

# **Exploring Person-Centered Care and Mealtimes for Residents with Dementia in Specialized Care Units**

**by**

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## Ethics Statement



The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

- a. human research ethics approval from the Simon Fraser University Office of Research Ethics,

or

- b. advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University;

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- c. as a co-investigator, collaborator or research assistant in a research project approved in advance,

or

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## **Abstract**

This qualitative study explored the dining experience of residents with dementia living in specialized care units, with a focus on person-centered care aspects in staff practices. Data were collected by multiple methods: participant observation, informal and formal interviews with care staff, and examination of relevant documents at a long term care facility in British Columbia, Canada. Data analysis revealed five person-centered categories in relation to dining: (1) Relaxed Pace/ Outpacing, (2) Respect/ Disrespect, (3) Connecting/ Distancing, (4) Empowerment/ Disempowerment, and (5) Inclusion/ Ignoring. Analysis also identified the ways in which staff understood person-centered care, and factors affecting its delivery. These categories provide insight into the psychosocial and physical environmental factors that affect residents' dining experience. The findings suggest that while staff practices reflect several aspects of person-centered care, a biomedical undercurrent continues to hinder the evolution of dementia care.

**Keywords:** dementia care, mealtimes, person-centered care, long-term care, physical environment

## **Dedication**

To both my grandmothers, for teaching me so much about the importance of family and living life with integrity, humility, generosity, patience, and empathy.

To my parents, for the steadfast support they have shown me through all of my endeavours. I am in a position to pursue my passions because of them.

To my partner, Joshua, for always believing in me.

And to those individuals living with dementia who have inspired me through sharing their experiences.

We can do better.

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# Chapter 1.

## Introduction

In 2010, it was estimated that over half of residents living in long-term care facilities in Canada had been diagnosed with some form of dementia (CIHI, 2010). As the proportion of older Canadians continues to increase, the number of people diagnosed with dementia is projected to reach 1.1 million by the year 2038 (Alzheimer Society of Canada, 2010). Further, as persons with dementia progress through the disease stages, the amount of care required will increase, and most likely consist of 24-hour nursing care provided by a care facility (Alzheimer Society of Canada, 2010).

Dining experiences in care homes have been described as a key aspect of quality of life for residents living in long-term care facilities, where food continues to hold the potential as a therapeutic activity (Kehyayan, Hirdes, Tyas & Stolee, 2015; Venturato, 2010; Fjellström, 2004). For many, the dining room and mealtimes serve as an important daily ritual, an exercise of cultural traditions, an anchor of temporality, and the social focal point within the care unit (Campo & Chaudhury, 2012; Franskowski, Roth, Eckert & Harris-Wallace, 2011; Moore, 1999; Savishinsky, 1995). There is considerable potential to foster social interactions and relations, as mealtimes are typically a shared activity, and therefore a natural setting for social interactions between residents and staff (Gilmore-Bykovskyi, Roberts, Bowers & Brown, 2015; Hopper, Clearly, Baumbach & Fragomeni, 2007). In particular, for those residents with cognitive impairments, mealtimes may serve as the most important point in the day to partake in such in exchanges (Campo & Chaudhury, 2012; Doyle, de Medeiros, Saunders, 2011; Saunders, de Medeiros, Doyle & Mosby, 2011).

Multiple interacting factors have made mealtimes a persistent challenge within long-term care facilities, resulting in malnutrition among more than half of Canadian

residents (Keller et al., 2014; Boström, Van Soest, Kolewaski, Milke & Estabrooks, 2011; Bowman & Keller, 2005). For residents experiencing advanced dementia, mealtimes can be especially challenging. As dementia progresses, there are increased instances where the person may be unable to recognize food items, identify hunger and thirst, or face chewing and swallowing difficulties (Haroldlas & Lawrence, 2015). Physical limitations may result in dulled taste and smell, and make eating with utensils a strenuous activity (Stanner, 2007). Further, numerous external factors can make mealtimes difficult for a resident with dementia. Changes in lifelong eating patterns, unfamiliar caregiver-care receiver interactions during eating assistance, culturally inappropriate foods, limited eating assistance, unsupportive utensils and dinnerware, and over-stimulating dining spaces can result in increased stress and anxiety amongst residents (Whear et al., 2014; Aselage & Amella, 2010). Resident responsive behaviours, such as those commonly referred to as “agitation” and “aggression”, in combination with care staff who interpret these responses as aversive feeding behaviours, where then eating assistance ceases prematurely, only perpetuates the risk for malnutrition and diminishes the psychosocial benefits of mealtimes for residents (Haroldlas & Lawrence, 2015; Aselage & Amella, 2010).

Numerous efforts have been made to address the issue of nutritional risk through clinical nutrition interventions (i.e., oral nutritional supplementation, fortified foods), albeit with mixed results (Sloane, Ivey, Helton, Barrick & Cerna, 2008). Those interventions that have yielded positive and sustained outcomes, however, have targeted not only individual factors associated with eating, but also factors associated with interactions between the social, physical, and organizational environments that contribute to the quality of a mealtime experience (Haroldlas & Lawrence, 2015; Whear et al., 2014; Keller et al., 2014; Reimer & Keller, 2009). Extensive mealtime training for care staff, supportive and encouraging management, and home-like dining facilities have shown to contribute not only to an increase in nutritional intake, but an overall enhanced dining experience for residents (Haroldlas & Lawrence, 2015; Chaudhury, Hung & Badger, 2013; Hung & Chaudhury, 2011; Gibbs-Ward & Keller, 2005; Zgola & Bordillon, 2001).

The recent movement towards multi-dimensional approaches to nutritional interventions for residents with cognitive impairments is reflective of a fundamental shift

in dementia care -- the hierarchical medical model, which emphasizes task-oriented efficiency, is now evolving into care environments that make the personal needs and preferences of residents priority; in practice this is referred to as *person-centered care* (Ducak, Keller & Sweatman, 2015; Keller, Beck & Namasivayam, 2015; Vikström et al., 2015; Keller et al., 2014; Penrod et al., 2007; McCormack, 2004 Kitwood, 1997b; Kitwood & Bredin, 1992a).

Kitwood (1997) identified this form of dementia care as a method of preserving the identity and honouring those persons with dementia through meaningful relationships and communication; however, its definition and therefore practical application remains largely abstruse as it “means different things to different people in different contexts” (Brooker, 2003, p.216). Reimer and Keller (2008) attempted to place person-centered care within the context of mealtimes in long-term care as taking the form of promoting of social interactions, providing food choices and preferences, supporting independent eating, and showing respect throughout services and assistance. Yet, the authors acknowledge that without considering the multilevel determinants that affect the dining experience - inadequate staffing, lack of staff education and knowledge, disconnected management, unsupportive physical environments, and inimical organizational policies and culture, efforts to create person-centered mealtime experiences will continue to be inefficacious endeavours (Keller et al., 2015; Reimer & Keller, 2009).

Mealtimes serve not only the functional purpose of providing nutrition, but also an avenue to engage in meaningful interactions with staff and residents. Currently, there is limited understanding as to how a person-centered care philosophy is practically enacted during mealtimes in facilities that aim to support residents with cognitive impairments. Even less research has been conducted on the influence of the physical environment in supporting this care approach. By exploring interactions between the subjective experiences of both residents and staff, the interactional environment which includes both social and physical factors, as well as the socio-political climate within and outside care facilities, more comprehensive and viable approaches to improve mealtimes may be developed (Keller et al., 2015; O’Connor et al., 2007).

## **Purpose of Research**

The purpose of this study is to examine the process in which person-centered care is delivered to and experienced by persons with dementia during mealtimes in special care units (SCUs). Specifically, it seeks to address the notion of personhood in dementia by identifying the psychosocial and physical environmental factors that may impede or enhance a person-centered dining experience. It is essential that care staff, including care aides, nurses, dietitians, occupational therapists, managers, educators, and other decision-makers, understand their roles in shaping the unique experiences of residents. By doing so, mealtime care practices may be more responsive to the needs of residents by reinforcing meaningful rituals and fostering social relationships. A focused ethnographic approach was employed to explore the relationships between residents, care staff, dining space, and the organizational setting in a residential care facility with a contemporary best-practice physical setting and a recognized leader in the delivery of person-centered care in the province of British Columbia. This study includes participant observations, structured and unstructured interviews, and document review. These research methods provide a means to gain an in-depth and nuanced understanding of staff care practices and subjective experiences of persons with dementia in the context of mealtimes.

## **Chapter 2.**

### **Literature Review**

The literature review for this study presents a synthesis of the multiple domains of literature related to the study focus. It begins by looking at the importance of food and the meaning of mealtimes in long-term care facilities among residents with dementia, followed by a discussion on factors associated with malnutrition that affect this population. The review then examines the philosophy of personhood, its application through person-centered care, specifically during mealtimes. Finally, the domain of the physical environment in dining areas of care facilities is reviewed.

### **The Meaning of Food in Long-Term Care Facilities**

Mealtimes serve many important purposes; not only are they necessary for the functions of the body, they are also symbolic of an individual's culture, history, and the human spirit (Fischler, 1988). Food events and food sharing regulate key social relations and are a medium through which one maintains their social connections both within the home and in the community (Counihan & Van Esterik, 1997). A meal placed at a table and those around it is evidence of overall social hierarchies, political stratum, historical contexts, and gender definitions - power and powerlessness (Counihan & Van Esterik, 1997; Haroldlas, 1975; Mead, 1970). Meals (including food access, preparation, interaction, eating, digesting) and significant eating events are important rituals of everyday life and continue to hold a climacteric role across the life course (Devine, 2005; Evans, Crogan & Schultz, 2005). The relationship between an individual and food in later life maintains its significance and increases in complexity, as it is the result of the accumulation of biological, psychosocial, and environmental contributors within a specific historical and social context (Devine, 2005; Winter Falk, Bisogni & Sobal, 1996). For example, a study on a group of rural older adults living in the United States found

that food sharing within their community not only supplemented their diet, which was limited by changes in their physiological functions and income, but also was a way of maintaining social bonds among group members (Quandt, Arcury, Bell, McDonald & Vitolins, 2001). These older individuals were able to respond to food access barriers, while preserving the unique meaning of meals that were reflective of their socio-cultural context and personal histories. The way in which an older adult navigates their relationship with food, and therefore their social connections within the context of an institution, however, is a much different experience than the one described by Quandt and colleagues (2001).

Food holds different meanings and purposes over the life course; in institutional settings, these meanings can change based on the individual's need for love, nurturance, and security (Savishinsky, 2003). Theorists, such as Goffman, have argued that when an individual enters an institution they partake in a transformation, or *mortification*, of the prior social self into a new entity capitulated to those policies that govern that environment (Henderson, 2003; Goffman, 1962). At the same time, the relinquishing of food choices – the embodiment of self-determination and control, and a vehicle for social exchange – can mean a diminished ability to uphold one's identity (Manthorpe & Watson, 2002). Ethnographers who have relayed mealtime experiences of older adults living in long-term care describe something similar to these transformations, where mealtimes and their symbolic meaning are threatened by the resident's contention with changes in personal control, nurturance, social connectedness, and pleasure through the context of meals within the institution (Franskowski et al., 2011; Savishinsky, 2003). Understandably, those who experience dementia face a greater challenge in maintaining identity through such mediums as mealtimes. The combination of decreasing cognitive capacities and physiological limitations may impede a resident with dementia's abilities to eat independently and interact with others in ways they once did, or in ways that are socially acceptable as an adult seated at the dinner table (Manthorpe & Watson, 2003). Further, if these physical and psychosocial environments are not supportive in the face of these declining abilities, opportunities to socially engage and interact during mealtimes may be missed (Lam & Keller, 2012; Reimer & Keller, 2009; Beard, 2004).

## **Mealtimes and Malnutrition in Long-Term Care**

The change in the relationship between residents, food, and meaningful social interactions through mealtimes can be further understood by examining literature on health issues associated with poor nutritional status among residents in long-term care. Despite the accessibility of food and the predictability of mealtimes in these settings, malnutrition - defined as a “subacute or chronic state of nutrition in which a combination of varying degrees of over- or under-nutrition and inflammatory activity have led to a change in body composition or diminished function” (Soeters et al., 2008, p.708), has been identified among more than half of the residents in Canadian care facilities (Sitter & Lengyel, 2011; Allard et al., 2004; Aghdassi, McArther, Liu, McGeer, Simor & Allard, 2007; Carrier, Oullet & West, 2007; Bowman & Keller, 2005). This is in part a result of physiological changes among residents, where chronic illnesses and other factors, such as poor dentition, swallowing disorders, sensory impairments, mental health issues, enteric problems, symptoms of medication use, and metabolic disorders have been linked to malnutrition (Sloane et al., 2008; Reed, Zimmerman, Sloane, Williams & Boustani, 2005; Keller et al., 2003). Residents who are malnourished are at higher risk of weight loss, infections, falls, increased hospital admissions, pressure ulcers, functional and cognitive decline, and death in long-term care (Donini et al., 2011; Amaral et al., 2010; Iizaka, Okuwa, Sugama & Sanada, 2010; Ölund, Koocheck, Ljungqvist & Cederholm, 2005; Zuliani et al., 2001). Residents with a cognitive impairment, such as Alzheimer’s disease, have been found to experience even higher rates of malnutrition, where 70% of residents in some Canadian long-term care facilities were affected (Muurinen, Savikko, Soini, Suominen & Pitkälä, 2015; Carrier et al., 2007; Keller et al., 2003). Factors that affect mealtimes specific to those with cognitive impairments include increased frailty, dysphasia, and a lack of proper eating assistance (Sloane et al., 2008; Reed et al., 2005). Difficulty with eating contributes most frequently to malnutrition among this subpopulation, where the key mechanism affected is the inability to remember the voluntary steps required to eat and swallow food (Sloane et al., 2008).

The majority of empirical literature exploring mealtimes in long-term care environments adopts a clinical focus, where interventions targeting malnutrition emphasize the increase in oral intake (Gibbs-Ward & Keller, 2005; Pearson, Fitzgerald &

Nay, 2003). For example, augmenting caloric intake with nutritional supplements, serving specialized diets to address particular medical conditions and nutritional needs, and mechanically altering the texture of food to reduce swallowing difficulties are among the interventions applied in such settings. However, evidence of consistent improvements in nutritional status using these interventions have been mixed – showing either short-lived improvements, none, or unintentional weight loss due to unappetizing and/or unfamiliar foods (Sloane et al., 2008). This intense focus on nutritional intake is reasonable when considering the large proportion of residents affected by or at risk of malnutrition. Yet it is apparent that even with nutritional interventions in place, if other aspects of mealtimes are left unaddressed, it is very difficult to improve the nutritional status of residents (Reimer & Keller, 2009). Those who have taken to expanding mealtime interventions to include factors beyond oral intake, such as creating home-like settings (Carrier et al., 2006; Nijs, de Graaf, Kok & Staveren, 2006), enhanced lighting (McDaniel, Hunt, Jackes & Pope, 2001), using supportive dining furniture (Zgola & Bordillon, 2001), reducing excess noise (Reed et al., 2005) and playing calm music (Hicks-Moore, 2005; Denney, 1997) have found positive results, where there were cases of greater nutritional intake and reductions in restlessness and agitation. Still, there are fewer studies that have attempted to purposefully intersect the clinical and social aspects of mealtimes among residents with dementia in a meaningful way.

## **Personhood and Person-Centered Care in the Long-Term Care Context**

A fundamental shift has taken place within the past three decades in the field of dementia research and dementia care: there is increasing recognition that the experience of dementia - the subjective and intersubjective (the junction of one's subjectivity with the subjectivity of another), with greater emphasis on the unique needs and preferences of the individual, is critically important for progress in the area of dementia care (Hubbard, Cook, Tester & Downs, 2002; Sabat, 2005; Kitwood, 1997). This is contrasted against the unyielding medical model that holds tightly to a highly hierarchical, systematized, and task-oriented approach to care, and one that offers little in the way of personalization and individualization (Penrod, et al., 2007). Recent

theoretical discourse surrounding the subjective experience, (i.e. ‘who and what constitutes a person?’), specifically the integrity of identity construction and maintenance among person with dementia, is not a discussion restricted to theorists and academics; instead this conversation manifests readily in the everyday lives of those directly and indirectly affected by dementia (Sabat, 2005). It is not surprising then, that Tom Kitwood’s philosophy of *personhood* and its utilitarian application via *person-centered care* has become synonymous with good quality dementia care (Brooker, 2003).

Personhood, defined by Kitwood as “a standing or status that is bestowed upon one human being, by others” places the person with dementia – a social being, within the context of relationships that honours that person through trust and respect (1997b, p.8). The philosophy acknowledges that the self is a social construction enhanced and reinforced through interactions with others, regardless of limitations in cognitive abilities (Kitwood, 1997b, p.8; Goffman, 1959). Kitwood posited that symptoms commonly associated with this disease might be attributed more to a failure to understand the subjective dementia experience and provide proper care, than to the structural failures of the brain (Kitwood, 1997b). The idea that the neurological impairment itself cannot sufficiently explain all of the behaviors displayed by those persons with dementia is the crux of Kitwood’s philosophy (Hung & Chaudhury, 2011; Kitwood, 1997b). Therefore, he proposed that the dementing process extends beyond the neurological impairment to include the interplay between the impairment, the individual’s psychology, and the social psychology (Kitwood & Bredin, 1992b). Conceptually, he accounts for the factors that result in the experience of dementia in the equation as follows: “Dementia = P + H + B + NI + SP”, where “P” is personality, “H” stand for physical health, “B” indicates biography (or life history), “NI” is neurological impairment, and finally “SP” that represents both the social and psychological environments in which the person with dementia exists (Hung & Chaudhury, 2011; Kitwood, 1997b). It is this combination of factors that results in the dementia experience, and whether that experience promotes or obstructs the relative well-being (expressed by degrees of personal worth, sense of agency, social confidence, state of hope) of those individuals with dementia (Kitwood & Bredin, 1992b).

The preservation of personhood among those with dementia is a psychological and neurological task, one that is essential in the face of multiple losses associated with

cognitive decline (Kitwood, 1997b). Upholding personhood requires both the efforts of the person with dementia and those around them (Kitwood & Bredin, 1992a). Therefore, it can be said that the true agenda for dementia care is the maintenance of personhood through relationships and communication (Brooker, 2003). By accounting for the resident's history, routines, and personal preferences, cues can be interpreted to better understand their present behaviour, wishes, and needs (Evardsson, Winblad & Sandman, 2008). This in turn can offset the degeneration and fragmentations associated with neurological impairment within the context of a person's social and physical environments (Brooker, 2003; Kitwood & Bredin, 1992b). Kitwood describes interactions that incorporate such exchanges as affirming the person with dementia's uniqueness, validating their subjective experiences, as well as collaborating on daily tasks and activities that will help to preserve the personhood of those with dementia (Kitwood, 1998). These care interactions that uphold a resident's personhood have come to be recognized as having a *person-centered* approach to care – in practice referred to as *person-centered care*.

