its use has spread beyond traditional disciplinary fields (e.g., anthropology, sociology) to more applied fields (e.g., healthcare, education). Although there exists no single, agreed-upon definition of ethnography, it is typically characterized by an emphasis on studying a small number of cases, working with unstructured data, and exploring the routines and rituals, and beliefs and customs that individuals use to make sense of their world (Atkinson & Hammersley, 1994; Muecke, 1994).

Given that this somewhat generic description could readily apply to other qualitative methodologies, Savage (2006) provides further elaboration and clarification. She notes that key elements of ethnographic research (not all of which are necessarily present or similarly emphasized in all ethnographies) include: the recasting of everyday understandings and practices that are taken for granted; prioritizing the gaining of an emic, or insider's, perspective of a particular group; immersion in the life of the 'researched' over a prolonged period of time, where the researcher serves as the primary 'tool' for data collection; data collection that does not follow a pre-determined design, but rather is responsive to what is found in the field; and an analysis that focuses on understanding meaning or providing detailed description. In particular, Savage

(2006) asserts that it is the manner in which ethnography makes links between the micro and macro, everyday action or interaction and wider cultural formations through its emphasis on context that most noticeably separates ethnography from other qualitative approaches (p.385).

With its emphasis on context, ethnography lends itself particularly well to the field of health care research (Allen, 2004); however, certain aspects of the ethnographic tradition (e.g., focus on theory building, lengthy immersion in the field) are not always compatible with the limited budgets and fixed time schedules of applied health settings. Subsequently, a distinct branch of ethnography, known as focused ethnography, has emerged. Studies adopting this applied approach typically have a more narrow focus of inquiry, a predetermined topic of interest (with very specific research questions) and are context-specific (Muecke, 1994; Savage, 2006).

In retaining the focus on context, it is suggested that focused ethnography differs from the ethnographic tradition more in terms of degree (or scope) as opposed to in kind (Savage, 2006). For example, focused ethnographies still attend to the emic or insider perspective, but do so by focusing on actions, interactions and social situations by means of more time-limited field visits (Knoblauch, 2005). Similarly, the mixture of data sources typical to any ethnography (e.g., participant observation, in-depth interviews and document analysis) is preserved. What remains essential is that individuals are comprehensively and accurately contextualized within their social and physical environment (Muecke, 1994, p.203).

Given the above, focused ethnography offered the necessary methodological direction for exploring the influence of the organizational care environment on care provision. As talk (i.e., what people say in an interview) and action (what they do in practice) may differ, utilizing both participant observation and in-depth interviews provided a more holistic approach to understanding the relationship between the care environment and care provision. Focused ethnographies narrow in on the naturally-occurring situated performances that are present in everyday social interaction (Knoblauch, 2005); as such, they are particularly useful for analyzing the structures and patterns of interactions between RCAs, residents and the organizational care context during the provision of care. As noted by Savage (2006), focused or applied ethnographies can also be effective in uncovering the tacit skills and subtleties in jobs labeled as routine or unskilled (as the provision of care in a long-term care setting has been described). In this manner, a focused ethnography offered RCAs a rare and valuable opportunity to discuss the complexity of what they do.

It is important to recognize that ethnography is "neither wholly inductive nor wholly objective", but rather is shaped by historical circumstance, by the subjectivity and conceptual stance of the ethnographer, as well as by those with whom the ethnographer works (Muecke, 1994, p.195). Given that within ethnography the researcher functions as the primary research tool, it is essential that we articulate and attend closely to the worldview (i.e., values, belief systems) we bring to the research setting, so as to remain aware of its influence on data collection, and the interpretation and description of findings (Allen, 2004; Roper & Shapira, 2000).

My interpretive lens, or worldview, includes a belief in ontological realism, or what Guba and Lincoln (1994) refer to as historical realism. While I assume reality to be apprehendable, I view it as virtual or historical, shaped over time by a series of factors (e.g., social, cultural, political, gender, ethnic). Similarly, I hold knowledge to be both transactionist and subjective (Guba & Lincoln, 1994); that is, as something that is accumulated through an interactive process in which I (the researcher) and the researched mutually influence one another, with my stance and values inevitably shaping the results of the inquiry (i.e., knowledge is value-mediated and dependent). Applying this theoretical stance to my research means that I perceived RCAs working within the nursing home setting as subject to similar contextual forces that constituted a particular reality for them, and that my interactions with the aides led to a jointly-constructed knowledge of the influence of the organizational care environment on care practice.

The use of focused ethnography presupposes an intimate knowledge of (and familiarity with) the field to be studied (Knoblauch, 2005). Having worked in the field of dementia care for almost 20 years, in both a front-line (i.e., as an activity coordinator and casual activity worker) and research capacity, this knowledge is well-developed. However, such knowledge is a mixed blessing. While it helped me enter the field, speak the 'language' and establish credibility with participants, it had the potential to limit my angle of vision during my observations. Consequently, I sought to remain diligently aware of the biases and assumptions I brought to the study. Engaging in reflexivity (e.g., through journaling) throughout the course of the study helped me to better understand

the influence of my previous experience on the research process. The notion of reflexivity is discussed in greater depth in the subsequent section on establishing scientific rigour.

3.3 Data Gathering

3.3.1 Negotiating Access

Given the study's focus on examining the influence of the care environment on dementia care provision, I sought to select study sites with dementia care units that featured characteristics identified as promoting quality dementia care (e.g., Rabig et al., 2006; Verbeek et al., 2010); that is, units that were small in scale, housed fewer than 15 residents per unit, featured archetypal aspects of home and utilized a consistent staffing model.

In October 2012, I met with the Residential Health Services Administrator from the local health authority to identify potential study sites. She provided an overview of the complex care facilities within the local health service area that had specific dementia care units, noting the facilities' unique characteristics, the quality of care provided and which, if any, were currently involved in other research projects. Having previously worked in a dementia care unit in the area (which closed in 2003), I was familiar with some, but not all, of the sites mentioned and her comments were consistent with my knowledge of the sites. Several potential sites were identified[1] and the Administrator

1 One of which was immediately excluded as one of my extended family members was a resident.

agreed to contact two sites (Meadowview and Aspen Grove[2]) on my behalf, providing them with my research proposal, to gauge their interest in participating. While I had worked briefly (i.e., less than a month) at Meadowview as a casual employee almost 20 years ago, the facility had since been sold and rebuilt, and there were new management and front-line staff. By early December, both sites had expressed interest and thus I began discussions with them.

In late December, I received an email from my contact at Meadowview indicating that while the facility was very excited about the study, they were experiencing some leadership changes that precluded committing to any additional projects. Given the facility's interest and the flexibility of the research schedule, I suggested that I simply delay my fieldwork at the site by several months; they agreed and it was decided I would enter the field in late Spring 2013, by which time they believed things would be more settled organizationally.

I subsequently focused on negotiating access to the second site, Aspen Grove. Senior management, particularly the general manager, were very enthusiastic about the project and the general manager assured me they would be willing to assist with recruitment, both of staff (i.e., by distributing study material internally) and residents (i.e., by following up with families upon initial distribution of study material). However, shortly after our initial meeting in February 2013 the general manager went on sick leave and the workload of the other managers dramatically increased. While I had begun (albeit slowly) to recruit RCAs, it soon became clear that I would not be able to

2 In order to maintain anonymity, pseudonyms are used to refer to all study sites and participants.

recruit families without facility support. In early April, I received a short email from one of the managers, indicating that while they were supportive of the research, they could not accommodate my request for assistance with resident recruitment (i.e., contacting families to see if they would be willing to have their contact information forwarded to me so I could contact them to further discuss the project). Upon discussion with my supervisors, it was decided that I would withdraw from the site. I contacted the few RCAs who had provided consent and thanked them for their interest, but explained that given the difficulties recruiting residents, I was going to have to withdraw from the site.

In the meantime, another potential study site (Rivermead) recommended by the Residential Health Services Administrator had heard about the study and expressed interest in participating. Again, I was familiar with this site as they had participated in a research project[3] with which I was involved about 10 years ago; however, since that time the facility had experienced several management changes and none of the former participants were still alive. A former colleague of mine was working at Rivermead and put me in touch with the general manager, who was very excited about the study and eager to get started. She assured me that they had the organizational capacity to help with resident recruitment, and within the span of three weeks, the ethics committee at Rivermead's parent organization had approved the study.

3 Which focused on extracting information from residents' charts; consequently, I had no direct contact with participants.

3.3.2 Study Sites

Four dementia care units in two complex care facilities (Meadowview and Rivermead) in British Columbia, Canada served as the setting for this research. Both facilities were relatively new (open less than 10 years), purpose-built and home to 100-plus residents. The dementia units were small-in-scale, housed 10-11 residents per unit, featured archetypal elements of home and employed a consistent staffing model, in which RCAs were permanently assigned to their respective unit. While both facilities were privately-owned, Meadowview by a small, regional for-profit organization, and Rivermead by a larger, not-for-profit chain, they were publicly-funded. That is, they received a set per-diem rate from the provincial Ministry of Health for the majority of their residents, including those on the dementia units.

Meadowview

Meadowview's two dementia units shared an identical floor plan, although only one of the units had access to an outdoor courtyard. Each unit had four secured entrances/exits, three of which were controlled by a keypad, to which staff and visitors had the code, and one of which (off the kitchen) had a regular lock, for which only staff had a key. Both units featured single-occupancy bedrooms with an ensuite bathroom (i.e., toilet and sink); approximately half of the bedrooms featured ceiling track lifts that ran width ways across the room, but did not extend into the ensuite bathroom. Each bedroom was furnished with a single, hospital-style, bed, a nightstand, chair, a four-drawer dresser and freestanding wardrobe. While residents were able to bring small furnishings/personal belongings with them, not all of them had; hence there were

varying degrees of personalization in the décor. The units also featured several small sitting areas (one with a TV, another with a fireplace), a main dining area, a bathing room, a communal resident washroom, staff storage areas and a secure medication room. There was also a small kitchen, however it was deemed off-limits to residents. With the exception of a few breakfast items (e.g., dry cereal, toast) all meals were prepared in the facility's central kitchen and brought to the unit slightly ahead of mealtimes. Each unit had a secure medication room which, although initially designed to function as a nursing station, had neither a computer nor fax machine; subsequently, residents' charts were located at nursing stations on adjacent units.

Meadowview's staffing model followed the traditional nursing home hierarchy. RCAs were responsible for all resident care (separate departments took care of the units' housekeeping and laundry) and were supervised by an LPN, who was responsible for all medication administration. As the LPN for each dementia unit also oversaw two other units (for a workload of approximately 40 residents), they primarily entered the unit to administer medications or in response to RCAs' requests for assistance. A clinical practice leader was available to the units as a resource, although the position was eliminated partway through the study. The LPN reported to the Director of Care, who in turn reported to the general manager, both of whom had professional nursing designations.

Each unit was staffed with a combination of full-time and part-time RCAs. For the majority of the day (7:30 a.m. to 2:30 p.m.; 3:30 p.m. to 9:30 p.m.), there were two RCAs in each unit. Outside of these times, the units were staffed with one RCA;

between 11:00 p.m. and 7:00 a.m. each unit shared a RCA with a neighbouring unit. RCAs belonged to one of the larger health care unions in the province, and received an hourly wage of approximately $20 (British Columbia's hourly minimum wage at the time was $10.25), as well as medical and employment benefits.

Rivermead

Rivermead's two participating dementia units also shared an identical floor plan. There were two secured entrances/exits, each one controlled by a keypad for which only staff had the code. Residents' bedrooms were single-occupancy; however, they did not feature ensuite bathrooms and there were no ceiling track lifts (in the event a resident became non-weight bearing, they were transferred to another unit). Residents' rooms featured a single, hospital-style bed, a night-stand and a closet. Again, residents were encouraged to bring small furnishings/personal items with them, resulting in varying degrees of personalization in residents' bedroom décor. There were four communal bathrooms, each of which featured a toilet and sink, and two of which featured a bathtub or shower. Both units had one kitchen (off-limits to residents), two living rooms, each with a fireplace and television, two dining areas, a secure courtyard and a laundry room. Medications were stored in a secure cupboard in the kitchen area, along with the medication administration records and current care plan. As charting was predominantly computerized, each unit also had its own computer.

Rivermead's staffing model also reflected the traditional nursing home hierarchy; however, RCAs, were considered multi-skilled workers and as such were

responsible for all resident care, as well as medication administration, meal preparation, laundry (linens and residents' personal laundry), cleaning and recreational activities. One LPN oversaw both units (as well as two additional units; for a workload of approximately 40 residents) and reported directly to an RN, who in turn reported to the general manager. A clinical educator served as an additional resource person; however, the position was eliminated midway through the study.

In one of the units, what was once a second kitchen had been converted into an office and served as the nursing station for all the dementia units. Consequently, the LPN had a greater presence in this unit than the others. The LPN (and occasionally the RN) made a point of briefly connecting with RCAs at the start of the day shift to highlight any specific care issues; otherwise, their presence was limited to administering medications beyond the RCAs' scope of practice (e.g., insulin) or responding to aides' request for assistance.

All Rivermead RCAs were employed on a full-time basis. Each unit was staffed with two RCAs between 7:30 a.m. and 7:30 p.m., and one RCA from 7:30 p.m. to 7:30 a.m. At night, the units shared an LPN with the another part of the building. Rivermead RCAs belonged to the same health care union as Meadowview RCAs, and received an hourly wage of approximately $21, in addition to medical and employment benefits.

3.3.3 Negotiating Entry and Participant Recruitment

Laying the groundwork for the establishment of trust and rapport is essential to successfully negotiating entrée into the field (Kayser-Jones, 2003). Consequently, I

spent the first month (i.e., May 2013) at both sites introducing the study. Given the relatively small number of staff and residents working and living in each unit, participation was sought from all (i.e., day, evening and night-shift) RCAs and LPNs, and residents. Administrators at each site facilitated my initial access to potential participants by distributing an information letter and study brochure to RCAs and LPNs on the selected units, via their paystubs, and to senior management staff, via email. Study brochures were also distributed throughout the units, at the nursing station, in the staff room, on bulletin boards and at the facility reception desk. I also attended shift changeovers and regularly-scheduled staff meetings to speak with staff directly (i.e., to further explain the research process, to answer any questions staff may have and to request their potential participation).

Eligibility criteria for participation included: (i) a minimum of 3 months employment at the site, in a full-time, part-time or casual capacity; and (ii) willingness to provide informed consent. Between the four units there were a total of 28 full-time/part-time RCA positions and eight LPN positions; informed consent was received from 20 of these RCAs and three LPNs. Of the 13 non-participants (eight RCAs, five LPNs), only one RCA explicitly refused participation; the remaining 12 did not respond to my attempts at recruitment. For much of the study, two of the 16 permanent RCA positions on the Meadowview units (i.e., one per unit) were vacant, filled by a series of rotating casuals. Consequently, three casual RCAs who spent considerable time on the units were also approached, and in turn consented, to participate. Of the six senior managers at the two sites, five consented to participate. Again, the lone non-

participant did not explicitly refuse participation, but rather did not respond to my attempts to recruit them. Management were not informed of who participated in the research. In recognition of RCAs' time and effort, a draw was held at each site for a $100 gift certificate to a local shopping mall. Management and supervisory staff received no incentive for participation.

Given the study's focus on care provision (i.e., interactions between RCAs and residents with dementia) and the centrality of participant observation to data collection, it was imperative that the personhood of the resident be recognized and consent for their participation also sought, either from them or their proxy. Resident participation was thus contingent upon their or their substitute decision makers' willingness to provide consent and/or assent (a process which is described in greater detail in a subsequent section of this chapter).

Information letters and study brochures were mailed to each resident's primary family contact/substitute decision maker (residents under guardianship of the Office of the Public Guardian and Trustee were automatically excluded from the study as the Office considers it outside their jurisdiction to grant permission for research participation). Two information sessions (one morning, one evening) were held for family members at each site; however, only two family members attended, both of whom were from Rivermead. Family members were also contacted by a facility representative (at Meadowview, the administrative assistant; at Rivermead, a volunteer) and asked if they would be willing to have me contact them directly to discuss the project in greater depth. Family members who expressed interest were then

contacted by me directly, at which time I outlined the research process in greater detail, answered any questions and requested their resident's potential participation. Once I was on the unit and engaged in data collection, I had additional opportunities to speak to family members whom I missed when initially negotiating entry into the field.

Informed consent was received for 39 of a possible 52 residents. For three of the non-participating residents, the substitute decision maker could not be reached and one resident had no substitute decision maker (and was not registered with the Office of the Public Guardian and Trustee). Three substitute decision makers were not approached (due to fractured family relations/study nearing completion) and six substitute decision makers declined their family member's participation. As three residents passed away between the time consent was received and the start of data collection, the final sample included 36 residents. Again, management were not informed of which residents participated in the study.

I had initially hoped to conduct my fieldwork concurrently at both study sites. However, I quickly realized that doing so would limit my ability to fully immerse myself at each site. Hence, following discussion with my supervisors, the fieldwork was conducted sequentially. As recruitment was slightly further ahead at Meadowview, I started data collection there, spending six months on-site (from July 2013 to January 2014). I contacted Rivermead staff and families, explaining that data collection would be delayed several months; data collection subsequently began at Rivermead in January 2014 and concluded in late June 2014.

3.3.4 Study Sample

Participating RCAs were predominantly female, Caucasian and Canadian-born. They ranged in age from 34 to 64 years (mean 48 years), had worked as an RCA between 8 months and 25 years (mean 11 years) and had been employed at their current site between 6 months and 25 years[4] (mean 8 years). All of the aides had their RCA certificate, typically obtained following a 4-6 month community college course combining classroom and practicum experience. In British Columbia, it is mandatory for all RCAs working in publicly-funded (but not privately-funded) residential care facilities to be registered with the B.C. Care Aide and Community Health Worker Registry[5]. As both Meadowview and Rivermead are publicly-funded facilities, all participating RCAs were registered on the list.

The LPNs and management staff were also primarily female and Canadian-born. All (but one) held a professional nursing designation, had at least 10 years' experience in residential care and had been employed at their current site between 3 months and 10 years (mean 3 years). While LPNs were unionized, management was not.

Of the 36 participating residents, 23 were female and 13 were male. Residents ranged in age from 61 to 96 years (mean 82.7 years) and had resided on their current unit between 1 month and 7.5 years (mean 1.6 years).

4 As Meadowview had built a new facility, several RCAs had worked in the previous facility.

5 See http://www.cachwr.bc.ca

3.3.5 Data Sources

To address the research questions, a variety of data collection methods were used, including participant observation, in-depth interviews and a review of relevant documents (e.g., facility policies and procedures). Primary data collection lasted 12 months (July 2013 to June 2014), with 6 months spent at each site.

Participant Observation

Participant observation is characterized by the "interweaving of looking and listening, of participating and asking" (Lofland et al., 2006, p.18). It offers an opportunity to strategically link participants' actions and interactions with what is said, thus identifying congruencies and incongruences between the two (Roper & Shapira, 2000). For example, Funk and Stajduhar (2009) caution against uncritically accepting participants' interview accounts as reflective of their care experiences, noting that such accounts may be subject to processes of social desirability, reactivity and the influence of broader social norms and ideologies. Combining ongoing observations of participants' naturally-situated social action during immersion in the field with interview data thus has the potential to yield additional insight into the complexity of dementia care provision, providing a more nuanced account than that from interviews alone (Funk & Stajduhar, 2009). Consequently, over the course of the study, I conducted 239 hours of participant observations, during which I sought to explore the extent to which RCAs' everyday care practices reflected their perceptions of quality dementia care, and to understand how the care context influenced care provision. I focused my observations on RCAs' caregiving routines, their communication and interaction with residents,

colleagues and supervisors, and formal/informal meetings. As a novice ethnographer, I followed the advice of Emerson and colleagues' (2011) and limited my observations to intervals of 3 to 4 hours at a time, so as to lessen the likelihood of forgetting key details.

During the participant observations, I assumed the role of observer-as-participant; that is, I sought to be known and recognized by participants as a researcher, interacting with them 'casually and non-directively' (Adler & Adler, 1994, p.380). I always wore a nametag identifying my name and position (i.e., student researcher) and when staff, residents or visitors asked what I was doing, I would explain the study and that I was 'hanging out' on the unit. I functioned much like a volunteer would, assisting with the serving of snacks and meals, helping residents to the dining room, accompanying residents to group activity sessions (e.g., music therapy), and assisting residents at mealtimes (as directed by staff). Much of my time was spent sitting in the units' common areas (i.e., lounge, dining area). As residents tended to congregate in these areas, I frequently sat amongst them, interacting with them. I often had my pocket-sized notebook with me and while I sought to be discreet in my jottings, I did not seek to hide what I was doing. If a resident or RCA expressed interest in what I was writing, I would share one or two of the recent jottings. I also attended shift changeovers and staff meetings which allowed me to observe staff interactions and communication.

In addition to 'hanging out', I shadowed RCAs as they went about their daily routine (e.g., providing morning/evening care, completing unit tasks). Given the smaller, more confined physical spaces in which resident toileting and bathing occurred,

and the limited opportunity for me to situate myself unobtrusively within the space, no care provision was observed within resident bathrooms or bathing areas. Prior to each shadowing encounter, I obtained consent/assent from both staff and residents. Throughout the course of my observations, I engaged in multiple informal conversations with staff and residents, which allowed me to probe participants regarding the behaviours and interactions I witnessed. Doing so provided me with a better understanding of the relations and interactions between RCAs, their colleagues and residents than could be obtained during the more formal, semi-structured interviews (Fontana & Frey, 2005). Such conversations also served as a means of clarifying or validating my observations.

I adopted a flexible observation schedule so as not to restrict myself to a limited view of unit life. Observations were conducted on weekdays and weekends, at varied times throughout the day. I conducted a handful of early morning (i.e., 4:30 – 7:00 a.m.) and late night (i.e., 11:00 p.m. to 2:00 a.m.) observations, but as few, if any, residents were up at this time, I concentrated my observations between the hours of 7:00 a.m. and 10:00 p.m. Observational data gathering continued until saturation occurred, that is, when findings began to consistently replicate earlier material (Adler & Adler, 1994).

Observations were recorded through the writing of detailed field notes. Field notes are the means by which the ethnographer captures and preserves the descriptions and insights of the situations and events observed (Emerson et al., 2011). In an attempt to produce detailed recollections of the day's happenings, I expanded my field jottings (i.e., brief phrases, key words, verbatim snippets of conversation,

diagrams) into more fully developed, typewritten field notes as soon as possible upon leaving the setting. Such notes included concrete, sensory descriptions of the physical setting, the people present, conversations heard (both paraphrased and verbatim, the latter of which were distinguished through the use of quotation marks), actions and interactions, and verbal and non-verbal emotional expressions, as well as my general impressions and feelings about what I was seeing (Emerson et al., 2011; Lofland et al., 2006) (see Appendix A for the detailed field note guide). Consequently, my field notes were both descriptive and reflective, thus helping me achieve a sense of what Geertz (1973) describes as 'thick description'; that is, "describing and interpreting social actions within the context in which the actions occurred, capturing the thoughts, emotions and web of social interaction among participants, and assigning motivations and intentions for such actions, such that the reader experiences (or feels they could) the events being described" (Ponterotto, 2006, p.542/3).

As I wrote up my field notes I was careful to distinguish between description and interpretation, a process that was facilitated by entering the notes into an Excel spreadsheet. For example, the first column contained the descriptions of events observed, the second my impressions and reflections of such events, and the third my analytical/interpretive notes. Notes in the second column included my reflections on what I learned that day, what I had observed that was particularly interesting, what I found confusing, and whether what I was observing was similar or different to that which I had already observed (Emerson et al., 2011). A fourth column was used to flag observations and interpretation for which additional follow-up (e.g., clarification or

elaboration) was required, and from whom (e.g., specific RCA, LPN supervisor, manager) the additional information should be sought. I would then insert a sticky note into my notebook as a cue for the next time I entered the site.

In regularly reviewing my field notes, I began the analytic process, asking myself, what do I see going on here, what is the broader significance of what I am seeing, and how might larger structural constraints (i.e., concepts drawn from Estes' (2001) political economy of aging framework) be influencing what I am seeing. Regularly re-reading my field notes also allowed me to link what I was seeing with the interview data, both in terms of congruence and incongruence. For example, during the interviews several RCAs spoke of how, when they had spare time, they liked to pamper the female residents (e.g., curling their hair, polishing their fingernails); yet, I witnessed these same RCAs, when they did have spare time, retreat to the kitchen to check their email on their smart phone, chat with a colleague or complete a unit chore (e.g., putting away the dishes).

In-Depth Interviews

A key data source within ethnographic research, in-depth interviews seek to discover informants' views of a particular topic or experience offering an opportunity to gain information about experiences and events beyond those observed (Lofland et al., 2006). Over the course of the study, 37 semi-structured interviews were conducted. Participants were interviewed at least once, with some interviewed multiple times to more thoroughly explore emerging themes. The interviews were conducted at a

location of participants' choosing, on non-paid time, and lasted between 45 minutes and 2 hours. The majority of RCAs and LPNs elected to be interviewed off-site at a local café, while the remainder chose to be interviewed on-site but off-unit, prior to or following their shift. All management staff were interviewed in their offices, on paid time.

At the start of each interview, I collected relevant socio-demographic data (e.g., gender, age, length of time working as an RCA, length of time employed at site; see Appendix B). An interview guide, developed prior to entering the field, provided some structure to the conversations (see Appendix C). As an introductory ice-breaker, I asked RCAs/LPNs to describe their typical workday. Key questions included, "Tell me what it is like to work as a RCA/LPN on a unit for people with dementia?", "What do you think makes for good dementia care?", and "What aspects of the organizational (and physical) environment make it easy or difficult to provide such care?" Additional probes explored what made for a 'good' day, the extent to which they felt able to provide 'good' care, management support and the influence of policies, procedures and care routines on their work. Similarly, management staff were asked "Tell me what it is like to manage a unit for people with dementia?" Probes were then used to explore specific managerial, facility and unit practices and explanations about why things were the way they were.

Following each interview, field notes were typed to help recall interview specifics (e.g., date, time, location, and atmosphere), my initial impressions and my personal feelings (to elicit any biases or preconceived assumptions). As with the participant observations, interviews continued until data saturation occurred.

All but two of the interviews were audio-recorded (for these interviews, key discussion points were captured via handwritten notes) and transcribed verbatim by an experienced transcriptionist, who had worked with one of my supervisors. In an attempt to keep the nuances of the conversation from the audio-recording to paper, the transcriptionist was asked to record (insomuch as is possible, given the interpretive nature of transcription) what was heard, including hesitations and pauses (Tilley, 2003). Sections in which she was unable to distinguish the words being said were denoted using a series of dashes (---)(Bird, 2005; Morse & Field, 1995). In order to correct any errors that may have occurred during transcription, denote emotional expression and to fill in any blanks that I was able to recall, I reviewed each transcript while listening to the audio-recording. Doing so not only helped ensure the accuracy of the transcripts, thus contributing to the overall rigour of the study, but also offered an opportunity to gain initial analytic insights into the data (Lofland et al., 2006; Poland, 2002). For example, I began to notice that when asked to describe their day, RCAs' responses were strikingly similar, peppered with references to care tasks (e.g., dressing, toileting residents) and unit tasks (e.g., preparing breakfast, cleaning, tidying), with few if any references to the residents themselves.

Select Review of Relevant Documents

In light of the focus on the care environment, I also conducted a select review of facility documents and Licensing regulations, guided by participants' references to such documents/regulations and observational data. Reviewed documents included formal job descriptions (RCAs and LPNs), shift routines, relevant staff memos (e.g.,

documenting changes to care delivery processes), staff meeting minutes, relevant formal policies and procedures (e.g., attendance policies, compensation policies) and provincial licensing regulations (e.g., meal service) (see Appendix D for a complete list). Such documents helped provide context to the observational and interview data (Hammersley & Atkinson, 2007). For example, in reviewing the RCAs' job descriptions I noted that while reference was made to respecting residents' uniqueness, dignity, self-worth and promoting functional independence, the descriptions were heavily weighted towards the functional nature of the RCAs' work (e.g., meeting residents' activities of daily living, keeping the environment clean and safe) with little mention of the relational aspects of care.

3.4 Data Analysis and Interpretation

To facilitate data management and analysis, all transcribed interview and field note data were entered into a computer-assisted qualitative software program (NVivo 10). Consistent with qualitative research, data analysis and data collection were conducted concurrently, resulting in an iterative process of data generation, management and analysis (Hammersley & Atkinson, 2007). This dynamic process allowed me to dig more deeply into issues that appeared particularly salient to the RCAs. For example, 'keeping things calm' was an expression that appeared relatively frequently in the initial interview transcripts. Similarly, during my observations I noticed that RCAs devoted a good deal of time and effort to keeping residents, the environment and their co-workers calm. Hence, in subsequent interviews and informal conversations RCAs were asked to elaborate on why 'keeping it calm' was so important to their work.

My analysis was facilitated by multiple, line-by-line readings of the transcripts and field notes (Lofland et al., 2006) which resulted in the generation of codes (documented in a codebook), derived from recurring patterns in participants' narratives, behaviours and activities. During the initial coding of the transcripts, I focused attention on participants' emotions, their emphasis on particular words, and the ideas they expressed with regards to the care environment and quality dementia care provision (Miles & Huberman, 1994). When initially coding the field notes, I focused on what the observed event, behaviour, or interaction might represent, what it was an example of and what was being said and done (Lofland et al., 2006).

Initial codes focused on key descriptive terms and phrases, e.g., 'teamwork', 'communication', 'workarounds', 'management support', 'co-worker relationships', 'role talk'. These codes were then clustered into thematic categories, compared and contrasted within and between data sources, and subsequently refined, leading to the development of themes (Miles & Huberman, 1994; Saldana, 2013). For example, the codes 'teamwork, 'co-worker relations' and 'LPN support' were brought together under the theme, 'on valuing and negotiating relationships'. Simultaneous data collection and interpretation facilitated the exploration, collapsing and expansion of themes from earlier interviews and observations and the tailoring of subsequent data collection to emerging themes.

It was through this process that I came to realize the salience of the organizational environment for the RCAs in their daily care provision. I had initially planned to explore how both the physical and organizational care environment

facilitated or impeded dementia care provision; however, RCAs experienced difficulty articulating how the physical environment influenced their work with residents and colleagues, and whether, as a result, care provision was made easier or more difficult. In contrast, my formal and informal conversations with RCAs were permeated with references to the organizational care context, as they spoke passionately and at length about how it influenced their care provision and relationships. Similarly, the observational data highlighted the impact staffing coverage, formal and informal policies and procedures, co-worker and supervisor relationships, access to resident information and human resource management practices (e.g., vacation/sick time) had on RCAs' care experiences. As such, I focused in on the role of the organizational, rather than the physical, care environment. This is not to say that the physical environment is not important in dementia care provision, but rather that organizational issues emerged as more immediate in influencing RCAs' care practice, thus warranting further in-depth exploration.