In order to improve the well-being of the person with dementia, the key task of carers is to uphold the individual's personhood through honoring the person's life history and personality (Kitwood & Bredin, 1992a). Yet more often than not, the mutually beneficial relationship that can exist between persons with dementia and those around them (i.e. care staff, family, etc.) is stifled by a 'malignant social psychology' – a social environment that reduces the personhood of individuals (Kitwood, 1998). The current Western context - the intersection between the biomedicalization of aging and an ageist culture (emphasis on youth, independence, and cognitive abilities), places those with dementia in a vulnerable location, and serves as an exemplar of this repressive milieu (Brodaty, Draper & Low, 2003). Further, biomedical institutions, such as long-term care environments, have a history of restricting the experience of degenerative diseases to that of clinical presentations (Stafford, 2003). While the experience of dementia has been subject to the same reductionist attitudes as other illnesses, it can be argued that the implications of diluting this experience to that of a collection of symptoms can have deleterious effects on relative well-being of those persons with dementia (Penrod et al., 2007). The personal beliefs held by facility staff regarding the degree to which the person with dementia has or has not lost their self (or diminished personhood) can have

an immense impact on the quality of life and well-being of residents: If care staff assume that the person with dementia has not maintained a sense of self and proceeds to treat this person in derogatory ways, and if the person with dementia then reacts negatively, the result is an attribution of negative behaviour to the disease as opposed to the repressive culture that surrounds that person with dementia (Sabat, 2005; Brodaty et al., 2003). Negative perceptions and careless approaches to dementia care can be perpetuated by certain organizational climates – ones that fails to recognize the critical role of staff as full participants in the social system surrounding their residents (Norbergh, Hellzén, Sandman & Asplun, 2002). This dissociative culture is sustained through a lack of education, high staff turn over, improper training, and poor communication between staff and management (Brodaty et al., 2003). Kitwood is clear that such conditions found in ‘malignant social psychology’ environments may not necessarily be a result of maleficence, but instead a consequence of ignorance and lack of insight by care staff, management, organizational policies, and the health care system at large (Kitwood & Bredin, 1992b; Kitwood, 1997a).

As discussed earlier, person-centered care is most often utilized in long-term care facilities among residents with cognitive impairments, and a practice that is strongly associated with good quality care. It can be understood as an “approach to caregiving that uses care recipients’ unique personal preferences and needs to guide providers as they customize health care” (Talerico, 2003, p.12-13). Determining an appropriate operational definition for this care approach, however, has proven to be much more challenging, as person-centered care is a guiding framework as much as it is a philosophical approach (Brooker, 2003; Talerico, 2003). Still, there is agreement among scholars that several key elements encompass person-centered care: (1) regard personhood in people with dementia as increasingly concealed rather than lost; (2) provide care that is reflective of the individual’s values, preferences and needs; (3) create a positive, personalized social environment so that relative well-being is supported; (4) encourage freedom of choice and emphasize individually-defined, reasonable risk-taking; (5) interpret behaviour from the perspective of the person with dementia; and (6) prioritize the trusting relationship to the same extent as the care tasks, which includes involving the person’s family, friends, and social network (Evardsson et

al., Talerico et al., 2003). These six components reflect the essence of maintaining personhood through care interactions.

Person-centered care approaches have been applied in long-term care by way of staff care interactions, policies, and programming, as well as through the physical environment. Person-centered care interventions have shown to have positive effects on residents' well-being and quality of life, and also improve staff perceptions of residents' experiences (Hoeffler et al., 2006). The positive perception of care staff is especially important, as this dictates the nature of social interactions between them and residents in the face of declining cognitive capacities. For example, a randomized controlled trial of person-centered interventions for bathing residents with moderate to severe dementia found that the residents' discomfort and agitation declined significantly during bathing times in the intervention group, but remained the same in the control group (Sloane et al., 2004). The intervention, which focused on regulating the physical environment and bathing tools to suit each resident's comfort and preferences, had a noticeable impact on staff's feelings of ease with bathing tasks, as well as confidence in their caregiving abilities (Hoeffler et al., 2006). Other applications of person-centered approaches include reminiscence (Cotelli, Manenti & Zanetti, 2012) and validation therapies (Neal & Barton Wright, 1999), incorporating biographical knowledge into clinical care (Clarke, 2000), prioritizing the well-being of residents over routines and care tasks (Kontos, 2005), and enhancing and personalizing residents' surroundings (Cohen-Mansfield & Werner, 1998).

## **Person-Centered Care at Mealtimes**

Mealtimes are an important ritual for residents to not only reinforce their identity through food, but also through having a shared experience and finding communion through food with other residents and staff. A considerable amount of residents' time is dedicated to mealtimes – getting dressed, making their way to the dining room, waiting to be served, eating, interacting, and digesting (Gibbs-Ward & Keller, 2005). As mealtimes are a significant part of a resident's day and afford the opportunity to socially engage and reinforce relationships, they provide an ideal occasion for staff to administer person-centered care. Residents' dining experiences are enhanced when staff recognize

the important role of mealtimes through honouring the individual and supporting the social aspect that mealtimes afford (Hung & Chaudhury, 2011; Reimer & Keller, 2009). However, meals in long-term care facilities are more often than not provided in ways that fail to place the resident with dementia's needs and preference first. Instead, there is a tendency among care staff to treat mealtimes with a task-oriented approach, which can include rushing a resident through a meal, ignoring their questions or requests, invalidating their feelings and perceptions, and/or interacting with them in a patronizing manner (Hung & Chaudhury, 2011). To place sole responsibility of that mealtime experience on staff would be unreasonable and futile; instead the experience can be understood as a multi-faceted issue, resulting from the interaction between several factors at multiple levels within a long-term care facility: external influence, which includes staff approach and organizational policies, and the physical dining environment (Keller, Beck & Namasivayam, 2015; Gibbs-Ward & Keller, 2005).

Kitwood emphasizes the importance of recognizing those persons with dementia as social beings who work to maintain their personhood through social exchanges. Relationships are at the heart of person-centered care, therefore positive social interactions between persons with dementia and their carers during mealtimes are an important part of providing care. Yet, as issues such as poor staff training, understaffing, unsupportive management, and an overarching disparity of viewpoints as to whether mealtimes are more "functional" (providing nutrition in an efficient manner) or "domestic" (support social goals and personal needs) are left unaddressed, aspects of care that uphold personhood tend to yield to mechanistic and methodical approaches (Pearson et al., 2003; Batstone, 1983).

Social interactions can be understood in the simplest of terms as "a dynamic interplay between two or more individuals, where participants interpret and react to one another's actions" (Campo & Chaudhury, 2011, p.402). Among persons with dementia, this may take the form of interpreting verbal and non-verbal expressions, such as body posture, facial expressions, touching, and eye contact (Hubbard, Tester & Downs, 2003; Hubbard et al., 2002). Research that has examined the social environment of persons with dementia residing in long-term care facilities has consistently found that residents are fully capable of forming social relationships, communities, and groups, regardless of

their cognitive impairment (Doyle et al., 2011). Mealtimes have the capacity to “be the starting point for building and sustaining social relationships” (Curle & Keller, 2010, p.190), however, studies exploring social interaction report considerable variation in the amount of socializing that occurs between residents and staff at the dinner table. In a study conducted by Pearson and colleagues (2003), the authors noted a fair number of tablemates who interacted minimally with other residents, or not at all, unless prompted by staff. These findings are also supported by a study conducted by Curle and Keller (2010), where instances of meaningful interactions between residents were limited. Factors that may affect a resident’s ability to socialize during mealtimes include symptoms of chronic illnesses, side effects of medications, sensory impairments, cognitive impairments, and the concentration required to eat independently (Pearson et al., 2003). As well, both these studies and others similar to them also note the effect that staff have on supporting or hindering the social environment during mealtimes (Hung & Chaudhury, 2011; Curle & Keller, 2010; Gibbs-Ward & Keller, 2005; Pearson et al., 2003; Kayser-Jones & Schell, 1997).

The role of care staff during mealtimes is multifaceted in that it involves not only serving food and assisting residents with feeding, but also facilitating social exchanges between residents and staff. A table shared amongst residents does not necessarily result in social interactions or meaningful connections, therefore staff have the ability to enhance the social environment so as to provide opportunities for residents to re-establish identities through food and social connections with others. In a literature review conducted by Reimer and Keller (2009) that examines how mealtime care practices can be more person-centered, several tactics and interventions were found that increased participation among tablemates: conducting a general knowledge quiz; placing more talkative residents with those who tend to be quieter; family-style dining; and care staff eating alongside residents. To enhance staff-resident interactions during meals, lessons on care approaches that uphold personhood can be drawn from Hung and Chaudhury’s (2011) ethnography exploring the dining experiences of residents with dementia. Here the authors found that providing meals and assistance at a relaxed pace, that made the residents feel safe and secure, that provided appropriate stimulation, respected each individual resident’s preferences, validated individual realities, and fostered social togetherness and inclusion resulted in not only improving the dining experience of

residents, but also staff job satisfaction (Hung & Chaudhury, 2011). Hung and Chaudhury (2011) also found that elements such as organizational culture and staff support from managers were dominant factors in determining care staff's ability to provide person-centered care. When comparing two facilities with differing organizational cultures, the care staff that had management that valued and supported staff contributions provided a higher quality of care to residents compared to the facility with less supportive management, where a lower quality of care observed (Hung & Chaudhury, 2011).

The findings mentioned above demonstrate that using person-centered care approaches extend beyond individual care staff and their attitudes towards mealtimes to include management, policies and organizational culture (Frankowski et al., 2011; Reimer & Keller, 2009). Such cultures can stem out of necessity; facilities that struggle with inadequate staffing, poor staff training, and insufficient supervision can result in negative mealtime experiences and poor eating among residents (Simmons, Osterweil & Schnelle, 2001; Amella, 1999; Durnbaugh, Haley & Roberts, 1996). Further, there appear to be inconsistencies with the application of person-centered care among long-term care facilities that have actively adopted this care approach (Brooker, 2003; Morgan & Yoder, 2012). These fluctuations may partially be explained by the lack of consensus or explicit agreement on the definition of 'person-centered care'; for example, there are those who understand it as a set of techniques, while others view it as a phenomenological perspective (Brooker, 2003). Furthermore, person-centered care is oftentimes used interchangeably with 'patient-centered care' – an approach that emphasizes the biophysiological needs of the person with dementia at the expense of their personhood needs (Evardsson et al., 2008; Penrod et al., 2007). There is a clear necessity for a more explicit translation from the theoretical understanding of personhood and person-centered care to its practical applications if this care approach is to be effectively implemented and sustained within our long-term care system (Hung & Chaudhury, 2011; Alzheimer Society of Canada, 2011; BC Ministry of Health, 2012).

## Physical Environment of Dining Spaces in Long-Term Care Facilities

Physical environments that have been thoughtfully designed have the ability to behave as a therapeutic resource that promotes well-being, and that can maximize functionality among residents with dementia. Furthermore, personhood and person-centered care approaches can be channelled if the environment is supportive of social, cultural, and psychological needs (Haroldlas & Lawrence, 2015; Hung, Chaudhury & Rust, 2015; Chaudhury, Hung & Badger, 2013; O'Connor et al., 2007). These benefits, however, extend to include the interplay that exists between an individual's ability to sufficiently navigate the structure of their physical environment and how well the environment is suited to the abilities and needs of the individual; in other words the "degree to which the needs of a person are congruent with the capability of the environment to meet those needs", referred to as *environmental fit* (Moore, 2005). Within an aging perspective, Lawton and Nahemow's (1973) offers the *ecological model of aging* that posits that when the behavioural competencies of an individual decrease with age, the inverse is an increase in environmental factors that makes navigation more challenging. Competence, the degree to which an individual is able to sufficiently interact with their environment, can be observed from five domains specific to older adults: biological health, functional health, cognition, time use, and social behaviour (Lawton, 1989). Over the past two decades, there has been growing evidence of the adverse effects of long-term care environments that do not "fit" their residents. For those older adults with cognitive impairments, this is a particularly salient issue as they face increased risk of becoming disoriented and anxious in unfamiliar environments. Although Kitwood's focus was on the psychosocial aspects of 'malignant social psychology', evidence suggests that the structural environment of the dining room can be a significant contributor to either fostering or hindering personhood, and staffs ability to administer person-centered care (Haroldlas & Lawrence, 2015; Hung & Chaudhury, 2011; Pearson et al., 2003).

Special Care Units (SCUs), identified as "segregated units that accommodate only cognitively impaired individuals" (Day, Carreon & Stump, 2000, p. 406) offer multiple specialized design features, including smaller groups of residents, specially

trained staff, and private dining rooms, open kitchens, low visual and auditory stimulus, and specially designed social spaces, among other design elements (Abbot, Sefcik & Van Haitisma, 2015). In a literature review conducted by Day and colleagues (2000), findings from studies examining dementia design interventions were mixed as to whether SCUs offered additional benefits compared to traditional long-term care environments. While some studies found that residents had reduced behavioural disturbances and increased social functioning and communication in these units, others were found to have little or no positive effects on residents' functionality, cognition, or behaviour (Day et al., 2000). The authors note that it is difficult to draw substantive conclusions on the therapeutic effectiveness of SCUs based on extensive design variations among units, as well as other factors (i.e., the extent of the specialized design features, staffing, resident activities, etc.) that make it difficult to distinguish the impact of the specialized design itself on the well-being of residents (Day et al., 2000). Yet, design criteria that is inherent to enhancing quality of life does not necessarily require empirical research to justify their implementation (Day et al., 2000). Cohen and Weisman (1991) outline eight goals that address the basic human needs and challenges of those with dementia: (1) maximize safety and security; (2) support functional abilities; (3) maximize awareness and orientation; (4) facilitate social contact; (5) provision of privacy; (6) regulation of stimulation; (7) provision of opportunities for personal control; and (8) provision of continuity of self. By applying components of this comprehensive design framework that foster positive behaviours, the probability of symptoms associated with the progression of dementia would likely decrease. Further, these goals assist not only in planning therapeutic environments, they but also in providing rationale for design decisions, program development, and policy development (Chaudhury & Cooke, 2014)

A recent literature review conducted by Chaudhury and colleagues (2013) applied this set of therapeutic design criteria to assess what elements of long-term care dining room design supports a person-centered care philosophy. The authors found that uniform, soft lighting (Weisman, Lawton, Calkins, Norris-Baker & Sloane, 1993), contrasting colours (Briller, Proffitt, Perez, Calkins & Marsden, 2001), and steps to reduce background noise supported functional ability (McDaniel, Hunt, Hackes & Pope, 2001). Evidence suggested that maximizing orientation for residents could be done through proper wayfinding pathways that carefully situate the dining room near common

social spaces (Marsden, 2005). The smell of baked goods and a large clock in the dining room were also found to stimulate appetite (Berg, 2006), as well as indicate to residents that it was mealtime and reduced confusion and agitation (Nolan & Matthews, 2004). A sense of safety and security were created by constructing pathways big enough for wheelchairs and gait aides, and by clearing other obstacles from walkways, like medication carts and garbage bins (Hung & Chaudhury, 2011). Posturing at the dining table, whether it is the position of chairs or table height, residents should be at the correct height so as to support proper eating and enhance socialization with tablemates (Briller et al., 2001; Zgola, 2001). Creating a dining room that is familiar or homelike creates a more pleasant atmosphere for mealtimes. Family-style dining, accessibility to plated food or tray service has shown to improve nutritional intake (Carrier et al., 2006; Nijs et al., 2006). Individual and cultural preferences of the dining environment should also be considered and reflective of those residents who use it in order to instill a sense of belonging (Hung & Chaudhury, 2011; McDaniel et al., 2001). Optimal sensory stimulation was supported by reducing the number of residents dining in a space, as this reduces noise, distractions, and social interactions that may be too overwhelming (Calkins, 2014; Ulrich, McCutcheon & Parker, 2011; Schwarz, Chaudhury & Trofle, 2004; Briller et al., 2001). However, playing music that is calming by nature has shown to positively affect both resident and mealtime staff (Ragneskog, Kihlgren, Karlsson & Norberg, 1996). Environments that supported privacy and residents' personal control were found to be ones that seated smaller groups of residents during mealtimes and had an intimate, homelike feeling (Perivolaris, LeClerc, Wilkinson & Buchanan, 2006). Interventions that included staff participation through verbal cues to encourage self-feeding and engaging with residents in meal preparation tasks were shown to both enhance the mealtime experience and increase nutritional intake (Perivolaris et al., 2006). Perhaps one of the most important elements to person-centered care is supporting residents' social interactions amongst themselves and with staff. Environments that were shown to uphold this social component were ones that accounted for seating arrangements to maximize social interactions, facilitated family-style dining, and altered peripheral furniture to reduce additional distractions (Geboy, 2009). Furthermore, staff presence and interactions was also shown to have a significant impact on how well residents' were able to socialize during mealtimes (Roberts, 2011). Chaudhury and colleagues (2013) note that the vast majority of the literature reviewed

on therapeutic interventions targeted behavioural and nutritional intake, with less consideration paid to the extensive symptoms associated with dementia, such as cognitive changes, communication difficulties, and functional limitations. Moreover, the authors note the obvious absence of interventions that utilize mealtimes as opportunities to improve social interactions and relationships. Similar findings were echoed in more recent literature reviews conducted by Haroldlas and Lawrence (2015) and Whear and colleagues (2014) where the authors concluded that alterations made to traditional, institutional dining environments can have positive influences on residents' intakes and improve behavioural symptoms, and that even smaller-scale changes can improve dining experiences.

As evident in these literature reviews, mealtimes within long-term care facilities are complex and multi-faceted rituals. The resident, with their individual history and personal preferences, interact within a social and physical environment that involve negotiations between staff from various disciplines and management, the design of the dining room, and the organizational climate. Together, all of these interacting factors determine the mealtime experience. The following chapter presents the methodological approach and steps that will be used to further understand our understanding of the mealtime experience within SCUs.

## **Research Questions**

This study is designed to explore the dining experiences of persons with dementia living in a long-term care facility, specifically SCUs. It focuses on the relationship of the resident with dementia with their psychosocial and physical environments during mealtimes, within the context of person-centered care.

The primary guiding research question is:

1. What are the key characteristics of person-centered care practices during mealtimes in residential care facilities?

The secondary guiding research question is:

2. What role does the physical environment of a dining space have on staff care practices and residents' mealtime experiences?

## **Chapter 3.**

### **Methods**

The dining experience for people with dementia living in long-term care facilities is a complex phenomenon, resulting from the interplay between the residents, the social context, and the physical environment. Applying Kitwood's philosophy on personhood and person-centered care, a focused ethnographic approach was used in this study, as it allowed for a thorough and targeted understanding of the associated complexities of the participants' perspectives, and their shared behaviours and experiences (Cruz & Higginbottom, 2013). This chapter begins with a description of the research design, study setting, and participants. It then presents the researcher's stance, description of data collection and data analysis. The chapter concludes with a discussion on ethical considerations and trustworthiness issues.

### **Theoretical Perspective**

As discussed earlier, Kitwood's (1997) work on personhood and person-centered care looks to contend ethical discourse that frames the person primarily as a separate individual, where instead he argues human life to be one that is "interdependent and interconnected" (p.8). To elucidate, the person with dementia remains a sentient agent, one who engages and makes things happen in their world, and one who is worthy of other's respect (Brooker, 2004; Kitwood & Bredin, 1992b). Care for those with dementia, then, should be centered on authentic communication and relationships in order to uphold the individual's personhood and well-being (Brooker, 2003).

The theoretical perspective that underpins this focused ethnographic study is Kitwood's philosophy of personhood. Kitwood (1997) identified 17 elements that encompass a 'malignant social psychology' or a harmful care environment that damages

personhood, such as ‘treachery’, ‘disempowerment’, and ‘accusation’ (p.46-47). These elements are not meant to imply “evil intent” on the part of caregivers; they identify a malignancy that is inherent to our cultural inheritance (Kitwood, 1997, p.46). Ten elements to uphold personhood and counter a stifling environment, also referred to as ‘positive person work’, are identified as ‘recognition’, ‘holding’, and ‘validation’, etc. (Kitwood, 1997, p.90-91). This set of dynamic interactional elements were developed by Kitwood and Bredin (1992b) as a part of their observational method of Dementia Care Mapping that looked to systematically document aspects of the psychosocial environment within formal care settings (Brooker, 2005).

There are select instances where research has explored Kitwood’s person-centered care during mealtimes in long-term care (Reimer & Keller, 2009). Research that has explored these psychosocial environments have identified the most salient elements present during meals, and ones that are reflective of the social dynamics that ensue at the dinner table within care environments (Chaudhury et al., 2013; Hung & Chaudhury, 2011). The elements of interaction identified in Hung and Chaudhury’s (2011) research will be used as sensitizing concepts for this study, with emphasis placed on categories that pertain to staff care approaches, residents’ dining experiences, and the physical environment: relaxed pace/ outpacing; holding/ withholding; stimulation – appropriate level/ too much or too little; respect/ disrespect; validation/ invalidation; connecting/ distancing; empowerment/ disempowerment; inclusion/ ignoring (see Appendix D).

## **Focused Ethnography**

Ethnographic inquiry has been recognized as a valuable method within the area of health care research, as it offers a “holistic way of exploring relationships between different kinds of evidence that underpin clinical practice” (Savage, 2006, p.383). Ethnographies allow for the exploration of beliefs and practices of specific groups to be understood in the context within which they occur, offering a deeper insight into individual experiences, as well as the organization and delivery of health care (Savage, 2000). While preserving the advantages conventional ethnographies offer in healthcare research, focused ethnographies allow for a targeted approach when exploring “shared

features of individuals in groups so that they can focus on common behaviours and experiences” (Cruz & Higginbottom, 2013, p.38). As mealtimes are highly ritualistic, communal activity in long-term care settings, focused ethnographies are an ideal method to address individual and shared experiences that take place at the dinner table. Focused ethnographies commonly employed data collection strategies used in traditional ethnographies, such as structured and unstructured interviews, document analysis, and participant observations carried out in a shorter-ranged, non-continual field visit (Cruz & Higginbottom, 2013). To compensate for condensed fieldwork, focused ethnographies collect a larger amount of data, varying in type, for example, video-recordings, interview transcripts, and field notes, and memos (Knoblauch, 2005).

Its suitability as a means of inquiry into the experiences of those persons with dementia makes this method particularly appropriate when examining the phenomenon of mealtimes within SCUs. There is often an assumption in healthcare research that persons with cognitive impairments are incapable of conveying their thoughts and opinions due to challenges with verbal communication and memory deficits (Nygård, 2006). As a result, the subjective experience of this population has tended to be overlooked, despite an extensive amount of research conducted on matters related to living with dementia. However, there is a growing body of research that clearly documents that persons with dementia are often aware of their situation, and are able to contribute insights about their experiences (Bartlett & O’Connor, 2007). Focused ethnographies then, give opportunity for unstructured observations that can allow for the exploration of “the social worlds of people with dementia in care settings” (Hubbard et al., 2003, p, 352), paying special attention to non-verbal communication, such as body posture and facial expressions (Hubbard et al., 2002). Therefore, persons with dementia, who would normally be excluded from research (i.e., being unable to participate in an interview), are given an option to elicit their immediate reactions and feelings to the researcher during mealtimes (Hubbard et al., 2003).

## **Site Selection**

The study was conducted in two cottages in the Stroud-Fung Alzheimer Centre (SFAC) (pseudonym) in the Lower Mainland of British Columbia, Canada. SFAC

consists of 6 cottages, each housing 12 residents. The care facility was constructed for the purpose of creating an environment most conducive to dementia care. The two cottages were selected in the facility based on the physical environmental differences in their kitchen and dining spaces. Both cottages emphasized a homelike character, with facilities mirroring that of a home that included not only a full functioning kitchen and dining area, but also two sitting areas, a laundry room, 12 private resident rooms with full bathrooms, and access to a large outdoor garden and pathway. The first cottage, Maple Lane's kitchen and dining area were situated in a long, rectangular shape next to one another. The dining area was open, where all residents ate together. The second cottage, Willow Way's dining area, on the other hand, was divided into two dining spaces by its kitchen.

## **Participant Selection**

### **Resident Participants**

As there were a small number of residents living in each cottage (n=12), resident participants were selected by method of convenience sampling. Sampling was motivated to include the dining experiences of every resident within each cottage. As mealtimes were an intimate experience for these groups, I wanted to account for as many individual experiences and the social milieu. Ideally, data saturation, "the point at which no new information or themes are observed in the data" is an indicator as to whether or not to continue recruitment (Guest, Bunce & Johnson, 2006, p.59). However, in this situation full saturation was unattainable because of the fixed number of residents in each cottage. Eligibility was restricted to those residents whose substitute decision-makers provided informed consent on behalf of the residents, in addition to verbal and/or non-verbal assent from residents. In total, 17 residents assented to participate in the study, 8 from Maple Lane, and 9 from Willow Way.

### **Staff Participants**

To understand staff care practices during mealtimes, staff were observed during meals, as well as recruited to participate in one-on-one telephone interviews. In order to

obtain diverse perspectives on the complexities of mealtimes, a total of 16 staff members consented to participate in study observations: 6 licensed practical nurses (LPN), 5 resident care aides (RCA), 2 registered nurses (RN), 1 Recreational Therapist (RT), 1 occupational therapist (OT), and one registered dietician (RD). Because of the small numbers of care staff who worked regularly in the two cottages, telephone interviews offered a discreet opportunity for staff to share sensitive and personal insights about their mealtime care experiences (Sturges, 2004). Eight staff consented to participating in a one-on-one telephone interview: 3 LPNs, 3 RCAs, 1 OT, and 1 RD. In order to respect confidentiality, both the OT and RD are referred to as Interdisciplinary Team (IT) members.

## **Researcher's Stance**

Collecting and interpreting the findings of ethnographic fieldwork is the by-product of interaction between the researcher within the social world of a group of people, and how the researcher interprets these experiences (Emerson, Fretz & Shaw, 2011). Specifically with focused ethnographies, a presupposition of intimate knowledge on the field of study is required before fieldwork begins (Knoblauch, 2005). In the following section, I will attempt to account for the interpretive lens through which these experiences have been understood.

## **Researcher's Relationship with the Setting**

My relationship with the SFAC began with this study; however, it was selected based on collaborative work with my supervisor (Dr. Chaudhury), and other graduate students from the Department of Gerontology at Simon Fraser University. These previously established relationships facilitated my initial access into the facility. It is important to note that by the time ethics approval was obtained and data collection was to commence, SFAC's director of care had resigned and the post was transferred to a nurse who, up until that point, had held a management position for some time. The nature of my relationship with the study site changed with this transition, which did have an impact on my ability to access pertinent facility information, garner support from staff, and general interest in the relevance of the study. Furthermore, this change in

leadership may have impacted the organizational culture and the delivery of care by staff members.

In light of this time of transition, it was important for me to build rapport and trust with the staff and residents, who may have been hyper-aware of my presence, and therefore may have modified their care practices and/or would have been more inclined to restrict their opinions during data collection. To overcome these barriers, I employed the following strategies:

1. Prior to data collection, I met with the previous director of care to establish my research objectives and the nature and duration of my data collection methods. I also met with another researcher who was concurrently conducting an evaluation on meal services in the health authority, and discussed possible ways to share findings. Shortly after I had a separate meeting dedicated to discussing the purpose of my research with the interdisciplinary team. During this meeting, staff were able to give me their interpretations of mealtimes at SFAC, what they were curious about, ask me any questions or point out possible barriers, and generously offer their support for the study.
2. Prior to data collection, I travelled to SFAC on two occasions to meet informally with care staff who were on shift to let them know who I was, the purpose of my research, and for them to ask me any questions. This also gave me the opportunity to informally observe how staff and residents interact, and to familiarize myself to the social and physical environment of the two cottages. I also handed out homemade cookies to staff as I spoke with them. As SFAC was 46km away from the city centre, carrying out additional informal visits was not possible.
3. During data collection, I tried my best to be aware of my own assumptions when watching staff deliver care, and attempted to empathize with staff, especially when they discussed with me frustrations and challenges they had when working. Instances where I felt it difficult to sympathize with staff were processed with journaling, and then revisited in the forms of memos if thought relevant to the study.

4. After mealtimes, I stayed in cottages to chat informally with staff to talk about their experiences, their families, and to give them opportunities to ask me more personal questions.
5. Building rapport with residents was a much slower process that involved me limiting my interactions initially, so as to respect the time they needed to adjust to my presence. I spent time observing residents' personalities and demeanours, how they chose to communicate with staff and one another, in addition to their cognitive and functional abilities. I spent time with residents before and after mealtimes, sitting with them at tables, or going for walks with them in the garden so that we both had opportunities to learn about each other. This process also played an important part in later gaining assent from residents who had consent from their substitute decision makers.

## **Data Collection**

Data collection involved multiple sources: residents with dementia, staff (LPNs, RCAs, occupational therapist, and dietician), field notes and journaling, and archival documents. Data were collected by conducting participant observations, informal conversations with residents and staff, one-on-one staff interviews, and review of documents. Variation in data collection methods and sources allowed for the verification process of triangulation. By observing "valid and reliable multiple and diverse realities" (Golafshani, 2003, p.604), it was possible to "play each method off against the other" in order to "maximize the validity of field efforts" (Flick, von Kardoff & Steinke, 2004, p.179).

Data collection was carried out in multiple phases so that rapport could be established with the residents and staff members, and data collected in the initial phases informed data collection process in the later phases. The first phase of my fieldwork consisted of familiarizing myself with SFAC's values and care philosophy from websites and informational DVDs. A physical environmental observation was conducted of the kitchen and dining room areas to familiarize myself with the spaces. I was provided with educational materials prepared and delivered by SFAC's OT to care staff members on improving mealtime experiences and safety precautions when dining. The process of obtaining informed consent from staff and substitute decision makers, and in particular,

assent from residents was a key goal of this first phase. It was important that I learn how each resident chose to communicate their willingness to participate in this study; I did this through observations and insights from care staff. The second phase involved mealtime observations, ongoing assent with residents, and preliminary analysis of findings, which was the basis of my thematic categories and codebook. This initial analysis would also inform my interviews with care staff. Phase 3 consisted of continued mealtime observations and one-on-one interviews with staff. Phase 4 included a continuation of observations after interviews were completed so as to provide me with the opportunity to follow up with any issues discussed during interviews with staff. Table 1 shows the chronology of the study process.

**Table 1. Chronology of Fieldwork**

Phase	Month	Action
	November 2014	- Permission granted by facility administrators to conduct study at site
	December 2014 – April 2015	- Proposal submitted and defended - Ethics application submitted to Office of Research Ethics SFU and FHA Research Ethics Board
Phase 1	April 2015	- Examination of mission statements and informational DVD on care delivery philosophy, educational lecture on improving mealtimes experiences and safety measures - Informal meetings and observations with staff and residents - Obtained informed consent from substitute decision maker on behalf of participants - Obtained assent from resident participants - Obtained informed consent from care staff members - Physical environment observation - Keeping field notes, writing memos and journaling regarding entry into field, participant recruitment, and assent process with residents
Phase 2	May 2015	- Obtained assent from residents; ongoing assent process with residents - Formal meal observations, 6 carried out between two cottages - Field notes, memos, and journaling continue - Preliminary categories and codebook established for analysis

<b>Phase 3</b>	June 2015	<ul style="list-style-type: none"> <li>- Ongoing assent process with residents</li> <li>- Formal meal observations, 6 carried out between two cottages (pre staff interviews)</li> <li>- Staff one-on-one interviews (telephone), 8 conducted amongst care staff from both cottages, 1 RD, 1 OT</li> <li>- Field notes, transcription, memos, and journaling continue</li> <li>- Ongoing development of categories, coding, identifying emerging categories</li> </ul>
<b>Phase 4</b>	July 2015	<ul style="list-style-type: none"> <li>- Formal meal observations, 6 carried out between two cottages (post staff interviews)</li> <li>- Field notes, memos, and journaling continue</li> <li>- Transcription, data analysis, refinement of categories</li> </ul>
	August 2015 – October 2015	<ul style="list-style-type: none"> <li>- Transcription, data analysis, confirming categories</li> <li>- Writing initial draft of thesis</li> </ul>
	November 2015	<ul style="list-style-type: none"> <li>- Review of committee members' feedback, refining draft</li> </ul>
	December 2015	<ul style="list-style-type: none"> <li>- Thesis defense</li> </ul>

## Participant Observation

Ethnography involves the researcher to participate as “fully and humanly as possible in another way of life” and in doing so, the ethnographer “learns what is required to become a member of that world and to experience events and meanings in ways that approximate members’ experiences” (Emerson et al., 2011, p.3). Observations took place in the kitchen and dining areas of the two cottages to explore the social and care interactions between residents and staff, applying a person-centered care conceptual lens. Special attention was paid to how residents communicated their thoughts and needs with others, as most residents were advanced in the progression of dementia. The role of the physical environment during mealtimes was examined: Who and how often dining spaces were used, and who had access to which parts of these dining spaces was noted. In addition, factors that influenced residents’ relationship with their food, and the ways in which the residents interacted with one another at the dining tables were also carefully observed.

In each cottage -- 3 breakfasts, 3 lunches, and 3 dinners were observed, totalling 18 observations in two cottages over a period of period of 2.5 months. The focus of my observations was the residents who provided me ongoing assent, however, significant

exchanges with other residents were also noted. Each observation session lasted 90-120 minutes, depending on how long participating residents took to finish their meals. Throughout the mealtime, I selected different locations in the dining area to observe the residents and staff: in the kitchen, sitting areas, seated with residents at tables, or just off to the side of the dining area.

Being a participant observer, on occasions, I helped serve the residents food, prepare their coffee or tea, pour them juice, and engage with them in mealtime conversation. Throughout my interactions in these cottages, I was sensitive about any potential effect of my presence on the residents' mealtime. In general, residents began to recognize me when I arrived at the start of observations, and would often take hold of my hand while sitting, or suggest we go for walks in the garden. When situations arose where residents were feeling highly emotional or were too upset to eat, I was surprised that my time spent with them over those weeks proved to be of comfort for some. For example, there was one day when Ruby was upset during lunch where she felt that no one wanted to be friends with her, and that she had "lost [her] people". She had been offered a plate of food by staff, but turned it down. I sat down in a chair next to her and sympathized with her situation. I offered to warm her up a cup of coffee left over from breakfast, and she accepted the offer. I thought venturing into the kitchen might be something she would enjoy. We stood up and stood in front of the fridge for a moment, staring at the food as one might do at home. I tried to entice her with the plate she was offered previously, and she accepted it. We both sat down at a dining table and I chatted with her while she ate her meal. This situation with Ruby showed me that a willingness to eat, while a biological drive, is also heavily dictated by how a person is feeling in that moment. Ruby's feelings of loneliness overpowered her hunger, and it was not until she felt that she had companionship that she was she ready to begin her meal.

Emerson and colleagues (2011) offer five practical and reflective procedures for time spent in the field, in what they refer to as "participating in order to write": (1) make note of initial impressions (i.e., physical setting, noise, movement, etc.) in order to become accustomed to the setting; (2) identify what you think is significant or unexpected to document important events or incidents in the social context (i.e., impressions, interactions – verbal and non-verbal, reactions, etc.), while being aware of

your own personal reactions; (3) identify what those in the setting deem as “significant” or “important” and how they react (i.e., events that catch resident/staff attention, actions that generate concern, reactions and interpretations etc.); (4) focus on routine actions in the setting and how they are organized and take place (motivations as to how something occurs and is produced as opposed to why maintains attention on the social and interactional processes of the context); and (5) as fieldwork progresses, the researcher should be open to different forms of past observed events to ensure richer and more textured descriptions (p.24-29). These procedures, used in conjunction with my observation guidelines (Appendix D), provided me with enough structure to maximize the effectiveness of my time in the field as part of the mealtime experience and an observing “outsider”.

Typically, I would begin my observation day by looking at the white board in the administration office to see which staff were on shift for that meal; this was noted in my book, and also prepared me as to whom I was to interact with that day. When I would first enter the cottage, I would greet the residents and staff members, then go into the kitchen and record the menu posted on the fridge door. If residents had already begun seating themselves, I would draw a diagram of the seating arrangements with time stamps. There were instances where some residents would decide to switch seats after getting up – this was recorded. Once staff had served meals and were seated next to residents who required assistance, this was noted. As the summer months continued, I was also conscious of room temperature, lighting, and noise, as this would vary considerably between meals. The first sets of observations were somewhat overwhelming, with many procedures and rituals going on, particularly when food was being plated and served. I made note of what I believed to be significant, and learned the different patterns each staff member (noting differences between full-time and part-time staff) used when preparing meals, and how this in turn affected residents’ experiences. Conversely, I noted how residents’ personal preferences and rituals were respected by staff and affected their daily service routine. Once I felt I had a grasp of the general patterns of meals in each cottage and became comfortable with the routines, I began focusing my attention on social exchanges and situations that would deviate from this pattern, for example dinner arriving late to the cottage, a part-time staff pushing a

non-verbal resident in a wheelchair to a seat they do not normally sit at, or two residents upsetting each other with verbal or non-verbal exchanges.

It is important to note that as several residents in both cottages were further along in their dementia experience, I learned that non-verbal exchanges were of critical importance during observations. Residents who had challenges with expressing themselves verbally were observed for expressions through refusing to eat, leaving the table, pushing utensils or cups away, leaning into food, smiling at staff and making eye contact, etc. In situations that were more emotionally charged, I would note my feelings towards the situation, for example, I became frustrated when a staff member would not accommodate a resident's request (these feelings were then later examined through journaling). Instances where residents and staff did not share the same reactions as I had, I noted as significant in that it was reflective of the culture or some additional information about these individuals I was not yet (or would ever be) privy to. The similarities and differences between part-time and full-time staff provided me with triggers to re-examine my own projections as to how mealtimes in both cottages played out; part-time or casual staff often had different ways of preparing meals and interacting with residents that made me question how a particular mealtime task or ritual would be carried out.