Throughout the course of data collection and analysis, I utilized memos to reflect on the research process and fieldwork incidents (e.g., witnessing verbal abuse between an aide and resident), to capture my insights and ideas about emerging codes/themes, and to conceptually link codes and explore how they related to larger structural issues (Lofland et al., 2006; Roper & Shapira, 2000). Estes' (2001) analytic framework of the political economy of aging was particularly useful here as I drew on concepts of neo-liberal ideology, market-driven reforms and restructuring, commodification of care, medicalization, gender and class to help interpret and explain why I was seeing what I

was; for example, why task completion continued to be prioritized over relational care, why RCAs experienced ongoing disempowerment, and why management-RCA relations were marked by a lack of recognition, respect and trust. Such documentation was fundamental to the overall analytic scheme, for it provided an intermediate step between coding and the first draft of the completed analysis (Lofland et al., 2006).

3.5 Establishing Scientific Rigour

Over the past 25 years, there has been much discussion and debate as to how to demonstrate and assess the quality, or rigour, of qualitative research (Sandelowski & Barroso, 2002). While it is well-recognized that the traditional, positivist criteria for establishing scientific rigour (e.g., internal/external validity, reliability, generalizability) are not applicable within the qualitative paradigm, consensus has yet to be achieved as to which criteria should be used to establish 'qualitative goodness' (Tracy, 2010). Regardless of the criteria used, I agree with Guba and Lincoln (2005) that the underlying question to be answered is,

> *"Are the research findings sufficiently authentic that I may trust myself in acting on their implications? More to the point, would I feel sufficiently secure about these findings to construct social policy or legislation based upon them?' (p.205).*

Common to a number of the criteria proposed in the literature are the elements of reflexivity, triangulation, member checking and auditability. The following section outlines how I drew on these elements to establish the trustworthiness and authenticity of the findings.

3.5.1 Reflexivity

As social researchers we are part of the social world which we study (Hammersley & Atkinson, 2007), such that our role in the research setting is intimately connected to that which we discover (Allen, 2004). The practice of reflexivity requires accounting for our 'selves' in the research process, making transparent how our personal assumptions, values and biases may influence the research process (Miles & Huberman, 1994; Cutcliffe, 2003). It entails attending to our social positioning (e.g., our age, gender, race, professional status) and its influence on how we are received in the field and our interpretation of the data (Allen, 2004; Patton, 1999).

As noted previously, having worked in the field of dementia care for a number of years, I am intimately familiar with residential care settings; however, such familiarity carries with it the risk that certain behaviours may be overlooked, and assumptions or judgements made about the meaning of certain events without clarification being sought (Allen, 2004). Through engaging in reflexive journaling, peer debriefing and ongoing discussions with my dissertation supervisors, I continually examined, and sought to understand, how my experiences influenced the way in which I asked questions and interpreted the data, and how in turn I might be influencing study participants.

Negotiating my social positioning within the field was an integral part of my reflexive practice. As a white, relatively financially-comfortable individual with a recreation background and in pursuit of an advanced degree, I entered the field in a position of power within the care facility hierarchy. Given the relatively small

community of residential care and the mobile workforce, I was also known to several participants, having either worked in the same facility (long-since closed) with them (albeit in a different department) or with colleagues/friends of theirs. While I questioned whether these participants would feel obligated to participate, they appeared eager to reflect upon and share the changes they had witnessed in the field of dementia care.

Given my positioning, I took great pains to 'demonstrate my roots in ordinary practice' (Allan, 2004, p.21). I dressed in a manner similar to that of staff, with minimal make-up and jewellery. I conducted participant observations in the early morning and late evening, as well as on weekends, and was willing to pitch in (e.g., walking with an agitated resident) when asked, all in the hopes of (somewhat) leveling the perceived status differences between myself and the RCAs. In a number of ways my attempts to do so were successful; RCAs appeared to treat me as an 'insider', as someone familiar with the roles and functions, care procedures and equipment associated with dementia care. This was particularly evident in the language RCAs used to explain unit or care practices (e.g., HS care, sit-to-stand lift, MARs[6]). However, I had to remain diligently alert to comments such as 'well, you've worked in the field, you know what I mean', so as not to impose my interpretation from my own experience. In such instances, I would nod in agreement while following up with 'how?' or 'could you explain a little more?'.

6 HS care refers to evening or bedtime care; it comes from the Latin 'hora somni' meaning 'at bedtime'. MARs refers to the Medication Administration Records; that is, the sheets on which medication administration is documented.

While RCAs may have seen me as an insider, they also ascribed to me the role of 'expert', occasionally seeking my thoughts on a particular resident's behaviour, or on something they had read about dementia care practice. In such instances, I carefully weighed my responses, offering a thought or two, but encouraging them to raise the issue with their LPN. While I strived very hard not to overstep my mark, given that I was in the facility as a researcher not as a practitioner or consultant, I also felt the pull of reciprocity. Throughout my fieldwork, RCAs were candid in sharing their experiences; they spoke freely (and passionately) about the frustrations and rewards of their work and of their relationships (e.g., being 'bullied', altercations with colleagues/supervisors). Hence, when appropriate, I saw sharing my knowledge as a way of reciprocating, or 'giving back'.

When it came to sharing their experiences, RCAs noted that I was one of the few, if not the first, to express an interest in their work. The power that participants imbued in me as a result was something for which I was unprepared, and at times, felt quite overwhelming. For example, one long-tenured RCA indicated that being asked about her experiences and having the opportunity to share her insights as part of the interview process was a career highlight. Another, upon receiving the transcript of our interview, shared it with her daughter who responded by telling her how proud she was of her for the work that she did. The RCA explained how she had in turn left the transcript out on her dresser to serve as a daily reminder of the importance of her work, and how far her practice had come since she had first started. One of the LPNs concluded our last conversation with, "all of us, myself included, feel fortunate to have had the opportunity

to say what we think because we don't always get that opportunity". Consequently, in documenting the research findings I have felt great responsibility in trying to accurately portray/represent the voices of individuals who so often are not heard. At the same time, such comments lend a sense of credibility to the findings.

The issue of positionality and power was brought to the forefront when I happened to witness an episode of verbal abuse between a participating RCA and a resident. As documented in the letter of informed consent, I was obliged to report such incidents. As a result of my reporting, an investigation was immediately launched and both the RCA who perpetrated the abuse and the RCA who witnessed the episode (and who did not step forth to report her colleague) were suspended with pay. Upon my return to the facility, the week following the investigation, I addressed the issue 'head-on'. While I told RCAs that I could not speak to what happened, I explained that I was legally obligated to report the incident, and that it served as a reminder of the importance of supporting the difficult work done by RCAs. During these conversations, several RCAs highlighted their frustration, explaining that when they reported instances of poor practice/abuse little, if anything happened. The immediacy of management's response to my reporting thus served to reinforce the lack of power and voice experienced by RCAs.

While one of the managers suggested that my fieldwork at the site was likely over, the trust and rapport I had sought to establish with RCAs potentially shattered, my experience proved otherwise. In conversations with RCAs upon my return, I explicitly asked whether they were okay with my continued presence on the unit. With the

exception of the RCA who perpetrated the abuse and subsequently labelled me a 'spy', all indicated that they were, which could be interpreted as a testament to the concerted efforts I had made to establish trust and rapport over the course of the fieldwork.

Practicing reflexivity was particularly important in helping me attend to the internal pull I felt between researcher and practitioner; a pull which at times (e.g., upon my initial entry into the field) was exceedingly strong. For example, at both study sites, there was minimal activity programming for the residents, which meant that outside of care activities, mealtimes and the occasional structured activity program, residents were left largely to their own devices. Given my background in recreation programming, such absence of activity impacted me deeply; I found it very difficult, when not shadowing staff, to simply 'sit' in the common areas, particularly when a resident was becoming increasingly agitated. Hence, at times, when RCAs (typically casual staff) did not respond to an escalating episode of agitation, I did 'interfere', for example, sitting beside an agitated resident, holding their hand and engaging them in song or reading a book; my rationale was that as a researcher exploring care quality (and as a compassionate human being), it was unethical to sit there and do nothing.

Upon my initial entry into the field, I also struggled with my preconceived notions as to what constituted person-centred care. At times, I would come home and express (either through journaling or peer-debriefing with a student colleague) my frustrations at witnessing particularly task-oriented care practices. However, as the study, and my analysis, progressed I came to realize that many of the RCAs cared deeply for their residents, acting with compassion and kindness in situations that were at times,

not of their own making. As such, I was forced to challenge my assumptions and beliefs about the provision of quality dementia care; acknowledging and exploring these assumptions and beliefs in turn helped me better understand and interpret the influence of larger structural issues within the care context.

In addition to journaling my thoughts and experiences, monthly discussions with my supervisors and bi-weekly debriefing sessions with a fellow doctoral student provided ongoing opportunities to address the issues arising from my fieldwork and emergent study findings. Such discussions were invaluable in helping me step away from the field to examine the issues with individuals not as emotionally invested in the study sites and participants.

3.5.2 Triangulation

Within qualitative inquiry, triangulation involves the comparison of data relating to the same phenomenon but derived from different data collection techniques, phases of fieldwork, or participants with different perspectives (Hammersley & Atkinson, 2007). Several authors highlight that the point of triangulation is not to demonstrate that different data sources yield essentially the same results (Patton, 1999), or that the aggregation of data from such sources will unproblematically lead to a more accurate or complete picture (Hammersley & Atkinson, 2007). Rather, it is suggested that triangulation be viewed as a means for testing consistency, with an emphasis on studying, and attempting to understand, when and why differences or inconsistencies arise (Patton, 1999). In this study, triangulation was achieved by utilizing a combination

of different procedures (e.g., interviews, observations, document review) and collecting data from participants with differing points of view (e.g., RCAs, supervisory staff, management) at two different sites, thus exposing congruence and incongruence within the data.

3.5.3 Member Checking

Member checking refers to the process of ensuring that participants have input into the interpretations of their experiences by the researcher (Sandelowski, 1993). While initially conceptualized as a continuous process during data analysis, member checking is predominantly used by researchers to verify the overall results with participants (Morse, Barrett, Mayan, Olson & Spiers, 2002). However, this is potentially problematic as the results will have been synthesized and decontextualized such that individuals looking for their own selves and reality in the account may not recognize themselves or their experiences (Morse et al., 2002; Sandelowski, 1993). Hence, following Tracy's (2010) suggestion, I also sought input from participants during the analytic process. Emerging interpretations were shared with participants during informal interactions (e.g., in conversation as participants went about their daily routines) and with key informants once data collection was complete. I also developed closer relationships with several key informants with whom I had more regular one-on-one conversations over the course of the study. In addition, I offered participants the opportunity to review the transcripts of our interview(s); more than half expressed interest in doing so. Each of these approaches offered opportunities for participants' questions, critique and feedback. As such, member 'reflections' were not so much a

test of the findings, but rather an opportunity for collaboration and reflexive elaboration (Tracy, 2010).

3.5.4 Auditability

Auditability entails the use of an audit (i.e., decision) trail that clearly documents the researcher's decisions, activities, choices and insights regarding the research process thereby allowing the reader to assess whether the researcher's interpretation is supported (Onwuegbuzie & Leech, 2006; Savage, 2006; Tracy, 2010). In this study, the audit trail was documented in my research log, which included a detailed study timeline and notes as to how and why decisions were made.

3.6 Ethical Considerations

Ethics approval was received from the University of Victoria Research Ethics Board, the local health authority and the participating facilities. As noted previously, a letter of initial contact (see Appendix E) was provided to all unit staff and residents' families/substitute decision makers at the outset of the study, outlining the study purpose and emphasizing the voluntary nature of participation and the ability to withdraw from the study at any time. Prior to formally beginning data collection, I sought informed consent from all participants, with separate consents used for the observation and interview component of the study (see Appendix F). Given the continual nature of participant observation, informed consent was seen as an ongoing process. During fieldwork, I continually reminded participants of who I was and why I was in the setting. My small, pocket-sized notebook in which I made field jottings, also

served to remind participants that I was collecting data. It is important to acknowledge that RCAs and supervisory staff who were not active study participants, but who were aware of my position as a researcher, also initiated informal conversations with me during my time in the field. However, as these individuals had not provided informed consent, I took no notes on these conversations and did not use them in my analysis.

Given the nature of the study, it was difficult to ensure anonymity of participation as I was seen spending one-on-one time with staff. Consequently, I ensured that there was a time lapse between consent provision and the staff member's interview/involvement in participant observation, thus giving them time to reflect on their consent and an opportunity to change their minds should they desire (although no one did). In order to further protect anonymity, all participating staff, regardless of gender, were referred to as female in both the analysis and the writing of this dissertation report.

Once in a typed format, all data (i.e., field notes and transcripts) had any identifying markers, such as names and locations, replaced with pseudonyms or removed so as to protect the anonymity of participants. Only the anonymized data was shared with my dissertation committee for the purposes of analysis. All consent forms and data were stored in separate locked cabinets accessible only to me.

3.6.1 Obtaining Informed Consent from Residents with Dementia

Conducting research in residential dementia care entails important ethical considerations related to the inclusion of individuals with dementia, considered by

ethics boards to be a 'vulnerable' population. The process of obtaining informed consent from individuals with dementia is inextricably linked to the determination of their capacity to consent; that is, the extent to which they are able to understand the information presented (i.e., the nature of the research), to appreciate the implications of participation, and to make a reasoned choice (Cubit, 2010). While capacity can be viewed as largely situational and dependent on the complexity of the decision (Dewing, 2007), the difficulties with comprehension, judgement, communication, reasoning and remembering that typically occur with more advanced dementia may limit decision-making capabilities (Hubbard et al., 2002), and the ability of the individual to fully express their concerns or reservations (van Baalen et al., 2010).

For individuals with dementia who lack capacity to provide free and informed consent on their own behalf, the use of proxy consent can be considered a more appropriate approach (Bartlett & Martin, 2002; Sherratt, Soteriou, & Evans, 2007). Central to this approach is the belief that the proxy (most commonly a family member) has knowledge of the individual prior to their onset of dementia and that the decision to consent will be based on the individual's best interests. However, research has revealed potential conflict between people with dementia and their proxies when consenting to research (McKeown et al., 2010). Consequently, here in Canada it is required that assent be sought from the individual with dementia prior to each research encounter (Hubbard et al., 2002; Sherratt et al., 2007; Slaughter et al., 2007).

Given that the ability of individuals with dementia to provide consent or assent can fluctuate over time, in this study, residents' ability to provide consent/assent was

seen as an ongoing process as opposed to an a priori event (Bartlett & Martin, 2002; Hubbard et al., 2002). While I had initially anticipated using a combination of informed consent, and informed consent by proxy and assent, it became evident during my initial observations and interactions with residents, and in conversation with staff and family members, that unit residents did not have the capacity to provide informed consent. Consequently, I sought informed consent from residents' proxies (i.e., substitute decision makers) and assent from the residents. During my conversations with proxies about the consent process, I garnered background information as to how their resident expressed discomfort or decreased well-being to better facilitate my understanding of what an expression of assent or dissent would look like for each resident. Resident assent was sought prior to each contact (e.g., when shadowing staff) to ensure that residents had the opportunity to agree or refuse participation in the encounter. When obtaining assent, I drew on my expertise from my previous work with individuals with dementia to speak to residents using language appropriate to their cognitive status. Residents for whom proxy consent was not received (n=13) were not included in the research; similarly, when a resident refused to assent to an encounter (which happened only two or three times), I did not pursue the observation.

3.7 Introduction to the Study Findings

Having detailed the theoretical perspective and research methods guiding this study, I now turn to the study's key findings, which are presented in the succeeding three chapters. Following the University of Victoria's format for a publication-based dissertation, each chapter is a stand-alone manuscript to be submitted for publication.

Chapter 4 addresses RCAs' conceptualizations of quality dementia care. It highlights the role tensions experienced by RCAs as they sought to incorporate social interaction with task completion and co-workers' conflicting expectations. Quality dementia care was articulated, and exhibited in RCAs' daily care practice, as that which focused on tangible care outcomes (i.e., keeping residents clean, comfortable, calm and happy), their care approach (i.e., being compassionate, patient and affectionate) and was guided by family ideology. Chapter 5 illustrates RCAs' experiences of disempowerment; that is, their lack of decision-making authority and the repeated discounting of their opinions and observations by supervisors and management. It examines how, in drawing on and negotiating their peer and supervisory relationships and selectively breaking procedure, RCAs sought to 'care in spite of' such disempowerment. Chapter 6 explores RCAs' experiences of personhood, demonstrating the dissonance that exists between RCAs' experiences and the conceptual/theoretical ideals espoused in the literature. It highlights the centrality of management-staff relations (i.e., RCAs being known and valued by their managers) and workplace policies and practices (i.e., work-life balance, staffing coverage, human resource management practices and information sharing) to RCAs' sense of personhood. Following these three chapters, a final discussion chapter draws out the key insights and associated implications and recommendations emerging from the research.

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CHAPTER 4: RESIDENTIAL CARE AIDES' CONCEPTUALIZATIONS OF QUALITY DEMENTIA CARE

4.1 Background

In recent years, there has been a paradigmatic shift in facility-based dementia care, as providers seek to move beyond a highly-scheduled, task-oriented, medical model that prioritizes physical care to more individualized, social models. Such models emphasize the uniqueness of the person with dementia (PWD), flexible care routines respectful of residents' values, preferences and needs, the development of consistent and caring relationships, and an enriched social environment (Brooker, 2007; Edvardsson, Winblad, & Sandman, 2008).

Central to these models is the notion of person-centred care (PCC), a philosophy advocated by Kitwood in his writings on dementia and personhood (Brooker, 2007). Kitwood (1997) viewed the essence of quality dementia care as the enhancement and maintenance of personhood; that is, the recognition, respect and trust engendered when status is bestowed upon one human being, by others, in the context of relationship and social being (p.8). However, while PCC is increasingly viewed as synonymous with quality dementia care (Brooker, 2007), its widespread adoption and integration remains elusive (Talerico, O'Brien & Swafford, 2003). As such, greater examination is required of care provision and the experiences of the Residential Care Aides (RCAs; also known as nursing assistants/aides) who, in providing the majority of hands-on care, wield enormous practical influence albeit little formal power (Jaques & Innes, 1998). This paper explores RCAs' conceptualizations of quality dementia care,

whether they act upon such conceptualizations and the contextual factors potentially influencing their conceptualizations.

While the world of the care aide has been explored in several ethnographies (e.g., Diamond, 1985; Lopez 2006), none have focused specifically on dementia care settings. Rather, much greater effort has been expended on exploring the experiences of 'professional' staff (e.g., nurses, ward managers, activity staff, social workers) (Kalis, Schermer & Van Delden, 2005; Zingmark, Sandman & Nordberg, 2002).

To date, the majority of studies examining RCAs' experiences have focused on caregiver attitudes and job satisfaction (e.g., Zimmerman et al., 2005), job strain/stress (e.g., Brodaty, Draper & Low, 2003; Ejaz, Noelker, Menne & Bagakas, 2008), and the influence of the regulatory environment (e.g., DeForge, van Wyk, Hall & Salmoni, 2011; Kontos, Miller, Mitchell & Cott, 2010). Few have explored staff perceptions of what constitutes quality care for individuals with dementia (e.g., Edvardsson, Fetherstonhaugh & Nay, 2010) or how staff construe daily care provision (e.g., Chung, 2013; Colomer & de Vries, 2014).

Key themes identified in studies examining predominantly professional staff perceptions mirror conceptual/theoretical aspects of PCC; that is, attending to individual needs, preserving residents' sense of self, respecting dignity, adopting flexible care routines and facilitating resident well-being (Kalis et al., 2005; Zingmark et al., 2002). However, Stockwell-Smith and colleagues (2011) found RCAs' narratives regarding personal and peer practice bore little resemblance to the person-centred philosophies espoused by management. While RCAs considered interacting with residents the most

enjoyable aspect of their work, residents' needs were peripheral to their narratives. RCAs defined their roles as the completion of tasks within an allotted time frame, which Stockwell-Smith et al. suggest was due in part to standardized care practices.

This tendency to describe good care in traditional task-oriented ways has been noted in several studies (Chung, 2013; Colomer & de Vries, 2014), where RCAs highlighted the importance of resident cleanliness, comfort and happiness. Yet RCAs also emphasized conducting care in an affectionate, patient, flexible and respectful manner, thus highlighting the implicitness of the humanistic philosophy of respect, a central tenet of PCC (Colomer & de Vries, 2014).

Exploring RCAs' conceptualizations of care entails clarifying the assumption that how RCAs think about care and/or residents guides their care delivery. Anderson and colleagues (2005) found RCAs utilized two 'mental models' – 'the Golden Rule' and 'mother wit' to interpret care situations and determine the relevant action. The 'Golden Rule' steered RCAs towards treating residents as they themselves would want to be treated, while 'mother wit' drew on RCAs' experiences as mothers, guiding them towards treating residents as they would their own children. The use of such models, however, potentially impedes the provision of PCC. Focusing on one's own preferences and desires could preclude learning (and acting upon) residents' individual preferences, while likening care duties to those of a mother or child-care worker may serve to infantilize residents (Anderson et al., 2005).

In a similar study, RCAs perceived residents in one of three dominant ways – as fictive kin, a commodity and an autonomous person (Fisher & Wallhagen, 2008). RCAs

who viewed residents as fictive kin highlighted the emotional connection between themselves and residents, their care practices highly-attentive, protective and respectful. Those who framed residents as a commodity tended to objectify residents, ensuring residents were well-groomed and dressed, such that they could be deemed 'lounge-quality' (p.30). RCAs who construed residents as autonomous persons emphasized their reciprocal relationships with residents, and resident independence, choice and autonomy, thus exhibiting practices most closely resembling PCC.

As RCAs provide the bulk of the hands-on, day-to-day care, they possess considerable capacity to shape the daily life experiences and well-being of PWD. Yet research suggests dementia care ideals espoused in the literature or by management/professional staff do not necessarily align with those of front-line staff. As part of an ethnographic study focused on the influence of the care environment on dementia care provision, I examined how RCAs conceptualized quality dementia care, whether they acted upon their conceptualizations, and how the care context might engender or hinder such conceptualizations. The study was informed by several concepts from Estes' (2001) framework of political economy of aging, specifically the role of ideology, the commodification of care, medicalization and gender.

4.2 Study Design and Methods

4.2.1 Sampling

Four dementia units in two complex care facilities in British Columbia, Canada were purposively selected for the presence of features advocated to promote quality

dementia care (e.g., Verbeek et al., 2010); small in scale, they housed 10-11 residents each, featured archetypal features of home and employed consistent staffing, with RCAs permanently assigned to their units. Both facilities were purpose-built, and had been open less than 10 years. While privately-owned (Meadowview[7] by a small regional, for-profit organization, and Rivermead by a larger, not-for-profit chain), both were publicly-funded, receiving a set per-diem rate from the provincial Ministry of Health for the majority of their residents.

Meadowview

Meadowview's dementia units shared an identical floor plan, featuring private bedrooms with ensuite bathrooms, a small kitchen, several small sitting areas and a dining area. Each unit was overseen by an LPN, responsible for all medication administration. RCAs were responsible for all resident care; separate departments took care of housekeeping, laundry and meal preparation. Each unit was staffed by two RCAs, except from 2:30-3:30 p.m. and 9:30-11:00 p.m. (when one RCA was on), and between 11:00 p.m. and 7:00 a.m. (when neighbouring units shared a RCA). Members of one of the larger health care unions in the province, RCAs received an hourly wage of approximately $20, and medical and employment benefits.

Rivermead

Rivermead's dementia units also shared an identical floor plan, with private bedrooms, four communal bathrooms (two with bath/shower facilities), a kitchen and

7 Facility, resident, and staff names are all pseudonyms.

two dining and sitting areas. Both units were overseen by an LPN and staffed with two RCAs between 7:30 a.m. and 7:30 p.m., and one RCA from 7:30 p.m. to 7:30 a.m. Considered 'multi-skilled workers', RCAs were responsible for all resident care, including medication administration, meal preparation, cleaning and laundry. Members of the same union as Meadowview RCAs, they received similar benefits and were paid approximately $21 per hour.

Recruitment

Following approval from the University and Health Authority Research Ethics Boards, all RCAs and LPN supervisors were invited to participate. Eligibility criteria included: (i) at least three months' employment on-site (full-time, part-time or casual); and (ii) willingness to provide informed consent. RCAs' names were entered into a draw for a $100 gift card (per site) to a local shopping mall; supervisory staff received no incentive for participation.

Participants included 20 (of 28) full-time/part-time RCAs, 3 casual RCAs, and 3 (of 8) LPNs. RCAs were predominantly female, Caucasian and Canadian-born. Ranging in age from 34-64 years (mean 48 years), they had worked as a RCA between 8 months and 25 years (mean 11 years) and at their current site from 6 months to 25 years (mean 8 years; Meadowview had built a new facility on an existing site, and several RCAs had worked at the previous, on-site facility). All had their RCA certificate, obtained following a 4-6 month community college course, and were registered with the BC Care Aide and Community Health Worker Registry (mandatory for all RCAs in publicly, but not

privately-funded, sites). Supervisors were primarily female, Canadian-born, held a formal nursing designation (i.e., LPN/RN), and were unionized. On average, they had worked at their current site for 6 years.

4.2.2 Data Collection

Data collection lasted 12 months (6 per site) and included 37 semi-structured interviews and over 230 hours of participant observation. All participants were interviewed at least once, with some interviewed multiple times to explore emerging themes. Interviews lasted between 45 minutes and 2 hours, were conducted at a location of participants' choosing (typically off-site at a local café or on-site but off-unit), and were digitally-recorded and transcribed verbatim.

Observations focused on caregiving routines, communication and interactions between RCAs, residents and supervisors, informal/formal meetings, and informal conversations with staff and residents. Field jottings were made throughout and subsequently expanded into more detailed field notes, which also included the ethnographer's initial impressions and personal feelings (to elicit biases or preconceived assumptions). Qualitative data management software (NVivo 10) aided with data management and retrieval.

4.2.3 Data Analysis

Data analysis overlapped temporally and conceptually with data collection (until saturation occurred; Morse et al., 2002). Thematic analyses were facilitated by multiple line-by-line readings of the data. Descriptive codes designated topic areas (e.g., 'role

talk', 'care approach'), with common codes conceptually grouped into broader categories (Saldana, 2013). As new codes emerged, new themes were identified and existing ones refined. Emergent findings were discussed with key (RCA) informants, providing opportunities for questions, critique and feedback.

4.3 Study Findings

Data illustrated how RCAs conceptualize good care and the influence structural factors have on such conceptualizations. Most noticeable was the universality of their narratives, from which emerged four main themes: 'role tensions'; 'good care as tangible outcomes'; 'good care as approach'; and 'good care as guided by family ideology'.

4.3.1 Role Tensions

Challenge of Incorporating Social Interaction with Task Completion

As an introductory 'ice-breaker', RCAs were asked to describe their typical workday. Their responses, which varied little across units or sites, were peppered with 'task talk'; their day construed as a sequence of tasks to be performed. For example, day-shift RCAs spoke of conducting morning care (washing, dressing and grooming residents), serving breakfast, toileting residents, serving lunch, toileting again, and lying residents down for an afternoon nap. Interspersed were unit tasks; one aide, Dana, described it thus, "*Getting the breakfast ready, cleaning, getting lunch ready for everybody, more cleaning and just getting care done. That's pretty much our mornings. That's pretty much what we do.*"

Noticeably absent from the descriptions was any mention of the residents; they entered into the conversation only in terms of care tasks performed upon them (e.g., putting on their pajamas, assisting with their feeding). Only three RCAs explicitly highlighted interacting with the residents. As Felicia explained,

> *So* [at the start of my shift] *I put the coffee on and go and sit down with them. That's the only time I have with them because overnight they're sleeping…. I go and sit in between [*residents in the living room*], and put my feet up… otherwise I have no time with them.*

Participant observation confirmed this pattern of task behaviour; when not performing care or unit tasks, it was not uncommon (particularly during the day shift) to witness RCAs retreat to the kitchen to talk amongst themselves.

Most incongruous with these task-oriented descriptions was that RCAs deeply valued their relationships and interactions with residents. Seeing the residents, talking with residents, and making residents smile were considered the most enjoyable aspects of their work.

> *We have a lot of fun with our folks. We tease them, they tease us back, sometimes there's that interaction where you don't even have to say anything. It's just the look or the touch.* [Pam, RCA]

> *I mean it's amazing, if you just take the time sometimes to talk, they will talk* [Angela, RCA]

> *Making them smile, without a doubt… they need that. When I smile at them, and call them dear and honey… they just soak it up.* [Tamara, RCA]

However, with the exception of several evening/night-shift RCAs, sustained or repeated interactions with residents, beyond care activities, were not observed to be a central feature of daily unit life. Conversations with residents, even during mealtimes when RCAs sat beside residents to assist them, tended to be brief, task-focused and superficial with little attention or support given to residents' emotional status.

Interacting with residents was commonly viewed as an add-on, to occur following task-completion. For example, "*So long as I can get everything done and still have a little bit of time to try and spend with as many as I can, that's a good day*." [Tamara, RCA]. Another aide, Kerri, lamented, "*There are some casuals who don't want to work. They fool around, sit down and relax with the residents, not doing work. You need to get work done first and then sit down with residents*." When RCAs found themselves with 'spare time', they gravitated towards task completion, as illustrated below:

> Nicole is in the kitchen wiping down the counters. She tells me it was pretty quiet on the weekend. 'I got so much done. I mopped the floors, cleaned out the residents' rooms, disinfected the unit, and did some laundry, although it was pretty much all caught up so there wasn't much to do.' She pauses, 'Like what else is there to do?' She goes on to answer her own question. 'I spent some time with the residents but many of them were sleepy'. [Field notes, 02/05/14]

The continued prioritizing of tasks over interaction led one LPN to question whether, despite the proliferation of PCC philosophies, there has been any substantive change in care practice. Her sense was that few changes, beyond that of an improved physical environment, had occurred as a result of adopting a more resident-centred approach,

suggesting that although promoted as an ideology by managers and health-care organizations, it has not translated into lasting change on the front-lines.

> *Because I think in our own way, we're as custodial as they were in* [names old psychiatric hospital] *days. I really do feel that, because how much has actually changed that isn't just 'pretty-fication'?* [Sabrina, LPN]

Conflicting Expectations of Co-workers and Management

Taking care of residents (i.e., doing to) and interacting with residents (i.e., being with) were seen by RCAs as two distinct entities. The tension this created for those with a more person-centred approach is characterized by Shona, an evening-shift RCA,

> *And there's lots of time when we just sit and chill with them. And sometimes I feel bad but I figure, okay, like I am still doing my job, as long as I'm sitting there with them and joking around.*

Similarly, a day-shift colleague commented,

> *Some people are stuck in a mode. They're used to working in other units where it's all about getting the work done and they don't understand sometimes you have to stop your work, your taking care of the residents, to actually sit with the residents. It's hard to make them understand it's not a crime, that that's what they need.* [Aimee, RCA]

It therefore appears that for some RCAs relational care was not seen as a key component of their work. Having segregated doing to and being with, there seemed to be little realization that relational care could be conducted while attending to physical care tasks. Such tensions were exacerbated by unit policies:

> Gayle suggests Teresa take her morning break. Teresa agrees and tells Gayle she's going to sit in the courtyard. 'No, you can't do that' says Gayle, 'we're not allowed to, because if families came in and saw us sitting there, they wouldn't know if we were working or not'. [Field notes, 05/08/13]

This excerpt also highlights the importance of families' expectations and their potential lack of awareness of PCC, and how such expectations play a role in the policies set by management.

While RCAs did not explicitly report feeling strapped for time or burdened by heavy workloads, their use of phrases like "we're running behind" or "I'm catching up" conveyed a pervasive sense of needing to complete a certain amount of 'work' in a certain amount of time. As such, RCAs appeared to perceive that their task completion was more valued by the organization and their colleagues than their relational work.

Conflict also existed between shifts (particularly days and nights), in terms of the expectations around tasks they felt *should* be completed prior to the next shift starting. For example, one LPN described how RCAs on one of the units she oversaw were very good at keeping the unit and their residents clean and tidy. However, the day-shift RCAs treated the night aide quite harshly, as garbage cans were not fully emptied or supply cupboards fully stocked when they started their shift. This despite the LPN's belief that the night aide provided:

> *beautiful care to the residents in terms of talking to them and looking after them and making sure they're toileted when they get up in the night and tucked back into bed. But they would rather it was, if they're up, 'don't put 'em back to bed, get 'em dressed'.* [Sabrina, LPN]

In relaying a story about her experience with intra-shift conflict, Vanessa, an RCA, explained:

> *If someone comes into the unit and it's dirty, the floors are dirty and there's fingermarks on the wall, it's embarrassing because I represent*

> [the organization]. *You come into the cottage and you see me… It represents* [the organization] *but if the person on nights isn't helping…*

For Vanessa, unit cleanliness was about impression management. She perceived families would hold her responsible for the uncleanliness, judging her as uncaring about the unit and, by extension, the residents.

4.3.2 Good Care as Tangible Outcomes

When initially asked what good dementia care meant to them, RCAs appeared unsure how to answer. "*Like, how you should be at care*?" asked Rebecca. "*Are you talking about physical or emotional care*?" said Vanessa. "*I don't know, I've never thought of it…*" replied Jolene, a longer-employed aide. RCAs' narratives about what constitutes good dementia care featured repeated references to four tangible outcomes; keeping residents clean, comfortable, calm and happy.

Keeping Residents Clean and Comfortable

A primary focus of RCAs' care was keeping residents clean and physically comfortable. Considerable pride was drawn from ensuring that residents were well-groomed and presentable. Clean and tidy thus appeared a euphemism for 'lounge-ready'; for example, "…*after you've woken them up, and gotten them ready, I mean they should look well-cared for, hair done, dressed nicely*." [Rebecca, RCA]. Impression management was particularly important; having residents with neat hair, coordinated clothes and clean nails was seen as going above and beyond, a way of demonstrating the extra initiative RCAs put into their work. RCAs were particularly sensitive to being

unfairly judged by families; the implication being that an unkempt resident meant an aide was not doing her job.

> *Instead of getting them up and just giving them a little face wash, and brush your teeth or whatever, get them in the shower, blow dry their hair, they are fresh from head to toe… And I think they smell better, the family can see that they're better, well-cared for.* [Nicole, RCA]

RCAs' explanations suggested that offering comfort and meeting needs were primarily construed in physical, rather than emotional, terms. Yet explanations of a commonly-observed practice (i.e., covering residents with a warm blanket) alluded to the emotional component of comfort.

> *Good care is… make sure they're clean and tidy and have all those little things that they enjoy, like Lynne laying on the couch with a pillow and a warm flannel blanket. Nick when he's sitting in a recliner after breakfast covered with a warm blanket. It's good care because he's comfortable and he's happy.* [Bonnie, RCA]

For the RCAs, focusing on resident cleanliness and comfort provides tangible, outward evidence of the work that they do and for which they may receive praise. Conversely, family members and supervisors may not readily notice interactional or relational aspects of care, in part due to the predominant understanding of the culture of care, and to such aspects being less obvious than tangible physical outcomes. Recognition or praise for interactional/relational aspects may thus be less forthcoming.

Keeping Things Calm

Participants unanimously spoke about the need to keep residents, the environment and their colleagues calm. Doing so helped keep residents free from

upset, thus minimizing their distress and anxiety and the need for additional PRN medication.

> 'It's important to remain calm because otherwise you end up winding up the residents… What would it be like to be agitated or anxious all day? How would that leave you feeling? We want to try and prevent that feeling. And you don't want the agitation to spread from one resident to another because you don't want them all feeling anxious. It's bad enough that one resident may feel that way; you really don't want more than one resident experiencing that. Plus, when they get distressed then they may need to be medicated and you don't want that'. [Pam, RCA, Field notes, 03/18/14*]*

RCAs attended closely to sensory stimuli in the surrounding environment, ensuring they kept the overhead lights dim, did not bang dishes or doors and kept music at a low level.

> *We've had family members come in before and say, 'oh, it's so quiet in here and it's so boring', and it's like yeah, but you know what? Crank up the music and start talking too much and start laughing too much and watch them all get wound up, and they're very unhappy… We just want them all to be at peace and have a good day.* [Rebecca, RCA]

There is, however, a fine line between keeping things calm and creating an environment completely devoid of sensory stimulation. RCAs on one Meadowview unit were firmly convinced that bright lights overstimulated residents, thus overhead lights in several sitting areas and the dining area remained off for much of the day. As little natural light infiltrated these areas, the unit was perpetually dim; yet, in the other (identical) Meadowview unit, the dining area and main sitting area were typically bathed in artificial light.

Keeping Residents Happy

Good care was also equated with promoting a sense of happiness. RCAs drew considerable satisfaction from their attempts to keep residents happy; outward expressions of happiness (i.e., facial expressions, laughter) provided a tangible sign RCAs were doing a good job.

> *It's nice to find out things that make them feel better. Like she can't engage you in conversation or anything like that, but they* [her family] *know that she's happy and that we enjoy her being happy.* [Jaime, RCA]

For Rebecca, keeping residents happy entailed being aware of the different everyday activities she believed facilitated a sense of contentment:

> *Leonard, he likes anything on wheels. So providing a walker or wheelchair, sometimes he'll even find a table that has wheels. Just as long as he can keep busy and move things around, that's just his way of feeling productive. And then you've got someone like Anabel; she likes to sit and look at her magazines and books... And then you have Hank, you know, just to make small talk with Hank so he doesn't feel lonely. Offer him his coffee. You know, they all have their own different way of feeling content.*

While such attempts underscore Rebecca's efforts to individualize care, it is unclear whether they facilitated a sense of meaningful engagement. Although Hank voiced appreciation for his continued receipt of cookies and coffee, he repeatedly expressed a desire to do more than just sit around. Similarly, Leonard's fixation with maneuvering wheelchairs and over-bed tables around the unit could be viewed more as an expression of boredom than contentment.

Given the contexts in which RCAs talked about keeping residents happy, it too appeared a euphemism – for keeping residents comfortable, calm or free from upset. For example:

> HC*: Happy according to who? Who's definition of happiness?*
>
> Kendra*: Mine. I think more mine. Because if I believe myself that I've made people laugh at least a couple of times before they go to bed, or if I'm giving the hugs and that before they go to sleep, then I feel like inside of them they're comfortable…*
>
> HC*: When you say they're happy, is it really happy or is it the absence of anxiety?*
>
> Ginny*: Absence of anxiety. Whether they're happy… your guess is as good as mine… And when you don't see that [*anxiety*], then that's a good day, consider it a good day.*

4.3.3 Good Care as Approach

For the RCAs, good care was also about how care was delivered – compassionately, patiently and affectionately.

Being Compassionate

All RCAs, even those who were particularly task-oriented, considered being kind and caring as essential to their role. RCAs' narratives and daily practice accentuated the importance of a gentle manner, being soft-spoken, moving at the residents' pace and respecting wherever residents happened to be at a particular point in time. Adopting such a manner was also integral to ensuring a sense of calm.

> *Gentleness and softness. For me, that's what good care is… Being gentle in how you speak to them, how you touch them, how you approach them… If they don't want your care, what you're doing at the moment,*

> *you walk away from it, because if you push it, they push right back.* [Rhonda, RCA]

RCAs felt badly for residents for leaving their own homes and having their most intimate care provided by someone other than family. When providing care, RCAs offered step-by-step explanations to alleviate residents' distress.

> *Like there's certain residents I feel so badly for because they wake up in the morning and it's almost like they're in the twilight zone. Every morning they have to start over 'Where am I? Why am I here? Where's my family?' So it's mainly about trying to ease that, and help them through their day because they're scared…. I explain every little step I'm doing because I want them to be comfortable, I don't want them to be scared. It's… for their own mental and emotional benefit.* [Rebecca, RCA]

RCAs prided, and defined, themselves as nurturers; individuals who loved, and felt compelled, to care for others, and had what they called 'heart'.

> *I think it's more of a calling. But nowadays you seem to be getting more and more people that are just doing it because you start off at a good wage. You can tell the people that are … here for the paycheque. You can just tell by their work ethic, just how they treat everything… But you can tell the ones that have their heart into it and care. You can pick up on it pretty easy.* [Jolene, RCA]

Being Patient

RCAs considered patience essential to working with individuals with advanced dementia. Alluding to residents' communication challenges, RCAs believed patience was imperative to both understanding and being understood.

> *I mean they're all human beings, that all still have the emotions and feelings. They can't express themselves the way they would like to get their point across. And I feel bad for them… because you see frustration building in them when they can't get their message across… Patience is huge. You have to have so much patience to do the job right…* [Pam, RCA]

Having patience also meant taking sufficient time with each resident, not rushing through care tasks, or pressuring them to do something to which they objected, for not doing so meant running the risk of upsetting the resident, thus potentially making care more difficult.

> *And the one thing is you have to be more patient. I have to be more patient, give them time. Because if you go at your own pace, they can't catch up…* [Felicia, RCA]

> *You need to be patient and very soft-spoken. You can't be running around, rushing around because that right there, it agitates residents.* [Rebecca, RCA]

Being patient was also about focusing on the resident's needs, as opposed to the RCA's (i.e., to complete the task quickly and efficiently), and being willing to walk away from the situation and try again later.

> *You have to have the patience and understanding and maybe it's not the right time. Sometimes maybe ten minutes later. It just becomes a whole different focus.* [Ginny, RCA]

Implicit in RCAs' narratives was the role being patient played in individualizing care, recognizing that what works for one resident might not work for the other. It was about having the patience to try out different approaches to find what worked best for each individual resident.

> *Be patient, very patient. Don't get mad, don't get upset; maybe for a few seconds ok, but you have to understand severe dementia. Every resident you have to try a different approach.* [Kerri, RCA]

However, RCAs acknowledged that given the demanding nature of the work, it was not always easy to be patient and so having a good colleague, who could step in

and take over and prevent nerves from fraying (both the RCA's and the resident's), was essential.

> *And being human, sometimes you do start losing your patience. So that's where you need a really good co-worker to say, "take a breath, hold on, just step back and I'll step forward, and you can be there if I need you"…* [Aimee, RCA]

Being Affectionate

Good care was also about building relationship and fostering a sense of trust and security with residents; being affectionate provided an avenue by which to do so. There were numerous instances in which RCAs were observed touching residents outside of everyday care tasks, be it through a hug, or holding their hand, as they sat or walked beside them.

> It is drawing close to the end of Nicole's shift. She walks into the living room and stands behind the sofa. Louise follows her in and stands beside her. Nicole reaches her right arm up and around Louise's shoulders, giving her a one-armed hug. Louise snuggles in to the hug. 'That's nice, you're so good', she tells Nicole. Nicole turns to me and tells me that Louise is one of her favourite huggers. Louise beams in response. [Field notes, 05/20/14]

The affectionate exchange conveys not only Nicole's fondness for Louise, but also how secure and comfortable Louise feels with Nicole. For residents with more limited verbal skills, offering a hug or a hand to hold affords RCAs an opportunity to communicate on another level, providing reassurance and comfort non-verbally.

> *Trying to build a trust relationship with people with Alzheimer's and dementia, I think is one of the hardest things. You can't talk to them and tell them, 'I want to be your friend. I want a relationship with you.' So it's in gestures, how you do things, how you're walking down the hallway with them, talk to them while you're walking with them. If you're not*

> *communicating with your residents even though they can't talk, they're not going to understand anything.* [Kendra, RCA]

> *I think they need to be touched… like a little hug, grab their hand and walk with them. Because I think that does them a world of good.* [Tamara, RCA]

Offering affection while performing care, or while trying to get residents to cooperate with a request, also made it easier for RCAs to do their work. In the absence of affection, residents may refuse to cooperate, and/or become upset, potentially disrupting the 'smoothness' of the shift. Kendra noted,

> *If you're not giving that love and affection while you're doing care… they're not going to want to do stuff or… to move. They're going to be upset.*

As not all residents' families visited regularly, RCAs believed it their duty to provide the affection typically provided by family members.

> *You have to go beyond the scope of the job and make them your friends and give them kindness and compassion. They may not have family or they have family that don't come in and neglect them because of this dementia. So then you become like their sole caregiver… They need some love and some kindness too… A little bit of kindness goes a long way.* [Teresa, RCA]

Here it is implied that the relational aspects of care are above and beyond the RCAs' scope of practice, which is not surprising given the emphasis of RCAs' job descriptions on the functional nature of the work (e.g., meeting residents' activities of daily living needs, keeping the environment clean and safe). While demonstrating compassion also features in the descriptions, it appears that, for the RCAs, the entrenchment of task

completion within the culture results in a more narrowly-focused job scope (i.e., on bed and body tasks).

4.3.4 Good Care Guided by Family Ideology

RCAs' narratives were permeated with fictive kin-like references. They spoke repeatedly of how thoughts about their own parents/grandparents and how they would want them treated if they were in care, guided their care provision. Underlying the kin-like attachments formed with residents was the notion of reciprocity, that it was the residents' turn to be on the receiving end of care after having raised their own families.

> *That's what's always in my head when I'm providing care, how I would like to see my mom and dad be treated. That's the way these guys deserve to be treated, right? Because that's where everything that your mom and dad have done for you, like all those years of taking care of you and giving, giving, giving, you want to give back. It's their time, their turn.* [Jolene, RCA]

For those with no surviving parents/grandparents, the familial-like bonds served as a substitute for the absence of such relationships or as compensation for difficult relationships with their own parents. Distinguishing residents as their 'work family' or their 'family away from home' was also perceived as a way of going above and beyond their job description.

> *But you get attached, I don't care. Any good care aide gets attached. There's no way around it. Because there's your home family and your work family and these are my work moms and grandmas, you know what I mean?* [Tamara, RCA]

The challenge is that such discourse potentially precludes RCAs from seeking to understand residents' own preferences, thus limiting the enhancement of residents' personhood. For example,

> 'I believe they should be going to bed early. People at an old age like to go to bed early'. I ask her if she knows if any residents are night owls, i.e., did they stay up late when they lived in the community. 'No, not really', she replies. [Kendra, RCA, Field notes, 06/03/14]

4.4 Discussion

This article explored how RCAs conceptualized quality dementia care and whether they acted upon such conceptualizations. RCAs experienced a sense of role tension, as they sought to incorporate social interaction with task completion and co-workers' conflicting expectations. RCAs articulated, and exhibited in their daily physical care provision, quality care as that which focused on tangible care outcomes, on their care approach and was guided by family ideology.

In keeping residents clean, comfortable, calm and happy and providing compassionate, patient and affectionate care in the context of kin-like relationships, RCAs demonstrated attention to residents' individual needs and well-being, thus exemplifying good quality *of* care. However, far less attention was devoted to quality of life concepts (e.g., continuity of self, choice, independence and autonomy) advocated by researchers (Kane, 2001) and individuals with dementia (Clare, Rowlands, Bruce, Surr & Downs, 2008). Such a finding illustrates the ideological gap that exists between espoused organizational philosophies (and those espoused in the literature) and the reality of daily care practice; a finding that has been noted elsewhere (Zimmerman et

al., 1997). While organizational policies and procedures articulated the importance of enacting person-centred philosophies (particularly given their small, home-like environments), structural and organizational constraints (e.g., market discourses of productivity and efficiency; limited support and recognition for relational care) appear to have prevented such philosophies from being fully adopted by front-line staff. As such, one questions whether resident-centred ideology has been embraced more as a marketing strategy, with monies directed towards improving facilities' outward physical appearance.

RCAs' tendency to prioritize tasks over resident interaction has been repeatedly documented (Colomer & de Vries, 2014; Lopez, 2006; Stockwell-Smith et al., 2011). Despite the presence of features believed to produce quality care (i.e., relatively high wages, high staffing ratios, familial-like relationships with residents and small-scale, home-like environments), participating RCAs exhibited a similar tendency; a focus highly incongruous with the value they ascribed to resident relationships and interactions. This may be accounted for, in part, by RCAs' internalizing of neo-liberal market notions of productivity and efficiency, and the intense criticism received from co-workers when social interaction with residents was foregrounded over task completion; criticism which appeared to carry far greater weight than that of management, who rarely appeared on the units. Such castigation may also reflect an implicit expectation that, for the system to run efficiently, requisite tasks be completed prior to shift-end, particularly if the subsequent shift lacks sufficient staff to attend to the missed tasks.

The continued prioritization of task completion also appears to reflect the increased patterning of facility-based care along market principles, in which care is narrowly conceptualized as quantifiable tasks to be counted and measured and valued for its ability to provide services deemed appropriate (e.g., nutritional needs met, bodies kept warm and dry) (Day, 2013). The ongoing focus on residents' physical needs also reflects the medicalized notion of people as body parts, with little recognition of the emotional and social support required as part of their care (Armstrong & Banerjee, 2009). Prior to shift-end, RCAs were responsible for charting residents' food/fluid intake, sleep patterns and bowel/bladder elimination. There was no checkbox for capturing resident-staff interaction; rather, residents were tracked and monitored purely in terms of their physical status. Use of the MDS-RAI, a standardized assessment instrument which requires RCAs to document residents' mood, behavioural symptoms, bowel/bladder control, pain, nutritional status and activity, further reinforces the physical nature of resident care. Indeed, the MDS-RAI has been repeatedly critiqued for its lack of attention to residents' quality of life (Rahman & Applebaum, 2009). Thus, even though both facilities attempted to embrace a more social model of care, they operate in a system primarily concerned with objectively measurable and functional tasks. Hence, it is of little surprise that RCAs viewed residents' needs and their work in primarily physical terms, their interactions with residents and residents' emotional needs remaining 'invisible and unmentioned' (Diamond, 1985, p.1291).

Within the theme of good care as tangible outcomes, ensuring residents were 'lounge-ready', physically comfortable and free from upset was a source of pride. RCAs

were particularly conscious of how they were perceived (and judged) by families and management; focusing on tangible outcomes thus conveyed how deeply RCAs cared for their residents. This emphasis bears striking resemblance to the findings of several studies conducted in both dementia and complex care settings (Chung, 2013; Colomer & de Vries, 2014; Fisher & Wallhagen, 2008). Existing research (Bowers, 1998; McGilton & Boscart, 2007) indicates families value the caring attitude exhibited by staff through their attention to residents' personal appearance and genuine concern about residents' comfort. Indeed, while it is difficult for families to know if dignified care is being provided, tangible outcomes offer a way for families to 'see' such care.

In focusing on keeping residents calm and happy, RCAs accentuated how they sought to minimize resident distress and anxiety. Increased agitation and aggression have the potential to not only decrease residents' quality of life, but also disrupt care routines and RCAs' time spent with other residents, thus heightening job stress. RCAs' experiences underscore a potential pitfall of small-scale environments, for when a resident does become agitated, it is difficult to create sufficient distance between residents, so as to prevent others' behaviour from escalating.

For the RCAs, good care was not only about delivering compassionate and patient care, but about being compassionate individuals for whom care work was a calling. Positioning themselves thus distinguished RCAs from colleagues who did not provide such care, and were there simply for the paycheque (interestingly, no participants expressed being there for the paycheque). RCAs in U.S. nursing homes explain their work as a calling in part because, given their poor wages, they 'cannot be in

it for the money' (Dodson & Zincavage, 2007, p.916). In contrast, the relatively well-paid RCAs in this study emphasized the importance of being in it for *more* than the money. This suggests that wages alone are insufficient to explain the 'caring as a calling' motivation, and raises the question as to what extent such motivations are influenced by gendered expectations regarding the nature of care work. Positioning good care as affective care may help RCAs achieve self-meaning, their caring work reinforcing their (gendered) self-image as nurturers who are compelled to care (Berdes & Eckert, 2007). Given the ongoing societal devaluation and stigma associated with care work, it also offers a way for RCAs to ascribe and elevate the value of their work (Pfefferle & Weinberg, 2008).

The theme of good care as guided by family ideology drew on RCAs' beliefs about how they would want to see their own parents/grandparents treated. The use of family metaphors to describe and guide care has been identified in several prior studies, although none specific to dementia care settings (Berdes & Eckert, 2007; Dodson & Zincavage, 2007; Fisher & Wallhagen, 2008). Invoking family metaphors suggests that RCAs draw on their gendered experiences as daughters and/or granddaughters, thus emphasizing the use of their tacit knowledge (Berdes & Eckert, 2007). However, while fictive kin-like attachments may deepen relationships, promote empathy and contribute to care quality, they can also potentially impinge upon PCC. Conceptualizing residents as one's own parents/grandparents may preclude seeking and incorporating residents' own preferences, thus inhibiting as opposed to enhancing residents' personhood (Anderson et al, 2005).

4.5 Conclusion

Study findings suggest that RCAs' conceptualizations and enactment of quality dementia care are not independent of societal, families', managers' and co-workers' expectations regarding care provision, or of a system that remains primarily concerned with objectively measurable and functional tasks. Rather, RCAs appear to have internalized market ideologies of efficiency and productivity and gendered expectations of care, which implicitly inform the manner in which they seek to provide quality care to residents with advanced dementia. As such, small-scale, home-like environments, well-remunerated and trained staff and high staffing ratios (the latter of which are frequently touted as a panacea for improving care quality) do NOT appear sufficient to ensure the consistent provision of PCC.

Through their provision of hands-on, day-to-day care, RCAs possess considerable capacity for shaping the daily life experiences and well-being of PWD. Discerning how they conceptualize quality dementia care and the structural constraints that potentially impinge upon such care broadens our understanding of dementia care delivery, as we seek to ensure a responsive and therapeutic care milieu. As Edvardsson and colleagues (2010) note, the danger in failing to attend to the tensions and complexities of dementia care provision is that person-centred care becomes nothing more than 'a political slogan to identify a user-based approach to care' (p.2612).

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CHAPTER 5: CARING IN SPITE OF: RESIDENTIAL CARE AIDES' EXPERIENCES PROVIDING DEMENTIA CARE IN THE FACE OF ORGANIZATIONAL CONSTRAINTS

5.1 Background

Prompted by Kitwood's (1997) person-centred care philosophy, facility-based dementia care is experiencing a shift towards care models that emphasize the uniqueness of the person with dementia, flexible care routines respectful of residents' values, preferences and needs, the development of consistent and caring relationships, and an enriched social environment (Brooker, 2007; Talerico, O'Brien, & Swafford, 2003; Edvardsson, Winblad, & Sandman, 2008). Increasingly referenced in the research and practice literature, such individualized, social models of care are considered synonymous with quality dementia care (Brooker, 2007), yet their widespread adoption and integration remains limited (Talerico et al., 2003).

In providing the majority of hands-on, day-to-day care for persons with dementia, Residential Care Aides (RCAs; unregulated workers also known as nursing assistants/aides, personal support workers, health care aides) possess considerable capacity for shaping the daily life experiences and well-being of persons with dementia. They are, however, often situated on the lowest tier in the health-care hierarchy, the least educated and lowest paid, and sometimes afforded as little power, respect or recognition as those for whom they provide care (Innes, 2002; Tellis-Nayak & Tellis-Nayak, 1989). RCAs thus find themselves in a paradoxical position, with considerable practical power and influence over those for whom they care but little formal authority

or status (Jaques & Innes, 1998). If we are to improve our understanding of person-centred care approaches, and in turn the quality of dementia care, greater attention must be devoted to examining RCAs' care experiences – their challenges, frustrations, motivations and satisfactions (Jacques & Innes, 1998); this paper seeks to do just that.

Research suggests that RCAs feel overwhelmed and ill-equipped to cope with the demands of caring for individuals with dementia, their ability to provide quality, compassionate, relational care hindered by their current work environments (Banerjee, Armstrong, Daly, Armstrong, & Braedley, 2015; Holmberg et al., 2013). RCAs routinely experience heavy workloads, inadequate staffing, highly regimented routines, insufficient training opportunities, little decision-making autonomy (regarding care routines and/or unit management) and increased regulatory oversight (Banerjee et al., 2012; Caspar & O'Rourke, 2008; Daly & Szebehely, 2012; DeForge et al., 2011). RCAs liken such routinized, task-oriented care to that of an assembly line (Banerjee et al., 2015), a far cry from the individualized, person-centred care advocated in the literature.

When asked what would most improve their work environment, RCAs overwhelmingly respond with smaller staffing ratios (e.g., 4 to 6 residents/RCA, versus the actual 10-12 or higher; Holmberg et al., 2013), better compensation, greater work flexibility, involvement in work-related decisions, and improved work relationships (e.g., better communication, increased supervisory respect and support, improved collegial support) (Bishop et al., 2008; Kemper et al., 2008; Parsons, Simmons, Penn & Furlongh, 2003). Such factors are intimately linked to the quality of care provision (Eaton, 2000). Indeed, Caspar and O'Rourke (2008) found RCAs' structural empowerment (i.e., access

to support, resources, information, opportunities for increased knowledge and skills, and formal and informal power) to be significantly associated with their provision of individualized care. Similarly, Hamann (2014) found empowering RCAs in managerial decision-making (regarding staffing, care services, menu planning, determining care standards) to be strongly related to families' perceptions of care quality. As a means for improving care quality, empowering RCAs proved more important than empowering nurses (RNs/LPNs). Hamann suggests that including RCAs in decision-making offers them an opportunity to advocate for decisions that facilitate greater consideration of relational care dimensions.

Such research highlights the importance of staff personhood, an essential yet oft-overlooked aspect of quality dementia care provision (Brooker, 2007; Kitwood, 1997; Nolan, Ryan, Enderby & Reid, 2002). As with persons with dementia, attending to staff personhood entails conveying recognition, respect and trust within the context of relationship (Kitwood, 1997) and acknowledging and valuing RCAs' worth as unique individuals (Brooker, 2007). Yet it is not only about creating a sense of individual recognition and belonging, but also, as noted above, about recognizing RCAs as an integral and valued part of the care team and empowering them within their daily care practice by engaging them in decision making and the care planning process.

While much is known about the structural constraints facing RCAs in their work environment, far less is known about *how* they continue to provide care in the face of such constraints. Existing research alludes to the importance of RCAs' peer relationships; being a team player (i.e., working together and helping co-workers when

requested/required), and having co-workers with good attitudes (i.e., who are there to do a good job) have been found to contribute to both work and care quality (Pennington, Scott & Magilvy, 2003; Schirm, Albanese, Garland, Gipson & Blackmon, 2000). The quality of peer relationships is also highlighted in te Boekhorst et al.'s (2008) study which explored job satisfaction and burnout among care staff in group living homes for people with dementia (which feature small-scale, home-like environments with multi-tasking staff) and traditional nursing homes. Te Boekhorst and colleagues posited that group home staff, who typically worked alone or with only one other staff member, would experience lower levels of social support and increased job demands than staff in traditional homes. However, group home staff actually experienced higher levels of social support, leading the researchers to suggest that social support may be more readily determined by the quality, as opposed to the quantity, of peer interactions.

Research has also highlighted how RCAs seek to actively manage their ongoing experiences of 'denigration and exploitation' (Jervis, 2002, p.13). In exploring how RCAs worked in and around the pyramid-shaped power hierarchy common to many nursing homes (with power concentrated in the hands of a few top administrators/managers), Jervis (2002) found aides adopted several low-level resistance strategies that provided a feeling of empowerment yet minimized the potential retribution associated with more open defiance. Strategies included setting boundaries on their care work (e.g., doing no more and no less than that for which they were paid), and subversive attempts at

sabotage (e.g., being careless with supplies and disposing of soiled linen rather than sending it to the laundry).

Drawing on data collected from an ethnographic study examining how the organizational care environment impedes or facilitates the provision of quality dementia care, this paper explores how RCAs in dementia care units provide quality care in spite of ongoing structural constraints. In doing so, this paper seeks to broaden our understanding of the dynamics of dementia care delivery and the manner in which more social models of care may be facilitated.

5.2 Methods

This work was informed by Estes' (2001) framework of political economy of aging, which emphasizes the implications of political, economic and social relations for older adults and society's treatment of them (Estes, 1999). It explicitly acknowledges how structural influences, such as social relations and societal institutions (e.g., political and economic systems, ideology, gender, race, class), shape the meaning and experience of old age and the distribution of resources; that is, how individuals are defined and treated through the reproduction of prevailing power arrangements and inequalities (Estes, 1999; Estes, Biggs & Phillipson, 2003). It thus draws attention to the processes that lead to empowerment and control for some, yet create dependency and powerlessness for others (Phillipson, 2006). As much of the empirical and practice literature on care work is situated at the micro-level, described and analyzed in terms of relationship (or lack thereof) between the care worker and care recipient (Daly, 2013),

drawing on a political economy perspective brings into focus the importance of the meso- (organizational) level, within which everyday care practice is enacted, and the broader socio-political context.

This research utilized a focused ethnographic approach. Focused ethnography adopts a topic-oriented, time-limited exploratory approach that focuses on a specific area (e.g., dementia care provision) within a discrete community (e.g., front-line care staff) (Muecke, 1994). Concerned with actions, interactions and social situations (Knoblauch, 2005), it retains a focus on context and draws on data sources typical to classical ethnography; the key difference being the degree or scope as opposed to the nature of the data collected. Focused ethnographies are considered particularly effective in uncovering the tacit skills and subtleties in jobs, such as care work, that are labeled as routine or unskilled (Savage, 2006).