My exchanges with the residents during the observations were very casual, and were dictated by their willingness to interact with me. By approximately my 6<sup>th</sup> observation, I had learned all residents' names, which helped in building rapport and trust with them. Some residents were more interested in spending time with me than others, which was also reflective in their verbal abilities and sex (female residents seemed to be the most engaged with my presence). In these situations, I would ask the residents questions like, "How are you enjoying your meal? Have you had enough to eat? Why did you choose to sit here today instead of your usual spot?" Meaningful exchanges and rapport was built with those residents who were unable to use words to express themselves by smiling, making positive and encouraging comments, and placing a gentle hand on the arm or shoulder.

Jottings made in field were done when I felt there was a lull or downtime during a meal where fewer social exchanges were observed. However, if there was a significant event that occurred, especially if words were exchanged – amongst residents, between staff and residents and/or myself, I often stepped out of the scene and recorded as accurately as I could to account for words and body language used by staff and residents. Immediately after leaving the field, I elaborated on these significant events in the form of memos. Once back home, I expanded these jottings into full field notes to be later coded and analyzed.

## **Interviews with Staff**

In order to gain deeper insight into the care practices and contextual factors during residents' mealtimes, I conducted one-on-one semi-structured telephone interviews with staff who worked in Willow Way and Maple Lane (3 RCAs, 3 LPNs, 1 occupational therapist, 1 registered dietician). Originally I had proposed holding a series of focus groups among staff members, however, due to the maximum number of staff available on shift, recruiting the recommended number of 6-8 participants for discussion was not possible (Plummer-D'Amato, 2008). Although I was not able to record discussion generated from a group setting, individual interviews permitted me to "see that which is not ordinarily on view and examine that which is looked at but seldom seen" (Rubin & Rubin, 2005, p. vii). More specifically, semi-structured interviews allowed me to guide the conversations, while at the same time providing respondents freedom to talk about and explore what they viewed as salient components to mealtimes (Hesse-Biber & Leavy, 2006). Interviews lasted 45-90 minutes with staff members during their personal time. As outlined in the chronology of the study process in Table 1, interviews were conducted in the third phase of data collection to provide me the field time required to ask meaningful questions to staff, as well as to understand their references to their specific contexts. This also allowed me the opportunity to identify other aspects of mealtimes not originally noted in Phase 1 of data collection. During interviews, staff were asked to describe their feelings on providing person-centered care, comment on the residents' mealtime experience, discuss the impact of the physical environment, and share opinions on the overall organizational culture of SFAC (see Care Staff Interview Guide Appendix O).

## **Additional Sources of Data**

Documents that were relevant to mealtimes and made available by the facility was information on philosophy of care through an informational DVD produced by SFAC, and a Powerpoint presentation prepared by the occupational therapist on enhancing the residents' mealtime experience and safety measures. The director of care provided resident information regarding cognitive status and age. In addition, informal conversations with managers, interdisciplinary team members, and family members also enhanced my understanding of mealtimes within the two cottages.

## **Data Analysis**

The overall focus of data analysis was on discovering the key characteristics of applying person-centered care during mealtimes for residents with dementia, while taking into account influencing physical environment factors. Study data were interpreted using analytic induction, whereby analysis begins with deduced propositions (i.e., examining data using theory-driven sensitizing concepts), accompanied by an inductive approach that "looks at the data afresh for undiscovered patterns and emergent understandings" (Patton, 2015, p.543).

## **Procedures**

I began the process by rereading observations field notes, transcripts of staff interviews, memos, and journal entries in order to identify significant patterns and salient issues. Using NVivo10, deductive analytic coding was guided by a select number of sensitizing concepts comprised of Kitwood's elements of interaction most relevant to mealtimes in care settings (see Appendix D) (Boyatzis, 1998). These elements provided "directions along which to look" (Blumer, 1969, p.148) in order to examine how they are given "meaning in a particular setting" (Patton, 2015, p.545), while providing a tangible method by which to identify examples of this care philosophy. Sensitizing concepts were examined critically against data in order to allow for opportunities to elaborate and expand their meaning and application.

Concurrently, concepts were also identified using an inductive approach, where a select number of transcripts, field notes, and memos were initially coded line-by-line using “active codes” to help define what was emerging from the data (Charmaz, 2002, p.685). Active codes identified patterns observed and described both the social and physical environments. For example, codes emerged related to the nature of relationships between residents and staff, and the types of interactions between staff and the physical environment. Focused coding was then performed to sort and synthesize active codes into more precise categories. As these codes were developed from multiple field notes and interviews, they represent recurrent categories that are reflective of a fit between “emerging theoretical frameworks and their respective empirical realities” (Charmaz, 2002, p.686).

As I continued with fieldwork, I took opportunities to inquire with staff and observe residents for patterns that emerged from data, such as ways residents and staff connected with one another during meals. Interviews with staff, which were conducted towards the end of fieldwork, allowed me the opportunity to identify and explore key issues and patterns in greater detail. This iterative process of checking, confirming, as well as rejecting categories was carried on throughout data collection.

Towards the end of the data analysis process, categories that were developed by integrating and building from all sources of data began to reveal their interconnectedness with one another and how their relationships resulted in the delivery of person-centered care and the dining experience for residents. By processing these connections through memo writing, journaling, and peer-debriefing, analytic categories were collapsed into broader categories that were increasingly more reflective of the embedded nuances in the delivery of person-centered care and the mealtime experiences of residents with dementia.

Applying an analytic inductive approach allowed me the opportunity to determine whether and to what extent Kitwood’s sensitizing concepts clouded my interpretation of the data by comparing and contrasting sets of categories (Charmaz, 2002). Furthermore, this process assisted in the development of a more texturized and expanded understanding of Kitwood’s concepts in that they assisted in identifying elements of each

that were not a part of their original definitions. For example, these more descriptive nodes gave way to expanding the definition of sensitizing concept such as “*connecting*”, where a reciprocal element between residents and staff were recognized by observing social exchanges and accounts made by staff during interviews. The application of both deductive and inductive analyses allowed for a more comprehensive understanding of the phenomena of mealtimes within an SCU, driving forward understandings of theory-based sensitizing concepts, while allowing space for more “grounded” categories to emerge, adding both depth and diversity to the understanding of person-centered mealtimes. These findings are presented in Chapter Four.

## **Establishing Scientific Rigour**

Qualitative research looks to establish scientific rigour, or “trustworthiness”, which described by Lincoln & Guba (1985), as when findings of a qualitative study represent reality. The authors operationalize trustworthiness through five methods: credibility, transferability, dependability, and confirmability. Each method involves its own respective technique to establish trustworthiness.

*Credibility* is when researchers are able to demonstrate that their interpretations of a phenomena are true. In order to establish credibility, I partook in the four techniques outline by Lincoln & Guba (1985). First, I undertook a *prolonged engagement* of 25 visits over the span of 2.5 months that allowed me to acquire a strong sense of the culture of SFAC, as well as build rapport and trust among staff member and residents. *Persistent observation* of the site over approximately 50 hours between the two cottages, as well as the administrative office allowed for sufficient time to account for any distortions of the data, and enable me the time to explore details and salient issues. Third, the verification process of *triangulation*, whereby multiple types of data (i.e., interviews, observations, fieldnotes, memos) gathered from varied sources (care staff, management, residents), provided a means to increase the probability that my interpretations were credible. Lastly, I engaged in *peer-debriefing* with classmates and committee members, an analytic session to expose any aspects of my inquiry that would have remained unacknowledged otherwise.

*Transferability* attempts to ensure that the data found in this study is applicable to others in similar situations. Further, it is the researcher's responsibility to "provide data base that makes transferability judgements possible" to those potentially applying study findings (Lincoln & Guba, 1987, p.317). The transferability, then, of this study is achieved through thick description of both the social and the physical environment, as well as the methodological applications and explicit theoretical application.

*Dependability*, which some argue is essentially the equivalent of a study's *reliability*, allows the others to make a judgement on the worth of a study by comparing their own interpretation of the research with that of their own understanding (Long & Johnson, 2000). This is achieved through the auditability of the research, a process whereby the researcher outlines the decisions made throughout the data collection and analysis process. Throughout the study, I kept an audit trail in the forms of field notes, databases, memos, and reflexive journaling so that others could follow my decision-making process, as well as how and when my personal biases were accounted for.

*Confirmability or objectivity* establishes that the study findings are ones that emerged from the data, and not from the researchers own predispositions (Shenton, 2004). Providing an audit trail of my study process, I offer readers a transparent and systematic record demonstrating the ways in which the findings and conclusions reported were grounded in my data.

## **Ethical Considerations**

### **Residents, Substitute Decision-Makers, and Visitors**

The perspectives and subjective experiences of the person with dementia has typically been excluded from research as the process and confirmation of obtaining informed consent is linked to their compromised cognitive capacity, resulting in instances where their perspectives are denied legitimacy (Hubbard, Downs & Tester, 2003). It is acknowledged among experts in the fields of dementia and research that a diagnosis of dementia does not necessarily negate a person's ability to express their thoughts and feelings; perpetuating this perspective can be considered morally unacceptable, as gaining perspective of persons with dementia is required to thoroughly inform policy and

service development (McKeown, Carke, Ingleton & Repper, 2009; Slaughter, Cole, Jennings & Reimer, 2007; Dewing, 2002). In order to capture aspects of the residents' mealtime experiences, the consent process involved obtaining assent from the resident, in addition to informed consent from their substitute decision-maker. Before the process of assent/dissent with residents began, packages were mailed to substitute decision-makers that included the following: letter explaining the purpose of the study (see Appendix A), informed-consent form (see Appendix F), information on the assent/dissent process (see Appendix M), letter and consent form related to their participation during meals when visiting SFAC (see Appendix G). Consent was required by substitute decision-makers in order to approach residents for recruitment.

The process of gaining assent or dissent from residents to participate in observations was an ongoing process that involved re-informing and re-checking their willingness to participate throughout data collection (see Appendix N). The purpose of the study was reiterated to residents in appropriate and meaningful way at the beginning of each visit, depending on the individual communication needs of residents. For example, if a resident used verbal communication, my explanation would be similar to: "Hi Ruby! My name is Sarah, I'm a student at Simon Fraser University and I'm interested in learning about your mealtimes. Would you be ok with me spending some time with you during meals?" Depending on the resident, their personality and cognitive status, paired with personal information I was given by staff members and family members on that resident, I would be sensitive to their communication abilities in order to determine assent or dissent. This meant paying close attention to non-verbal signs indicating distress or agitation either caused by my presence or a disinterest in participating. If I felt that I could not clearly determine whether they were willing or not, I would try again at the beginning of the next observation. If I was not able to gain assent after two more attempts, the resident was not included in the study. The assent/dissent process was documented carefully in field notes, with a detailed explanation of each residents' response and my rationale for including or not including them in the study.

## **Care Staff**

All staff members working in the two cottages were provided with a letter of

information (see Appendix A) explaining the purpose of the study and consent forms to participate in observations (see Appendix E) and interviews (see Appendix P). Care staff recruitment involved two information sessions and continual recruitment during participant observations until all staff who worked in Maple Lane and Willows Way had been contacted about the study. While at SFAC, I wore a nametag so that staff could identify me; I also handed out my business cards to the staff so they could contact me at any point with questions or concerns. To protect confidentiality and anonymity, names of care staff observed during interviews and interviewed were not recorded; instead participant IDs were created for each based on discipline.

Prior to the commencement of the study, ethical approval was obtained from Simon Fraser University's Office of Research Ethics and the related health authority's Research Ethics Board.

## **Researcher's Experiences and Beliefs**

Having worked in the field of gerontological, geriatric, and health systems research for the past six years, I have spent this time settled onto a "perch", observing the transformation from individual to patient in health care settings, and the complex interplay between the patient and clinicians. I have been present in the most acute settings - emergency departments and operating rooms, and observed the ins and outs of daily life within long-term care environments. The field of research has afforded me opportunities to explore the realities of health care providers, patients/residents, their families, and the overarching organizational climate. While my varied experiences in these health service settings serve as contrasting exemplars to one another in terms of differing priorities (i.e., acuity versus quality of life), the same "gut feeling" manifests within me when situations – regardless of the health care environment, somehow dishonours an individual. It is not my belief that any health care provider would purposefully impose harmful or abusive treatment to patients, yet situations where a person is treated less than they deserve is a continual occurrence. The negotiation of "humanness" or how to maintain individuality and autonomy within health care systems is something I continue to observe as a never-ending struggle experienced by all who use the medical system, but especially amongst older adults.

One way I believe “humanness” is maintained is through food. Food, the act of preparing and eating it, has always been a keen interest of mine – figuratively and literally speaking. However, it was when I enrolled in a nutritional anthropology course with Dr. Penny Van Esterik in my third year of my undergraduate degree that I was given the opportunity to explore such an overlooked, yet relevant ritual that all peoples hold in common. Our ongoing relationships with food behave like a litmus test to identify our social location - this has always fascinated me. The combination of these two topics - maintaining identity within health systems and maintaining identity through food, in light of a threatened sense of self through the loss of cognitive functioning (i.e., dementia) provided the opportunity for me to examine this phenomenon. It is my aspiration to eventually assist in creating environments that are better suited to honouring residents’ relationships with food and key individual and social rituals.

## **Chapter 4.**

### **Findings**

This chapter presents the findings of the study guided by the questions: What are the key characteristics of person-centered care practices during mealtimes in residential care facilities? And, what role does the physical environment of a dining space have on staff care practices and residents' mealtime experiences? The chapter is divided into several sections, reflective of the complex interplay of factors that influences a mealtime. First, a typical mealtime routine for both cottages is described. Second, resident participants living in Willow Way and Maple Lane are discussed, including individual personalities and interactional accounts that occurred during meals. Third, the physical dining environment and immediate surrounding areas of each cottage are discussed, paying special attention to safety and the functional support of the physical environment. Suggestions offered by staff to improve the dining space are also presented. Fourth, staff's perceptions of person-centered care are examined, identifying the most essential elements of delivering good care. Person-centered care categories and how they are associated in the dining experience will be explored and expatiated. Lastly, inhibitors and facilitators of delivering person-centered care within this context are identified by staff and discussed.

#### **“Typical” Mealtime Routine**

Mealtime routines are quite similar between Willow Way and Maple Lane. With the exception of breakfast, meals are prepared and cooked within the facility by dedicated cooks and kitchen staff. Menus and snacks are developed and monitored by the dietician, and are reviewed for texture and taste by the occupational therapist. Once food is prepared, it is served in royal blue stoneware casserole dishes and platters, and placed in warming carts that transport the food from the kitchen to each of the six

cottages. Upon arrival, the kitchen staff wheel the warming cart into the kitchen, where dishes are removed and placed on countertops. Each dish is then checked for temperature and portioned out for each resident. Special plates are made up for those with dietary restrictions, as well as texture requirements. Meals are tailored, where possible, to match individual resident preferences and eating abilities. As there are only 12 residents per cottage, most LPNs and RCAs (those who are employed full-time) have formed close relationships with residents and have learned their food likes and dislikes. For example, RCA2 knows that Doris likes her tea with brown sugar instead of white sugar. Florence is encouraged to feed herself as much as possible, and so her toast is turned into a peanut butter and jelly sandwich as it is easier to hold.

Breakfasts are prepared by those LPNs and RCAs on shift within the cottages. Overnight staff prepare a large pot of porridge that is kept warm in the oven for the following morning. At 7 AM, the LPN begins waking residents and helping them with personal care. Meanwhile, the RCA prepares breakfast by boiling eggs, toasting bread, making coffee and tea, and slicing fruit. Breakfast is most often served around 8 AM, although there are some instances when it's served later around 8:30AM or 9 AM if residents are slow to wake and get ready. Lunch is delivered from the main kitchen starting at 11:45 AM until all six cottages have their prepared meals. Lunches are often the heaviest meals of the day, with large servings of proteins, such as meat loaf, BBQ pork ribs, baked fish, and sweet and sour chicken. Vegetables consist of green beans, cauliflower, and broccoli. Carbohydrates/starches are prepared in the form of mashed potatoes, hash browns, bread, and rice. Dinners, served at around 5 PM, are the lightest meals of the day, and consist of such dishes as macaroni and cheese, soup and sandwiches, quiche, and hamburgers. Desserts are served with lunch and dinner, and can be canned fruit, rice pudding, strawberry mousse, tapioca, applesauce, and various cakes. Wine is also available, depending on the residents' health and medication. Family members bring in speciality food items that residents enjoy. For example, Doris loves marmite, and so her daughter or son would leave marmite in the kitchen for her. Gilbert has a sweet tooth, and so has an assortment of syrups to be poured over pudding, yogurt, and tapioca. His wife also brings in milkshakes whenever she visits. Medication is administered to residents prior to meals or after meals, but never during meals. SFAC

does not use medication carts; instead LPNs prepare medication in the pantry located at the back of the kitchen out of site from the residents.

Activities before and after mealtimes are dependent upon the resident and their individual routines. Most meals last between 45 and 60 minutes; however, residents are free to take as long they needed to finish their food. If residents want to continue sitting at the table even after they had finished eating, they were welcome to do so. As the dining room and kitchens are situated in the centre of each cottage, it allows for considerable flexibility around eating times, as well as a reduction in the amount of time residents wait to be served. However, those residents who require assistance with eating tend to wait the longest for their food, as staff are not able to sit down and help them until all other residents are served. In the mornings, some residents head straight to the dining room, while others pace around the cottage until food is served. Several residents require guidance to sit at the table, and to be prompted to remain there while food is being plated. Those in wheelchairs are most often in need of assistance with being pushed close enough to the tables. Organized group activities after meals include music therapy, painting, or throwing a ball back and forth. Individual activities may be going for a walk in the garden, sorting patterned socks, or listening to music. Family members are welcome to visit at any time, although there were only three occasions where family was present during observations. Facility-wide events are held often, for example, a Father's Day luncheon was held in the main meeting room in the facility for family and residents. As well, there are regular instances where families take residents out for meals or for family gatherings.

As mentioned above, although food is served in the cottages at approximately the same time each meal, there is considerable variability in terms of when meals are eaten. If a resident sleeps in or does not feel like eating at a particular time, their plate is kept in the fridge and warmed again at a later point. Some residents preferred to eat at the table, while others preferred to eat in their rooms. One resident, Eddy, had a chair he spent the majority of his days in – which also included all of his meals and snacks.

Differences in mealtime routines differ between cottages with regards to how residents and staff navigate the dining and kitchen areas. For example, staff in Willow

Way had less of an ability to monitor residents seated on the “independent eating” side of the dining room because the kitchen was located in between these two dining spaces. This meant that staff could not readily observe how residents were fairing with their meals, monitor social dynamics between residents, provide assistance when necessary, offer additional helpings, or eating assistance. The role of the physical environment is discussed in more depth in a coming section (Physical Environment).