5.2.1 Setting

Four purposively-selected dementia care units in two complex care facilities in British Columbia, Canada served as the setting for this research. The facilities were selected for features advocated as promoting quality dementia care (e.g., Rabig, Thomas, Kane, Cutler, & McAlilly, 2006; Verbeek et al., 2010); that is, they were small in scale, housed 10-11 residents per unit, featured archetypal elements of home, and employed a consistent staffing model, in which RCAs were permanently assigned to their respective unit. Both facilities were relatively new (open less than 10 years), purpose-built and home to 100-plus residents. They were also both privately owned;

the first, Meadowview[8], was operated by a small, regional for-profit organization, while the second, Rivermead, was part of a larger, not-for-profit chain. Both facilities were publicly-funded, that is, they received a set per-diem rate from the provincial Ministry of Health for the majority of their residents, including those on the dementia units.

Meadowview

Meadowview's two dementia units featured almost identical floor plans. All resident bedrooms were single-occupancy and included an ensuite bathroom (i.e., toilet and sink); approximately half of the bedrooms featured ceiling track lifts that ran width ways across the room, but did not extend into the ensuite bathroom. The units also featured several small sitting areas, a main dining area, a bathing room, a communal resident washroom, staff storage areas, and a secure medication room. There was also a small kitchen (deemed off-limits to residents); however, with the exception of a few breakfast items (e.g., dry cereal, toast) all meals were prepared in the facility's central kitchen and brought to the unit slightly ahead of mealtimes.

Meadowview's staffing model followed the traditional nursing home hierarchy. RCAs were responsible for all resident care (separate departments took care of the units' housekeeping and laundry), while an LPN (responsible for two other units in addition to the dementia unit for a workload of approximately 40 residents) administered medications and served in a supervisory capacity. A clinical practice leader was available as a resource, although the position was eliminated partway

8 For purposes of anonymity, all names are pseudonyms.

through the study. The LPN reported to the Director of Care, who in turn reported to the Site Administrator, both of whom had professional nursing designations. With the nursing station located in an adjacent unit, the LPN primarily entered the unit to dispense medications or in response to care aides' requests for assistance.

Each unit was staffed with a combination of both full-time and part-time RCAs. For the majority of the day (7:30 a.m. to 2:30 p.m.; 3:30 p.m. to 9:30 p.m.), there were two RCAs in each unit. Outside of these times, the units were staffed with one RCA; between 11:00 p.m. and 7:00 a.m. each unit shared a RCA with a neighbouring unit. RCAs belonged to one of the larger health care unions in the province, and received an hourly wage of approximately $20, as well as medical and employment benefits.

Rivermead

Both participating dementia units shared an identical floor plan. Unlike Meadowview, residents' single-occupancy bedrooms did not feature ensuite bathrooms and none had ceiling track lifts (in the event a resident became non-weight bearing, they were transferred to another unit). There were four communal bathrooms (two per side), two of which featured either a bathtub or shower. Both units had one kitchen (off-limits to residents), two living rooms and dining areas (providing access to a secure courtyard), and a laundry room. Medications were stored in a secure cupboard in the kitchen area, along with the medication administration records and current care plan. As charting was predominantly computerized, each unit also had its own computer.

Rivermead's staffing model also reflected the traditional nursing home hierarchy; however, RCAs, were considered multi-skilled workers and as such were responsible for all resident care, as well as medication administration, meal preparation, laundry (linens and residents' personal laundry), cleaning and recreational activities. One LPN oversaw both units (as well as two additional units; for a workload of approximately 40 residents) and reported directly to an RN, who in turn reported to the site administrator. A clinical educator served as an additional resource person; however, the position was eliminated midway through the study.

In one of the units, a former kitchen had been converted into an office and served as the nursing station for all the dementia units. As such, the LPN had a greater presence in this unit than the others. The LPN (and occasionally the RN) made a point of briefly connecting with RCAs at the start of the day shift to highlight any specific care issues; otherwise, their presence was limited to administering medications beyond the RCAs' scope of practice (e.g., insulin) or responding to aides' request for assistance.

All Rivermead RCAs were employed on a full-time basis. Each unit was staffed with two RCAs between 7:30 a.m. and 7:30 p.m., and one RCA from 7:30 p.m. to 7:30 a.m. At night, the units shared an LPN with those in another wing. Rivermead RCAs belonged to the same health care union as Meadowview RCAs, and received an hourly wage of approximately $21, in addition to medical and employment benefits.

5.2.2 Participants

Following approval from the University and Health Authority research ethics boards, all RCAs and LPNs (i.e., day, evening and night shifts) from the selected units and senior management were invited to participate. Eligibility criteria included: (i) a minimum of three months' employment at the site, either on a full-time, part-time, or casual basis; and, (ii) willingness to provide informed consent. Management was not informed which staff were or were not participating in the project. In recognition of RCAs' time and effort, a draw was held at each site for a $100 gift card to a local shopping mall; LPNs and senior management received no incentive for participation.

The sample included 23 RCAs (i.e., 20 of 28 full-time/part-time RCAs; 3 casual RCAs), 3 (of 8) LPNs and 5 (of 6) senior managers. RCAs were primarily female, with an average age of 48 years (range 34-64 years). More than half had worked as a RCA for over 10 years (range 8 months - 25 years), and at their current site for 8 years (range 6 months - 25 years; several Meadowview RCAs had worked at the former, on-site facility which the new building replaced). All had completed a 4-6 month community college course to obtain their RCA certificate and were registered with the BC Care Aide and Community Health Worker Registry (mandatory for all aides working in publicly-, but not privately-, funded care facilities). The majority were Caucasian, and all but three were Canadian-born. The LPNs and management staff were also predominantly female and Canadian-born. Employed at their current site for an average of 3 years, they had all worked in the residential care field for at least 10 years. While the LPNs were unionized, management staff were not.

5.2.3 Data Collection

Fieldwork was conducted between July 2013 and June 2014 (i.e., 6 months per site), and included 37 semi-structured interviews and over 230 hours of participant observation. Each participant was interviewed at least once, with some informants interviewed multiple times to more deeply explore emerging themes. Key interview questions included, "Tell me what it is like to work as a care aide/LPN on a unit for people with dementia?", "What do you think makes for good dementia care?", and "What aspects of the organizational environment (e.g., care philosophy, policies and procedures, staffing) make it easy or difficult to provide such care?" Additional probes explored the most challenging and enjoyable aspects of their work, the extent to which they felt they were able to provide 'good' care, how management supported their work, and how policies/procedures and/or care routines affected their work with residents and co-workers. Similarly, management staff were asked "Tell me what it is like to manage a unit for people with dementia?" Probes were used to explore specific management practices and explanations about why things were the way they were.

Participants were offered their choice of interview location; the majority of RCAs and LPNs elected to be interviewed off-site at a local café, while the remainder chose to be interviewed on-site, but off-unit. Management were interviewed in their offices. Interviews ranged from 45 minutes to 2 hours, and were digitally recorded.

Participant observations focused on caregiving routines, communication and interactions with colleagues, supervisors and residents, and informal/formal meetings. Multiple informal conversations occurred with both staff and residents on a variety of

topics related to the care experience. Jottings made in the field were typed out more fully following each observation. Field notes from both the observations and interviews also recalled the ethnographer's initial impressions and personal feelings as a means of eliciting biases or preconceived assumptions. NVivo 10 aided with data organization and retrieval.

5.2.4 Data Analysis

All interview data were transcribed verbatim and reviewed to ensure the content was accurately represented. Guided by Lofland and colleagues (2006), iterative line-by-line readings of the interview and observational data focused on key descriptive terms and phrases. These codes were categorized, compared and contrasted allowing for the development of themes (Saldana, 2013). For example, the codes 'policies as guidelines', 'rules versus reality', and 'workarounds' were brought together under the theme of 'breaking procedure'. Simultaneous data collection and interpretation facilitated the exploration and expansion of themes from earlier interviews and observations, and the tailoring of subsequent data collection (e.g., interviews, informal conversations) to emerging themes. To ensure trustworthiness of the data, emergent findings were discussed with key (RCA/LPN) informants throughout the analytic process, thus providing opportunities for questions, critique, and feedback regarding the analytic conclusions and assumptions (Tracy, 2010).

5.3 Findings

While RCAs' work environments featured smaller staffing ratios, manageable workloads and relatively good compensation, they experienced little power and voice. The first key theme, 'on being bum wipers and bottom feeders', highlights RCAs' experiences of disempowerment. The subsequent two themes, 'valuing and negotiating relationships', and 'breaking procedure', illustrate how RCAs sought to provide quality dementia care in the face of such continued disempowerment; that is, how they 'care in spite of'.

5.3.1 On Being Bum-Wipers and Bottom-Feeders

RCAs were highly cognizant of the position they occupied in the staffing hierarchy: "*we're the bottom of the barrel… that's how we're viewed and we know it*". However, they bristled at being viewed and labelled this way by 'higher ups' (e.g., as 'bottom feeders'), fervently asserting that they were more than just a 'bum-wiper' or a 'poop cleaner-upper'. While they recognized there were gaps in their formal knowledge (particularly when it came to medications), RCAs felt that, by virtue of being around the residents 8-12 hours per day, they were intimately aware of their residents' personalities and care needs. Such tacit knowledge was acknowledged by Vanessa (a RCA): "*I would include the care aides more, listen to them more. Because they're very smart, although they're not as educated…*"

While RCAs spent 8-12 hours per day providing care to the residents, observations revealed that their knowledge was frequently overlooked. For example,

one morning a resident experienced a series of small seizures. Concerned, the RCAs called in the LPN, who notified the care manager. As lunch was being served, the care manager and clinical practice leader entered the unit, walked over to the dining table, bypassing the RCAs who were serving lunch, and asked the resident how he was feeling. They discussed, somewhat loudly, what the RCAs had reported, "*they say, he's twitchy and not looking himself";* as they did, the RCAs retreated to the kitchen. The only question posed to the RCAs (done by calling over to them) was whether the resident's hands were always cyanotic. The managers briefly discussed whether to give the resident oxygen and shortly thereafter, left the unit. No sooner were they out the door, than the two aides turned to one another:

> 'Can you believe that?' asks Jolene incredulously, 'that was so demeaning'. 'They have no respect for us', says Rebecca, 'we're not peons that don't know anything, we're not idiots. Why do they always have to talk down to us? They swoop in here, 'is he always cyanotic', she parrots. Why do they have to show off like that?' [Field notes, 10/25/13]

The above interaction left the RCAs feeling that they, and their knowledge, were sidelined. This experience was not unique; RCAs expressed continued frustration at having their opinions repeatedly disregarded by both supervisors and management. At both sites, some RCAs had more experience working with individuals with dementia than several LPN team leaders. This, in conjunction with the limited time LPNs spent interacting with residents, compounded the frustration felt by RCAs when their observations and opinions were discounted.

> *I think our opinions need to matter. We work with the residents 24/7. Not the LPN, not the RN, not management, not the doctor. Our opinions need to matter, but our opinions never matter. If I say that I think this*

> *resident had high anxiety today, yesterday, the day before, well* [the response is]*, yeah whatever, they look fine today.* [Nicole, RCA].

> *It's happened to me, where I've just lost it because I can't take it anymore, where I'm dismissed as knowing nothing, because I'm just the 'bum-wiper'.* [Management's attitude is] *you do what I tell you do, and that's it. I'm not supposed to think. I'm not supposed to know anything. I'm not supposed to question. THAT's what bothers me… Don't demean me because I'm 'just' a care aide.* [Vanessa, RCA]

RCAs' comments reflect a rallying against the dominant view of care work as unskilled. While they highlight the perceived expectation for RCAs to mindlessly carry-out their care/unit tasks at the behest of those above them, their comments also capture the aides' desire to be able to think independently, to have their suggestions acknowledged and their input valued. Such tightly-bound expectations of the RCAs' role are mirrored in a comment made by one of Vanessa's managers, who assumed the voice of a RCA as she explained:

> *You cannot expect me to think. I am hired to do, not to think. If I'm expected to sit down and talk with residents, then that means I've got to think. But we're not hired to think. I'm hired to do the dishes and wipe the bums and bathe the people and swab the decks... Why don't you talk to people? Well, I can't do that, I don't know how to do that* [Shirley, Manager]

While both Vanessa and Shirley appear to desire the same thing, there is the sense that they are either restricted from (RCAs' view) or incapable of (management's view) doing so.

In response to their lack of decision-making authority, and the discounting of their observations and opinions, RCAs narrowed their focus, concentrating their

attention on that which they could control; that is, what they termed 'just doing their job'.

> *Right now, I'm in my mode where I just go to work, do the job to the best of my ability and go home*. [Ginny, RCA]

> Jolene: *…But I just think everything's becoming so impersonal. You're just here to do the job.*
>
> HC: *That's what you think they're* [management] *thinking?*
>
> Jolene*: That's right, yeah.*
>
> HC: *Or is that the way you've started to approach it as well?*
>
> Jolene: *Well, that's the way I'm feeling now…*

Jolene's comments reflect how RCAs, sensitive to management's perceptions of their role, internalize such perceptions and adjust their roles accordingly. As Tamara noted, "*Management has been awesome to me; mind you I never complain, I never step out of my boundaries.*" Indeed, Vanessa reiterated, "…*you just shut up, and do your job, and then you're ok*".

The challenge in RCAs narrowing their focus to concentrate on 'just doing the job' is that it potentially reinforces their tendency to prioritize task completion over social interaction. By virtue of their position in the organizational structure, RCAs are responsible for much of the task completion associated with resident care, yet when they are not recognized for all that they bring beyond such task completion (i.e., their intimate knowledge and observations of residents' needs and behaviours), the provision of person-centred care is potentially curtailed, resulting in standardized, as opposed to individualized care.

5.3.2 On Valuing and Negotiating Relationships

Within this environment of 'just doing their job', however, the majority of RCAs were able to provide what they considered to be quality dementia care (i.e., keeping residents clean, comfortable, calm and happy, in a compassionate, patient, affectionate and kin-like manner). Central to RCAs' ability to provide such care (i.e., to 'care in spite of') was the quality of their co-worker relationships, with both their fellow RCAs and LPN supervisors.

With the small-scale environments typically staffed with two RCAs, good working relationships were paramount in ensuring that RCAs' care work, and their workday, ran seamlessly. In light of the physically demanding nature of the job, and the potential for resident agitation and aggression, such relationships were also essential for ensuring RCAs' physical safety. As one aide noted, "*If you don't have teamwork as a care aide, you're screwed, and injured*".

Working with a 'good' care partner meant working co-operatively and sharing responsibility for resident care, as opposed to viewing residents as 'yours' or 'mine'; for example, stepping in and assisting a resident or completing a task if their partner were otherwise occupied. Working as a team, RCAs sought to capitalize on their co-worker's respective strengths and abilities and relationships with residents, thus facilitating the care of residents with whom they did not necessarily 'click'. Dependability and reciprocity were considered critical; being ready and willing to help when their care partner needed them, meant that they, in turn, could call on their partner when needed.

> [My co-worker] *she's got your back. When she was sick the last time, I went 'Noooo'!. The world ends when she's not here. We totally, you know, feed each other ideas, 'We should try this' or 'I'll take this person, you take that person'… it's teamwork.* [Aimee, RCA]

> *You have to be able to work as a team. You have to. You've got to be able to depend on them just as much as they depend on you, right. You can't do everything on your own. You'd burn out real quick.* [Pam, RCA]

Ginny, cognizant of the way in which she and her co-worker were reliant upon one another for their physical safety, highlighted how she always checked in with her co-worker before leaving at shift-end. For her, it was about ensuring that her co-worker did not require additional help with the handful of residents still awake and pacing the unit, who at times became embroiled in altercations with each other or with residents already in bed. She explained,

> *I always say to my co-worker, "Are you comfortable with me leaving?" and if she's not then I'll stay. And the LPN has already said, 'I'll put in for that'. It's a safety thing…* [like last night] *I wouldn't have left my co-worker in that mess, that's not fair.*

Her comment underscores the difference LPN support can make. In informing Ginny that she will be paid for staying beyond the end of her scheduled shift, the LPN acknowledges the importance of Ginny and her co-worker's physical safety and that Ginny's time is worthy of remuneration. Ginny and her co-worker are thus afforded both respect and value. This particular LPN was new to the unit, but had many years of experience working with individuals with dementia. The RCAs working under her commented how refreshing it was to have someone who kept them informed (e.g., of residents' medication changes), and who took the time to listen to RCA's questions and

suggestions. As Shona noted, "*And the first week that I worked with her, I'm going, "Oh my God… is this how it's supposed to be?" No, I love working with her.*"

RCAs particularly valued their relationships with LPN supervisors who understood the challenges of their position, who responded in a timely fashion to requests for assistance, who pitched in to help with physical care (and did not see it as beneath them to do so), who trusted their input and judgement, and who, like a good RCA colleague, had their back. As Jaime succinctly noted, "*When I'm supported by my nursing staff, my job is good; when I'm not, it's really bad*."

> *Our LPN that works on our rotation, she's fabulous… I have had nurses that are just like, 'No, I'm busy' or whatever, and then you'll walk over to the other wing and they'll be sitting at the nurses' station talking…* [Nicole, RCA]

> *And you know what; it's nice to have someone who will back you up. We know how they're* [the residents] *acting, we know if they're different, if they're showing signs of aggression that they're not usually like that… With the nurse I work with, she trusts that. I know that there's a difference, so if I've worked with somebody else and they say, 'well, maybe they're just…' 'No, I know they're not just thirsty, obviously I've tried that, I've done this, this and this [*she sighs*]. It's nice to work with someone who's like, 'yeah, ok, we'll do this. We'll follow these steps…' And that's really important to me. I feel really comfortable about my job, I love working here.* [Stephanie, RCA]

For night-shift RCAs, who worked alone, such recognition and support was invaluable. Interestingly, these RCAs expressed a distinct preference for working nights because, even though it required a significantly different lifestyle, working alone meant they did not have to deal with co-workers, nurses or family members whom they perceived as difficult. Working alone, with a responsive and supportive team leader,

spared them from experiencing the disillusionment and frustration of non-responsive co-workers or those with differing care approaches.

> *Instead of having a co-worker beside me, when I work alone, my patience is great, like I'm way calmer. If I have other workers beside me, sometimes I find myself getting agitated with the worker, not my residents. It's the worker. Because* [as happened in another unit] *sometimes you'll be in an area where you're asking for help and someone will say, 'well, I'm too busy right now", and then they don't want to help you. Or, say you see something they do and you don't quite like how they did it, then you're feeling irritated by that co-worker.* [Kendra, RCA]

> *…the reason I choose to continue to work nights is because together we've built a good team of regular staff. I know how they work, I know who they are and I don't treat that lightly.* [Sabrina, LPN].

RCAs acknowledged how stressful it was to work with someone with whom they did not get along. Unlike larger, more traditionally-designed units, there were no separate wings to which RCAs could retreat and work; in such small-scale environments they would inevitably end up encountering their colleague.

Challenges arose for RCAs when they encountered the minority of co-workers who were controlling, manipulative or adamant about care/unit tasks being done a certain way; that is, a 'my way or the highway' mentality. Such individuals were termed 'bossy', 'alpha personalities' or 'bullies'. As it happened, they were the predominantly task-oriented RCAs who had difficulty placing the residents' needs at the centre of the care process. Jolene, one of the more experienced RCAs, described how she dealt with particularly task-oriented casuals:

> *When I'm working with a casual that doesn't work the area very much, I've learned to take control and say, 'This is how we do it here'. Sometimes it works and sometimes you just get somebody that's so head-*

strong and so set on doing it this way… that you're thinking well, we're not here for you, we're here for them and this is what they're used to…"

However, when it came to dealing with the 'alpha personalities' of several regular staff, RCAs were considerably more reluctant to speak up. Such reluctance stemmed from what they perceived as an absence of anonymity when a complaint was put forth. With so few staff working on the unit, they believed it would be relatively easy to trace the complaint back to the source. In addition, RCAs witnessed few if any observable repercussions for the RCA being reported, thus contributing to a perceived lack of management support. Consequently, the RCAs believed that complaining led to greater conflict and discord. For them, the fear of retribution from a co-worker who, following a complaint, may be increasingly reluctant to assist them with various aspects of resident care (e.g., aggressive behaviour; lifts and transfers), potentially jeopardizing their safety, outweighed the challenges of working with such an individual. As Tamara noted,

But, you know what's going to happen? It becomes a he said, she said, you know. That's all it's going to be. Ninety percent of the time there's no repercussions to the person being reported, you know? What do you do? You can report it if you want to but you're going to pay the price. And it's not a matter of right and wrong. It's a matter of okay, I'm going to have to work under those pressures now because I reported this…

As a result, some RCAs sought to work around the conflict in the hopes of creating a situation that would be more harmonious for them and result in better care for the residents.

Rhonda: *I feel with her that she likes to push people, push them because she wants the reaction… She's trying to find a way to bully people… and*

no, you're not going to bully me… She does several things that in my opinion that we've been told not to do or it's not good practice.

HC: *So in that instance, then, can you go to your supervisor and say…?*

Rhonda: *I'm probably expected to, but is that like tattling and then they take it and they go "Well, Rhonda says this and Rhonda says that"…? So, it causes more conflict and what good is that? Who does that help? It doesn't help me coming in to work in a happy mood and it doesn't help* [my colleague]*, who thinks I'm a tattletale. And then it definitely doesn't help the residents.*

For the RCAs, working co-operatively with dependable and responsive care partners and team leaders made their experiences as 'bum-wipers and bottom-feeders' tolerable, and provided a supportive work environment that better enabled them to attend to residents' individual needs and well-being. When RCAs encountered collegial relationships and a sense of teamwork, they experienced mutual respect, trust and the security to try new approaches and ideas for personalizing care, thus promoting quality care provision. In contrast, the lack of support for (and RCAs' resultant reluctance in) speaking up about poor or questionable care practices meant that such practices were likely to continue, to the detriment of residents and quality care provision.

5.3.3 On Breaking Procedure

For just over half of the RCAs, who were more attuned to person-centred care provision, the ability to 'care in spite of' was also influenced by their selective resistance to the regulatory and institutional policies and procedures designed to enforce and standardize care delivery. In their eyes, a considerable disjuncture existed between the facility 'rules' and the reality of their daily care practice, such that strict adherence to the policies and procedures (i.e., 'going by the book') hampered their ability to provide

quality dementia care. Consequently, policies and procedures were seen more as general guidelines.

For these RCAs, dementia care was not black and white, as implied by formal (and informal) organizational policies and procedures and Licensing regulations, but rather very grey. A 'one size fits all' approach was not perceived as appropriate to dementia care; with few organizational policies and procedures specific to the dementia care units, what might work on another unit, or for some residents, was not always feasible or suitable on the dementia unit or for another resident. For example, at one site, written policy dictated that all staff were to follow the designated lift/transfer procedure determined by the physiotherapist. Yet in the context of dementia care, greater flexibility was required in order to recognize the fluctuating abilities and needs of the residents, and thereby individualize the care. As Ginny commented, "*you can have a policy, but there's black and white and there's grey. And I just find on our unit, there's a lot of grey…"* Such 'greyness' led these RCAs to draw on their knowledge, skills and their own beliefs about care quality as they actively resisted the formal and informal policies and procedures they believed detrimental to the residents' best interests.

> *There are policies that we have to follow… but then again, working with dementia, following all those procedures, it doesn't work… I could provide more care, I could give them more of my support, in doing what I believe… the paper is just a guideline.* [Felicia, RCA]

> *Now we're being told that it should be one transfer for all shifts. And it's like, well that's totally unfair. It's not flexible. I mean you're dealing with human beings and it's not black and white. And I said "Well, it looks like I'll be getting in crap then… because if Gerald can stand and walk, I will*

> *walk with him. Like if you guys classify him as a full sling lift 24/7, if he can walk in the morning, I'm not going to tell him 'no'. And it's frustrating, because we can tell just by talking with him, you know when he's first waking up, we can usually sense he's off to a good start."* [Rebecca, RCA]

Instances of 'breaking procedure' not only included formal policies/procedures, but also informal policies/procedures (e.g., changing residents' incontinence pads more than the recommended two times/shift; changing residents into their pajamas before dinner), and the occasional Licensing regulation (e.g., serving dinner prior to 5 p.m.; the time dictated by Licensing). In the eyes of the RCAs, all of the above were done to preserve the residents' best interests. However, such resistance can also be seen as a way for RCAs to regain a sense of agency and empowerment; a means of resisting the subjugation and domination experienced as part of their work. The secluded nature of the dementia units (their physical separateness, and minimal surveillance from supervisors and management) facilitated the selective 'breaking procedure' thus enabling RCAs to give the care they believed most appropriate for each individual resident and to reclaim a sense of power.

Challenging institutional policy, however, was at times risky. One of the most contentious policies, the two-person mobility assist existed to preserve the safety of the resident and the RCAs (i.e., to minimize workplace injuries); if RCAs were injured while single-handedly transferring a resident deemed a two-person assist, the provincial Workers Compensation organization would not cover their injury claims. Yet despite this risk, RCAs revealed how they broke procedure to better accommodate what they believed worked best for their resident(s). Pam explained:

> *Sometimes knowing what works and following the policies and procedures are two different things… Say for instance Claire* [a resident]*. As far as following policies and procedures with her care plan say… she's a two-person. But you know, because you know her, that you could probably do her on your own, right? But if you do and you're injured and it comes back that they found out that you did that care on your own, you can get in a lot of trouble. Because the care plan, you're supposed to follow that procedure and if you're not and something happens to you, you're shit out of luck….* [Yet] *with Claire, she does wonderful with one on one. If you get a couple of people in there, it's too much for her sometimes.*

Pam's narrative illustrates the tension experienced by these RCAs as they grappled with the rules, their safety and the reality of daily care practice. At times, however, breaking procedure was not a personal choice but a forced one, borne out of conflicting unit policies and staffing constraints. For example, Meadowview aides' explained how they were always supposed to have one RCA 'on the floor', particularly if residents' behaviour started to escalate. Yet with only two RCAs on the unit and several residents classified as two-person transfers, the RCA providing care was placed in a difficult position, forced to do what she had to do (i.e., perform the transfer single-handedly). Similarly, there were several times during the day when only one RCA was scheduled to be on the unit. The frustration and cynicism felt by one RCA is palpable in the exchange below:

> Rebecca: *..this is where I get confused with the rules that they throw out there. I mean, there's a lot of things, you know, in a half an hour that could be classified as work for two people. So why do we not have two people, you know? I mean… don't throw rules at me if you guys can't even make it so it's a reality.*
>
> HC: *So what would happen in that instance if you have a resident who is a two-person transfer but there's only one of you? So what happens between 7:00 and 7:30 or 2:30 and 3:00?*

> Rebecca: *I do it on my own. And I do the majority…I mean honestly we do a lot of work that's classed for two people. We do it as one. But I'm not breaking my back doing it. I mean I would never do something if it was going to harm the resident or harm myself. But I mean, if something did happen, if I did hurt myself, yeah, I would be in crap and I wouldn't be covered. But… how would that be my fault?*

For the RCAs, selectively breaking procedure was thus a double-edged sword. When done as a personal choice, it offered the means to assert their (limited) power and further support residents' independence, autonomy and choice. However, when undertaken as a result of organizational constraint, it served to further disempower RCAs (and residents), placing them both at unnecessary risk.

5.4 Discussion

Consistent with RCAs in other long-term care settings, RCAs in this study were afforded little power and voice (Banerjee et al., 2015; Bowers et al., 2003; DeForge et al., 2011). While such continued disempowerment has the potential to impede person-centred care provision, RCAs' ability to draw on and negotiate co-worker relationships helped them provide what they considered to be quality dementia care (i.e., keeping residents clean, comfortable, calm and happy, in a compassionate, patient, affectionate and kin-like manner); an outcome that was, for certain aides and at certain times, more readily achieved than others. For RCAs whose care practices more consistently included elements of person-centred care provision (e.g., attending to residents' preferences and needs; supporting resident independence, autonomy and choice), the ability to 'care in spite of' was also facilitated by their selective breaking of institutional policies and procedures.

RCAs viewed themselves as important sources of knowledge regarding residents' preferences and needs, yet as in previous research (Banerjee et al., 2015; Caspar & O'Rourke, 2008; Kontos et al., 2010), their input into care and unit management decisions was sought relatively infrequently, if at all. The fact that RCAs experienced such disempowerment, despite the presence of smaller staffing ratios (5-6 residents/RCA), relatively good compensation ($20-21/hour with benefits), minimal surveillance from supervisors and management, and a greater degree of flexibility in carrying out their daily care tasks, highlights the potential role of larger structural constraints. While both study sites had adopted key features of more individualized, social models of care, they still adhered to a pyramid-shaped staffing hierarchy, the legacy of the hierarchical disciplines of medicine and nursing (Jervis, 2002). With the majority of power centered in the hands of a few administrators and managers, RCAs found themselves working within an oppressive hierarchical structure, in which they felt invisible and devalued.

The experiences of RCAs in this study challenge us to question how care work is currently viewed and organized. On the surface, care provision looks like work done in the home, believed to consist of routine, manual, simple labour requiring skills that women know how to do by virtue of being female (Armstrong, 2013). Yet participating RCAs sought to work collaboratively and effectively as a team, capitalizing on their co-worker's respective strengths and relationships with residents, and selectively breaking procedure to provide care they believed better accommodated residents' fluctuating needs and abilities. Such skills, however, remain invisible, in part because of continued

societal assumptions about skills and care (Armstrong, 2013). While RCAs have less formal education than their team leaders (i.e., LPNs) and managers (i.e., RNs), they possess considerable tacit knowledge; yet such knowledge does not seem to be valued to the same degree.

In addition, with residential care increasingly patterned along market models of care (Day, 2013), the system remains primarily concerned with objectively measurable and functional tasks, with residents tracked and monitored in terms of their physical status. Consequently, care facilities continue to retain a strong focus on task completion. With a task-focused approach valued and promoted, and RCAs' low status and social positioning within the labour hierarchy, it is of little surprise that RCAs, responsible for much of the task completion associated with resident care, were positioned as doers and not thinkers. Interestingly, thinking skills (critical thinking, problem-solving, decision-making) are one of three key foundational concepts (the others being safety and professional practice) upon which British Columbia's provincial curriculum for RCAs is based (Government of B.C., 2008). Yet while RCAs may learn these skills, working in a system that does not recognize or value such contributions prevents RCAs from further developing the skills they possess and know are required (Armstrong, 2013), thus making it difficult for them to move beyond their role as doer. Management, working within the same task-focused system, may find it similarly difficult to empower RCAs to think independently and LPNs to consistently acknowledge and respect RCAs observations and opinions. Offering additional support and training to

help managers better understand how to provide leadership in a person-centred care context may help in this regard.

By virtue of the amount of time spent with residents, RCAs hold considerable knowledge regarding residents' needs, preferences and behaviours. As such, greater consideration is required as to how to better incorporate RCAs' perspectives and knowledge into the care context. Several models have successfully demonstrated how increasing RCAs' decision-making latitude and ability to self-manage may help RCAs feel like an integral part of the care team, and redress the power imbalance inherent in the traditional staffing hierarchy. For example, the Green House model utilizes a flattened staff hierarchy, in which RCAs work as a small, self-managed team in consultation with other clinical professionals, which has been found to benefit both staff and residents (Bowers & Nolet, 2011; Kane et al., 2007). Similarly, Yeatts and Cready's (2007) work on empowered RCA work teams reveals that RCAs who were involved in management decisions pertaining to their work, and who participated in both regularly-scheduled and impromptu meetings to review residents' conditions and care needs and other issues of concern to aides, were more likely to share information regarding residents' unique needs and preferences with colleagues and supervisors, and engage with residents.

The success of a flattened staff hierarchy, however, is reliant on effective supervisory practices. Yet, as a result of labour restructuring within residential care in B.C., diploma-trained LPNs, who have less clinical preparation than RNs and are paid lower wages, are increasingly replacing degree-trained RNs as the source of licensed nursing staff (CIHI, 2004). Consequently, adequate support and training must be

available to LPN supervisors to help them better understand their role and improve their supervisory skills, especially as research suggests they find themselves ill-prepared for such supervisory responsibilities (Schirm et al., 2000).

For RCAs in this study, the ability to 'care in spite of' continued disempowerment was shaped by the valuing and negotiating of their peer, and supervisory, relationships, which helped create a more tolerable and supportive work environment. As in previous studies (Pennington et al., 2003; Schirm et al., 2000), when RCAs encountered dependable and reciprocal peer relationships, they were better able to meet the physical and emotional demands of their work. In sharing care responsibilities, building on each other's strengths and working together to problem-solve, RCAs' peer relationships also helped facilitate the meeting of residents' needs. Such relationships, when they occurred, provided a sense of security and belonging; attributes identified by Ryan and colleagues (2008) as essential to caregivers' delivery of quality dementia care.

Not surprisingly, RCAs valued their relationships with those LPNs who positioned them as 'thinkers' and not just 'doers', who valued, respected and acted upon their knowledge and opinions, and who did not see it as beneath their status to pitch in and help out with resident care. Such support has important implications for quality care provision; as Bishop and colleagues (2008) noted, RCAs working under LPNs who respected and relied upon their knowledge of resident care were more likely to express an elevated sense of responsibility towards their residents.

Of particular concern, given its potentially detrimental effect on quality care provision, was the manner in which RCAs negotiated their relationships with the

minority of aides they considered 'bullies' or 'alpha personalities', predominantly task-oriented aides who firmly believed their care approach was the only/right way to care. In spite of concerns about these individuals' poor or questionable care practices, RCAs were reluctant to convey their concerns to their supervisors/management, past experience having taught them that such complaints went primarily unheeded, leaving them to deal with the resultant discord and conflict with their colleague. Management's perceived failure to deal with such complaints or provide support may serve to further devalue and diminish RCAs' experiences, reinforcing to them how little power and voice they have. Such a finding highlights the importance of implementing an effective whistle-blower policy as a means of supporting and encouraging staff to speak out.

The ways in which RCAs valued and negotiated their co-worker relationships lends credence to the findings of te Boekhorst and colleagues (2008) regarding the quality versus quantity of RCAs' peer interactions; that is, it is not how many RCAs are on shift, but rather who is on shift, that is important to RCAs', and in turn the residents', care experience. A heretofore relatively unexplored area of research, further examination of the quality of RCAs' relationships offers a valuable direction for future inquiry. For example, while much has been written about inadequate staffing levels and their association with care quality, there exists only weak empirical evidence showing that staffing levels influence care quality (Castle, 2008). Attempts to further elucidate the staffing-quality relationship have identified the importance of including additional staffing variables, such as staff stability (i.e., length of tenure), professional staff mix, and the use of agency (i.e., temporary) staff (Castle & Engberg, 2008). In light of the

current findings, future analytic models should also include the quality of RCAs' work relationships.

The historic and ongoing devaluation of women, care and care work means that RCAs experience limited capacity to influence the nature and the organization of their work (Campbell, 2013). However, for RCAs in this study, the selective resistance to, and breaking of, formal and informal policies/procedures and regulations offered a means by which to circumvent the black and white policies and procedures that existed to structure their care provision. Such selective resistance not only allowed them to better accommodate residents' fluctuating abilities and needs, thereby individualizing care, but also potentially facilitated RCAs reclaiming of a sense of agency and empowerment.

Part of the challenge is that outside organizations are not set up to accommodate flexible care approaches. For example, in terms of facilities' lift and transfer policies, procedures are put in place whether they work or not, because the organization that compensates injured workers does not appear to have the ability to be a flexible enough system. Similarly, while such policies appear designed to prevent the resident from being placed at undue risk, they also potentially reduce the chance of litigation, should a resident (or RCA) be injured.

At issue for the RCAs was that certain policies, procedures and regulations took away their ability to make care decisions based on their intimate knowledge and observations of residents' needs and behaviours, and on what they felt was best for the resident at any particular point in time. To the RCAs, a 'one size fits all' approach did not seem fair, to them or to their residents. Part of the problem may well stem from

RCAs' limited ability to shape the policies directly affecting their work (Armstrong, 2013), as well as a lack of understanding as to why particular policies are enacted; the implication being that if RCAs are offered the potential to provide input into policies or have a greater understanding of why certain policies exist, they may be more inclined to follow them.

The disconnect between the rules and realities of care practice has been highlighted in several other studies (DeForget et al., 2011; Kontos et al., 2010; Lopez, 2006). However, unlike in Lopez's (2006) work, in which rule-breaking was seen to compromise care quality, the current findings reflect those of DeForge et al. (2011) and Kontos et al. (2010), in which breaking procedure was employed by RCAs as a means of individualizing care because existing rules, regulations and policies otherwise curtailed their ability to do so. By consciously engaging in rule-breaking, RCAs were able to care for their residents in a manner that felt intuitive and tailored to residents' needs (DeForge et al., 2011). Indeed, participating RCAs' rule-breaking was selective rather than routinized, contingent on how residents were doing on any particular day. For example, if residents had a busy afternoon and were hungry at 4:30 p.m., dinner was served early; if a resident was in a good mood, and unlikely to be upset by having two people in the room assisting her, then the two-person mobility assist rule was followed.

Breaking procedure, however, was not always done to individualize care. Although not explicitly mentioned by Meadowview management, there were cost-savings to be had by having fewer than two RCAs on between 7 a.m. and 11 p.m. As a result, RCAs were periodically left with little option but to single-handedly conduct a

two-person mobility assist. While performing such assists alone provided a quick fix, in that they allowed RCAs to efficiently complete their work, the underlying cause (e.g., neo-liberal ideologies and the need to create suitable profit margins) remains unaddressed, with both staff and residents' safety potentially placed in jeopardy on a daily basis.

5.5 Conclusion

This paper contributes to an improved understanding of the complex dynamics surrounding dementia care provision by exploring the manner in which RCAs seek to provide quality dementia care in the context of continued disempowerment. Study findings illustrate how, despite smaller staffing ratios, relatively good compensation, manageable workloads and flexibility in terms of how they carry out their daily care tasks, RCAs and their knowledge were repeatedly devalued. It is essential, given the pivotal role that RCAs play in shaping the point-of-care decisions of residents with dementia, that we find ways to redress such devaluation. Integrating RCAs more fully into resident care and unit decision-making, supporting the establishment of quality working relationships with their peers and LPN supervisors and their reporting of poor care practice, and inviting RCAs' input into policy-making that supports (rather than hinders) their daily care realities offer a good starting point. Indeed, as Thomas (1996) asserts, in linking residents' quality of life with the quality of RCAs' working environments, if we wish RCAs to afford residents greater value and respect, then facility management must grant staff the same value and respect.

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CHAPTER 6: STAFF PERSONHOOD IN DEMENTIA CARE SETTINGS… "DO THEY CARE ABOUT ME?"

6.1 Introduction

In recent years, facility-based dementia care has experienced a paradigmatic shift as providers endeavour to move beyond a highly-routinized, task-oriented medical model that prioritizes physical care. The resultant individualized, social models of care highlight residents' uniqueness; flexible care routines respectful of residents' preferences and needs; consistent, caring relationships between residents and staff; and an enriched social environment (Talerico, O'Brien & Swafford, 2003; Edvardsson, Winblad & Sandman, 2008). This shift stems largely from the person-centred care philosophy advocated by Kitwood in his writings on dementia and personhood (Brooker, 2007). For Kitwood (1997), the essence of quality dementia care is the enhancement and maintenance of personhood; that is, the recognition, respect and trust engendered when status is bestowed upon an individual, by others, in the context of relationship and social being (p.8). Considered synonymous with quality dementia care (Brooker, 2007), person-centred care is increasingly viewed as the defining standard of practice (Brownie & Nancarrow, 2013); however, its widespread adoption and integration has yet to be fully realized (Talerico et al., 2003).

Residential Care Aides (RCAs; unregulated workers also known as nursing assistants/aides, personal support workers, health care aides) provide the majority of hands-on care for persons with dementia and thus possess considerable capacity for

shaping their daily life experiences and well-being. Yet, situated on the lowest tier of the health-care hierarchy, RCAs are the least educated and lowest paid, typically afforded little power, respect or recognition (Innes, 2002). This is an issue that bears particular importance given the assertion that RCAs will never grant their residents more value and respect than that which they are granted by their employer (Kitwood, 1997; Thomas, 1996). Indeed, Kitwood (1997) and others (Brooker, 2007; Nolan, Ryan, Enderby & Reid, 2002) acknowledge that the provision of quality dementia care not only entails fostering the personhood of residents, but also that of staff, a factor which, to date, remains overlooked in much of the empirical literature.

Central to the notion of personhood is the idea that each person has absolute value – as such, there exists an obligation to treat our fellow beings with respect, to view them as ends, as opposed to means to some other end (Kitwood, 1997). Too often, however, RCAs are viewed in this latter manner, as interchangeable cogs in a wheel turning out a quota of standardized care procedures on each shift (Ronch, 2004). Attending to staff personhood entails acknowledging and valuing RCAs' worth as unique individuals (Brooker, 2007). As with persons with dementia, it is about conveying recognition, respect and trust in the context of relationship (Kitwood, 1997), and fostering a sense of security, continuity, belonging, purpose, achievement and significance (Nolan et al., 2002). As Brooker (2007) notes, person-centred care is about the building of authentic relationships. If RCAs are to understand (and uphold) the importance of communication, integrity and nurturing in their work with residents, then such principles should be reflected in the interactions between an organization and

their workers (Brooker, 2007). In other words, organizations seeking to provide quality dementia care must also attend to creating caring, person-centred workplaces.

To date, only a handful of studies have explored staff personhood (albeit without naming it as such) in the context of person-centred workplaces. Sikma (2006) explored the experiences of caring and being cared for with paid staff (including RCAs) in two nursing homes with a community reputation for excellence. Staff emphasized the importance of their own humanity being valued and acknowledged, of being connected to something larger than oneself, of knowing (individuals and situations) and being known, and of teamwork. Key organizational characteristics, including the provision of adequate staffing and material resources (i.e., equipment/supplies), a sense of trust (i.e., to do one's job with the freedom to make mistakes), and open communication with colleagues and supervisors to access the information necessary to do their work, were not only viewed as essential to workers' capacity to care, but also to workers' sense of being cared for. In having their personhood recognized and their own needs met, staff reported feeling better equipped to care for their residents, thus reducing the potential for poor care of residents (Sikma, 2006).

Bowers and colleagues (2003) highlighted how the continued devaluation of RCAs' personhood contributes to the ongoing issue of staff turnover. For RCAs, dissonance between management rhetoric (i.e., 'we value you and your expertise') and messages embedded in organizational policies and practices (e.g., around staffing, absenteeism, orientation and compensation) led to their feeling personally and professionally dismissed. Such dismissal occurred in the form of what the researchers

labelled minimizing (i.e., devaluing their skills; disparaging their character) and levelling (i.e., failure to distinguish individual RCAs based on their skills, expertise and character). For example, RCAs perceived the use of temporary staff, brought in to address staff shortages, as indicative of the fact that management viewed all RCAs as interchangeable, thus dismissing their intimate knowledge of residents and its role in facilitating care provision. Similarly, RCAs relayed stories of hallway interactions in which management walked by without acknowledging RCAs' social greetings, leaving them feeling invisible (Bowers et al., 2003). Such practices repeatedly affronted RCAs' personhood, discounting their experiences as workers and human beings.

Believing managers to play a central role in the development of person-centred workplaces, Tellis-Nayak (2007) examined the link between the quality of RCAs' managers and work environments, and RCA engagement (i.e., satisfaction, loyalty, commitment). As expected, RCAs' engagement deepened when managers cared about them and listened to them. Similarly, increased RCA engagement was associated with managers who assisted in times of job stress, created safe workplaces, ensured provision of adequate equipment/supplies and offered training to assist with difficult residents and families. RCAs' ratings of management and workplace quality were significantly correlated with families' ratings of residents' quality of life, quality of care and quality of service, illustrating the link between person-centred workplaces and resident quality of life.

Such studies accentuate the importance of attending to staff personhood and the potential role of managers and workplace culture in facilitating quality dementia

care provision. To better understand the dynamics of care delivery, this paper draws on data from an ethnographic study examining the influence of the organizational care environment on dementia care provision to explore RCAs' experiences of personhood in two small-scale, dementia care units. The study was informed by Estes' (2001) framework of political economy of aging, which explicitly acknowledges how structural influences, such as social relations and societal institutions (e.g., political and economic systems, ideology, gender) shape individual experiences.

6.2 Methods

6.2.1 Study Sites

Four dementia care units in two complex care facilities in British Columbia, Canada served as study sites. The units, purposively-selected for their presence of features identified as promoting quality dementia care (e.g., Rabig, Thomas, Kane, Cutler & McAlilly, 2006; Verbeek et al., 2010), were small-in-scale, housed 10-11 residents per unit, featured archetypal aspects of home and utilized a consistent staffing model in which RCAs were permanently assigned to their respective unit. The facilities in which the units were housed were purpose-built, had been open less than 10 years and were home to 100-plus residents. While both sites were privately-owned (the first, Meadowview[9], by a small, regional for-profit organization; the second, Rivermead, by a larger, not-for-profit chain), they were publicly-funded; that is, they received a set per-

9 For purposes of anonymity, all names are pseudonyms.

diem rate from the provincial Ministry of Health for the majority of their residents, including those on the dementia units.

Meadowview

Meadowview's two dementia units featured an almost identical floor plan. Both units included private bedrooms with ensuite washrooms, several small sitting areas, a main dining area, small kitchen, bathing room, communal resident washroom and several staff storage areas; however, only one unit featured access to a secure outdoor courtyard. As there was no functioning nursing station on either unit, residents' charts were located at the nursing station on adjacent units.

RCAs were responsible for all resident care (separate departments were responsible for meal preparation, housekeeping and laundry), and were supervised by a LPN, who was responsible for all medication administration. As the LPN for each dementia unit also oversaw two other units (for a workload of approximately 40 residents), they primarily entered the unit to dispense medication or in response to RCAs' requests for assistance. The LPN reported to the Director of Care, who in turn reported to the General Manager, both of whom had professional nursing designations.

Each dementia unit was staffed with two RCAs between 7:30 a.m. and 2:30 p.m., and 3:30 p.m. to 9:30 p.m., but one RCA outside of these times. At night (i.e., 11:00 p.m. to 7:00 a.m.), each unit shared a RCA with a neighbouring unit. As members of a provincial health care union, RCAs received an hourly wage of approximately $20 (more

than the province's minimum hourly wage at the time of $10.25), as well as medical and employment benefits.

Rivermead

Rivermead's two participating dementia units shared an identical floor plan. The units featured private bedrooms (although, unlike at Meadowview, they did not include ensuite bathrooms), four communal washrooms (one of which included a bathtub, another, a shower), two living rooms and dining areas, a kitchen, laundry room and a secure outdoor courtyard. Medications, along with medication administration records and current care plans, were kept in a secure cupboard in the kitchen area (off-limits to residents). Charting was predominantly computerized and so each unit had its own computer; a converted kitchen in one of the participating units functioned as a nursing station, at which residents' paper charts were kept.

RCAs fulfilled multiple roles, responsible for all resident care, as well as medication administration, meal preparation, laundry, cleaning and recreational activities. RCAs were supervised by an LPN who oversaw both participating units, as well as two other units (for a workload of approximately 40 residents). While the LPN (and at times, the RN) briefly connected with RCAs at the start of the day shift to communicate any specific care issues, their presence was typically limited to administering medications considered outside of the RCAs' scope of practice (e.g., insulin) or responding to RCAs' requests for assistance. The LPN reported directly to an RN, who in turn reported to the General Manager.

For the majority of the day (i.e., 7:30 a.m. – 7:30 p.m.), each unit was staffed with two RCAs. At night (i.e., 7:30 p.m. – 7:30 a.m.) there was one RCA on each unit, supported by an LPN who was shared with another building. Rivermead RCAs were part of the same union as Meadowview RCAs; as such, they received an hourly wage of approximately $21 per hour, and medical and employment benefits.

6.2.2 Participants

Following ethics approval from the University and Health Authority research ethics boards, letters of invitation and study brochures were distributed to all (i.e., day, evening and night-shift) RCAs and LPNs on the selected units, and senior management[10]. Staff meetings and shift changeovers were attended to further explain the study. To be eligible for participation, staff had to: (i) have been employed at the site for a minimum of 3 months, in a full-time, part-time or casual capacity; and (ii) be willing to provide informed consent. Management were not informed who took part in the study. In recognition of RCAs' time and effort, participants' names were entered into a draw (at each site) for a $100 gift card to a local shopping mall. LPNs and senior management received no incentive for participation.

Participants included 20 full-time/part-time (of a possible 28) RCAs and 3 casual RCAs, 3 (of 8) LPNs, and 5 (of 6) senior managers. RCAs were primarily female, Caucasian and Canadian-born. They ranged in age from 34-64 years (mean 48 years), had worked as an aide between 8 months and 25 years (mean 11 years), and had been

10 Recruitment materials were also sent to residents' families; as data collection included observations of staff-resident interaction, informed consent was sought from residents' proxies, while assent was sought from residents themselves.

employed at their current site between 6 months and 25 years (mean 8 years; as Meadowview had built a new facility on an existing site, several RCAs had worked at the previous, on-site facility). All were in receipt of their RCA certificate, obtained following completion of a 4-6 month community college course, and were registered with the BC Care Aide and Community Health Worker Registry (mandatory for all aides working in publicly-, but not privately-, funded, care facilities). LPNs and managers were also predominantly female, and Canadian-born. Most held a professional nursing designation, had at least 10 years' experience in residential care and had been employed at their current site between 3 months and 10 years (mean 3 years). While LPNs were unionized, management were not.

6.2.3 Data Collection

Data collection occurred between July 2013 and July 2014 (i.e., 6 months per site), and included 37 semi-structured interviews and over 230 hours of participant observation. All participants were interviewed at least once; some were interviewed multiple times to more thoroughly explore emerging themes. Lasting approximately 45 minutes to 2 hours, interviews were conducted at a location of participants' choosing (typically, off-site at a local café, or on-site but off-unit), audio-recorded and transcribed verbatim. The interview protocol included a series of open-ended questions such as, "Tell me what it is like to work as a RCA/LPN on a unit for people with dementia", "What do you think makes for good dementia care?", and "What aspects of the organizational environment make it easy or difficult to provide such care?". Follow-up questions focused on the challenges and rewards of their work, the degree to which they felt able

to provide good care, management support, and the influence of policies, procedures and care routines on their work. Similar questions were asked of management, with additional probes used to explore specific managerial, facility and unit practices.

Participant observations sought to capture the dynamic patterns of everyday caregiving activities and interactions with colleagues, supervisors and residents. Throughout the field observations, informal conversations were held with staff on various aspects of their work environment. Activities, interactions and conversations were captured via field jottings, which were subsequently expanded into more detailed typewritten field notes. Field notes (from both observations and interviews) also captured my initial impressions and personal feelings so as to foster awareness of any biases or preconceived assumptions. Data management was facilitated by entering all transcripts and field notes into NVivo 10.

6.2.4 Data Analysis

Thematic analysis was facilitated by multiple, line-by-line readings of transcripts and field notes (Lofland, Snow, Anderson & Lofland, 2006). Initial codes focused on key descriptive terms and phrases, which were then categorized, compared and contrasted and further refined, resulting in the development of themes (Saldana, 2013). For example, the codes 'recognition', 'appreciation', and 'trust' were brought together under the theme of 'personhood undermined – management-staff relations'. An iterative process of data collection and interpretation facilitated the exploration and expansion of themes from earlier interviews and observations, and the tailoring of

subsequent data collection (e.g., interviews, informal conversations) to emerging themes. Analytic memo writing was used to help conceptually link codes and explore how codes related to larger structural issues. Throughout the analytic process, emergent themes were discussed with key (RCA/LPN) informants, thus providing opportunities for questions, critique, and feedback regarding analytic conclusions and assumptions (Tracey, 2010).

6.3 Results

Despite work environments that featured smaller staffing ratios, relatively good compensation, manageable workloads and a greater degree of flexibility in their implementation of daily care tasks, RCAs encountered repeated affronts to their personhood. Two overarching themes, 'personhood undermined – management-staff relations' and 'personhood undermined – workplace policies and practices', illustrate the dissonance between RCAs' experiences of personhood and the conceptual/theoretical ideals espoused in the literature. The first theme, 'personhood undermined – management-staff relations', encompasses the importance of recognition – of RCAs as persons and of their job demands, and appreciation – of their work and effort being recognized in non-market terms. The second, 'personhood undermined – workplace policies and practices', highlights the role of work-life balance, a full-staffing complement, human resource management practices and information sharing in RCAs' experiences of personhood.

6.3.1 Personhood Undermined – Management-Staff Relations

Management-staff relations featured prominently in RCAs' experiences of personhood. While RCAs deeply valued their relationships and interactions with residents (as illustrated in Chapter 4); there was little evidence of such connection in RCAs' relationships with management. Rather, RCAs felt unsupported, unrecognized and unappreciated, believing managements' interactions with them featured little of the compassion, respect and empathy that RCAs sought to convey in their daily interactions with residents. As Angela declared:

> *Management staff has nothing to do with why I get a good feeling around here… if it wasn't for me loving those residents, I tell you, I probably wouldn't be here still.*

Similarly Jaime, a long-time RCA, noted:

> *I think that if our unit, our six girls… didn't care about each other, we would think that nobody cared about us, other than the nursing staff.*

RCAs' narratives highlighted RCAs desire to be known (i.e., recognized as persons outside of their RCA status and of the demanding nature of care work), and to be valued (i.e., appreciated for their work and effort in non-monetary terms).

On Being Known

RCAs repeatedly expressed a desire to be cared about, and related to, as 'normal human beings' with families and lives outside of work; to be seen as more than 'just' an aide. As such, RCAs foregrounded the importance of 'being known' by management, a sense that was facilitated by informal conversations between management and RCAs either on- or off-unit. Jaime, reflecting on how things had changed since the unit first

opened, commented, "*They'd* [management] *come around and just chat. They actually knew who we were.*" RCAs relayed how little effort they felt current management made to connect with them on a more personal level. As Ginny stated,

> *Management has never introduced themselves. She'll do a walk through on the unit but not acknowledge anyone. There is just no verbal communication. I mean if I was in a managerial position, I would at least make an effort to go onto a pod and introduce myself.*

For RCAs, hallway encounters in which management failed to greet them by name or inquire about their children conveyed the sense that management were simply not interested in knowing them. They expressed frustration with such non-recognition, interpreting it as a sign of disrespect:

> *I don't think you should walk down the hallway and have to be the first one to say hello to your manager… I think that if you're in that role, whether you're up to your ass or not in stuff, you need to treat your employees well and respect them. I don't find that happens here.* [Nicole, RCA]

Such non-recognition also potentially reflects the low social status and social positioning experienced by RCAs in the labour hierarchy.

'Being known' was particularly salient for Meadowview RCAs; having lost several long-tenured managers to retirement, the facility was in a state of organizational flux. Aware of the unsettling nature of such change, administration asked if I could postpone my entrée into the facility by several months, to allow them to regain their footing. While I did so, the newly-hired managers remained with the organization for a shorter period than expected, thus resulting in the hiring of more new managers over the course of data collection. Not surprisingly, RCAs keenly felt the absence of the former

managers who they believed (given their long tenure with the organization) really knew them as individuals. For the RCAs, the non-recognition they experienced during hallway encounters with new managers reinforced the existing power hierarchy.

> Rebecca: *I think she's okay, but still nobody has really gotten to know her that much. She… stays in her office, she's not very personal… I still miss* [names former managers]… *They were stern when they needed to be, but they were also personal, you know? They cared about their staff.*
>
> HC: *So you're not feeling that?*
>
> Rebecca*: No, not at all… At least remember my name… it's made very clear that they* [management] *have the authority, they have the status.*
>
> HC: *What did the former managers do that would help facilitate the relationship between management and staff?*
>
> Rebecca: *Just little things. If you were walking by them, they'd say 'how's it going, how's your family?' Like they'd take the time to say, 'how are the kids doing?', or they'd talk to you like another staff member… it wasn't like 'I'm your boss'… You know it was more family-oriented. And now, it feels very business-like, very business oriented.*

Rebecca's comments also reflect the ongoing influence of commodification, in which RCAs are viewed less as individuals and more as a vehicle by which care is produced and profit exchanged.

Managers at both sites were rarely observed on the dementia units, typically entering only to tour a visiting official (i.e., Licensing) or in response to a resident incident. This was not lost on RCAs, who perceived their current managers to have little understanding of the demanding nature of dementia care. Dana lamented:

> *… our care coordinator, like we've barely talked to her… We don't see her and she doesn't come in as much.* [Former care coordinator] *was doing it all the time. She would come in and it was like, 'how are you girls doing?'*

For the RCAs, such periodic checking-in transmitted a sense of 'I know what you're doing and I care about what you're doing', thereby conveying that RCAs' experiences, and their work, mattered. Checking-in also offered RCAs an opportunity to debrief about the challenging nature of their work (for which formal opportunities were rare); as Pam noted, "*Unloading, when you feel like you're heard*, *that's helpful*. Vanessa concurred, "*All I need is somebody to understand, not to say you should do this or you should do that.*" RCAs were quick to point out that they tried not to take their work home, and did not share their experiences with their spouses or family, thus underscoring the importance of debriefing opportunities while at work. Nicole made the link between managements' checking-in and staff morale, commenting:

> *I think that if you have a good management team, you have a good work environment and you have good morale. And I think if you're open and honest with your employees and you get out there and you visit them and ask them if things are going okay, then…*

On Being Valued

Central to RCAs' experiences of personhood was a sense of 'being valued', of being recognized and appreciated for their work and the effort which they put into it. Expressions of recognition and appreciation conveyed the perception that management cared, about them and their work; when absent, RCAs were left feeling devalued and disrespected. Consider one of Ginny's first encounters with her new manager:

> *My first introduction to her was not very good. I had my glasses broken by Josephine; it was the third pair she'd broken… I filled out an incident report and management was just changing… and the old manager put a note on my report that said, "To the new manager, historically we replace them, we're responsible for these glasses". And when it was presented to the new manager, she told me, "I am not responsible to replace your*

> *glasses"… I commented, "Actually you are"…. They did pay for them in the end, but it wasn't a good feeling at all.*

'Being valued' was about more than just favourable compensation; while relatively well-remunerated, RCAs' desire for non-monetary forms of recognition was palpable. As Rebecca noted, "*most of us are here for the right reasons, but it's hard when your efforts aren't recognized*". Bonnie, a long-standing RCA, explained how she had recently reached a significant milestone with the organization, yet her length of employment was never acknowledged.

> *'*No card, they never said nothing. How rude. They could've acknowledged it but they didn't.' She waves her hand dismissively in the air, 'who cares'. [Field notes, 09/24/13]

While Bonnie attempted to brush off the lack of acknowledgement, she appeared deeply hurt by how little management seemed to value her long-standing commitment to the organization and the residents in her care. As a result, she expressed how she was seriously considering leaving her position for something less stressful. The connection between being valued and remaining on the job was also expressed by her colleague, Shona:

> *….* [My former manager]*, she told me when I first started working… 'I have no worries when you're up there'…* [The LPN] *says, 'I don't see how you can have patience like you do with these guys'. But that's not coming from management, that's coming from a nurse. But… it's very nice to hear; that you're appreciated and that they like the job you're doing… It gives you more incentive to come to work… There's times I was sitting there thinking about going someplace else to work, but then I figured, no, I'd miss these guys too much.*

Being valued thus provides an important incentive for motivation, which would appear particularly critical in a physically-demanding, stressful and under-compensated job such as that of RCA. As Bonnie and Shona allude, the absence of such an incentive may lead RCAs to leave the organization, resulting in increased turnover thereby impacting RCAs' workload, administrative workload and care quality.

RCAs emphasized that while they currently had 'good' staff, in order to keep such staff some acknowledgement of their efforts was necessary. Yet RCAs relayed how they no longer received many 'pats on the back' for a job well-done, and how, in turn, staff morale had begun to drop. When asked whether she felt valued for her work, Jolene responded:

> *No, not any more. Not like I used to. You used to get appreciated… they would do things for you like have a potluck or a draw, just to make it known that you were appreciated. Now, I don't think they care.*

Her comment illustrates how even 'small' efforts can have a significant effect on staff morale. However, as one team leader noted, somewhat dishearteningly, "*Now it's all about the dollar and not about the person*".

The salience of non-monetary recognition suggests that non-monetary benefits may help compensate for the lack of increased remuneration; yet in the absence of both monetary and non-monetary recognition and appreciation, RCAs felt deflated and discouraged.

> *…the way the cutbacks have been going… we don't have anybody come around and give us a pat on the back. It's just not happening… And it's hard on the staff because we're not getting monetary recognition. We*

> *know that we're in a budget constraint. We're not going to get any benefits that way.* [Jaime, RCA]

6.3.2 Personhood Undermined – Workplace Policies and Practices

RCAs' narratives and daily care experiences also illustrated how the absence of work-life balance, full RCA coverage, supportive human resource management practices, and information sharing hindered the provision of person-centred workplaces, further undermining staff personhood.