## **Residents at Mealtimes**

A total of 17 residents with dementia participated in this study: 9 from Willow Way and 8 from Maple Lane. The average age of residents was comparable between the two cottages. Those living in Willow Way had an average age of 80, with a range from 69-91 years, and the average age in Maple Lane was 82.5, with a range of 73-92 years. Of those who participated in the study, 5 residents from Willow Way were female (4 male), and from Maple Lane, 7 were female (1 male). The ethnicity of these residents was predominantly Caucasian in both cottages.

The Director of Care at SFAC assessed the level of dementia of participating residents in both cottages to be between mild and severe. The Global Deterioration Scale (Reisberg, Ferris, deLeon & Cook, 1982) categorizes Alzheimer’s disease into seven stages of ability. Stage 5 is referred to as “moderately severe cognitive decline”, where an individual may require additional prompts to bathe or eat. Stage 6 is categorized as “severe cognitive decline”, where the person loses awareness of more recent experiences, requires assistance with dressing and bathing, and may experience a decrease in functional ability to use the toilet or is incontinent. Stage 7, “very severe cognitive decline”, is when a person loses the ability to walk and sit up, requires assistance with eating, and will experience a decline in vocabulary, eventually being limited to single words. The majority of residents in both cottages were assessed to be at Stage 6.

SFAC does not utilize mobility assessments on their resident’s functioning, however, based on observations, a range of physical functioning was observed among residents in both cottages. The majority of residents were able to walk independently, or

with a gait aid, such as a walker or a cane. Some residents required the use of a wheelchair at all times, while a select number of residents used wheelchairs intermittently with walkers, depending on their personal preferences and level of physical functioning that day.

### ***Eating Rituals and Preferences***

Residents maintained eating habits and rituals that were important to them during mealtimes. Whether it was sitting in the same spot for every meal, or requesting their cup of tea be prepared “just the way” they like it, residents communicated these preferences to staff. For those residents where verbal communication was difficult, staff were attentive in learning what each resident wanted and tried to accommodate them as often as they could. Maintaining these rituals, regardless of cognitive or functional abilities, was important to both residents and staff. As one staff member stated, “[mealtimes] are all about them, right?” (RCA 1, Willow Way). These rituals took the form of food preferences, timing of meals, and seating arrangements.

While some residents were quite happy to eat whatever food was served to them, a number of residents were more selective. Residents would communicate these preferences either by leaving food unfinished on their plate (quite often this was observed as coleslaw and green beans), or making specific requests. Doris (Maple Lane) would always voice a concern she had about having marmite available to her at breakfasts for her toast. Gilbert (Willow Way) had a sweet tooth, and so would tend to eat more yogurt if chocolate or strawberry syrup was drizzled on top.

*[RCA3] walks over to Gilbert to speak with him about his lack of appetite. She offers him yogurt instead of what's already been prepared for lunch. He seems eager by this proposition. [RCA3] goes into the kitchen and mixes yogurt and chocolate sauce in a bowl. She places it down in front of him and puts a spoon in his hand. He digs in, and a big smile appears on his face, "Thank you, all of you!" (Willow Way, Lunch, Day 13)*

On days when Ruby (Willow Way) felt lonely and homesick, she appreciated a glass of wine after her meal and would drink it sitting in her room. Edith (Maple Lane), once calm again after meals, would approach the kitchen using her walker and request a warm glass of milk; she did this at the end of almost every meal.

Timing of meals was another way residents maintained their individual rituals. Because each cottage had their own kitchen, saving residents meals for when they are ready to eat was possible. This meant that residents could eat when they were ready to, instead of having to conform to the dining schedule set out by the facility. Breakfast was the meal that varied most in terms of number residents present in the dining room, as many residents enjoyed sleeping in later. For instance, Harold (Maple Lane) tended to wake around 10AM. Staff knew to save enough food to make a plate for him when he was ready. Similarly, Eddy (Willow Way) would wake up around 9AM, just as breakfast was finishing. He tended not to eat large breakfasts, and so staff would have a glass of ensure (meal replacement shake) and a banana waiting for him.

Seating arrangements in both cottages were, for the most part, consistent with every meal. Regardless of whether a resident required assistance with eating or not, taking the same seat for every meal was an important part of dining. This also included those residents who chose to eat separately from everyone else. For example, Eddy (Willow Way), who spent most of his days sitting in a corner chair in front of the TV, would stay in that chair to have his meals.

*Eddy stayed in his chair in front of the TV and did not join the group. I'm informed by the staff that this is what he used to do at home, and so staff do not try and get him to sit at the table. The RCA places his plate on the small side table to the left of him, but he hasn't begun eating yet. He repositions himself so that his right leg hangs over the arm of the chair. He runs his fingers through his hair to smooth it out, and continues to watch TV. (Willow Way, Lunch, Day 1).*

Ruby (Maple Lane) would often feel upset and weepy just before her meals, and so preferred to eat the majority of her meals in her room for privacy. Edith, who tended to become quite agitated before mealtimes, would begin her meal in her room, and continue eating half way through with the rest of the residents in the dining room. Changes in seating were made only when certain residents did not get along with one another. It is well known in each cottage by staff that certain residents have a tendency to quarrel with one another. While most residents make an effort to get along, there are instances where residents are observed having a disagreement or altercation at the table. This would cue staff to make adjustments to seating arrangements. For example, if Loretta is in a bad mood and begins to argue and say rude things to Ruby, Loretta is

placed at the end of the table with ample space between her and the others so that her attention is focused on her meal instead of her tablemates.

### ***Appetite and Eating Abilities***

Residents' interest in their meals, as well as their abilities to eat greatly impacted their mealtime experience. While some resident's appetites could be described as "hearty" – consuming their meals with great gusto and pleasure - regardless of the types of food on the plate, others could be seen picking at their food, being selective with what they chose to eat, and leaving much on their plate at the end of the meal. There were also those who struggled to stay awake at the table, and would fall asleep intermittently. The ability for a resident to feed himself or herself not surprisingly impacted how much they were able to consume during a meal, the pleasure of eating food, and their overall mealtime experience.

Certain residents, regardless of what was served for that meal, always finished their food. For example, Anna, Doris, Loretta, and Clifford always cleared their plates. Others, however, were observed to be more selective with their meals, like Florence, Daniel, and Harold. This lack of appetite could be partially explained by the change in food texture these residents required in order to reduce the chances of choking:

*SW: What do you think is the biggest reason for residents not wanting to eat?*

*RCA1: Sometimes... I think maybe sometimes, it's the taste or texture, because they have to do changes to the food when they're not eating, you know. It's not regular food anymore. (Willow Way, Interview)*

Those who could eat independently, but had to receive minced or pureed food tended to eat the least amount compared to those who did not require texture changes and those who required full assistance.

*The food doesn't look that appetizing today, and this is reflected in the residents not eating or not finishing their food - it doesn't look very appetizing on the plate. (Maple Lane, Lunch, Day 2).*

The alertness of residents and how that impacted their mealtime experience was particularly evident. There were several residents in each cottage who struggled to stay

awake during their meals, regardless of the time of day. Residents who did tend to fall asleep were often those who required mealtime assistance, as continuous awakening and prompting was required by staff in order for residents to eat a sufficient amount of their meal. Residents who were drowsy would periodically wake from cues by staff, where they would then take small bites of food. However, staff prompts did not always result in residents eating the majority of their meals. In such situations, meal replacement drinks were provided to residents.

*Florence's eyes are shut again. "Florence, I made this for you." says the LPN, trying to entice Florence to eat her plate of food. Florence opens her eyes, then pushes her plate to the centre of the table. The LPN is perched on a stool between her and Peggy. The LPN turns to Peggy who has also fallen asleep in her wheelchair. Apparently Peggy is usually awake for meals, but happens to be quite drowsy today. "Earthquake! Earthquake!" the LPN yells as she grabs the bottom of the wheelchair and shakes it. I'm startled by this method of cuing the resident. This doesn't seem to do much in the ways of waking Peggy. The LPN attempts to feed Peggy and brings a spoonful of pureed meatloaf to her mouth. Peggy opens her mouth slightly and takes a bite, though her eyes are still shut. She manages to eat everything on her plate that meal. (Maple Lane, Lunch, Day 2)*

The ability to eat independently played a significant role in residents' mealtime experience. The degree to which residents required assistance ranged from periodic prompts with no physical assistance, periodic prompts with some physical assistance, and complete assistance with constant prompting required. Those who required full and partial physical assistance were seated at tables with staff. It is not surprising that these residents tended to consume the most food, as staff were present to monitor and assist throughout the meal. Those who were seated at tables who did not require physical assistance, but still needed verbal prompts took longer to eat or had difficulty finishing their meals. Gloria is an example of a resident who was seated at the non-assist table, but was on the verge of requiring physical assistance. In order for Gloria to successfully manoeuvre bite sized food onto her utensil and bring the food to her mouth required almost all of her concentration, resulting in little to no verbal communication with tablemates during meals.

*I can see that Gloria is one of two people left at the non-assist table. She is taking her straw and attempting to suck her scrambled eggs through it. I walk over to her, "Gloria, I'll trade you that straw for this fork." She*

*willingly switches object with me and goes back to her scrambled eggs; she has a hard time getting them on her fork. The RCA thanks me for helping her when she comes over to drop off a cup of coffee for Gloria. (Willow Way, Breakfast, Day 7)*

## **Social Interactions At the Table**

The nature and level of social interaction residents had with their fellow residents and staff members heavily influenced their mealtime experience. The combination of residents' individual meal preferences, their functional eating abilities, stage of dementia, and dining milieu determined how much social interaction a resident received. Residents who required more assistance during meals were seated next to staff members who would engage with them in conversation, in addition to providing eating prompts. For these residents in particular, as their verbal communication tended to be much more limited, mealtimes served as the most socially interactive aspect of their day. For staff members, this was also a time for them to connect and share in meaningful exchanges with residents.

*For me is just to have a conversation with them and talk to them. Because when you're giving care, you're doing a lot of things. Sometimes, you kind of get away from actually just hanging with them 'cause there's so much stuff going on in the cottage. (RCA2, Maple Lane, Interview)*

The separation of residents based on eating abilities also served as a way to address variations in mealtime socialization. Depending on the resident, their dementia progression, as well as preferred dining experience, how a resident behaves during mealtimes may not follow dining etiquette expected by other residents. For example, Harold, although physically capable of feeding himself, has a tendency to grab other residents' food, which would make others upset. As a result, Harold is seated at the assist table with staff members:

*Harold tends to grab food, if he is going to be sitting with people eating independently, he will be able to grab their food. At least if he is in our table, we can be able to easily distract or see before he does something. We can be able to prevent that. (LPN1, Maple Lane, Interview)*

There are also situations where residents are selective with their tablemates. In Maple Lane, Anna expresses herself by banging her hands on the dining tables in a rhythmic way. This tends to bother her fellow resident Rose. Because there is no physical divide between the dining tables, Rose will move to a different side of the room to avoid Anna's banging. In Willow Way, Gilbert and Beverly were observed regularly spitting food out and drooling during meals. As this upset a number of residents, both Gilbert and Beverly were seated at a separate table with staff. The physical layout of the dining space in Willow Way moderated the type of socialization a resident received. Willow Way's kitchen divided the dining spaces into two sections: staff assist and non-assist; the kitchen behaved as a visible barrier between the two spaces, providing a form of social relief for those residents who could not uphold traditional table manners. While the division was identified by staff as possible segregation of residents based on physical and cognitive abilities, the pragmatic aspect of these arrangements was difficult for them to contest in light of the situation. One interdisciplinary team member commented on this during an interview:

*Maybe it is sort of segregation and it's not a good thing, but I think it depends on how you look at it really - what your need is, what your specific need is for the person who's in there. (IT2)*

## **Physical Environment of the Dining Spaces**

The physical environment of the dining and kitchen spaces in Willow Way and Maple Lane were considerably different. This section describes key features of each of the two cottages, as well as identifies influential environmental factors that impact the level of functional support and the safety of residents during meals.

### **Willow Way**

#### ***Dining Space Description***

Willow Way's dining room and kitchen is the key focal point of the cottage, where the kitchen is located in the middle of the space, with small dining areas on either side. The kitchen is equipped with a full stovetop and oven, two sinks, dishwasher, fridge,

plenty of counter space, glass cupboards, and recycling area. A coffee machine and toaster sit next to the sink and are used everyday for breakfast. During breakfast, food would be left out in sealed containers: margarine, jam, baked goods, and bananas. A small pantry-like space is located in the back corner of the kitchen, where staff can store activity supplies, food, and prepare medications. The kitchen has an open concept where countertops look out onto the dining tables. There are two clear pathways to each dining space, which allowed staff to move easily between the two areas. Adjacent to each dining area is a sitting area. Both dining spaces look out onto a large garden, allowing for natural light to enter into the cottage. Twelve resident rooms make up the perimeter of the cottage. Each of the two dining spaces serves a particular purpose: residents requiring assistance eating are seated in one space (1 large table seats 6, 1 small table seats 3), while those who can eat independently are seated in the other dining space (1 large table seats 6, 1 small table seats 3).

### *Safety and Security*

The open design concept of Willow Way allowed staff to easily view most residents once they were out of their rooms, “It’s like a semicircle. They never really get lost and because of the way the rooms are designed, you know, as you pass you don’t ever miss anybody.” (RCA 1, Willow Way). Being able to monitor residents during mealtimes, however, was a challenge. Because the kitchen was situated between the two dining rooms, sightlines were obscured for staff who spent the majority of their time seated with residents who required assistance. This meant that those residents who did not require assistance received less social interaction, as well as assistance when they did require it. The kitchen and dining space provided adequate space to arrive and leave the dinner tables. However, for those in wheelchairs, moving independently in the dining area was sometimes difficult. Often times it would be staff who would push residents up to the table for meals, as it was too difficult for residents to negotiate navigating between tight spaces.

### *Support for Functional Abilities*

The dining spaces supported residents’ functional ability in multiple ways. There was plenty of lighting, in particular natural light, which entered through the glass doors during the summer months of observation (May, June, July, August). However, in an

effort to cool the space, staff would turn several lights off when the temperature became increasingly high and uncomfortable. While this made the room somewhat more comfortable, lighting during dinnertime was poor. The temperature of the cottage became increasingly problematic into the summer months, and was suggested by some staff to cause residents to lose their appetite.

*SW: How do you think [the temperature] affects the residents?  
LPN3: Well, I think it affects them quite a bit. I think that they're more agitated. They get really tired. It creates frustration and they don't know why they're frustrated and yeah, it's more challenging... I notice they started eating less. (Willow Way, Interview)*

As the facility had not installed air conditioning, many family members brought in fans for residents. These were kept on and directed at residents during mealtimes.

Glare on hardwood floors, windows and tables were minimal, as most surfaces had a matte finish. Tabletops were a dark wood colour, and provided a stark contrast against the white ceramic dinnerware. Chairs had high backs and arm rests to support residents in an upright position when eating. Chairs were a dark wood colour and sturdy, but not so heavy that residents had a difficult time moving them independently.

Having separate dining room spaces meant that residents were grouped in smaller numbers – 4 residents required eating assistance, and 7 residents could eat independently.

*It's quiet and the people that don't need to be over stimulated, they usually stay on that side 'cause they can keep themselves occupied. And the other side, we have a TV and with TV has a music so we can usually play the music there and that can keep them settled... So that was great 'cause that doesn't over stimulate them but keeps them settled." (LPN2, Willow Way, Interview)*

Separated spaces meant that environmental stimulation from additional staff and residents, and other noises were reduced, creating a home more-like dining experience.

Small tables that sat three to four people were adjustable in height, whereas larger tables were not. This was an issue for some residents who used wheelchairs and had difficulties sitting close enough to the larger tables. Noise that could be heard during meals, apart from residents and staff talking, was soft music playing on the non-

assistance side, and the TV on the assistance side. The TV was kept on during meals for Eddy who remained in his favourite chair for every meal.

Eddy did not join the group, but remained in his chair in front of the TV. This is apparently his preference – to eat his meal while watching TV. All other residents were seated at the tables. (Willow Way, Lunch, Day 1)

## **Maple Lane**

### *Dining Space Description*

The kitchen and dining area in Maple Lane made up about half of the shared space of the cottage, however was not a focal point, as it was in Willow Way. The dining area was a long rectangular shaped space, with the kitchen on one side and two sitting areas on the other. The kitchen was a long space that spanned the length of the dining room, with two entrances that were gated. It was equipped with a full stovetop and oven, two sinks, dishwasher, two fridges, and plenty of counter space. A small pantry at the back of the kitchen stored food, activity equipment, and medications. On the counter top was a coffee maker, toaster, electric kettle, and a variety of ceramic jars filled with tea. A spice rack and a stack of napkins sat in the corner of the kitchen. At breakfast time, spread for toast, fruit, baked goods, and eggs would sit out on the counters. A large garden area with a paved walkway can be seen from the dining area. Large glass doors and windows allow for natural light to enter into the cottage. Twelve resident rooms surround the common areas. Maple Lane also has a thirteenth resident – a grey male tabby who was often found either prowling the garden area or sleeping on a residents' beds. Most residents enjoy watching the cat move about the cottage, and the cat clearly enjoys the residents' company in the form of cooing and petting.

Unlike Willow Way, there is no physical barrier between those who require assistance to eat and those who can eat independently; all residents eat in the same area together. Three tables make up the dining area, where one assistance table (small table seats 4) is surrounded by two non-assistance tables (1 small table seats 4 and 1 large table seats 6).

## *Safety and Security*

The kitchen area remained closed off to residents for the most part. Though staff acknowledged the kitchen was for the use of residents, staff preferred if residents stayed in the dining room. Staff did this by locking gates during periods when they were assisting other residents with eating. Their reasons for this were that of safety and not having the time to clean up any messes made. Two residents in particular have poor hand hygiene practices, therefore staff feels the need to keep them out of that area, “she doesn’t wash her hands or she washes her hands in the toilet. And since hygiene is such a big factor for the kitchen, we’d rather not have her in there” (LPN 1, Maple Lane, Interview).

The large open dining space next to the kitchen and living room areas allowed staff to see residents easily in Maple Lane, “the nice thing is for the staff that they can kind of be eyeballing everyone while they’re perhaps helping a couple of people in the middle” (IT2, Interview). Another staff member emphasizes the importance of being able to monitor disruptive social dynamics, “Just because the residents can eat on their own, doesn’t mean they’ll behave. It’s good to be able to keep an eye on them.” (Maple Lane, Lunch, Day 4).

For the most part, navigating the dining space did not appear to be an issue for residents, even for those with walkers. However, for residents seated in chairs situated in between the table and living room couches, getting in and out from the table was a difficult process.

## *Support for Functional Ability*

Residents’ functional abilities were supported in Maple Lane in several ways. As the cottage was built with large glass windows and doors that opened out onto a garden, the communal areas received plenty of natural light during the day and for the majority of the evenings during the summer months of observation. Uncomfortable temperatures were even more so an issue for this cottage, because of the dining room’s orientation. This prevented some residents from participating in mealtimes.

*Peggy is nowhere to be found this afternoon. It's warm out in the main living room area, and I'm told this is the reason she's in her room. "It's too hot out here, she's lying down", the RCA explains. (Maple Lane, Lunch, Day 6)*

In an effort to address this issue, family members purchased individual fans, which staff members set up for every meal in order to keep residents cool during the day. However, residents could still be seen sweating through their clothes and showing little interest in food at times.

Glare on hardwood floors, windows, and tables were minimal because of matte finishes. Tabletops were light coloured, along with chairs which matched the hardwood floors. The white ceramic dinnerware did not have a strong visual contrast as it did in Willow Way. Staff reported issues between the colour change from hardwood flooring (light coloured) used in the kitchen and dining area, to the carpet (dark coloured) in the living room areas. This contrast in colours proved to be visually distressing for some residents who thought there may have been a step between these two spaces, and would at times refuse to cross from dining area to living room. Small tables had the capacity to alter their heights, making it possible for those in wheelchairs to be pushed right to the edge of the table. Unfortunately the larger tables were non-adjustable.

Noises during mealtimes were those associated with dining – plates being placed on tables, coffeemakers brewing, knives tapping against forks, staff and residents talking. Music was rarely played during meals in Maple Lane, and if the TV was on, the volume was kept quite low. Simulation during mealtimes was considerably different compared to the levels in Willow Way. As Maple Lane's dining space was one large rectangle, all twelve residents dined together, regardless of their eating abilities. Staff focused mealtime efforts on 4 residents who required full assistance, and observed the other 8 who could eat independently, or required few prompts. However, this dining room design caused issues for those residents who preferred a quieter and less stimulating dining experience, like Rose.

*I like the two dining rooms in Willow Way because we can separate residents from the other side, like for those people who are noisy. Anna, we would be able to place her on the other side and then the residents*

*who are quiet, like Rose who don't want Anna to bang on the table, she can sit on the other side. (RCA2, Maple Lane, Interview)*

## **Staff Suggestions for Improved Dining Space**

Participant observations and interviews revealed four aspects of the physical dining space staff felt could be altered in order to better accommodate and improve residents' mealtime experiences:

**Increased dining room space.** Staff suggested that both cottages did not have sufficient space for residents to ambulate and seat themselves at the dining tables. This was especially true for residents who used gait aids or were in wheelchairs. One LPN comments on the limited space of Maple Lane's dining area:

*Some of the wheelchairs are big and they'd have to sneak through it and the residents would have to move just so we can get by. (LPN1, Interview).*

In the above quote, the LPN is referring to having residents move around in their chairs to make way for residents in wheelchairs approaching tables. For those residents who can ambulate independently and are in the habit of getting up and down several times during a meal, having more space in between tables and chairs would allow them the option of seating themselves at the table.

**Menu variation.** Repetitive menus was identified as an issue by care staff, "...have you noticed they have potatoes with every meal? ... It's not fair for some residents who don't like potatoes." (LPN1, Maple Lane, Interview). There were also some cases where full menus were served twice in one week. Staff also mentioned that some dishes that were popular amongst residents, such as cabbage rolls, were removed from the menu. Staff thought of the menu as "just the same old" and consider "a little bit more variety than there is now" to improve residents mealtime experiences (RCA3, Willow Way, Interview).

**Reduce noise levels.** Staff identified noise levels as a component of the physical environment that they themselves could improve, however, have not sufficiently

addressed. Staff found that keeping the TV on during meals was the wrong type of background noise, in addition to something that distracted both residents and staff from focusing on meals, “it just draws the whole atmosphere, especially in Willow Way, to that one side” (IT2, Interview). Staff suggested that waiting to turn the dishwasher on after mealtimes were over would help reduce unpleasant noise, as well as reduce the amount of staff socializing in order to focus their attention on residents, “I actually think we should not make noise during mealtimes” (RCA2, Maple Lane, Interview).

**Comfortable room temperature.** Based on conversations with staff and observations during summer months, maintaining a comfortable room temperature seemed to be considerably difficult. The high temperatures during lunches and dinners made residents “not want to eat” (LPN2, Willow Way, Interview). In some cases, residents would not participate in mealtime activities because they were too hot. Staff expressed past efforts to have air conditioning installed, however, health authority policy would not allow these renovations.

*I asked if we can have air conditioning and the manager said ‘no’ because they have it throughout the buildings but not in the cottages. They’re like “seniors bodies can’t adapt to the air conditioning”. I’m like okay, well they’re struggling ‘cause it’s so bloody hot. You guys have to provide something ‘cause all you have is two ceiling fans and that don’t do anything. ‘Cause those fans that you’ve seen were actually put in from a family member. (LPN3, Willow Way, Interview)*

As mentioned by LPN3, family members from both cottages purchased enough fans to keep residents cool in common areas; approximately three to four fans were turned on in dining spaces (I was not able to determine whether fans were also placed in residents’ rooms).

## **Mealtime Care Practices: Categories**

Data analysis revealed two descriptive (1 and 7) and five deductive-inductive categories (2-6): (1) understanding person-centred care, (2) relaxed pace - outpacing, (3) respect - disrespect, (4) connecting - distancing, (5) empowerment - disempowerment, (6) inclusion - ignoring, and (7) factors affecting person-centered care

(Table 2). These categories are inherently related to the social nature of mealtimes, while accounting for how the physical environment contributes to residents' relationships with foods and meal rituals. While categories 2-6 are distinctive components of PCC, there are instances where elements of each will overlap with others, as social interactions are never singular exchanges. For example, a staff member may be feeling rushed to complete all the mealtime tasks, and so hurry a resident through their meal (outpacing), while at the same time ignoring (distancing) how their actions make that resident feel.

### **Staff Perception of Person-Centered Care**

SFAC's philosophy of care is predominantly the Eden Alternative, an approach that promotes culture change within long-term care. This model moves away from traditional institutional models of care towards one that "aims to promote autonomy and self-determination, and emotional and social well-being" (Brownie, 2011, p.64) for residents through the elimination of loneliness, helplessness, and boredom via the physical and social environment (Koren, 2010). The Eden Alternative is driven by 10 guiding principles, all of which are understood through a person-centered care lens.

Through interviews and observations, staff were asked to explain how they understood person-centered care, specifically during mealtimes within their respective cottages. Not surprisingly, defining this care approach was challenging; some staff needed time to work through their definition, while others could not outright define it at all. Yet, all staff identified - through their explanations and/or examples - a quintessential component of person-centered care and that was the resident's right to exercise "choice". By giving a resident choices throughout their day, staff honour them as an autonomous individual, and their ability to provide choice to that person is reflected in how well they know that resident. Staff emphasized that while the term 'person-centered care' is often used in health care, their understanding and ability to apply it in practice developed over time and with experience:

*You were taught in school what person-centered care is. But over time, you learn a lot of knowledge with experience. I mean, I know I wasn't always being able to be really good at person-centered care. (LPN2, Willow Way)*

In this quote, an LPN who works in Willow Way explains that his understanding of person-centered care was honed through his experiences at SFAC. He goes on further to explain that his abilities have come from team members who showed him practical ways of applying this approach to his responsibilities as an LPN. The following interview excerpts demonstrate how SFAC care staff understand person-centered care:

*I think it's allowing that individual to make their own choices and you work with that. (LPN3, Willow Way, Interview)*

*I would say it's taking the needs of the person into consideration over the needs of the facility or the people who are providing care... putting them first and making their care around that, around them. (IT2, Interview)*

*It's just really knowing their story and giving them choices. But yes, knowing their story I think is the most important. (RCA3, Willow Way, Interview)*

*It's understanding who that individual resident is and then making sure, to the best of your ability, that the care they receive is reflective of that. (IT1, Interview)*

All staff emphasized the importance of knowing who that individual resident is, specifically their “story” or history prior to moving into SFAC, so that person-centered care can be delivered. One LPN describes what it’s like to “know” a resident:

*Person-centered care is more and more an observation. It's getting to know somebody as if you're getting to know a family member. Because you see in their eyes if they're happy... You kind of know them. You build a relationship when you do person-centered care when you're perfectly dedicating your time at that moment to that one person. You're not treating them like a patient. You treat him as a person you know, a person that trusts you. (LPN2, Willow Way, Interview)*

Staff were asked during interviews to identify what they believed to be the “essence of good dementia care”. Their responses were reflective of their responsibilities as care providers, but also as individuals making genuine connections with others. The following were the most identified elements of what staff at SFAC believe to be good dementia care during mealtimes. While there is a temporal aspect to these elements, for

example, knowing the resident precedes being able to gain their trust, ultimately all should be executed in unison:

1. **Knowing the resident** and their individual preferences help staff predict what the resident may need, as well as identify any behavioural changes, for example, not wanting to eat or ways to engage the resident and keep their focus during meals. One LPN describes how she knows her residents in Maple Lane:

*... there's so many personalities. I think the main concern is like, understanding their personality and knowing them (LPN1).*

How well a staff member knew each individual resident was also evident in how they prepared and served meals. Altering foods to empower residents to eat independently, assisting with eating, knowing when a resident was ready to eat, and knowing what words to say to calm residents who may be upset were all ways in which staff utilized knowledge relayed by family members, in combination with their own experiences with residents, to delivery good dementia care.

2. **Gaining the resident's trust** in order to establish rapport and build a relationship so that the social component of mealtimes can be enjoyed, among other daily activities. Staff explain that it is their job to be that person in the cottage a resident can trust and take comfort in, especially when first adjusting to living at SFAC.

*I think the best thing is when they come in and they're kind of shy so they don't wanna mix and mingle and the next thing, you know, they're calling at you or they're coming and standing close to you. Or you could walk in and then they don't wanna leave the room. It means even though I didn't realize what I did, I did something to make them think that 'Okay, I can trust her.' (RCA1, Willow Way)*

3. **Patience and flexibility** when assisting residents and not forcing them to function at a pace they cannot meet or maintain, such as taking away their plate of food before they are finished, or not giving them enough time to eat independently. Also, recognizing that “[residents] needs are always changing” (RCA3, Willow Way), and so being flexible with expectations and personal preferences is required in order to deliver care that is person-centered.
4. **Effective communication** by being aware of not only what is said, but also how it is said to the resident was identified as a major component of good dementia care, “I think it's your tone of voice and how you talk to somebody. Talking with a smile – that goes a long way for some people” (LPN2, Willow Way). Non-verbal communication in the form of touching should be reserved for instances when a resident is familiar with a staff member and trusts them. Staff also mentioned that residents know when communication is insincere. An RCA from Maple Lane

comments on how staff need to enjoy what they do, because otherwise this is communicated to the resident:

*... [staff] need to love this job because if you don't, [residents] can sense it. The residents know when you're not happy... then they're not happy. (RCA2)*

- 5. Understanding dementia and its progression** so staff can better empathize when a resident may not be able to perform a certain task, or communicate a certain way, and that their experience of dementia is unique and personal. Staff also emphasized that understanding that certain behaviours may be a result of the dementia, and not a personal attack on care staff. An LPN from Willow Way describes what she would want if she were living in a long-term care facility:

*If I have Alzheimer's, I would hope that people know that I have an illness and I'm not choosing to be difficult. (LPN3)*

## Aspects of Person-Centered Care at Mealtimes

In order to identify the most salient aspects of person-centered care within this care context, an integrative deductive-inductive (analytic induction) approach was utilized to guide data analysis. As Kitwood and Bredin (1992) outlined clear sensitizing concepts in the delivery of PCC – from the caregiver to the person with dementia, its deductive use as sensitizing concepts made natural sense in analyzing the data (Table 2). However, Kitwood (1997) did not apply his theory of personhood, nor his person-centered care approach (Kitwood & Bredin, 1992; Kitwood, 1997) specifically to the context of mealtimes in long-term care settings, therefore, an inductive approach was necessary in order to explore and re-examine the delivery of care. Moreover, the inductive approach allowed for a wider interpretation of PCC to include both the role of the physical environment, as well as the nature and sources of social exchanges that take place during mealtimes.

**Table 2. Person-Centered Care Categories**

<b>Relaxed Pace</b> – Acting or speaking in a manner that accommodates a residents' preferences and abilities (i.e., serving meals	<b>Outpacing</b> – Acting or speaking in a manner that is too fast or too slow for residents to understand or react to (i.e., rushed eating
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when the resident is ready to eat, matching eating assistance with resident's abilities)	assistance, oversimplifying instructions, elderspeak)
<b>Respect</b> – Treating the resident as a valued member of the family unit by acknowledging their unique and personal preferences (i.e., preparing their coffee how they like it, plating foods based on their preferences)	<b>Disrespect</b> – Acting or speaking in a rude or condescending way while disregarding a resident's personal preferences (i.e., assembly line feeding, forcing residents to eat food when they refuse)
<b>Connecting</b> – Working to build a trusting relationship with residents through verbal and non-verbal communication (i.e., placing a gentle hand on a resident's arm when assisting with eating, giving a hug, using encouraging words)	<b>Distancing</b> – Creating an emotional and physical distance from residents by ignoring resident's efforts to connect (i.e., ignoring resident's feelings, dismissing resident's reality, using critical or disapproving words)
<b>Empowerment</b> – Acknowledging potential for control over resident and working to support abilities and skills (i.e., encouraging self-feeding, making hand-held snacks available, giving encouraging prompts, encouraging mealtime clean up if offered)	<b>Disempowerment</b> – Failing to acknowledge potential control over residents through a lack of support of remaining abilities (i.e., discouraging help with mealtime routines when offered, restricting residents to certain parts of the dining area, performing tasks on behalf of residents due to time restrictions)
<b>Inclusion</b> – Creating a supportive environment that actively includes residents in meaningful social exchanges and activities (i.e., facilitating conversation amongst residents, encouraging group activities, seating arrangements to promote group discussion)	<b>Ignoring</b> – Creating an unsupportive environment that actively disregards or ignores the presence or feelings of residents (i.e., seating arrangements based on eating ability, excluding residents in conversation, mocking residents in public spaces)

## Relaxed Pace-Outpacing

**Relaxed pace**, also referred to by Kitwood (1997) as *relaxation*, includes all forms of interaction expressed with the lowest level of intensity. Kitwood (1997) makes note that while relaxation can be carried out in solitude, it is of greater benefit to the person with dementia to relax surrounded by company. During meals, staff were observed trying to encourage residents to all sit and eat together, and set a relaxed pace by serving them each course one at a time so as not to overwhelm them with choices. The interdisciplinary team member commented on this dining approach during his interview:

*...at the table, you don't put a lot of plates and bowls at the same time. Maybe one item at a time. Don't clutter the table with food items. One at a time, they finish, you bring another one, so they don't get confused or they don't jump from one dish to the other. So one item at a time... simplify the table setting. (IT1, Interview)*

Staff involved with assisting residents with eating were observed consciously meeting the eating pace set by the resident. Verbal and non-verbal cues helped staff determine when they were ready. As well, it was evident that some staff knew residents and their preferences and abilities very well, which made mealtimes especially enjoyable. The following is an example of LPN3 who is particularly close with Norm, a resident with Parkinson's disease and Alzheimer's disease:

*LPN3: Are you enjoying this, Norm? [LPN3 sets down her fork and waits for him to answer.]*  
*Norm takes a moment, then looks at LPN3*  
*Norm: Yeah yeah! [Norm exclaims happily.]*  
*[This is the first time I have heard Norm speak! I actually didn't know he could. I'm completely amazed by this.]*  
*LPN3: Do you want some meat, Norm?*  
*Norm: Yeah!*  
*I make a comment to LPN3 that this is the first time I've heard him speak.*  
*LPN3: Oh yeah, he'll talk to you. [She grins.]*  
*She describes to me how Norm is good about opening his mouth when there's food in front of him, so normally staff keep feeding him without having to use their words to cue him, and so rarely give him opportunity to give them feedback.*  
*[I've seen people speak to Norm before, but he's never responded like this. He must really like LPN3.] (Willow Way, Lunch, Day 13)*

This quote above is particularly special, and demonstrates the benefits of knowing a resident well so that staff set a relaxed pace that meets the level and needs of that individual. Quite often, Norm would be spoken to, but without an expectation of him giving a verbal answer. By being patient with residents and by making a genuine effort to learn how that resident responds and reciprocates, a more enjoyable mealtime results, and ultimately trusting relationships are built, like the one between Norm and LPN3.

Staff also set a relaxed pace to mealtimes by recognizing residents' individual eating schedules. This is especially evident in the mornings, when some residents like to sleep in. Breakfast is scheduled between 8AM and 8:10AM. The following is an example of a resident who not only does not eat at the table, but also eats later than all other residents:

*At 9:30AM Eddy comes out of his room and takes a seat in his usual chair in front of the TV. He's in his boxers and white t-shirt.*

*Eddy: You got any beer?*

*SW: No, but I can check the fridge.*

*Eddy: Yeah, would ya? [He takes his right hand and smooths his long white hair back].*

*The RCA5 can hear our exchange so she heads over to the fridge with me and grabs a bottle of Ensure. She breaks the seal but leaves the cap on.*

*RCA5: There's your beer! [She plays along for his request for a drink and hands Eddy the bottle.]*

*Eddy: Thank you! [He twists the rest of the cap off, takes a sip, and places the bottle on the table. A moment later he smooths his hair back again] (Willow Way, Breakfast, Day 3)*

This example above has been described by staff as a routine that Eddy performed often in his home before moving into SFAC, and feels strongly about continuing on within the facility. Individual rituals, even those that do not align with the facility's routine, are approached by staff as important and ones they try to honour as best as they can. The flexibility, or relaxed pace, that staff are able to have with the timing of mealtimes is also made possible by having a functioning kitchen within the cottage. Staff are able to save meals for later, store special food brought in by family members, as well as improvise with snacks and alternatives if residents do not like what is being served for that meal from the main kitchen.

Kitwood (1997) defines **outpacing** as a situation where a person with dementia is given information - presented choices, for instance, in a way that is too fast for that person to understand or to react to. During mealtimes, this took the form of performing meal rituals where residents' were not given enough time to respond to staff. The following is an example of outpacing:

*Doris is making eye contact with me as she sits at the table. She gets up and walks over to me. Resting on her walker is a small black photo album.*

*Doris: Oh good, you're here! I wanted to you to look at these. [A big part of interactions with Doris is listening to her reminisce about her youth in England.]*

*SW: Thank you, Doris. I'm just busy at the moment, but I would love to look at these photos in a few minutes. I hope that's okay. [This explanation seems to satisfy her.]*

*Before Doris has a chance to turn back around, RCA2 silently comes up behind her and places a white apron over her head and walks away. She doesn't give Doris any warning that this is happening, nor does she ask her permission. Doris is startled and jumps at this. She then realizes what is around her neck, takes the strings and neatly ties a bow in the front. Doris then heads back over to the table and quietly sits down. (Maple Lane, Lunch, Day 6)*

Though having an apron placed over her head unannounced startled Doris, both she and the RCA were familiar with the mealtime routine of protecting Doris' clothing from food based on Doris' secondary reaction to tie her apron. Yet, the above quote also speaks to the mindset of the RCA, i.e., she did not think it was important enough to let Doris know what she was doing. Several staff members would give reasons for having to rush meals because they either did not have enough time, or did not have enough staff to help. This would sometimes result in food being removed from the table before residents were finished eating:

*...a lot of people, they don't have the patience so when they're like "Oh, she doesn't want to eat anymore", I'm like, "Actually, she's going to eat some more, and like, you need to wait." (LPN1, Maple Lane, Interview)*

In this above quote, a staff member is referring to the help she provides Peggy, a resident who requires full assistance during mealtimes. LPN1 is aware that Peggy requires extra time to eat her meals, and that her moving at a more relaxed pace should

not be interpreted as not wanting her food – staff are aware themselves that they have the ability to set the pace – or outpace – the residents.