On Work-Life Balance

Acknowledging their other roles as wives and/or mothers, RCAs emphasized how shift lengths and rotations at their respective facilities contributed to their well-being via work-life balance. Full-time Meadowview RCAs worked 8-hour shifts, resulting in rotations that featured a combination of 5 days-on 2 days-off, 5 days-on 3 days-off, and an occasional 6 days-on 2 days-off. In contrast, all Rivermead RCAs worked 12-hour shifts. They typically worked 2 days-on, 2 days-off, with every third rotation featuring 3 days-on, or 3 days-off, a schedule that resulted in them having every other weekend off. Although initially apprehensive about such long shifts, Rivermead RCAs had come to appreciate the work-life balance they promoted. Kendra explained:

> *I prefer the 12-hour shift because on 8-hour shifts… you've got to work full time if you don't have two incomes, right? So with an 8-hour shift, I've got to come in five days and six days to maintain a proper cheque… Whereas* [when] *I'm working 12-hour shifts, I only work seven days every two weeks… I have more time with my family and more time for myself when I need. On a 12-hour shift, I get one weekend on, one weekend off, so… I'm getting a break, I'm getting that down time. Whereas if I'm working 8-hour shifts, I've got to work… every single day continuous. And then I'm coming home and I've got to deal with my home. It's too hard.*

Similarly, other Rivermead RCAs indicated how they appreciated having more days off, noting that they only need to book two shifts off to receive a full week away from work.

In line with Kendra's comments above, Meadowview RCAs spoke of how fewer consecutive days working would help reduce the burnout (i.e., the mental and physical exhaustion) associated with their work; two days off was simply not sufficient a break. Rebecca pointed out,

> [Working here] 'you backburner your family for your job. There's lots of times I come in early and stay late. I go 2.5 months with no weekends off, I have 3 weekends off in a row and then I'm back to 2.5 months with no weekends'. [Field notes, 11/07/13]

Consequently, RCAs' shift patterns not only influenced their capacity to care, but also their sense of being cared for.

While 12-hour shifts appeared to foster RCAs' well-being and personhood (and, in facilitating continuity of staff-resident relationships, residents' personhood), their use was, in-part, rooted in economics. Rivermead management explained that 8-hour shifts would require one-third more staff, most of whom would require employment/medical benefits, thus increasing costs to the organization.

On Full-Staffing Coverage

At Rivermead, RCAs typically experienced a full-staffing complement; not once did I observe a RCA having to work a shift by herself. If an aide was on vacation or sick, her position was (most commonly) covered by a casual employee or by calling in a regular RCA for overtime. Meadowview, however, experienced ongoing challenges in

filling RCA positions on the dementia units; for much of the study, two of 16 permanent positions (one per unit) were vacant, filled by a series of rotating casuals. Shona expressed frustration at repeatedly having to work with different staff:

> *Like I have Ginny with me two or three days out of the week, and then after that…I have just about a different person every night. And that makes it hard because instead of getting that person to work three days or whatever, they get a different person every night… some of them have never been in before or they haven't been there for months and months…. I don't know if it's just because they* [the residents] *don't know them, they don't recognize them or what but I find that I have to do* [care for] *a lot of them.*

For Shona and her colleagues working with casuals was at times akin to working short. Unfamiliar with residents and routines, it took casuals much longer to complete residents' care, resulting in regular RCAs shouldering much of the workload. Such situations were stressful for all involved, impacting both RCAs' and residents' personhood. RCAs struggled to understand why the shifts could not be filled with just one casual; however, a senior staff member revealed that few casuals were willing to work on the unit. Indeed, several of the RCAs acknowledged that casuals appeared scared of the residents, something they ascribed to the limited (if any) exposure of casuals to the dementia units during their practicum for their RCA certificate, or their orientation upon being hired. The implication here being that dementia care requires little skill or additional training, reinforcing the perception that RCAs are interchangeable, performing routine, manual labour they know how to do by virtue of their being women.

Given the challenges in finding casuals, Meadowview RCAs were frequently called for overtime shifts, and at times, found themselves working alone, which created tension:

> A few weeks ago, Rhonda worked five double shifts in a row. 'It's hard to say no' she says, 'when scheduling tells you they really need somebody. They can be quite pushy. If I don't take the shift then I feel guilty because that means my co-worker is working by herself. I know how hard it is for me to work alone so I know how hard it is for my co-worker'. [Field notes, 09/10/13]

RCAs struggled with managements' perceived lack of action, believing that if management were truly concerned they would have found a more permanent solution to the short-staffing problem. Implicit in this perceived lack of action was that RCAs' working conditions (and thus RCAs) were of low priority:

> *I've done the odd overtime shift, but I refuse to do too much because I feel… as long as we keep on taking these overtime shifts, management is not going to fix the problem. They don't give a crap if we burn ourselves out. You know?* [Rebecca, RCA]

As one of her co-workers, Claudia, noted, "*it's all about the money, trust me*". Budget issues permeated RCAs' work; memos and offhand comments were received from managers regarding budget constraints which, in conjunction with the elimination of key resource positions at each site, created a sense of trepidation as to what might lie in store for the RCAs (e.g., front-line positions eliminated; rollback of benefits). With resources and supplies cut, RCAs were left feeling demoralized and devalued; the message conveyed by such actions that it **was** all about the bottom line.

On Human Resource Management Practices

For both RCAs and managers, the use of sick leave was particularly contentious; for RCAs because of the sense of distrust they perceived when calling in sick, and for managers because of the volume of sick calls and the associated personnel costs. RCAs bristled at being tarred with the same brush as their 'high flyer' co-workers, those RCAs believed to be abusing the system. For RCAs who rarely called in sick, being portrayed in such a light left them feeling disparaged and resentful. Rhonda explains how she felt upon overhearing a hallway conversation:

> [The manager] *said… "Oh yeah, they get two sick days paid a month and boy let me tell you, they sure use them to the disadvantage of the company. And they don't really need them. They use them on weekends and they use them for other reasons than being sick and they take full advantage of it." So… it's like, okay, that's what she feels about everybody that works here and now that's how I'm going to be portrayed, me, somebody who is rarely sick… And when you hear these conversations… and the way it's being said, and the tone it's being said in, it feels like it's directed at you personally.*

In an attempt to crackdown on spiraling sick-time costs, both sites had at one time or another implemented a policy whereby RCAs had to phone the general manager directly, as opposed to the scheduling office, a process that RCAs found intimidating. At times, a lack of replacement coverage meant that RCAs were asked to work their shift while sick. Jaime relayed her experience in having to leave mid-way through a shift:

> *And they said to me… "Well, it's [*names condition*]. You have to be off for* [X] *days"… Then in the next breath, I get a phone call, "There's nobody to work. We have to go into overtime. So you have to make this call - do you think you can finish out the day or do you have to go home?" And it's like… I wouldn't bloody well call in sick if I wasn't sick. I'm not that girl. And the old me would have said, "I'll work the rest of the day. I'll manage to get through it." And I thought, bullshit… if I'm contagious I'm*

> *not going to make these old people sick… I'm not going to feel guilty. If they've got to get overtime in, they've got to get overtime in. Why should I feel guilty because I'm sick? And they pull that a lot because there's not enough staff.*

Having to book off sick could thus be a stressful process, particularly when, despite being legitimately ill, RCAs felt they were not believed and placed in the difficult position of deciding whether they were too sick to work. Made to feel guilty, as if they were doing something wrong, RCAs' believed their integrity and honesty were being called into question. When employees of a health-care facility are asked to decide how sick is sick or to work when ill, their health (and that of the residents) is potentially negated, and in turn, their personhood undermined.

The issue of staff shortages also affected RCAs' vacation requests, making it difficult to take time off and leaving them feeling taken-for-granted, valued neither as a person nor as an employee.

> *If you need a night off, they always say, "we don't have enough staff"… I would like to see them being more considerate, saying, "Okay, have a day off, I will find a way." If they would pay for overtime, that would be it… I've encountered it a few times, "Well, if we give you a day off, that means we have to pay overtime." So are they caring about their money or do they really care about me?… I don't expect them to always say yes, but… at least be more considerate for our needs because we're like normal human beings who have a family, who have a life outside of work.* [Felicia, RCA]

Requests for time off, be they paid vacation or unpaid leave of absence days, were seen by RCAs as a way to take care of their physical and mental health needs. When requests were denied or only a portion of the request granted, RCAs experienced a sense of lack

of control over their well-being and the feeling that money (i.e., the bottom line) was more important than their well-being.

On Information Sharing

With the exception of one of Rivermead's units (which contained the nursing station for all the dementia units and hence all residents' paper charts), residents' paper charts were housed at the nursing stations on adjacent units; meaning that RCAs had to leave the unit to access the chart (which rarely occurred). Set-up this way to facilitate LPNs'/RNs' access to the charts, management and supervisory staff felt that the paper charts simply served as a filing system, full of 'old stuff' to which RCAs did not need ready access. Yet RCAs indicated that such information was useful for it provided a summary of the resident's medical history, in some (but not all) cases their life story, prior assessments and previous months' medication records. RCAs noted that if the charts were housed on-unit then whenever there was a quiet moment, they could pull one to learn more about a resident. As Julie commented:

> *"the more knowledge you have, the better you can do with each person. And to try to lock us away from that, doesn't help us with them at all".*

Kendra (also an RCA) agreed, suggesting that picking up and reading through the chart "*should be mandatory when working in this kind of environment*". Limiting RCAs' access to a (potentially) key resource discounts RCAs' attempts to acquire the intimate knowledge they believe necessary to quality care provision. It also potentially conveys that management and supervisory staff, rather than the RCAs, know best as to what knowledge is, or is not, relevant to RCAs' fulfillment of their job duties, conceivably

devaluing RCAs' role as a key member of the care team and an integral part of residents' lives.

RCAs also expressed a wish for better communication between shifts. All units had a communication book, into which they could jot notes about unit and resident happenings (e.g., malfunctioning equipment, upcoming resident appointments, missing resident items), however, they were not consistently read, and at times devolved into a 'bitch session' as RCAs on one shift grumbled about happenings on another. Given family or other job commitments, which prohibited an early arrival or late departure, RCAs typically had only 5 minutes at shift change to verbally share information; hence, only the most salient information (e.g., who had a fall or an altercation) was usually shared. While a few RCAs arrived 15-20 minutes early to catch up on unit/resident happenings, this was on their own, unpaid time. RCAs subsequently reminisced about their experiences at other facilities where each shift began with a formal 'report', in which the LPN/RN briefly discussed each resident's status/care needs for the previous/upcoming shift; a process constrained at the current sites due to staggered start times (potentially due to attempts to streamline the work environment and achieve cost-efficiencies) and increased LPN workloads.

6.4 Discussion

This paper explored RCAs' experiences of personhood in four small-scale, dementia units. Two overarching themes, 'personhood undermined – management-staff relations', and 'personhood undermined – workplace policies and practices',

illustrate how, despite exposure to features advocated in the literature as beneficial to their working environment, RCAs encountered repeated affronts to their personhood. As such, their experiences reveal a key disconnect between conceptual/theoretical ideals and workplace realities.

Conceptually, fostering staff personhood entails acknowledging and valuing RCAs' worth as unique individuals (Brooker, 2007), conveying recognition, respect and trust within the context of relationship (Kitwood, 1997), and promoting a sense of security, continuity, belonging, purpose, achievement and significance (Nolan et al., 2002). Yet with the priorities and provision of health services guided by neo-liberal values, imbued with market discourses of efficiency and accountability (Daly, 2013), there is little room for the humanistic values associated with the maintenance of personhood and person-centred workplaces. Indeed, consistent with existing research (Bowers et al., 2003, Lopez 2006), RCAs' encounters with management and workplace practices left them feeling unrecognized, unappreciated, disrespected and devalued. Their experiences reflect how, in part, their individuality was overlooked in the ongoing search for cost-efficiencies, cost-containment and cost-accountability, thus illustrating the lack of congruence that exists between the "care ethic of female-dominated health professions and the practice-setting culture" (Daly, 2013, p.40).

Within the theme of 'personhood undermined – management-staff relations', RCAs highlighted the importance of being known and being valued; that is, having both themselves and their work recognized and appreciated. Yet, hallway encounters with management and managements' limited presence on the units led RCAs to believe that

management had little knowledge of and little interest in either them or their work; a finding that may be accounted for by the continued low status and social positioning of RCAs within the labour hierarchy, the result of a historic and ongoing devaluation of women, care and care work (Campbell, 2013). While the RCAs were relatively well-compensated financially, earning almost twice minimum wage, the findings suggest that higher wages alone are not sufficient for staff to feel valued and appreciated. Rather non-monetary rewards (e.g., staff appreciation lunches, a written note of recognition/appreciation, a verbal 'pat on the back'), being heard and being respected also appear integral; a finding similarly documented by Kemper and colleagues (2008). Such a finding is particularly salient given the increasing fiscal constraints within which care facilities operate – non-monetary rewards cost little but carry considerable weight in addressing RCAs' need for security, recognition, achievement and significance.

While it may be easy to lay blame for the challenges in management-staff relations at the feet of managers, it must be noted that they too are subject to market-based discourses regarding the priorities and provision of facility-based care. Entrusted with the responsibility of cost-containment and maintaining the bottom-line, managers are potentially just another set of cogs in the "administrative machinery of the establishment" (Goffman, 1961, p.16) in which care is produced and profit exchanged.

Within the context of person-centred care, much greater emphasis has been placed on the interpersonal relationships of staff and residents (e.g., Kelly, 2010; McGilton et al., 2012; Willemse et al., 2015) than on those of staff and management; an understandable focus given the centrality of staff-resident relations to resident well-

being. While in the literature, much attention has been focused on the importance of RCAs adopting person-centred care practices that engender recognition, trust and respect for residents, little (if any) emphasis has been placed upon helping managers adopt person-centred management styles that foster recognition, trust and respect for staff. Yet research (Eaton, 2000) indicates that relationship-oriented leadership styles create teamwork and improve staff communication (both horizontally and vertically).

Compounding the issue of recognition, trust and respect in staff-management relationships is management turnover. During the study period, Meadowview was in a state of organizational flux; several managers retired and their replacements stayed only a short while before moving on, resulting in the hiring of more new managers. Thus, while being known and being valued by management were salient for RCAs at both study sites, they were particularly pressing for Meadowview RCAs. As Forbes-Thompson and colleagues (2006) suggest, frequent management turnover hinders the development of positive connections with RCAs, the trust required for open dialogue and conflict resolution, and effective communication patterns. While newly-arrived managers likely face a number of pressing issues, RCAs' experiences highlight how essential it is for them to devote the requisite time and effort to establishing personal connections and relationships. Closer examination of the impact of management-staff relations on care quality, and the relationship between management turnover, management-staff relations and care quality represent important avenues for future inquiry.

RCAs' narratives and daily care experiences also underscored the centrality of person-centred workplace practices to their sense of personhood. At issue for the RCAs, was the manner in which work-life balance, staffing coverage, human resource management practices and limited information sharing further devalued them and their work.

Particularly salient to RCAs' experiences of personhood was the degree to which their shift lengths and rotations supported their ability to fulfill their roles outside of RCA (e.g., as wives and/or mothers). While shift patterns at Rivermead enabled RCAs to enjoy every other weekend off, Meadowview RCAs could go as long as several months without a weekend off. In terms of helping combat the burnout associated with their work, Rivermead RCAs needed only to take 2 or 3 days' vacation to have 7 days away from work, yet Meadowview RCAs had to take 5 days' vacation to receive 7 days away, thereby using up their vacation allocation more quickly. Meadowview RCAs frequently used their unpaid leave of absence days to which they were entitled (20 per year), to relieve them of having to work the sixth day of their rotation. Given the relatively high levels of burnout experienced by RCAs (Estabrooks, Squires, Carleton, Cummings & Norton, 2015), the potential effect of shift patterns on RCAs' well-being warrants further attention.

For Meadowview RCAs, having full RCA coverage was an ongoing challenge. With several vacant positions filled by rotating casual RCAs, regular RCAs frequently lacked a consistent care partner who was familiar with residents and the care routine. Such staff shortages appear tied to neo-liberal ideology (i.e., the need to create suitable

profit margins and keep profit up). Although not explicitly indicated by management, there are cost-savings to be achieved by not filling vacant shifts or by utilizing casual staff who do not receive the same medical and employment benefits as regular staff. As with RCAs in previous studies (e.g., Bowers, Esmond & Jacobson, 2000), having to spend time orienting casual RCAs to the residents/routines and stepping in when a resident was resistant to a new, unfamiliar, face, increased rather than decreased RCAs' workload, creating a situation akin to working short. Consequently, who is working appears just as critical to RCAs' (and in turn, residents') care experience, as how many (RCAs) are working. Indeed, while much has been written about the association between inadequate staffing levels and care quality, empirical evidence demonstrating the influence of staffing levels on care quality is weak (Castle, 2008). Accounting for the use of casual staff may be a critical piece of the puzzle.

Both study sites experienced challenges finding sufficient casual staff to work, resulting in RCAs working alone, working double shifts, and being denied vacation (and periodically, sick-time) coverage, undermining RCAs' personhood. Such challenges reflect the larger systems issue of RCA shortages. With only a limited number of RCA résumés from which to draw, managers were unable to be as selective as they would like and found themselves in a difficult situation. Hiring someone with limited skills potentially increased existing RCAs' workload, and conveyed the message that any 'warm body' could do the job, yet if managers chose not to hire, they were forced to deny vacation coverage, thus creating the perception that RCAs' well-being and working conditions were of low priority. As changing demographics are only likely to magnify

this issue in coming years (Harahan et al., 2003), a collaborative effort is required between industry and government to seek ways to address such shortages.

Human resource management practices regarding sick leave and vacation coverage led to RCAs feeling disparaged, guilty and resentful, that their value as both an individual and an employee was overlooked. While RCAs in this study were rarely sick they were treated similarly to those who regularly booked off, a practice which potentially conveyed the belief that all RCAs lacked commitment and integrity. Exploring the reasons for absenteeism may help facilities find alternative ways of dealing with it that support RCAs' personhood. For example, Bowers and Nolet (2011) note how attending to workers' child care needs (through more flexible schedules) helped improve attendance in several Green House homes. Finding ways to help RCAs address the physical and emotional demands of their work (e.g., by expressing appreciation for their work, reducing the number of consecutive days worked and providing formal opportunities for them to debrief/unload) may prove helpful. Working collaboratively with RCAs to solicit their ideas on how to address the issues of sick time and vacation coverage may also prove fruitful, while simultaneously conveying to RCAs that they and their work matter.

RCAs' challenges with information sharing furthered their perception that management had very little understanding of all that was required to successfully carry-out their work. Given the salience of resident biography to the provision of person-centred care (Edvardsson et al., 2008) it was surprising to discover RCAs' limited access to the very knowledge that would allow them to enact such care. Such limited chart

access has direct implications for RCAs' and residents' personhood. Congruent with previous research (Caspar, 2014), RCAs' preferred method of information sharing was oral and in-person, yet they were afforded few formal opportunities to do so. Supervisory staff intimated that RCAs should be showing up for their shift 15 minutes prior to its start to catch up on unit/resident happenings. While some RCAs did indeed do this, they were not paid for this time. Such an expectation reflects the potential effect of health care restructuring (e.g., staggered shift starts, increased LPN workloads) on the organization of care work, such that RCAs are expected (and compelled) to compensate for such changes through their own unpaid labour (Baines, 2004). Expecting RCAs to work 15 minutes for free further degrades their personhood, conveying the message that their time is not worthy of remuneration.

Providing formal mechanisms for RCAs to debrief and discuss resident/unit concerns with their co-workers and supervisors could help facilitate RCAs' information sharing. Research (Wagner et al., 2014; Yeatts & Cready, 2007) indicates that the implementation of weekly, 15-30 minute, huddles between supervisors and RCAs enables staff collaboration, providing opportunities to discuss strategies for optimizing resident care and addressing RCAs' concerns. Essential to the success of such meetings is scheduling them at a time convenient to RCAs (Yeatts & Cready, 2007).

Central to the discussion on staff personhood is the perceived link between personhood and quality care provision. For Kitwood (1997) and others (Brooker, 2007; Nolan et al., 2002; Thomas, 2006) quality dementia care entails fostering the personhood of residents **and** the RCAs who provide the majority of their hands-on care.

While the link between staff personhood and care quality was not addressed in this study, research is suggestive of such a relationship. Scott-Cawiezell et al. (2005) found that managers in high-performing care facilities typically viewed staff as their greatest asset, providing recognition, reward and ongoing appreciation for their efforts. Staff felt valued, involved and empowered, and experienced clear communication about unit/resident happenings, their roles and expectations. In contrast, managers in low-performing facilities indicated that staff were their greatest concern; in these facilities staff felt unappreciated and unheard, and experienced little open communication.

Similarly, a conceptual link exists between staff personhood and empowerment. Construed as the provision of opportunities to gain knowledge, skills, competence and self-determination, access to support, resources and information, and input into decision-making (Chalfont & Hafford-Letchfield, 2010; Kostiwa & Meeks, 2011), empowerment can be viewed as a means of facilitating RCAs' personhood. Several studies have demonstrated an association between RCA empowerment and the provision of individualized care (Caspar & O'Rourke, 2008) and care quality (Hamann, 2014). Given the current findings, further exploration of the ways in which personhood may be supported, and the link between it and care quality offer important areas for future research.

6.5 Conclusion

Discerning how RCAs experience personhood helps broaden our understanding of the complex dynamics surrounding dementia care delivery. Study findings illustrate

how smaller staffing ratios, relatively good compensation, manageable workloads and greater flexibility in implementing daily care tasks are not sufficient to support RCAs' personhood. Rather, we must shift policy assumptions related to care to incorporate notions of worth, human interdependence and relational care (Daly, 2013); to recognize and value the individual behind the RCA label, conveying respect and trust through the development of additional person-centred management and workplace practices. In any human service organization, the most valuable asset is those who provide the service. Given the pivotal role that RCAs play in shaping the daily life experiences and well-being of residents with dementia, it is time to provide RCAs with the tangible evidence that they and their work matter.

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CHAPTER 7: DISCUSSION AND CONCLUSION

This chapter provides a brief overview of the study purpose and methods and summarizes the key findings. It highlights the major insights and associated implications and recommendations emerging from the study, and concludes with a discussion of the study's strengths and limitations.

7.1 Study Overview and Key Findings

Informed by a political economy perspective, the purpose of this study was to examine Residential Care Aides' (RCAs) experiences of quality dementia care provision. Specifically, I sought to understand how RCAs conceptualize quality dementia care, whether such conceptualizations are reflected in their daily care practice and how the organizational care context impedes or facilitates such care provision. Drawing on a focused ethnographic approach, I employed in-depth interviews, participant observation and the review of selected documents to contextualize RCAs' experiences within the organizational care environment. In-depth interviews conducted with RCAs in four small-scale dementia units yielded information-rich data about RCAs' care experiences and their relationships with residents, while participant observation afforded the opportunity to strategically link RCAs' actions and interactions (i.e., their daily care practice) with what was said, a feature missing from much of the previous research examining staff perceptions of quality dementia care. The select review of facility documents (e.g., job descriptions, shift routines, relevant staff memos) and

provincial licensing regulations provided additional insight regarding the relevance of the larger structural context to RCAs' experiences of care provision.

With much of the empirical and practice literature pertaining to care work situated at the micro-level, described and analyzed in terms of relationship (or the lack thereof) between care worker and care recipient (Daly, 2013), utilizing a political economy perspective to guide my analysis helped focus attention on the meso (organizational) level within which everyday care practice is enacted and the broader socio-political context. Certain concepts from Estes' (2001) framework of political economy of aging proved particularly helpful (e.g., ideology, market-driven health care reforms and restructuring, commodification, privatization, medicalization, gender and class) in highlighting the potential inter-relations between structural forces and RCAs' care experiences.

In general, RCAs conceptualized quality dementia care as that which focused on tangible care outcomes (i.e., keeping residents clean, comfortable, calm and happy), on their care approach (i.e., delivering care in a compassionate, patient and affectionate manner) and was guided by family ideology (i.e., invoking of family metaphors). Inherent in RCAs' conceptualizations was a sense of role tension, as they spoke of trying to incorporate social interaction with task completion and the conflicting expectations of their co-workers.

Participant observation revealed that RCAs' conceptualizations were consistent with their daily care practice. RCAs devoted considerable effort to keeping residents clean, comfortable, calm and happy, doing so (for the most part) in a compassionate,

patient and affectionate manner. They treated residents as they might an older family member, with familiarity and in a gentle, jocular/teasing manner. RCAs construed their workday as a sequence of tasks to be performed, a pattern that was reflected in their everyday practice; as such, sustained or repeated interactions with residents, outside of care activities, were not a common feature of unit life. When RCAs did find themselves with 'spare' time, they tended to gravitate towards additional task completion or retreat to the kitchen to talk amongst themselves.

RCAs' conceptualizations and daily care practice were, at times, consistent with certain aspects of person-centred care. While their emphasis on resident cleanliness, comfort and happiness reflects a traditional task-orientation, their references to compassion, patience and affection reflect an implicit sense of respect, a central tenet of person-centred care. Such emphases also demonstrate RCAs' attention to residents' individual needs, preferences and physical (and at times, emotional) well-being. RCAs sought to see things from the residents' point of view, acknowledging how frustrating and frightening it must be to live in a communal setting, away from family and friends, with their most intimate needs attended to by strangers. They also deeply valued their relationships and interactions with residents; to them, good care was about building relationship, and fostering a sense of trust and security between themselves and their residents. Yet despite the value ascribed to such relationships, RCAs' continued to prioritize task completion over social interaction. Consequently, while RCAs' conceptualizations and care provision exemplified good quality of care, less attention was devoted to fostering residents' quality of life (e.g., respecting freedom of choice,

maximizing individual potential, focusing on residents' remaining abilities and fostering independence and autonomy).

In examining the relevance of the organizational context to RCAs' experiences of quality dementia care provision, I drew on RCAs' conceptualizations of quality care as well as the conceptualizations of person-centred care identified in the literature (i.e., enhancement and maintenance of personhood, development of consistent, supportive relationships, respect for individual values, preferences and needs, knowledge of individual's biography, respecting freedom of choice, maximizing individual potential) (Brooker, 2004; Edvardsson et al., 2008; Kitwood, 1997b; Talerico et al., 2003). Hence in this, and subsequent sections, reference to the provision of quality dementia care reflects a hybrid of these conceptualizations.

Study findings revealed a series of contextual factors with the potential to facilitate quality dementia care provision. With smaller staffing ratios and more manageable workloads, RCAs did not appear to experience the same time constraints reported by RCAs in other empirical research (e.g., Banerjee et al., 2012; Lopez, 2006a); although, as noted previously, this did not always translate into extra time spent interacting with residents. Flexible care routines at both facilities enabled RCAs to adhere to residents' preferences for waking up and going to bed, allowing them to adjust residents' mealtimes if they chose to sleep late. Collegial relationships with dependable and responsive care partners and team leaders helped make RCAs experiences as 'bum-wipers' and 'bottom feeders' bearable, and created a more tolerable work environment that better enabled them to attend to residents' individual

needs and well-being. For RCAs whose care practices more consistently included elements of person-centred care (e.g., supporting resident independence, autonomy and choice), the units' relative seclusion enabled RCAs to selectively break formal and informal policies/procedures and regulations they believed detrimental to residents' best interests, thus enabling them to provide the care they believed most appropriate for each individual resident. Twelve-hour work shifts also helped facilitate a sense of work-life balance for the RCAs, potentially alleviating burnout such that they felt better equipped to care for residents.

Conversely, another set of contextual factors, at both the macro- and meso-level, appeared to have the potential to impede quality dementia care provision. Societal assumptions about the nature of care work (i.e., as unskilled, routine labour), the ongoing devaluation of women and care, and RCAs' low status and social positioning within the labour hierarchy conceivably contributed to the ongoing disempowerment experienced by RCAs; their knowledge of residents' individual needs and preferences overlooked, and their observations and opinions discounted by supervisors and management. In such instances, important knowledge (regarding residents' needs) may not be relayed, potentially resulting in standardized, as opposed to individualized, care. Similarly, the increased patterning of facility-based care along market principles, internalized neo-liberal market notions of efficiency and productivity, medicalization (e.g., of residents as body parts) and the conflicting expectations of management and co-workers appeared to reinforce the continued prioritizing of task completion over resident interaction.

Receiving little, if any, non-monetary recognition and appreciation for their work, dismissive hallway encounters with managers, managers' limited presence on the units and management turnover all appeared to contribute to the perceived lack of recognition, trust and respect between staff and management, potentially influencing RCAs' sense of feeling cared for and, in turn, their capacity to care. Non-person-centred workplace practices, such as the continued use of casuals to cover vacant positions (which created a situation akin to working short) or having to work while sick also potentially impeded RCAs' care provision, conceivably the result of a continued focus on profit margins. Similarly, RCAs' limited access to residents' biographical information and limited opportunities for inter-shift communication all potentially influenced the consistency and quality of care provided.

7.2 Major Insights and Key Implications/Recommendations

The four dementia care units in which this study was conducted were purposively-selected for features believed to promote quality dementia care (e.g., Rabig et al., 2006; Verbeek et al., 2010); that is, they were small in scale, housed 10-11 residents per unit, featured archetypal aspects of home and utilized a consistent staffing model in which staff were permanently assigned to the unit. Yet these features, in conjunction with other organizational aspects (i.e., relatively well-compensated staff, higher staffing ratios, manageable workloads, greater degree of flexibility in the implementation of daily care tasks) did not appear sufficient to ensure the consistent provision of quality dementia care, in which the personhood of both residents and RCAs was supported. As such, an ideological gap exists between espoused organizational

philosophies, and those identified in the literature, and the realities of front-line care practice. Such a disconnect underscores the importance of exploring RCAs' perspectives and experiences, for in providing the bulk of the hands-on care, they play a pivotal role in shaping the daily life experiences and well-being of individuals with dementia.

Several major insights can be drawn from the study findings. These include: structural constraints and the pervasiveness of a task-oriented work culture; the importance of attending to staff personhood; the role of supportive peer and supervisory relationships; and the need for fostering effective leadership. The following section discusses each of these insights, and the associated implications and recommendations, in greater depth. Most noteworthy, given the continued resource constraints within which residential care facilities operate, is that the majority of them require little, if any, additional financial resources.

7.2.1 Structural Constraints and the Pervasiveness of a Task-Oriented Work Culture

RCAs' tendency to prioritize task completion over social interaction is well-documented; the most commonly-noted reasons for which include inadequate staffing levels, heavy workloads and highly-structured routines which leave RCAs little time outside their required care/unit tasks for interacting with residents (Colomer & de Vries, 2014; Lopez, 2006a; McAllister & Silverman, 1999; Stockwell-Smith et al., 2011; Taylor & Brewer, 2015). However, in the current study RCAs experienced favourable staffing ratios, manageable workloads and flexible care routines, yet there still existed a pervasive tendency to foreground task completion (i.e., 'doing to') over resident

interaction (i.e., 'being with'). As such, structural and organizational constraints (e.g., market discourses of productivity and efficiency; limited support and recognition for relational care) may have limited the person-centred philosophies denoted in organizational policies and procedures from being fully adopted by RCAs.