Outpacing can also be extended to include instances where staff moved at a pace too slow for residents. This was most often observed during breakfasts, where residents who required assistance with eating would have to wait extended periods of time while their food became cold sitting in front of them until a staff member was available to assist with eating. The following is an example is a scene that occurred at dinner, where staff were reserved to the fact that not all residents would be served in a timely manner:

*I ask RCA1 and LPN2 whether I can help at all with serving dinner, as I'm concerned that some residents who are already seated don't have any food in front of them.*

*LPN2: They don't care, it's been the same routine for three years. (Willow Way, Dinner, Day 9)*

In this observation, staff are aware that they are outpacing residents, however, are under the assumption that residents are unaffected when meals are delayed. Outpacing in this form, in combination with disempowerment, was also observed when part-time staff would try and feed residents who were able to eat independently. Residents would often become frustrated and annoyed by this.

## **Respect-Disrespect**

**Respect** is treating residents as valued members of the cottage by acknowledging their unique and personal preferences (Kitwood & Bredin, 1992). At mealtimes, this was observed taking the form of providing residents with choices whenever possible, and respecting those choices. Respect included serving food based on personal preferences. Although both cottages received lunches and dinners from the main kitchen, breakfasts were prepared in each cottage by staff. This allowed for residents to have these meals prepared to their liking:

*RCA2 is busy in the kitchen making up Doris' plate. She places margarine and jam on the sides of the plate instead of spreading them on the toast. RCA2: Doris likes to put these on herself. Even if I tried to do this for her, she'd request to do it that way anyways. (Maple Lane, Breakfast, Day 12).*

In this example, the RCA knows Doris well enough that performing her own breakfast rituals is important to her. Further, by respecting Doris' choice to help prepare her own breakfast, the RCA is also empowering Doris' ability to do so. Another example of staff respecting resident's mealtime preferences is serving all three meals to Eddy at this chair in front of the TV - "Eddy is a super picky eater and he hardly ever wants to eat his meal. So we don't make him. And he never usually wants to sit at the table, so we don't make him." (LPN3, Willow Way, Interview). Staff respect that this is what he did at home, and so are happy to continue with this routine. At the same time, staff recognize that residents' preferences can change, regardless of their preferences in the past:

*RCA2: Like Edith, her family... they're very... I don't think they understand that she's different in the facility. They're like, "No she's not like this - really." Actually she is like this because we're here 24/7. (Maple Lane, Interview)*

In the above quotation, RCA2 is referring to the difficulties surrounding Edith's eating and her lack of appetite for most meals at SFAC. Edith tends to find food much too salty, but because food is prepared in the main kitchen, staff have little control over its flavouring. Edith's son, who is especially involved in her care, is adamant that his mother would not have so many issues with the food, but the RCA2 reinforces that she is familiar with Edith's preferences, and that they have changed.

Showing respect in the delivery of care during mealtimes was assisted through the physical design of the cottages:

*If it's already prepared by the kitchen, there's no more choice. They have to eat it. Like [resident], "I like boiled egg today. Can you make boiled egg?" At least I can be able to, okay, I'll boil the eggs then. If it's already prepared by the kitchen, it's already cooked. At least there's choice here... you're doing exactly what they asked for. (RCA2, Willow Way, Interview)*

Although the majority of meals were prepared in the main kitchen, having access to a small kitchen within each of the cottages allowed staff the flexibility to make breakfasts as personalized as possible and respect residents' choices.

**Disrespect** is acting or speaking in a rude or impolite way to residents, and overlooking their feelings and individual preferences (Hung & Chaudhury, 2011). As meals were an opportunity for social interaction, in addition to eating, disrespect was observed through actions and conversations. Interactions that were observed as disrespectful were situations where residents were undermined as persons, and treated as nuisances or somehow seen as ridiculous. The following is an example where Beverly, who lives in Willow Way, is having trouble staying awake and alert during breakfast. RCA5 is assisting her with eating, and then ends the meal prematurely:

*RCA5 is sitting next to Beverly helping her eat her breakfast. She is spooning porridge into her mouth, but Beverly continues to fall asleep during the meal.*

*RCA5: Beverly! Hello? [RCA5 grabs Beverly's glasses and gives them a shake on her face. She then reaches up and squeezes Beverly's cheeks. Beverly doesn't respond. RCA5 shakes her left shoulder, but she still does not open her eyes. RCA5 looks irritated.]*

*RCA5: Okay, Beverly, we are going to have to do lunch I think.*

*RCA5 picks up the bowl of oatmeal and places it in the sink. She then comes back over to Beverly, takes her hands, and walks her to her room without saying another word. (Willow Way, Breakfast, Day 3)*

In this example, the RCA disregards Beverly's disinterest or inability to eat breakfast at that time. Instead, the RCA spends considerable time trying to force Beverly to eat her meal at that particular time. Furthermore, instead of prompting with words, RCA5 tries to wake Beverly by poking and shaking her intrusively. The meal ends with Beverly being escorted to her room with no indication from the RCA where she is being led and why.

Other staff who worked at SFAC showed disrespect for residents. In the following quotation there were disrespectful exchanges amongst cleaning staff and care staff where the resident could overhear staff mocking or teasing them in a malicious way during mealtime:

*One of the cleaning staff has entered into the cottage after lunch. Doris, who had left a few minutes ago for her room, has now come back into the dining area with her adult underwear on the outside of her pants. Cleaning staff: [RCA1], look at what she's wearing! [Begins laughing] RCA1: Doris, what are you wearing? Is that a new style? [Says laughing]. Doris is first confused about what the staff are referring to, then realizes what she has done and becomes embarrassed. She continues to walk past them out into the garden (Maple Lane, Lunch, Day 2)*

This was a difficult exchange to observe, as staff not only mocked Doris' effort to change her undergarments on her own, they also offered no help to remedy the situation. Doris clearly felt embarrassed and ridiculed by staff, and so retreated to the garden. Here, staff treated Doris as someone who no longer had any feelings or self-awareness.

Disrespect also took the form of referring to residents by their functional eating abilities. Instead of addressing residents by their first names, some staff were observed alluding to residents based on how much assistance they need at mealtimes, "Beverly is a full feed". Other times staff referred to type of texture a resident required if they had swallowing difficulties, "Peggy is blended". Similarly to when staff called residents "mama" and "papa", identifying residents by their biomedical functioning undermines their individual identities by placing the emphasis on their physical and cognitive inabilities.

## **Connecting-Distancing**

**Connecting** can be understood as working to build a trusting relationship between the staff member and the resident. Establishing this connection can be done through verbal and/or non-verbal means, "I think there's something about, like, a gentle touch on the shoulder. It's welcoming, you know" (LPN1, Willow Way, Interview). Staff would be observed during meals, in particular those who were assisting residents with eating, to continually use encouraging, warm words, and using touch as a way of showing their support and connecting in that moment with the resident. Making that link during meals was not an easy feat, and required effort from both parties, as much of the resident's energy was focused on the task of eating:

*RCA1 is helping Daniel eat his macaroni. As she places each spoonful in his mouth, she gently holds one of his hands with her left hand.  
RCA1: Your eyes are open – great, Daniel!  
Words of encouragement are needed, as Daniel has been having a difficult time keeping his eyes open during this meal. (Willow Way, Dinner, Day 9)*

Establishing this connection is also a reciprocal process; acknowledging that residents also make an effort to be close with staff members is an important aspect of

this category. Staff described efforts made by residents in order to establish a sense of togetherness with them:

*SW: How do residents respond to you when you can give them that one-on-one special time?*

*RCA1: Well, the ones that can talk, they're telling you stories or they're talking about one of their children or they're talking about themselves... They're happy. You know, that happy feeling. (Willow Way, Interview)*

For those residents who are non-verbal, staff have learned how to engage with them on different levels in order to establish that connection. Evelyn is a resident who does not speak, however, will sing along with songs if someone prompts her. The following is an example of the first time I sang with her during a meal:

*RCA2: Do you want to hear her voice?*

*SW: Sure! [I'm slightly confused by this, as I've been told that Evelyn does not speak.]*

*RCA2 heads over to Evelyn's chair, squats down in front of her and begins to sing 'Happy Birthday'. Evelyn immediately chimes in and the two of them start the song off. By the middle of the song there are four other residents singing along. I tell Evelyn how wonderful it was to hear her sing. I ask RCA2 what other songs she enjoys singing.*

*RCA2: You could sing 'You Are My Sunshine'.*

*Evelyn and I sing that song, and Doris joins in. After that I try a classic jazz song, but I realize she's not familiar with it when she looks at me confused. I then try 'O' Canada'. Evelyn immediately starts singing. She leans forward in her chair, rests her elbows on her knees and intertwines her fingers and she continues. She begins weeping on the second verse.*

*RCA2 notices my surprised reaction and explains the situation -*

*RCA2: She recently lost her husband. He lived here; he was in Rose's room. She remembers him and gets upset sometimes.*

*I change songs and begin with 'Happy Birthday' again. Evelyn stops crying and sings along with me – her eyes are fixated on my mouth, like she is reading my lips. This seems to stop her from crying. For the rest of the meal, I can hear Evelyn singing or whistling 'O' Canada'. (Maple Lane, Dinner, Day 8)*

In this example, RCA2 has found a meaningful and specific way of connecting with Evelyn who, based on observations, has a difficult time interacting with others. She is often observed either walking around the perimeter of the cottage alone, or in her room. However, when she has the opportunity to sing along with others, a true connection is made. In this scene, other residents join in the singing, and for those few seconds

Evelyn made a connection with the rest of the dining room. Her distress was alleviated by this experience, and it carried through for the remainder of her meal.

Several environmental factors contribute to these important connections being made between staff and residents during meals. Because of the smaller number of residents in each cottage (i.e., 12 residents per cottage), and because the dining spaces were designed to feel homelike and intimate (i.e., less noise and distraction, smaller groups of residents sitting together, enough room at the tables for staff to be seated next to residents), staff and residents are given opportunities to have moments where connections are made, and relationships are made stronger.

**Distancing** is understood as creating an emotional, as well as physical, distance from residents. Staff were observed distancing themselves when they did not or could not deal with the distress of a resident. During meals, distancing was observed taking the form of ignoring personalized requests that staff felt they could not fulfill. Often times it was part-time staff who had the most difficulty relating to residents requests:

*Edith is seated at her usual spot at the end of the double non-assist table.*

*Edith: The police are coming! [Her eyes widen and she looks upset]*

*Sometimes Edith hallucinates during meals, most often about her house being broken in to, or about her son.*

*Part-time Staff: Yeah, yeah, the police are coming. Are you sure?*

*The staff member says this as she walks off into the kitchen. She does not appear to be concerned that Edith is agitated and upset. She continues with meal preparation.*

*Edith: The police are coming!*

*Edith stands up in her chair and grabs her walker, but isn't sure where she should go. She eventually decides to head back to her room. (Maple Lane, Breakfast, Day 18)*

The quotation above indicates a serious form of distancing by staff who made no effort to acknowledge or relate to Edith's reality. Not only did this staff member treat her hallucination as ridiculous, she then walked away into the kitchen area behind a counter. Edith, who felt unsupported by that staff member, retreated to be alone in her room.

Staff also distanced themselves from residents when providing assistance with eating. Regular staff often sat next to residents at the dinner table, that way they would all be at eye-level and it was easier to make and facilitate conversations, but also from a

safety perspective – being able to see whether a resident has swallowed their food or is choking can be seen when at eye-level. Standing over residents when assisting was only observed among those staff who were part-time or casual:

*The LPN is standing over Beverly while helping her eat dinner. She has just placed a spoonful of minced hamburger in to Beverly's mouth.  
LPN: Beverly, do you want another bite? Are you still chewing?  
She grabs Beverly's cheeks and squeezes to check whether there is still food in her mouth.  
LPN: You're hiding the food in your cheeks. Swallow the food.  
She brings her face three inches away from Beverly's to look inside her mouth.  
The LPN then turns her attention to Daniel.  
LPN: Daniel, here's some juice.  
She brings the cup with straw to his mouth and he begins to drink. The LPN is assisting four residents with eating their dinner. (Willow Way, Dinner, Day 16)*

In this example, the LPN fails to recognize the importance of her being connected with residents during mealtimes. This scenario is often described as “assembly-line feeding” within long-term care. It places the emphasis of the meal solely on the amount of food consumed, and neglects to address the emotional and social importance meals serve for residents, in particular those who require assistance. Here, the part-time staff member distanced herself emotionally from the residents at the table, as well as disrespected Beverly's personal space by treating her like an object with a purely physiological need.

The physical environment, in particular the gated kitchen area in Maple Way, contributed to staff physically distancing themselves from residents. The kitchen area was used when staff did not want to engage with residents who were displaying distress. Whether conscious of this act or not, staff used the gates as a form of keeping residents at distance.

*Doris is the first to see me enter the cottage this morning. She is still in her pyjamas, her glasses hanging from her neck, her hair is large and puffy. Doris' cheeks are red and she seems anxious.  
SW: Morning Doris! How are you doing?  
Doris: I'm doing badly! I can't find my marmite. I'd like to speak with someone who is an expert in marmite. I've tried to explain to these people, but they won't listen. They don't understand - they don't know what to do with it!  
Doris appears exasperated at this point. Doris has relayed her fondness*

*of marmite to me in the past, so I know this is upsetting for her. I explain how sorry I am to hear this, and that I will speak to the staff. I see LPN1 walking by and she overhears Doris talking about her marmite with me. I see her roll her eyes and sigh. She walks into the kitchen and closes the gate. In an effort to calm Doris down, I suggest she take a walk in the garden. She likes the idea and so we walk together to the entrance of the garden. (Maple Lane, Breakfast, Day 12)*

In the scene described, LPN1 distanced herself from Doris' distress and issue by walking away from the discussion. Furthermore, she rolled her eyes and went behind a gate, as to indicate to the both of us that she did not believe Doris' issue to be important at that time. She told me later that she had already had discussions with Doris about her missing marmite, and that she had searched but could not find it. Her concern on the matter was more about safety and health hazards, rather than trying to comfort Doris, who was extremely attached to having marmite with her meals.

## **Empowerment-Disempowerment**

**Empowerment** can be understood as the acknowledgement of the potential control staff have over residents, while at the same time working to support residents' abilities and skills (Kitwood 1997). Staff were highly conscious of the potential power and control they had in their role at SFAC, and expressed a sense of responsibility for maintaining residents' well-being and providing support when they could. During mealtimes, empowerment took the form of sustaining residents' eating abilities. Residents wanted to continue with their routines and rituals as much as possible. This varied based on each resident's physical and cognitive functioning. Some residents struggled to move food onto forks, while others had difficulties taking bites of sandwiches. Regardless of their capacities, staff were patient and accommodating while supporting residents during their meals. The following situation demonstrates the desire of residents to continue being involved with meals as much as possible:

*Doris has returned from her walk and is now standing at the entrance to the kitchen.*

*Doris: What are you doing?*

*SW: Peeling eggs.*

*Doris: Oh! I want to do my own.*

*LPN3: Okay, you can peel your own. I'll get one for you.*

*Doris heads over to her usual spot to sit down. LPN3 places an egg and*

*an empty bowl at her setting. Doris immediately begins picking away at the hardboiled egg. (Maple Lane, Breakfast, Day 12)*

In this example, Doris expresses an interest in preparing her own breakfast. Though breakfast is the most rushed meal of the day because the cottage staff prepare it with little assistance from the kitchen staff, the LPN knew that Doris takes pleasure in the ritual of mealtimes. Though it would take Doris considerably longer to peel her egg, the LPN knew how much Doris would enjoy the task.

For residents who ate more independently, empowerment included providing “different cutleries or different dishes that makes it easier to load up the food” (IT Member), or it may be words of encouragement or verbal prompts to cue residents to finish their meals, “Good job, Florence. You’re doing very well!” (RT, Maple Lane, Dinner, Day 11). Residents who required more assistance were empowered by positive words and prompts to eat as independently as possible, and also included serving foods that were easily consumed without the use of cutlery. The following is an example staff serving food to empower a resident’s abilities:

*RCA1 carefully places a piece of toast into Daniel’s hands. She’s encouraging him to hold the bread and feed himself. Daniel holds the toast in his hands for a moment, feeling the texture between his fingers before he moves it slowly towards his mouth and takes a small bite. RCA1 turns to me – RCA1: We sort of ruin their abilities by feeding them. When I can, I try to encourage him to feed himself. It depends on the food though – a piece of toast... or some cakes. (Willow Way, Breakfast, Day 7)*

The scene above is an excellent example of how a staff member empowers Daniel to eat on his own. Daniel is always seated at the full assist table, and depending on the day and on the type of food served, may be fed by a staff member. Yet RCA1 recognizes the importance of encouraging Daniel to continue to use his physical abilities. RCA1 refers to situations where residents’ functions are “ruined” by performing tasks on their behalf, either due to limited staff and/or time restraints. Having enough time to empower residents was a reoccurring category throughout my observations.

The above quotation also exemplifies how the physical environment – including the food itself, can empower residents in continuing on with their abilities. In Willow Way,

the division of residents who required full assistance and those who could eat independently was a way to encourage those who could eat independently to maintain their abilities, and also provide those who required assistance, with tools and the necessary support opportunities to maintain the physical functions associated with mealtimes.