With their opinions and knowledge of residents' needs and behaviours frequently disregarded by supervisory and management staff, RCAs narrowed their focus to 'just do their job', centering their attention on the 'bed and body' tasks for which they were primarily responsible. Mixed messages regarding the relative importance of 'doing to' versus 'being with' were also conveyed by management. While management espoused the importance of interacting with residents, policies that prohibited RCAs from remaining on the unit while taking their breaks (to avoid any confusion as to which RCAs were working or not) and offhand comments from supervisory staff (e.g., 'must be nice to have time to sit down') served to explicitly and implicitly reinforce the practice of 'doing to'. RCAs in a recent study (Talbot & Brewer, 2015) recounted a similar experience, whereby they were assigned extra tasks when the units were quiet. Rather than viewing RCAs as unable or unwilling to interact with residents, managers and supervisors need to be encouraged to reflect upon how existing policy and off-the-cuff conversations with staff may inadvertently reinforce patterns of task orientation, and adjust them to ensure congruence between words, policies and actions.

Also at issue is the manner in which the residential care system, increasingly modelled along market principles (Day, 2013), remains focused on objectively

measurable and functional tasks, with residents seen as the sum of their body parts (Armstrong & Banerjee, 2009), tracked and monitored in terms of their physical status. As Lopez (2006b) notes, real human relationships entail "meandering conversation, non-purposive interaction and time together" (p.145); yet such relational aspects are not readily quantifiable and, viewed through a neo-liberal lens, neither productive nor efficient. As such, residents' social and emotional care needs remain undocumented and invisible (Diamond, 1986), reinforcing the notion that care is task-based as opposed to relationship-based (Armstrong, 2013). One potential solution is to expand RCAs' daily charting practice to include documentation regarding residents' emotional needs/status and staff-resident interaction thereby reinforcing the importance of residents' emotional needs and the relational aspects of care.

In light of the above, it is of little surprise that for participating RCAs, visiting or socializing with residents (i.e., 'being with') was commonly viewed as an add-on, something to occur once all requisite tasks were completed. As a result, interactions with residents were infrequent and conversations predominantly brief and task-focused, offering limited support for residents' emotional needs; a pattern documented by others (Clare et al., 2008; Lopez, 2006b; McAllister & Silverman, 1999). Missing from much of the literature, however, is discussion of how RCAs can better integrate 'being with' with 'doing to' within their everyday care practice, such that they are not mutually exclusive. Peer tutoring may be one way to provide encouragement and direction to RCAs to help them understand how to incorporate interacting and socializing with residents within the provision of everyday care tasks (e.g., while walking residents to

their room, getting them ready for bed, or assisting them with dinner). Facilities within a particular health service area could band together and share resources, such that an aide at one site who has a particularly person-centred approach (i.e., is respectful and supportive of resident personhood) works one-on-one with RCAs at a different site to model such interaction.

However, for RCAs to be able to socially engage residents during care provision, it is also essential that they be able to draw on residents' biographical information. Doing so requires that such information be both documented (i.e., in residents' charts) and readily accessible, a process that was somewhat hit and miss in the current study. The challenges in accessing residents' biographical knowledge may also, in part, explain why despite RCAs' care provision being guided by thoughts of how they would treat their own parents/grandparents, RCAs did not appear to interact with residents in the same way they might their own family members. For example, conversations during care tasks tended to entail the provision of step-by-step explanations of what the RCA was doing. While such explanations were seen as a way of alleviating residents' distress, having ready knowledge of residents' biographical information and being exposed to how to use such information (via peer tutoring/modeling), offers an additional, more person-centred, means by which to distract residents and alleviate distress.

7.2.2 Attending to Staff Personhood

As Baldwin and Capstick (2007) note, there are multiple versions of the 'us-them' divide in dementia care and at times it is not just the residents, but also the direct care

staff themselves, who occupy the derided 'them' status. While Kitwood (1997) believed the personhood of direct-care staff to be as essential as that of persons with dementia, to date, it has received little attention in the empirical literature. Study findings reinforce the importance of attending to staff personhood, of acknowledging and valuing RCAs' worth as unique individuals (Brooker, 2007) and conveying recognition, respect and trust in the context of relationship (Kitwood, 1997). Although RCAs experienced features believed key to producing favourable work environments (e.g., favourable staffing ratios, manageable workloads, relatively good compensation, greater degree of flexibility in the implementation of daily care tasks) (Bishop et al., 2008; Kemper et al., 2008; Parsons et al., 2003), they still encountered repeated affronts to their personhood.

With the priorities and provision of facility-based care influenced by neo-liberal government policies values, infused with market discourses of efficiency and accountability (Daly, 2013), the RCAs' work was commodified, moulded into the language of business. As such, there appeared little room for the humanistic values associated with the maintenance of personhood and person-centred workplaces. Compared with acute care, residential care is not richly-funded and while residents' needs have become increasingly complex, funding cost models have not kept pace with residents' changing needs and increased care demands (Armstrong & Banerjee, 2009). As publicly-funded sites, both Meadowview (operated by a for-profit organization) and Rivermead (operated by a not-for-profit organization) received the same level of provincial funding; staff at both sites lamented the increased focus on cost-

containment, believing care was increasingly all about the dollar, rather than the person, thus illustrating the lack of congruence that exists between the "care ethic of female-dominated health professions and the practice-setting culture" (Daly, 2013, p.40).

Study findings also illustrated how other systemic factors potentially affected staff personhood. For example, both study sites encountered difficulties in finding sufficient casual employees to replace regular staff, resulting in RCAs working alone, working double shifts and being denied vacation (and periodically, sick-time) coverage. While this issue has received some attention in the literature (Harahan et al., 2003), with the number of residential care beds occupied by persons with dementia in Canada projected to more than double over the next two decades (Alzheimer Society of Canada, 2010), further discourse is needed between facilities, health authorities and the provincial government to identify potential solutions.

An additional challenge for RCAs is that in their disadvantaged position at the bottom of the labour hierarchy, they have little ability to influence the nature and organization of their work. As such, they find themselves in a situation where they experience limited acknowledgement and support of their personhood, yet their ongoing devaluation curtails their ability to resist or challenge the labour processes and care organization that place them in such a position (Campbell, 2013). As researchers, we therefore have an important role to play by conducting research that illustrates how the organization of care work may be better structured to facilitate staff personhood.

In conjunction with previous findings (Bowers et al., 2003; Sikma, 2006), the current research offers insight into how staff personhood may be better supported through the creation of caring, person-centred workplaces. At the most basic level, we need to shift our frame of reference, doing as Kitwood (1997) suggests with persons with dementia (i.e., moving from 'person with DEMENTIA' to 'PERSON with dementia'), to see beyond the RCA label, recognizing and valuing aides as persons. No additional financial resources are required for managers to greet RCAs by name when they pass them in the hallway, to inquire about their families or how their day is going, or to periodically enter the unit to check-in with staff, providing RCAs an opportunity to discuss challenges they may be encountering.

We need to recognize and respect the tacit knowledge that RCAs bring to care provision, and their intimate knowledge of residents' personalities and care needs, by involving them more fully in resident care and unit decision-making. Inviting RCAs to assist with policy-making ensures that policies better reflect the fluctuating abilities and needs of residents and the daily care realities of RCAs, such that RCAs no longer need to selectively break formal and informal policies and procedures to better individualize care provision. Implementing the above requires a move away from the pyramid-shaped staffing hierarchy whereby power is concentrated in the hands of a few key administrators and managers, to a more flattened hierarchy in which the considerable practical influence and informal power of RCAs is recognized and legitimized. Greater RCA involvement in decision-making may not only contribute to improved personhood, but also, as suggested by Hamann's (2014) research, to improved care quality, thereby

reinforcing Campbell's (2013) assertion that care conditions are intrinsically linked to care work conditions.

The provision of non-monetary forms of recognition is also important. A pat on the back or recognition in the facility newsletter for a job well-done, along with the occasional staff potluck or draw, costs little but potentially carries great weight in acknowledging and elevating the value of RCAs' work. The centrality of non-monetary forms of recognition to RCAs' sense of personhood presents an interesting avenue for future research. For example, given that RCAs in both Canada and the U.S. frame their work in non-market motivational terms (e.g., Dodson & Zincavage, 2007) would non-monetary recognition be seen as equally, or more, important than increased financial compensation? If that were the case, increased non-monetary forms of recognition may help compensate for the low wages received by RCAs in many nursing homes.

Greater attention to RCAs' work-life balance may also help facilitate staff personhood. While flexible work practices are often more a means of controlling labour and costs rather than improving care work conditions (Campbell, 2013), the 12-hour shifts implemented by Rivermead not only created economic benefits for the organization (e.g., fewer staff equals fewer paid employment benefits), but also created an improved sense of work-life balance for RCAs. As shift-length and rotation has received little, if any, attention in the literature, this too presents a valuable avenue for future research in terms of its impact on staff personhood (i.e., RCAs sense of being cared for) and care quality (i.e., RCAs' capacity to care; residents' experiences of care continuity/discontinuity).

Given the relatively high burnout experienced by RCAs (Estabrooks, Squires, Carleton, Cummings & Norton, 2015), and the manner in which human resource management practices in this and other studies (Eaton, 2000; Lopez, 2006a) left RCAs feeling disparaged and resentful, finding ways to help RCAs address the physical and emotional demands of their works also appears integral. Again, engaging RCAs in policy-making, by working with them to solicit their ideas on how to better address issues of sick-time and vacation coverage, offers a means by which to resolve such ongoing issues while also conveying the sense that staff, their well-being and their work matter. Similarly, facilitating improved information sharing by providing regular (paid) opportunities for RCAs to connect and debrief with their colleagues regarding resident and/or unit management issues, may also prove helpful.

Nolan et al.'s (2002) Senses Framework, in which six senses (security, continuity, belonging, purpose, achievement and significance) are identified as key prerequisites for good relationships within the care context, potentially offers a practical guideline for facilities interested in fostering staff personhood through the creation of person-centred workplaces. For example, a sense of security entails having the emotional demands of work acknowledged and being able to work within a supportive culture (e.g., having opportunities to debrief; working with supervisors who respond in a timely manner to requests for assistance and pitch in to help with physical care). Similarly, a sense of continuity highlights the clear and consistent communication of expectations and care standards (e.g., ensuring that formal and informal policies and supervisors consistently prioritize and reinforce staff-resident interaction, or 'being with' over task

completion). A sense of significance captures the importance of feeling that one's care practice is valued and one's work and efforts matter (e.g., being well-remunerated and/or receiving non-monetary forms of recognition).

Within the current study, the salience of personhood to RCAs' care experiences offers several important directions for future research. For example, are the issues of 'being known', 'being valued', work-life balance, supportive human resource management practices and information sharing as relevant for staff who are not well-compensated, and who do not experience favourable staff ratios or manageable workloads? Given that RCAs' work conditions and experiences are believed to be intrinsically linked to residents' care experiences (Armstrong & Banerjee, 2009; Campbell, 2013; Ryan, Nolan, Reid & Enderby, 2008; Thomas, 1996), and existing research demonstrating a relationship between staff empowerment and care quality (Caspar & O'Rourke, 2008; Hamann, 2014; Scott-Cawiezell et al., 2005), further exploration of the potential link between support for staff personhood and resident well-being (i.e., care quality) is also warranted.

7.2.3 Role of Supportive Peer and Supervisory Relationships

Woven throughout the findings is the role supportive peer and supervisory relationships play in helping RCAs 'care in spite of' continued affronts to their personhood. Congruent with existing research (Pennington et al., 2003; Schirm et al., 2000), dependable and reciprocal relationships with their peers and supervisors enabled RCAs to better meet the physical and emotional demands of their work.

Previous research (Lopez, 2006a) highlighted how varying care needs of residents led to widely different workloads for permanently-assigned staff. However, in the current study, supportive peer relationships enabled RCAs to work co-operatively and share responsibility for resident care. Doing so allowed them to capitalize on their co-worker's respective strengths and abilities, and relationships with residents, thereby facilitating the care of residents with whom they did not necessarily click or with whom (at times) they did not have the emotional energy to cope.

The study findings build on those of te Boerkhorst et al. (2008) regarding the quality versus quantity of peer interactions, highlighting that it is not only how many RCAs are on shift, but also who is on shift that is an essential part of RCAs', and in turn the residents', care experience. That is, to what extent do the RCAs on each shift work as a team? Are they regular or casual staff? Are their care approaches similar or at odds? While increased staffing (i.e., higher staffing ratios) is frequently touted as a panacea for improved care quality, the empirical evidence demonstrating the influence of staffing levels on care quality is weak (Castle, 2008). Indeed, the current study suggests that simply increasing the number of RCAs on each shift may not be sufficient, for it may be that those on shift are those with a predominantly task-oriented approach, who have difficulty placing the residents' needs at the centre of the care process and believe their care approach is the only/right way to care. Further exploration of the effect of RCAs' peer and supervisory relationships on care quality, in an attempt to further elucidate the staffing-quality link, thus represents an important direction for future research.

Study findings also offer insight into how quality peer and supervisory relationships may be better supported. Offering regular opportunities for unit RCAs to meet in-person to discuss potential sources of conflict (e.g., differing shift expectations for task completion/social interaction) and emerging care and unit management issues may help improve information sharing and reduce intra-shift conflict. Increased management presence on the unit may help managers acquire a better sense of RCAs' peer relationships and RCAs' care approaches, thus helping them identify where interventions may be required. Given the reluctance of RCAs to speak out about poor or questionable care practices, increased management sensitivity and responsiveness to RCAs' complaints about such practices also appear essential.

As a result of labour restructuring within residential care, diploma-trained LPNs, who have less clinical preparation than RNs and are paid lower wages, are increasingly replacing degree-trained RNs as the source of licensed nursing staff (CIHI, 2004). Yet existing research suggests that LPNs find themselves ill-prepared for their supervisory responsibilities (Schirm et al., 2000). Providing additional training to LPNs to help equip them with the skills to lead in a more person-centred manner (e.g., acknowledging and respecting RCAs' observations and opinions) may help strengthen RCA-supervisor relationships. Responding in a timely manner to RCAs' requests for assistance and (when needed/possible) pitching in to help with residents' physical care may also help foster a sense of trust and mutual respect.

7.2.4 Fostering Effective Management Practices

While the role of leadership within the context of person-centred care has received limited attention in the empirical literature (Rokstad, Vatne, Engedal & Selbek, 2015), the current findings suggest that management practices are integral to RCAs' experiences of dementia care provision. RCAs' encounters with management typically left them feeling unsupported, unrecognized and unappreciated, the interactions believed to feature little of the compassion, respect and empathy RCAs sought to convey in their interactions with residents. However, in the same way that we must refrain from laying blame for challenges in care provision at the feet of the RCAs, so too must we refrain from blaming managers. As managers, they are also subject to the larger neo-liberal discourse that devalues facility-based care and privileges efficiency, accountability and productivity. Paid lower wages than their counterparts in acute care (Armstrong & Banerjee, 2009), and entrusted with the responsibility of cost-containment and maintaining the bottom-line, managers are potentially just another set of cogs in the 'administrative machinery of the establishment' (Goffman, 1961, p.16) in which care is produced and profit exchanged. We need to recruit people into these positions who are passionate about improving quality of life for older adults and the quality of work life for those who provide their care.

While managers face a number of pressing demands on their time, RCAs' experiences highlight how essential it is for them to spend more time on the units establishing personal connections with RCAs, developing a first-hand awareness of the patterns and quality of care provision and an improved understanding of what RCAs

experience in their daily care practice. As with LPN supervisors, additional leadership training may also help equip managers with the skills necessary to adopt a more person-centred management style.

The importance of management presence on the units and support for direct care staff is confirmed in recent research examining the role of leadership in the implementation of person-centred care (Rokstad et al., 2015). Person-centred care was more readily implemented in the nursing home in which leaders were present on the units on a daily basis, took an active role in nursing practice, saw themselves as role models for staff and expressed admiration for RCAs' engagement to resident care. Not surprisingly, RCAs felt their initiatives to act in the best interests of the residents were accepted and appreciated, and their attempts to deliver quality care encouraged and supported. Such findings led Rokstad et al. to suggest that leaders wishing to develop person-centred care contexts practice situational leadership, in which they are present on the units, know the skills of their employees and choose appropriate leadership behaviour (e.g., directing, coaching, supporting or delegating) depending upon staff abilities and competence.

In the current study, issues of recognition, trust and respect within management-RCA relationships were compounded by management turnover. While considerable attention has been devoted to the issue of staff turnover and care quality (e.g., Bowers et al., 2003; Castle & Engberg, 2005), much less attention has focused on the influence of management turnover on care quality. Given that frequent management turnover has been noted to hinder the development of positive

connections with RCAs, the trust required for open dialogue and conflict resolution, and effective communication patterns (Forbes-Thompson, Bajewski, Scott-Cawiezell & Dunton, 2006), further examination of the impact of management-staff relations on care quality, and the relationship between management turnover, management-staff relations and care quality appear worthwhile directions for future research.

Attention must be drawn to the centrality of effective management practices in the preceding three insights and their potential for influencing the meso-environment in which daily care practice is enacted. As such, there is an interrelatedness between the insights whereby effective management practices shape a positive supportive culture (in terms of work culture and peer and supervisory relations), which in turn affirms staff personhood. For example, as site leaders, senior management are well-situated to facilitate an inclusive (rather than exclusive) work culture, in which contributions from all care staff are valued and encouraged. They have the ability to lead by example, demonstrating how to engage with, listen to and respect front-line staff. They also have the power to create the opportunity for RCAs and supervisors to come together to discuss emerging care and unit management and workload issues. Frequently responsible for policy setting within the organization, senior management are potentially able to influence the nature of formal and informal policies, ensuring that RCAs are engaged in the policy-making process, and that relational care aspects (e.g., staff-resident interaction) are emphasized/reinforced. Similarly, management has the ability to alter charting practices, so that residents' emotional needs and staff-resident interaction can be documented. In doing so, they are able to shape the nature of how

'work' is conceptualized, ensuring that care staff are recognized and rewarded, not penalized, for engaging with residents.

In creating an environment in which RCAs' tacit knowledge and experience are acknowledged, their input into policy and decision-making sought, and assistance in working through unit challenges (e.g., role expectations, workload) offered, a sense of trust and respect is developed, thus affirming, rather than undermining, staff personhood. Creating a positive, supportive work culture has the potential to result in caring, person-centred workplaces in which RCAs' efforts are recognized and valued thus facilitating personal and professional recognition.

7.3 Study Strengths and Limitations

A major strength of the current study was the fit between the methodological approach used and the topic of inquiry. In concentrating on the naturally-occurring situated performances present in everyday social interaction, focused ethnography proved ideal for examining the patterns of interactions between RCAs, their supervisors/managers, residents with dementia and the care environment, thereby uncovering the tacit skills and subtleties of RCAs' care work and the structural influences impacting upon it (Knoblauch, 2005; Savage, 2006). The concurrent use of in-depth interviews and participant observation allowed me to examine potential contradictions between RCAs' narratives about care provision and their actual care practice, a perspective heretofore missing in the literature examining RCAs' conceptualizations of care. For example, while RCAs spoke of how deeply they valued their relationships and

interactions with residents, sustained or repeated interactions (beyond care activities) with residents were not central to their daily care practice. Consequently, the triangulation of methods helped strengthen the study findings, furthering our knowledge about the influence of the organizational care environment on quality dementia care provision.

Given the qualitative nature of this dissertation, I did not seek representativeness of either the facilities or participants and thus the findings cannot be generalized to RCAs or dementia care settings elsewhere in B.C. or Canada. The collection of data from RCAs in other dementia care settings, health authorities, or provinces may result in different findings and conclusions. For example, participating RCAs experienced favourable staffing ratios and compensation and manageable workloads, yet still tended to prioritize task completion over social interaction and experienced affronts to their personhood. RCAs in facilities with less favourable staffing ratios and compensation and increased workloads may provide much less person-centred care and experience greater affronts to their personhood. In other words, the study sites may have experienced better care provision and attention to staff personhood than sites with poorer quality work environments. Consequently, organizational features such as favourable staffing ratios, compensation and workloads may be necessary but not sufficient to promote quality dementia care provision. It was also not possible to ascertain whether the conceptualizations, experiences and behaviour of study participants differed from those RCAs and LPN/RN supervisors who declined to take part in the research.

It is also important to acknowledge the role that my own positioning, experience and education played in documenting and interpreting RCAs' care experiences. However, ongoing input from my supervisors and colleagues during the analytic process helped broaden the lens with which the data were viewed, thus tempering the potential of my positioning from disproportionately guiding the interpretations presented in the preceding chapters.

Interestingly, given that many care workers are visible minorities born in countries other than Canada (Estabrooks, 2015) the concept of race did not play out in my data; however, this may be due to the limited ethnic diversity of the sample. While the sample reflected the demographic make-up of the surrounding area, it is possible that had this work been conducted in a location where other ethnic groups commonly involved in care work (e.g., South Asian, East Indian) are more prevalent, race may have been more of an issue. Similarly, as all participants were female, the inclusion of male care workers may have revealed additional findings. While participating RCAs had worked in the field for an average of 11 years (similar to RCAs in neighbouring provinces; Estabrooks et al., 2015), they had been employed at their current site an average of 8 years (almost twice that of RCAs in neighbouring provinces; Estabrooks et al., 2015). Given such employment length, participants could be considered knowledgeable informants with regards to the dementia care experience. However, it also means that the perspectives of 'short-stay' RCAs, for whom issues regarding the organizational environment and personhood may have contributed to their decision to leave, are not represented in the data.

In addition, there is the potential issue of reactivity; that is, that RCAs may have 'reacted' to my presence in the environment, potentially altering the routines and experiences I sought to capture (Madden, 2010). The pressure to provide good care could have made RCAs particularly susceptible to adapting their behaviour and/or responses when they were observed or interviewed to how they thought others might expect them to act or respond (i.e., in a socially-desirable manner). Although no data was collected to assess reactivity, my sense was that the RCAs felt comfortable with me and were candid during both the observation and interview sessions. My efforts to develop strong rapport with participants and my insider status may have also helped reduce the issue of reactivity.

7.4 Conclusion

Despite the above limitations, this study offers valuable insight into the complex dynamics surrounding dementia care provision and the manner in which more social (i.e., person-centred) models of care may be facilitated. In focusing upon the care experiences of RCAs, it affords the expression of their voices, a perspective missing from much of the nursing home/dementia care literature.

Informed by a political economy perspective, this focused ethnography revealed how, in general, RCAs articulated, and exhibited in their daily care practice, quality dementia care as that which focused on tangible care outcomes (i.e., keeping residents clean, comfortable, calm and happy), on their care approach (i.e., being compassionate, patient and affectionate), and was guided by family ideology. Inherent in their provision

of such care was a sense of role tension, in which RCAs sought to juggle social interaction with task completion and their co-workers' conflicting expectations. Study findings illustrated how, in the face of continued disempowerment and organizational constraints, RCAs' sought to provide quality dementia care by negotiating their peer and supervisory relationships and selectively breaking formal and informal policies/procedures. Salient to RCAs' experiences of personhood was the limited recognition and appreciation they received from management and the manner in which work-life balance, staffing coverage, human resource management practices and limited information sharing further devalued them and their work.

Taken together the findings draw attention to the importance of acknowledging the role of structural constraints in the pervasiveness of a task-oriented work culture, of attending to (and facilitating) staff personhood, of facilitating supportive peer and supervisory relationships and of fostering effective management practices as a means of potentially improving care quality. As such, the study sheds important light on what RCAs require within their work environments to help facilitate resident well-being, reinforcing the assertion that residents' care conditions are inextricably linked to RCAs' care work conditions (Campbell, 2013; Eaton, 2000; Ronch, 2004; Thomas, 1996; Lopez, 2006a). As we continue to seek ways in which to ensure responsive and therapeutic dementia care settings, it is clear that we must afford recognition, respect, status and value to not only those who live but also to those who work within their walls.

7.5 References

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APPENDIX A: FIELD NOTE GUIDE

Date/Time:

Facility/Unit ID:

ID of Care Staff on Duty:

1. Describe the physical environment
2. Describe the people present (clothing, behaviours, interactions)
3. Describe, in chronological order, activities, actions, interactions
4. Describe the dialogue (conversations heard and overheard)
5. Describe verbal and non-verbal expressions
6. Reflect on general impressions and feelings
    a. What did I learn today?
    b. What was particularly interesting?
    c. What was confusing?
    d. What is similar or different to that already observed?
7. Reflect on how my personal stance may be influencing my impressions and feelings
8. Describe initial interpretation
9. Flag any observations/interpretation for which follow-up required (note from whom additional information should be gathered)

(Adapted from Lofland, Snow, Anderson & Lofland, 2006; Emerson, Shaw & Fretz, 2011).

APPENDIX B: DEMOGRAPHIC INFORMATION FORMS

For Residents:

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Interview #:_____
Site Code:_____
Date:_____

Staff and Resident Experiences of the Dementia Care Environment

RESIDENT BACKGROUND INFORMATION

1. What is {name of resident}'s primary diagnosis (e.g., Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia)?_____
2. When was this diagnosis made (and/or how long have they had dementia)?

   _____
3. Does {name of resident} have any other illnesses? (e.g., CHF, arthritis)

   _____
4. How long has {name of resident} resided at the facility?

   _____
5. Gender:

   Male ☐
   Female ☐
6. Age:_____
7. What is the highest level of education they completed?

   Less than Grade 8 ☐
   Grade 8 ☐
   High school ☐
   Technical/Trade ☐
   College/University ☐
8. Country of birth:_____

9. If born outside of Canada, how long have they lived here?_____

10. What language(s) do they speak?_____

For Care Staff:

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Interview #:_____
Site Code:_____
Date:_____

Staff and Resident Experiences of the Dementia Care Environment

CARE AIDE DEMOGRAPHIC INFORMATION

1. How long have you worked as a care aide?

   _____

2. How long have you worked as a care aide at this site?_____

3. Have you worked in any other roles in residential care? _____

   If so, what & for how long?_____

4. Employment:

   Full-time ☐
   Part-time ☐
   Casual ☐

5. Education level (obtained in Canada):

High school	☐	Degree	☐
Certificate	☐	Masters	☐
Diploma	☐	PhD	☐

6. Gender:

   Male ☐
   Female ☐

7. Age:_____

8. Country of birth:_____

9. If born outside of Canada, how long have you lived in Canada?_____

10. What language(s) do you speak?_____

11. If born outside of Canada, do you have any post-secondary education in your country of origin?_____

    If so, what?_____

For Management:

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Interview #:_____
Site Code:_____
Date:_____

Staff and Resident Experiences of the Dementia Care Environment

TEAM LEADER/MANAGER DEMOGRAPHIC INFORMATION

1. What is your job title? (e.g., administrator, Director of Care, care coordinator)

   _____

2. What are your primary areas of responsibility?

   _____

3. Number of years working in this role at this site? _____

4. Have you worked in any other roles in residential care? _____

   If so, what & for how long?_____

5. Do you have a professional designation? (e.g., RN, LPN)

   If so, what is it?_____

6. Employment:

   Full-time ☐
   Part-time ☐

7. Highest education level (completed in Canada):

High school	☐	Degree	☐
Certificate	☐	Masters	☐
Diploma	☐	PhD	☐

8. Gender:

   Male ☐
   Female ☐

9. Country of birth:_____

10. If born outside of Canada, how long have you lived in Canada?_____

11. What language(s) do you speak?_____

APPENDIX C: INTERVIEW GUIDES

For Residential Care Aides:

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Interview #:_____
Site Code:_____
Date:_____

Staff and Resident Experiences of the Dementia Care Environment

CARE AIDE INTERVIEW TOPIC GUIDE

INTRODUCTION:

I'm interested in learning about what it is like to care for older people with dementia in a care facility. I'm particularly interested in what you perceive to be quality dementia care, and how the care environment might impact your ability to provide such care. By the care environment, I mean the physical environment (e.g., architectural features, interior design features, sensory attributes) and the organizational environment (e.g., policies, procedures, care routines). There are no right or wrong answers here, rather, I am interested in your experiences.

Question #1:

Let's start by talking about what it is like to care for older people with dementia in a care facility. Can you tell me what it is like to work as a care aide on a unit for people with dementia?

Potential Probes:

- What does a typical day look like for you?
- What is the hardest part of your day?
- What do you enjoy most about your day?
- What makes for a 'good' day?

Question #2:

For me to understand how the environment might affect your ability to provide care, I need to understand how you define good quality care for people with dementia. What do you think makes for good quality dementia care?

Potential Probes

- Do you get to give the kind of care you'd like to give?

Question #3:

a) Thinking about your answer to the previous question, are there any particular aspects of the physical environment (e.g., architectural features such as room size and layout, interior design features such as furniture and lighting, sensory attributes) of the unit that make it easy or difficult to provide such care?

Potential Probes:

- What do you like about the physical environment of the unit?
- What do you dislike about the physical environment of the unit?
- How do you feel the unit's physical environment affects your work with residents?
- How do you feel the unit's physical environment affects the way you work with other staff?
- How do you feel the unit's physical environment affects the residents?

b) If you could make changes to the unit's physical environment, what would you change?

Question #4:

a) Thinking about your answer to the earlier question, are there any particular aspects of the organizational environment (e.g., care philosophy, policies and procedures, staffing) that makes it easy or difficult to provide such care?

Potential Probes:

- How do you feel the unit/facility policies and procedures and/or care routines affect your work with residents?
- How do you feel the unit/facility policies and procedures and/or care routines affect the way you work with other staff?

b) If you could make changes to any of the policies/procedures and/or care routines, what changes would you make?

Question #5:

Is there anything else that you think is important for me to know about how the unit's physical and/or organizational environment influences the care you provide to residents?

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Interview #:_____
Site Code:_____
Date:_____

Staff and Resident Experiences of the Dementia Care Environment

SUPERVISORS/TEAM LEADER INTERVIEW TOPIC GUIDE

INTRODUCTION:

I'm interested in learning about what it is like to care for older people with dementia in a care facility. I'm particularly interested in what you perceive to be quality dementia care, and how you feel the care environment might impact the care aides' ability to provide such care. By the care environment, I mean the physical environment (e.g., architectural features, interior design features, sensory attributes) and the organizational environment (e.g., policies, procedures, care routines).

Question #1:

Let's start by talking about what it is like to be an LPN in residential care these days. Can you tell me what it is like to work as a LPN on a unit for people with dementia??

Potential Probes:

- What is the hardest part of your work?
- What do you enjoy most about your work?
- What makes for a 'good' day at work?

Question #2:

Thinking about care provision for people with dementia, what do you think makes for good quality dementia care?

Potential Probe:

- Where do you think your ideas about what care should look like come from?
- Has working with the residents changed your view of good care? If so, how?
- To what extent do you think care staff are able to provide such care here?
- What do you think of the care provided here?

Question #3:

a) Thinking about your answer to the previous question, are there any particular aspects of the physical environment (e.g., architectural features such as room size and layout, interior design features such as furniture and lighting, sensory attributes) of the unit that you think makes it easy or difficult for staff to provide such care?

Potential Probes:

- What do you like about the physical environment of the unit?
- What do you dislike about the physical environment of the unit?
- How do you think the unit's physical environment might affect the way care aides work with residents?
- How do you think the unit's physical environment might affect the way care aides work with other staff?
- How do you feel the unit's physical environment affects the residents?

b) If you could make changes to the unit's physical environment, what would you change?

Question #4:

a) Thinking about your answer to the earlier question, are there any particular aspects of the organizational environment (e.g., care philosophy, policies and procedures, staffing) that you think make it easy or difficult for staff to provide such care?

Potential Probes:

- How do you feel the unit/facility policies, procedures and/or care routines affect how care aides work with residents?
- How do you feel the unit/facility policies, procedures and/or care routines affect how care aides work with other staff?
- How do management support the care provided here?

b) If you could change any of the policies/procedures and/or care routines, what would you change?

Question #5:

Is there anything else that you think is important for me to know about how the unit's physical and/or organizational environment influences the care provided by care aides?

For Managers:

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Interview #:_____
Site Code:_____
Date:_____

Staff and Resident Experiences of the Dementia Care Environment

MANAGEMENT INTERVIEW TOPIC GUIDE

INTRODUCTION:

I'm interested in learning about what it is like to care for older people with dementia in a care facility. I'm particularly interested in what you perceive to be quality dementia care, and how you feel the care environment might impact the care aides' ability to provide such care. By the care environment, I mean the physical environment (e.g., architectural features, interior design features, sensory attributes) and the organizational environment (e.g., policies, procedures, care routines).

Question #1:

Let's start by talking about what it is like to be manager in residential care these days. Can you tell me what it is like to manage a unit for people with dementia??

Potential Probes:

- What is the hardest part of your work?
- What do you enjoy most about your work?
- What makes for a 'good' day at work?

Question #2:

Thinking about care provision for people with dementia, what do you think makes for good quality dementia care?

Potential Probe:

- To what extent do you think care staff are able to provide such care here?

Question #3:

a) Thinking about your answer to the previous question, are there any particular aspects of the physical environment (e.g., architectural features such as room size and layout, interior design features such as furniture and lighting, sensory attributes) of the unit that you think makes it easy or difficult for staff to provide such care?

Potential Probes:

- What do you like about the physical environment of the unit?
- What do you dislike about the physical environment of the unit?
- How do you think the unit's physical environment might affect the way care aides work with residents?
- How do you think the unit's physical environment might affect the way care aides work with other staff?
- How do you feel the unit's physical environment affects the residents?

b) If you could make changes to the unit's physical environment, what would you change?

Question #4:

a) Thinking about your answer to the earlier question, are there any particular aspects of the organizational environment (e.g., care philosophy, policies and procedures, staffing) that you think make it easy or difficult for staff to provide such care?

Potential Probes:

- How do you feel the unit/facility policies, procedures and/or care routines affect how care aides work with residents?
- How do you feel the unit/facility policies, procedures and/or care routines affect how care aides work with other staff?

b) If you could change any of the policies/procedures and/or care routines, what would you change?

Question #5:

Is there anything else that you think is important for me to know about how the unit's physical and/or organizational environment influences the care provided by care aides?

APPENDIX D: LIST OF POLICIES REVIEWED

Formal Policies and Procedures

A. Job Description and Routines

- RCA job description
- LPN job description
- Shift routines

B. Compensation (Wages and Benefits)

- Hours of work
- Leaves of absence
- Unpaid leave
- Vacation

C. Occupational Health and Safety

- Occupational health and safety policy

D. Employee Relations

- Complaint procedure
- Employee relations philosophy
- Performance appraisal

E. Terms and Conditions of Employment

- Attendance, lateness, absenteeism
- Break times
- Conduct and behaviour
- Internet and cell phone use
- Resident abuse
- Staff communication books

Staff Communications and Memos

A. Staff Bulletins (e.g., changes in leadership team roles and responsibilities; changes to care delivery processes)

B. Staff Meeting Minutes

Community Care and Assisted Living Act – Residential Care Regulation

(Retrieved from http://bclaws.ca/Recon/document/ID/freeside/96_2009)

A. Nutrition

- Food service schedule

APPENDIX E: LETTERS OF INITIAL CONTACT

For Residents' Family Members:

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Staff and Resident Experiences of the Dementia Care Environment

Study Information Letter (Residents' Substitute Decision Makers)

Are you interested in participating in a study about dementia care settings?

I am conducting a study to explore how the care environment (e.g., architectural and interior design features, facility practices and policies) influences care from the perspective of staff and residents. The research, which is part of my doctoral studies at the University of Victoria, is funded by the Alzheimer Society of Canada. It involves observing and talking with staff and residents as they go about their daily routine. I believe this research is important as it will offer valuable insight into how we can create dementia care environments that help staff provide quality dementia care. Findings will be shared with administrators and health care decision makers in order to inform health care planning.

[*Name of Health Authority*] and [*Name of Facility*] are supportive of my research and [*Name of Facility*] has kindly agreed to act as a study site. You are receiving this letter because you are the identified contact person (i.e., substitute decision maker) for a resident living on the [*Name of Dementia Unit*]. Please note that [*Name of Facility*] is sending this letter on my behalf; your contact information has NOT been released to me.

To accommodate varying schedules, **two sessions will be held – one on Wednesday, May 15 at 7:00 p.m., the other on Thursday, May 16 at 10:30 a.m.** Both meetings will be held in the multi-purpose room.

If you are unable to attend either of these sessions, but would be interested in learning more about the research, please let [*Name of Contact Person*], [*Title of Contact Person*] at [*Name of Facility*], know. They can be reached at (XXX) XXX-XXXX, extension XXX. With your approval, they will send me your contact information. I will

then contact you to talk about the research in greater depth. Please note that this does NOT obligate you to participate. It only allows me to discuss the study with you, after which you can decide whether you would like your resident to be included in the study. In the meantime, the enclosed pamphlet tells you a little more about the project.

I look forward to speaking with you soon about my research!

Regards,

Heather Cooke, PhD Candidate
Centre on Aging, UVIC

Please note: Participation in this study is entirely voluntary. You may refuse to participate or withdraw from the study at any time and your decision will in no way affect the care your family member or friend receives.

V2.1: 1/14/2013

For RCAs:

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Staff and Resident Experiences of the Dementia Care Environment

Study Information Letter (Care Staff)

Are you interested in participating in a study about dementia care settings?

I am conducting a study to explore how the care environment (e.g., architectural and interior design features, facility practices and policies) influences care from the perspective of staff and residents. The research, which is part of my doctoral studies at the University of Victoria, is funded by the Alzheimer Society of Canada. It involves observing and talking with staff and residents as they go about their daily routine. I believe this research is important as it will offer valuable insight into how we can create dementia care environments that help staff provide quality dementia care. Findings will be shared with administrators and health care decision makers in order to inform health care planning.

[*Name of Health Authority*] and [*Name of Facility*] are supportive of my research and [*Name of Facility*] has kindly agreed to act as a study site. You are receiving this letter because you work in [*Name of Dementia Unit*]. **I will be attending a number of shift changeovers over the next couple of weeks to speak about the project in more detail.** In the meantime, the enclosed pamphlet tells you a little more about the project.

If you have any questions, please feel free to contact me directly at (XXX) XXX-XXXX or by email at XXXX@XXXXXX.

I look forward to speaking with you soon about my research!

Regards,

Heather Cooke, PhD Candidate
Centre on Aging, UVIC

Please note: Participation in this study is entirely voluntary. You may refuse to participate or withdraw from the study at any time and your decision will in no way affect your employment status.

For Management/Supervisors:

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Staff and Resident Experiences of the Dementia Care Environment

Study Information Letter (Management/Supervisors)

Are you interested in participating in a study about dementia care settings?

I am conducting a study to explore how the care environment (e.g., architectural and interior design features, facility practices and policies) influences care from the perspective of staff and residents. The research, which is part of my doctoral studies at the University of Victoria, is funded by the Alzheimer Society of Canada. It involves observing and talking with staff and residents as they go about their daily routine. I believe this research is important as it will offer valuable insight into how we can create dementia care environments that help staff provide quality dementia care. Findings will be shared with administrators and health care decision makers in order to inform health care planning.

[*Name of Health Authority*] and {*Name of Facility*} are supportive of my research and [*Name of Facility*} has kindly agreed to act as a study site. You are receiving this letter because you work on/manage the {*Name of Dementia Unit*}. **I will be attending the upcoming staff meeting on [meeting date], as well as the next management meeting [meeting date], to speak about the project in more detail.** In the meantime, the enclosed pamphlet tells you a little more about the project.

If you have any questions, please feel free to contact me directly at (XXX) XXX-XXXX or by email at XXXX@XXXXXX.

I look forward to speaking with you soon about my research!

Regards,

Heather Cooke, PhD Candidate
Centre on Aging, UVIC

Please note: Participation in this study is entirely voluntary. You may refuse to participate or withdraw from the study at any time and your decision will in no way affect your employment status.

APPENDIX F: WRITTEN CONSENT FORMS

For Residents' Family Members:

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Staff and Resident Experiences of the Dementia Care Environment

Letter of Consent for Participant Observation (Proxy Consent for Residents)

Doctoral Candidate
Heather Cooke, MA
Centre on Aging, UVIC

Dissertation Committee

Supervisor:	Neena Chappell, PhD, FRSC, CRC, Professor, Dept. of Sociology, UVIC
Co-Supervisor:	Kelli Stajduhar, RN, PhD, Associate Professor, School of Nursing, UVIC
Member:	Denise Cloutier, PhD, Associate Professor, Dept. of Geography, UVIC
Member:	Habib Chaudhury, PhD, Associate Professor, Dept. of Gerontology, SFU

Your family member or friend is being invited to participate in an interview because they live in a facility where this study is taking place. Your consent is being sought for their participation as you are their identified contact person (i.e., substitute decision maker). This research is being conducted as part of my interdisciplinary doctoral degree requirements at the University of Victoria and is funded by the Alzheimer Society of Canada.

Background

In recent years, there has been a shift towards more person-centred, social models of dementia care. These models typically emphasize the uniqueness of the person with dementia, respect for residents' values, preferences and needs, the development of consistent and caring relationships, and an enriched social environment. However, we currently know very little about the factors that support or inhibit such approaches to care. The purpose of this study is to explore how the care environment (e.g., architectural and interior design features, facility practices and policies) influences care from the perspective of staff and residents. The study is taking place in two dementia care units in two different care facilities. Approximately 15-20 residents at each facility are being sought to participate in the observations.

Importance of the Research

To date, the experiences of care aides and residents with dementia are poorly represented in research. In order to create care environments that help staff provide quality dementia care, we must pay close attention to what it is like to work and live in such settings. Findings from this study will offer valuable insight that will be shared with administrators and health care decision makers in order to inform health care planning.

Participation

To learn more about how the environment influences care, I will spend up to four hours at a time, 'hanging out' on the unit observing daily life (e.g., participating in group activities, assisting staff as a volunteer might) and chatting with residents. I will also spend some time shadowing staff as they go about their daily routine. Out of respect for resident privacy, I will excuse myself when intimate care (e.g., toileting, bathing) is being provided. My presence should not add to care aides' workload. I will write down what I see and hear so that I don't forget. As the study will take place over several months, I will likely observe your family member/friend a number of times. The information I collect will help me understand how the care environment influences care provision.

Potential Benefits

Participation in the study offers residents the chance to share their thoughts about the environment in which they live. It gives them a voice that is too often silenced as a result of the stigma associated with dementia. Participation also offers residents the opportunity to make a meaningful contribution. This is important as residents with dementia typically have limited opportunities for meaningful activity and for helping others. Study participation may therefore provide a sense of empowerment and satisfaction. A small token of appreciation

(e.g., chocolates/flowers) will be given to the resident in recognition of their participation.

Possible Risks

As observations will be made during daily life, there is a potential loss of privacy. I will take special care to make sure that my presence does not upset the resident. If at any time during the observations (e.g., when I am in a common area, participating in an activity, or chatting with a resident), the resident appears upset by me being there, I will stop my observation and/or conversation and leave.

At the start of each shadowing session I will ask the resident whether they are okay with me being there. If they are not, I will leave the area and wait until the care aide moves elsewhere in the unit. I will do the same thing if the resident expresses concern or seems upset during a shadowing session. In addition, I will reassure the resident that none of what I observed will be recorded. If the resident repeatedly expresses concern or seems upset during the observations, I will contact you and remove the resident from the study. Please note that, as a researcher, I am obligated to report any serious health and safety concerns (e.g., abuse) that I may encounter during the research. In the unlikely event that this occurs, I will notify you and follow the reporting protocol established by the facility and [*Name of Health Authority*].

As I will be observing your family member/friend in common areas (e.g., lounge, dining area), other people at the facility may know they are taking part in the study. However, their data will remain private and confidential; no real names will appear in the notes (only code names will be used) and all identifying information will be removed. The notes will be kept in a locked cabinet in my home office and data will be kept on password-protected computers. Only I, and my dissertation committee will have access to the data (which for the dissertation committee will always be anonymized). Consent forms will be kept in a separate locked cabinet, to which only I have access.

Data Storage and Results

Data will be kept for five years following the study, after which all notes will be shredded and electronic data erased. During this time, I may re-analyze the data to answer other research questions related to the influence of the environment on care provision.

Results from the study will be made available to you, reported in my dissertation, presented at conferences, and published in academic journals or books.

For Further Information
If you have any questions or concerns about the observations, please contact me (Heather Cooke) at (XXX) XXX-XXXX or XXXX@XXXXXX. If you have any concerns about your rights or treatment during the study, you can also contact my supervisor, Dr. Neena Chappell at (XXX) XXX-XXXX or XXXX@XXXXXX, the Human Research Ethics Office at the University of Victoria (250) 472-4545 or ethics@uvic.ca, or the Chair of [*Name of Health Authority*] Research Ethics Board at (XXX) XXX-XXXX.

Consent to Participate
Your family member's/friend's participation in this study is entirely voluntary. **If you DO NOT wish them to participate you DO NOT have to provide a reason. Your decision will IN NO WAY influence the care they receive. If you do decide to have them participate, and then change your mind, you are free to have them withdrawn from the study at any time, without providing a reason. Should you wish to withdraw them from the study, you will be asked at that time whether their previously-collected data may be used in the analysis or whether you would prefer it be deleted. They will still receive a small token of appreciation in recognition of their participation to date.**

Your signature below indicates that you understand

- the conditions of participation described above,
- that you have had the opportunity to have your questions answered,
- that you have received a copy of this consent form for your records, and
- that you consent to your family member/friend's participation in the study.

Your Name	Resident's Name (& Relationship to You)
Your Signature	Date
Name of Witness	Signature of Witness

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Staff and Resident Experiences of the Dementia Care Environment

Letter of Consent for Resident Background Information (Residents' Substitute Decision Makers)

Doctoral Candidate
Heather Cooke, MA
Centre on Aging, UVIC

Dissertation Committee

Supervisor:	Neena Chappell, PhD, FRSC, CRC, Professor, Dept. of Sociology, UVIC
Co-Supervisor:	Kelli Stajduhar, RN, PhD, Associate Professor, School of Nursing, UVIC
Member:	Denise Cloutier, PhD, Associate Professor, Dept. of Geography, UVIC
Member:	Habib Chaudhury, PhD, Associate Professor, Dept. of Gerontology, SFU

You are being invited to participate in this brief interview because you are the identified contact person (i.e., substitute decision maker) for a resident living in a facility where this study is taking place. This research is being conducted as part of my interdisciplinary doctoral degree requirements at the University of Victoria and is funded by the Alzheimer Society of Canada.

Background

In recent years, there has been a shift towards more person-centred, social models of dementia care. These models typically emphasize the uniqueness of the person with dementia, respect for residents' values, preferences and needs, the development of consistent and caring relationships, and an enriched social environment. However, we currently know very little about the factors that support or inhibit such approaches to care. The purpose of this study is to

explore how the care environment (e.g., architectural and interior design features, facility practices and policies) influences care from the perspective of staff and residents. The study is taking place in two dementia care units in two different care facilities.

Importance of the Research

To date, the experiences of care aides and residents with dementia are poorly represented in research. In order to create care environments that help staff provide quality dementia care, we must pay close attention to what it is like to work and live in such settings. Findings from this study will offer valuable insight that will be shared with administrators and health care decision makers in order to inform health care planning.

Participation

During this brief interview I will be collecting some basic demographic data about your family member or friend; for example, the resident's primary diagnosis, when they were born, and the length of time they have lived at the facility. The interview will take place at a time and location convenient to you, and will last approximately 15-20 minutes. You can decline to answer any question that you do not wish to answer.

Potential Risks and Benefits

There are no known or anticipated risks associated with participating in this brief interview. In appreciation of your willingness to be interviewed, your name will be entered into a draw for a $25 gift certificate to [*Name of Local Mall]*.

Data Storage and Results

Your data will remain private and confidential. Hard copies of the data will be kept in a locked cabinet in my home office and electronic copies will be kept on password-protected computers. Only I, and my dissertation committee will have access to the data (which for the dissertation committee will always be in an anonymized format). Consent forms will be kept in a separate locked cabinet, to which only I have access.

Data will be kept for five years following the study, after which hard copies will be shredded and electronic data erased. During this time, I may re-analyze the data to answer other research questions related to the influence of the environment on care provision.

Results from the study will be made available to you, reported in my dissertation, presented at conferences, and published in academic journals or books.

For Further Information
If you have any questions or concerns about the interview, please contact me (Heather Cooke) at (XXX) XXX-XXXX or XXXX@XXXXXX. If you have any concerns about your rights or treatment during the study, you can also contact my supervisor, Dr. Neena Chappell at (XXX) XXX-XXXX or XXXX@XXXXXX, the Human Research Ethics Office at the University of Victoria (250) 472-4545 or ethics@uvic.ca, or the Chair of [*Name of Health Authority*]'s Research Ethics Board at (XXX) XXX-XXXX.

Consent to Participate
Your participation in this study is entirely voluntary. **If you DO NOT wish to participate you DO NOT have to provide a reason. Your decision will IN NO WAY affect the care your resident receives. If you decide to participate, and then change your mind, you are free to withdraw from the study at any time, without providing a reason. Should you withdraw from the study, you will be asked at that time whether your previously-collected data may be used in the analysis or whether you would prefer it be deleted. You will still remain eligible for the draw for the $25 gift certificate.**

Your signature below indicates that you understand

- the conditions of participation described above,
- that you have had the opportunity to have your questions answered,
- that you have received a copy of this consent form for your records, and
- that you consent to participate in the study.

Your Name	Resident's Name (& Relationship to You)
Your Signature	Date
Name of Witness	Signature of Witness

For Staff:

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Staff and Resident Experiences of the Dementia Care Environment

Letter of Consent for Interviews (Care Staff)

Doctoral Candidate
Heather Cooke, MA
Centre on Aging, UVIC

Dissertation Committee
Supervisor: Neena Chappell, PhD, FRSC, CRC, Professor, Dept. of Sociology, UVIC
Co-Supervisor: Kelli Stajduhar, RN, PhD, Associate Professor, School of Nursing, UVIC
Member: Denise Cloutier, PhD, Associate Professor, Dept. of Geography, UVIC
Member: Habib Chaudhury, PhD, Associate Professor, Dept. of Gerontology, SFU

You are being asked to participate in this interview because you work at a facility where this study is taking place. This research is being conducted as part of my interdisciplinary doctoral degree requirements at the University of Victoria and is funded by the Alzheimer Society of Canada.

Background
In recent years, there has been a shift towards more person-centred, social models of dementia care. These models typically emphasize the uniqueness of the person with dementia, respect for residents' values, preferences and needs, the development of consistent and caring relationships, and an enriched social environment. However, we currently know very little about the factors that support or inhibit such approaches to care. The purpose of this study is to explore how the care environment (e.g., architectural and interior design features, facility practices and policies) influences care from the perspective of staff and residents. The study is taking place in two dementia care units in two different care facilities. Approximately 10-12 care aides at each facility are being sought to participate in an interview.

Importance of the Research
To date, the experiences of care aides and residents with dementia are poorly represented in research. In order to create care environments that help staff provide quality dementia care, we must pay close attention to what it is like to work and live in such settings. Findings from this study will offer valuable insight that will be shared with administrators and health care decision makers in order to inform health care planning.

Participation
During the interview I will talk with you about what it is like to care for older people with dementia in long-term care. I'm particularly interested in what you perceive to be quality dementia care, and how the care environment (e.g., architectural and interior design features, facility practices and policies) impacts your ability to provide such care. There are no right or wrong answers, and you can decline to answer any question that you do not wish to answer. I will tape record the interview so that I can remember what you said. A transcript will be made, with all identifying information removed. The interview will take place at a time and location that is convenient for you, and will last approximately 30-60 minutes. I may interview you a second time to confirm my understanding of what you said in the initial interview, and of what I'm observing during my time on the unit. This interview will also last approximately 30-60 minutes and be tape recorded and transcribed. Information from the interviews will help me understand how the care environment influences care provision.

Potential Benefits
Participation in the study offers you the chance to share your experiences and express your perceptions of your work environment. It also offers recognition of the importance and value of your work. In appreciation of your willingness to be interviewed, your name will be entered into a draw for a $100 gift certificate to [*Name of Local Mall]*.

Possible Risks
As the interviews may occur on site, other people at the facility may know you are taking part in the study. Your data, however, will remain private and confidential; no real names will appear in the transcripts (only code names will be used) and all identifying information will be removed. The transcripts will be kept in a locked cabinet in my home office and data will be kept on password-protected computers. Only I, and my dissertation committee, will have access to the data (which for the dissertation committee will always be anonymized). Consent forms will be kept in a separate locked cabinet, to which only I have access. As a researcher, I am obligated to report any serious health and safety concerns (e.g., abuse) that I may encounter during the research. In the unlikely event that this occurs, I will follow the reporting protocol established by the facility and [*Name of Health Authority*].

Data Storage and Results
Data will be kept for five years following the study, after which all transcripts and notes will be shredded and electronic data erased. During this time, I may re-analyze the data

to answer other research questions related to the influence of the environment on care provision.

Results from the study will be made available to you, reported in my dissertation, presented at conferences, and published in academic journals or books.

For Further Information

If you have any questions or concerns about the interviews, please contact me (Heather Cooke) at (XXX) XXX-XXXX or XXXX@XXXXXX. If you have any concerns about your rights or treatment during the study, you can also contact my supervisor, Dr. Neena Chappell at (XXX) XXX-XXXX or XXXX@XXXXXX, the Human Research Ethics Office at the University of Victoria (250) 472-4545 or ethics@uvic.ca, or the Chair of [*Name of Health Authority*]'s Research Ethics Board at (XXX) XXX-XXXX.

Consent to Participate

Your participation in this study is entirely voluntary. **If you DO NOT wish to participate you DO NOT have to provide a reason. Your decision will IN NO WAY affect your employment. If you decide to participate, and then change your mind, you are free to withdraw from the study at any time, without providing a reason. Should you withdraw from the study, you will be asked at that time whether your previously-collected data may be used in the analysis or whether you would prefer it be deleted. You will still remain eligible for the draw for the $100 gift certificate.**

Your signature below indicates that you understand

- the conditions of participation described above,
- that you have had the opportunity to have your questions answered,
- that you have received a copy of this consent form for your records, and
- that you consent to participate in the study.

Your Name	Name of Witness
Your Signature	Witness Signature
Date	

Phone Number/Email: _____

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
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Staff and Resident Experiences of the Dementia Care Environment

Letter of Consent for Participant Observation (Care Staff)

Doctoral Candidate
Heather Cooke, MA
Centre on Aging, UVIC

Dissertation Committee

Supervisor:	Neena Chappell, PhD, FRSC, CRC, Professor, Dept. of Sociology, UVIC
Co-Supervisor:	Kelli Stajduhar, RN, PhD, Associate Professor, School of Nursing, UVIC
Member:	Denise Cloutier, PhD, Associate Professor, Dept. of Geography, UVIC
Member:	Habib Chaudhury, PhD, Associate Professor, Dept. of Gerontology, SFU

You are being asked to participate in this observation because you work at a facility where this study is taking place. This research is being conducted as part of my interdisciplinary doctoral degree requirements at the University of Victoria and is funded by the Alzheimer Society of Canada.

Background

In recent years, there has been a shift towards more person-centred, social models of dementia care. These models typically emphasize the uniqueness of the person with dementia, respect for residents' values, preferences and needs, the development of consistent and caring relationships, and an enriched social environment. However, we currently know very little about the factors that support or inhibit such approaches to care. The purpose of this study is to explore how the care environment (e.g., architectural and interior design features, facility practices and policies) influences care from the perspective of staff and residents. The study is taking place in two dementia care units in two different care facilities. Approximately 15-20 care aides at each facility are being sought to participate in the observations.

Importance of the Research

To date, the experiences of care aides and residents with dementia are poorly represented in research. In order to create care environments that help staff provide

quality dementia care, we must pay close attention to what it is like to work and live in such settings. Findings from this study will offer valuable insight that will be shared with administrators and health care decision makers in order to inform health care planning.

Participation

To learn more about how the environment influences care, I will spend up to four hours at a time, 'hanging out' on the unit observing daily life (e.g., participating in group activities, assisting staff as a volunteer might, attending shift changeovers and staff meetings) and chatting with residents. I will also spend approximately 1-3 hours at a time shadowing you as you go about your daily routine. In doing so, I'm hoping to get a sense of how the care environment supports or inhibits your ability to provide the care that you would ideally like to provide. Out of respect for resident privacy, I will excuse myself when intimate care (e.g., toileting, bathing) is being provided. My presence should not add to your workload. I will write down what I see and hear so that I don't forget. As I will be spending several months at the facility, I will likely observe you a number of times. The information I collect will help me understand how the care environment influences care provision.

Potential Benefits

Participation in the study offers you the chance to share your experiences and express your perceptions of your work environment. It also offers recognition of the importance and value of your work. In appreciation of your willingness to be observed, your name will be entered into a draw for a $100 gift certificate to [*Name of Local Mall*].

Possible Risks

As observations will be made during daily life, there is a potential loss of privacy. At any time during the shadowing you may ask me to leave the immediate area. As I will be observing you in common areas (e.g., lounge, dining area), other people at the facility may know you are taking part in the study. However, your data will remain private and confidential; no real names will appear in the notes (only code names will be used) and all identifying information will be removed. The notes will be kept in a locked cabinet in my home office and data will be kept on password-protected computers. Only I, and my dissertation committee, will have access to the data (which for the dissertation committee will always be anonymized). Consent forms will be kept in a separate locked cabinet, to which only I have access. As a researcher, I am obligated to report any serious health and safety concerns (e.g., abuse) that I may encounter during the research. In the unlikely event that this occurs, I will follow the reporting protocol established by the facility and [*Name of Health Authority*].

Data Storage and Results

Data will be kept for five years following the study, after which all transcripts and notes will be shredded and electronic data erased. During this time, I may re-analyze the data to answer other research questions related to the influence of the environment on care provision.

Results from the study will be made available to you, reported in my dissertation, presented at conferences, and published in academic journals or books.

For Further Information

If you have any questions or concerns about the interviews, please contact me (Heather Cooke) at (XXX) XXX-XXXX or XXXX@XXXXXX. If you have any concerns about your rights or treatment during the study, you can also contact my supervisor, Dr. Neena Chappell at (XXX) XXX-XXXX or XXXX@XXXXXX, the Human Research Ethics Office at the University of Victoria (250) 472-4545 or ethics@uvic.ca, or the Chair of [*Name of Health Authority*]'s Research Ethics Board at (XXX) XXX-XXXX.

Consent to Participate

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For Management:

University of Victoria

Centre on Aging
PO BOX 1700, STN CSC
Victoria, British Columbia
Canada V8W 2Y2
Phone: (250) 721-6369 Fax: (250) 721-6499
Web: http://www.coag.uvic.ca

Staff and Resident Experiences of the Dementia Care Environment

Letter of Consent for Interviews (Management/Supervisory Staff)

Doctoral Candidate
Heather Cooke, MA
Centre on Aging, UVIC

Dissertation Committee
Supervisor: Neena Chappell, PhD, FRSC, CRC, Professor, Dept. of Sociology, UVIC
Co-Supervisor: Kelli Stajduhar, RN, PhD, Associate Professor, School of Nursing, UVIC
Member: Denise Cloutier, PhD, Associate Professor, Dept. of Geography, UVIC
Member: Habib Chaudhury, PhD, Associate Professor, Dept. of Gerontology, SFU

You are being asked to participate in this interview because you work at a facility where this study is taking place. This research is being conducted as part of my interdisciplinary doctoral degree requirements at the University of Victoria and is funded by the Alzheimer Society of Canada.

Background
In recent years, there has been a shift towards more person-centred, social models of dementia care. These models emphasize the uniqueness of the person with dementia, respect for residents' values, preferences and needs, the development of consistent and caring relationships, and an enriched social environment. However, we currently know very little about the factors that support or inhibit such approaches to care. The purpose of this study is to explore how the care environment (e.g., architectural and interior design features, facility practices and policies) influences care from the perspective of staff and residents.

Importance of the Research
To date, the experiences of care aides and residents with dementia are poorly represented in research. In order to create care environments that help staff provide

quality dementia care, we must pay close attention to what it is like to work and live in such settings. Findings from this study will offer valuable insight that will be shared with administrators and health care decision makers in order to inform health care planning.

Participation

During the interview I will talk with you about what it is like to be a manager/supervisor in residential care. I'm particularly interested in what you perceive to be quality dementia care, and how you feel the care environment (e.g., architectural and interior design features, facility practices and policies) impacts care aides' ability to provide such care. There are no right or wrong answers, and you can decline to answer any question that you do not wish to answer. I will tape record the interview so that I can remember what you said. A transcript will be made, with all identifying information removed. The interview will take place at a time and location that is convenient for you, and will last approximately 30-60 minutes. Information from the interviews will help me understand how the care environment influences care provision.

Potential Benefits

Participation in the study offers you the chance to share your experiences and express your perceptions of your work environment. It also offers recognition of the importance and value of your work.

Possible Risks

You may choose to be interviewed on or off site. If you choose to be interviewed on site, other people at the facility may know you are taking part in the study. Your data, however, will remain private and confidential; no real names will appear in the transcripts (only code names will be used) and all identifying information will be removed. The transcripts will be kept in a locked cabinet in my home office and data will be kept on password-protected computers. Only I, and my dissertation committee will have access to the data (which for the dissertation committee will always be anonymized). Consent forms will be kept in a separate locked cabinet, to which only I have access.

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