**Disempowerment** can be defined as situations where staff fail to acknowledge their potential control over residents whereby residents' abilities are not realized and not utilized (Kitwood, 1997). Disempowerment also includes the failure to support residents in completing an action or task they have already initiated (Kitwood, 1997). During meals, disempowerment meant either providing too few prompts to residents, or too much assistance that residents become frustrated and embarrassed. The following is an example of a staff member not only disempowering a residents' ability to feed himself, albeit slowly, but also outpacing the resident by not giving him the time he needed to eat independently:

*Gilbert is breathing hard. He's holding the sandwich in front of his open mouth, but he doesn't take a bite. Then he grimaces again.  
RCA4: Gilbert, give me this one, dear. I'll put it away for you.  
The RCA4 takes the sandwich out of his hand and throws it away. She did not prompt him to finish it, and does not offer him any other food alternative. Gilbert's hands are still outstretched, as if the sandwich is still in his hands. (Willow Way, Lunch, Day 13)*

Situations also arose where staff would try to perform tasks that residents were able to do, however, did not want to engage in. The following situation finds Ruby quite upset during dinnertime. She has been weeping in her room, but has decided to come out and join the rest of the cottage. She sits herself down at the small table in the assist dining room side. This is not her usual spot – she is usually in the non-assist dining room, however, this table is directly across from her room:

*Ruby slowly walks out of her room and sits at the small table across from another female resident. The RCA4 puts a plate of food down in front of her: a beef burger cut in half and a small scoop of carrot salad.  
Ruby: I'm not hungry.  
RCA4: You have to eat, mama.  
Ruby: I don't want it.  
The RCA walks away from the table, and returns a few minutes later to*

*Ruby who has pushed the food around on her plate with her fork.  
RCA4: Here, let me help you.  
The RCA takes Ruby's fork and stabs the coleslaw. She brings it to  
Ruby's mouth.  
Ruby: I said I don't want any.  
Ruby's tone of voice is stern. She looks very frustrated and offended. The  
RCA walks away. (Willow Way, Dinner, Day 16)*

A number of issues arise in this scene. First, the staff failed to acknowledge the fact that Ruby was clearly upset – something that happens regularly just before and after mealtimes – a form of distancing from residents. Second, Ruby clearly states that she does not want to eat at this time, and understandably becomes upset when her wishes are disregarded, a type of disrespect. Lastly, Ruby - who is able to eat completely independently, is then disempowered when a staff member begins feeding her. This staff member, though permanent, is part-time and so refers to residents not by their first name, but by “mama” and “papa”. Because she does not know the residents as well as other staff members, she assumed that Ruby required assistance with eating because she seated herself in that particular dining area.

Disempowerment was also observed in the form of discouraging mealtime participation and restricting residents to certain parts of the dining area. There were several instances where certain residents in both cottages would try and assist with mealtime clean up, but then were told their help was not wanted by staff and asked to stop. This had become the mentality of Willow Way, so much so that other residents would begin scolding them as well. This form of participation from residents was seen as a nuisance by staff instead of as an opportunity to empower and support residents' capabilities to help. Unfortunately because informed consent was not gained from these residents' principal decision-makers, their experiences could not be further accounted for.

The physical design of the cottages was also used by staff to disempower residents. Residents were not only discouraged from participating from certain mealtime activities, but also were limited in the amount of time they could spend in the kitchen area. In Maple Lane, two double-locking gates closed off the kitchen to the dining area. During meals, these gates would be left open, as it was easier for staff to quickly move around and complete tasks. However, towards the end of the meal and during clean up,

the kitchen gates were shut. The following is an example of a resident wanting to enter the kitchen, but not being able to:

*Harold is seated in the living room, then gets up and heads over to the kitchen. The gates have been locked, as the staff are in the pantry getting medication sorted. Harold is trying to get into the kitchen. He forces the door with his body weight, then he tries to undo the latch but doesn't realize there is a second latch at the bottom of the gate. He gives up and stands by the gate. Then he grabs a dining room chair and pushes it over to the gate. I'm afraid he's going to stand on it and try to climb over. He stands there for a few minutes, as if he doesn't remember why he brought the chair over. He inches the chair closer to the gate. Florence then walks over to him to see what he is doing. Harold gently places his hand on her shoulder. He forgets that he wanted to go into the kitchen. The LPN comes out from the back room and sees him standing by the gate. She asks if he needs to use the washroom as she takes his hand and leads him away from the kitchen and towards his bedroom. (Maple Lane, Lunch, Day 4)*

When asked about reasons for why residents are restricted from the kitchen, staff expressed concerns over the issue of safety and hygiene:

*LPN1: The kitchen is for the residents and the family. The kitchen is not something like just for us. It's actually – so they're allowed to go there. But now that there -- like [resident], she used to be so good that she used to wash her hand. She used to help out in the kitchen like they'd let her in there. She used to wash the dishes. But now that hygiene is pretty – hygiene is a problem with our cottage. (Maple Lane, Interview)*

The above excerpt demonstrates how staff used the physical environment as a way to monitor resident activities, while at the same time disempowered them by preventing them from performing certain mealtime rituals. In this case, staff were concerned about the cleanliness of particular resident's hands in the kitchen. Instead of addressing the issue of hygiene, staff lock residents out of the kitchen – a space that is supposedly available to them.

## **Inclusion-Ignoring**

**Inclusion** is encouraging and supporting a social environment that actively includes residents in social exchanges and activities. This category is particularly pertinent to mealtimes, as they are the most socially intensive environments for

residents during the day. Apart from eating, staff were aware of the critical roles mealtimes served for residents, particularly those who spend the majority of their day alone as a result of the progression of their dementia and their ability to communicate with others. One LPN describes the opportunity for socializing in Willow Way:

*LPN2: It's like Loretta can talk. So she can engage with Ruby, Clifford and Bill. And at this time Beverly can't. So for Beverly, it's meaningful 'cause she doesn't... during the day when she's left alone and walks around, she don't have any communication with any of them. Nobody like... speaks to her. As this time it's kind of like she gets to enjoy having the company of another person. (Interview)*

As Beverly is a resident who requires full assistance while eating, LPN2 is cognisant of the fact that his role during meals is not only ensuring that she has enough to eat, but that it also includes facilitating genuine and meaningful exchanges with him and the other residents at the table.

*LPN2 is sitting at the table next to Gilbert and Beverly. He always remembers to prompt residents before giving them food.*

*LPN2: Chew and swallow, Gilbert.*

*LPN2 begins joking around about shaving his face and includes Gilbert in the conversation.*

*LPN2: Right, Gilbert?*

*Gilbert: That's nice [smile].*

*Beverly then lets out a big laugh. LPN2 goes to spoon some more macaroni into Beverly's mouth, but first takes his finger and carefully moves some hair that has fallen across her face.*

*LPN2: Here you go, Beverly. [She opens her mouth and takes a big bite.*

*Beverly then begins rubbing her hands together as she chews.]*

*RCA2 is seated between Daniel and Norm. I listen to her talk to them – she asks them questions about how they are enjoying their food, or if they want another bite. She sometimes asks them rhetorical questions or tells them a joke as she waits for them to finish between spoonfuls. (Willow Way, Dinner, Day 9)*

Moreover, those who required assistance with eating were also residents who had the most challenges communicating with other residents. In Willow Way, the division of the two dining rooms created smaller, more intimate spaces that gave a handful of residents the quieter social environment they needed to make those connections.

*Beverly walks around the cottage, then sits herself down at the table across from Gilbert. She stands back up again and stretches her hands*

*out and places them on the table in front of her. Gilbert sees her reaching towards him, looks up at her and gives her a big smile. She smiles back at him, and then makes her way out from between the chair and table and begins walking the perimeter of the cottage again. (Willow Way, Breakfast, Day 10)*

Seating residents together who struggle to verbally communicate in a quiet and intimate dining space allowed for a meaningful exchange such as this. As there is no physical divide between residents who require assistance and those who can eat independently in Maple Lane, it was more challenging for residents in this cottage to make those subtle connections more frequently due to additional stimulation and distractions.

Inclusion also had much to do with which residents were seated together. Staff were aware of the social dynamics between residents, in addition to functional and cognitive abilities during meals, "...compatibility... they know who is clicking with who and who is not, and put them at the same table" (IT2, Interview). One RCA describes her decision to place a new resident with certain people on the non-assist side of Willow Way:

*I mean for the longest time, he wouldn't come out of his room. It's just simple little things, like today – I don't know why I never offered him this before: so I've been sitting him and Ruby together. Just putting people together that converse, right? So lately, [resident] and Ruby have been together at the table. The two of them, they're there for an hour. We'll take their dishes away and they'll still be sitting there laughing and chatting... Yeah the most enjoyable thing for them, you know, is having somebody they can sit across from and visit with. (RCA3, Willow Way, Interview)*

This quotation indicates that staff are aware that social dynamics are complex, and that seating certain residents together can have a profound effect on the enjoyment of a meal. Furthermore, it also indicates the importance of new residents feeling included in the cottage, and forming important relationships with fellow residents.

The concept of **ignoring** can be understood as social situations that actively disregard the presence or feelings of residents. It includes situations where staff fail to recognize or inhibit opportunities for meaningful interactions with residents and among residents. Instances of ignoring during mealtimes were observed as staff sitting beside

residents while assisting them with eating, but would proceed to have conversations amongst themselves that residents would not be able to take part in:

*The RT, LPN1 and RCA2 are all sitting at the assist table helping residents with their meals. They are talking about expenses associated with hosting children's birthday parties. They laugh, their voices getting louder as they talk with excitement. The residents are not invited into this conversation at any point. The only time staff give residents attention during this time is a quick verbal prompt or offering a sip of a drink. No other residents are speaking in Maple Lane, just the staff. Doris grows tired of listening to their conversation and brings her attention to a bowl of canned mandarin oranges.*

*Doris: I wish we had real oranges [she says to herself]. (Maple Lane, Dinner, Day 11)*

In this mealtime observation, staff were observed ignoring the social importance of mealtimes for residents, while being more concerned about carrying on conversations amongst themselves. Because the design of Maple Lane's dining area encloses all residents into the same space, the staff's conversation took over the entire room, and discouraged residents from talking amongst themselves. Another form of distancing is creating socially awkward situations for residents among their cottage peers.

*LPN1 is speaking to RCA2 in the dining room about Florence's bowel movement. They speak loudly in front of a group of residents.*

*LPN1: You know when you poop, you usually pee? Well this lady doesn't [referring to Florence].*

*LPN1 then redirects the conversation to Edith, referring to her hallucinations as "talking to the air". She begins laughing at Edith and imitating her.*

*LPN1: "Peter, you're a bad person..." [laughing]. (Maple Lane, Breakfast, Day 12)*

This private and disrespectful conversation between two staff members was held in front of several residents who were already seated for breakfast. While neither Florence nor Edith reacted to this discussion, other residents listened and watched the staff mock these two women. Their actions distanced not only themselves from the two residents, but distanced Florence and Edith from their peers.

Some staff were aware of the influence they have on the social environment of the cottage. Here a staff member reflects on her impact of ignoring residents during meals:

*RCA2: Sometimes we talk, you know. We always talk regarding ourselves. I think we have to stop that but then sometimes if we let our emotions get away, like, we talk something else while we're feeding. I think we have to concentrate to what we are doing towards the residents. Sometimes we talk about our personal life... You have to concentrate to talk to them, but not to talk about your personal life to your partner or to the other care aide or other people too. (Maple Lane, Interview)*

RCA2 acknowledges that it is easier to speak to fellow staff about personal matters rather than to have to concentrate on including residents in mealtime conversations. Staff have the self-awareness to know when they are ignoring and distancing residents from key opportunities in the day to engage in meaningful interactions.

## **Factors Affecting Person-Centered Care**

Person-centered care is not a complex philosophy of dementia care delivery to understand, however, depending on the context of a care environment, the interpretation and delivery of this care can vary. Staff at SFAC are in a unique situation where the organizational culture, as well as the built environment, have been developed to support a person-centered approach. From observations and interviews, several factors have been identified that enable staff to provide good dementia care. As well, staff recognize that there are areas that can make it challenging for them to deliver what they know to be good dementia care.

### *Supporting Factors*

Several staff members who worked at SFAC were experienced care providers, and had worked for many years in numerous long-term care facilities. Having previous experience provided staff with perspective on the nature and realities of caring for older adults within facilities in British Columbia. This background helped staff identify and appreciate SFAC and the type of care it advocates for its residents. From observing staff within this unique context, and based on interviews, four facilitating factors of person-centered care were identified:

1. **Supportive management** was the most identified facilitator of person-centered care for staff. Staff described management as being strong in their understanding and promotion of the facility's care philosophy. Staff

felt that management was especially “hands on”, that they spent enough time within cottages to be aware of both the residents’ and care staff needs.

*...the management is so in tuned with what’s going on in the cottages and the staffs’ needs as well as the residents’ needs. (IT2, Interview)*

*I think they’re supportive by being hands-on themselves. They’re not just there sitting at the office and delegating the duty to someone else... Like to actually come there and try to understand themselves. (LPN1, Interview)*

Because management was involved in every-day care, positive and critical feedback was given to staff in order to improve their care delivery. For example, one LPN recalled the manager explaining why it is so important that staff be seated next to the resident at the table when assisting with eating. Moreover, staff felt comfortable approaching management when issues would arise, and asking for help. They felt that when possible, they received the assistance they required to perform their jobs.

2. **Teamwork** was identified as an essential aspect of being able to deliver person-centered care. Staff identified management and the interdisciplinary team (i.e., physiotherapist, dietician, etc.) as being team players. The mentality that “everyone acts like an equal” allowed for this interdependence and respect among co-workers.

*The LPN2 tells me how important it is that coworkers get along to get the job done. He speaks highly of [RCA1], and says they have “honest communication”. He says that they tell each other straight up what works and what doesn’t - they work it out amongst themselves. (Lunch, Day 1, Willow Way)*

Staff found that interdependence on one another was strongest when both staff on shift were full-time, as they would be more familiar with resident preferences and routines. Residents benefited from staff teamwork as they would receive care and engagement they found meaningful.

*Oh, it makes big difference. I mean a very big difference ‘cause if you’re working with somebody who doesn’t know the residents very well, it’s hard for them to take things up and keep them calm. And that’s very important. Yeah, very important. (LPN2, Interview)*

3. **Strong organizational culture** in order to maintain a certain type of dementia care was identified by staff. The person-centered care approach, in addition to a higher level of care provision needed for residents is made clear to all staff joining the team.

*I think they make here a really good effort to get through the people, where they'll be working and they make sure that they really understand the type of clients that they will be caring for in order to weed out those people who aren't appropriate. (RCA3, Interview)*

Those staff who are not prepared to deliver that type of care “don't last long”. SFAC is seen by staff as “something unique”, where the organizational culture makes an effort to deliver a type of care that is not well supported within a greater biomedical system.

4. **Staff characteristics** – including work history and individual personalities, were seen as an influencing factor in staff's ability to deliver person-centered care. Staff with previous work experience in facilities that were more task-oriented would not be applicable at SFAC's care setting.

*I have to say those and SFAC it does – it's a certain breed of caregivers that are attracted there and stayed there, because not everybody can do it. They just -- not everybody can do it. And you see people kind of come through there and they're gone, right, and other people that stay there, they really enjoyed these, the interactions of people. And it's a beautiful thing. It really is. (IT2, Interview)*

A staff's personality, specifically their ability to relate to residents (i.e., empathy, patience), as well as other staff members (i.e., interdependence) was identified by staff as a determining factor as to “how well the shift goes”. Those who had challenges adopting those values, ones you “can't learn in school” often did “not last long”.

### *Inhibiting Factors*

Staff recognized that while they were unique in their position at SFAC to be able to deliver person-centered care, there were several factors that inhibited their ability to provide this care steadily during mealtimes. Three influencing factors were identified as inhibiting staff's ability provide consistent good dementia care:

1. **Not enough staff** to assist with mealtimes was staff's biggest concern. Almost every staff mentioned that there were “not enough hands” available to help serve, assist with eating, and clean up. Usually the LPN and RCA would serve meals, however, there were occasions when a third person (most often a recreational therapist) would come to help for a few minutes. Third person assistance was usually in the form of aiding those residents who required help with eating.

*...it's not always fun and games... it is a lot of work and very demanding. Sometimes I feel overworked even though physically I*

*haven't been, but mentally I'm kind of drained trying to convince someone to put their clothes on... just trying to convince someone to sit on the toilet, right? It's a simple task that takes a long time. So that's what really you have to deal with in here. If you truly wanna have person-centered care, you have to invest in more employees as we're killing ourselves with two people trying to do everything while having that ideal model for person-centered care. (LPN2, Interview)*

Staff felt that they had too many tasks to perform during mealtimes that it took away from opportunities to assist and monitor residents, but more so to be able to deliver person-centered care.

2. **Health authority policies and procedures** were identified as factors that impeded the facility at large from delivering person-centered care. The standardization of care within long-term care facilities within the health authority to an extent “hand-cuffed” the facility’s ability to deliver personalized care during meals. For example, individual preferences and culturally appropriate food could not be prepared unless it was approved by the health authority. Further, staff felt there was an imbalance between health code restrictions, (i.e., wearing a hair net in the kitchen at all times) versus treating the cottage as it was intended to be lived in – like a home.

*No, it's not very practical. But you could leave the hairnet on if you want. But it doesn't feel homely. They want us to become a home environment, right. They want it as homely as possible, but if you have a hairnet and then you're in uniform all the time... It doesn't really feel like home for them. (LPN1, Interview)*

Staff also identified the health authority as responsible for restricting the number of staff scheduled per shift. Staff were adamant that having a third person during meals to assist would result in a more pleasant mealtime experience.

3. **A lack of ongoing staff education** was identified as a factor that limited not only staff’s ability to provide the best dementia care, but also as a missed opportunity to engage with colleagues and connect with management. Staff expressed keen interest in SFAC organizing in-services, workshops, and team meetings.

*I would tend to think it's like funding or maybe they don't have the funding for education. I don't know. [SFAC] has never been a place to push education. When I've worked at other places, they'd have the clinical educator and they are always constantly encouraging you to take workshops or I don't know, just a like a day -- course on something where at [SFAC], we don't have that. (LPN3, Interview)*

Staff education regarding mealtimes within SFAC has been facilitated by the occupational therapist. A recent presentation covered functions of swallowing, eating assistance techniques, and environmental aspects of dining. While some staff were present for this educational session, others were unaware of the opportunity.

## **Chapter 5.**

### **Discussion**

The experience of mealtimes for residents at SFAC encompassed interactions with care staff and residents, nutritious food, assistance with eating, all while seated in a homelike dining environment. While a person-centered care practice was observed, variations in the consistency and interpretation of this care approach among staff, as well as between the two cottages, was also evident. Furthermore, environmental design differences between the dining spaces of the cottages were found to play a critical influencing role in residents' mealtime experiences. This final chapter presents a discussion on expanding our understanding of the importance of the psychosocial context and physical environment of residents with dementia during meals. Findings also point to the need to explore our understanding of how personhood and person-centered care are conceptualized within the current dementia care discourse and how these materialize within care facilities. Study limitations are discussed, and implications for future research are proposed.

### **Negotiating Person-Centered Care**

The role of food, the act of eating, and communion at the dinner table have been well documented in the literature as opportunities to reinforce identity and key social relations throughout the life course (Devine, 2005; Evans et al., 2005). Findings in this study reflect this perspective, where the impetus to carry on with daily food rituals - regardless of physiological or cognitive decline - was observed among every resident through their relationships with particular foods (i.e., Doris' beloved Marmite, Gilbert's affinity for sweets), eating habits (i.e., Eddy's TV-dinners), and social interaction with fellow residents and staff. Efforts to improve the experience of dining through social interactions and the physical environment were made by SFAC, where the adoption of

the Eden Alternative and person-centered care philosophies attempted to promote autonomy, self-determination, and emotional well-being among residents (Brownie, 2011).

Person-centered care has become synonymous with good dementia care, and has been widely adopted by many institutions predominantly within the long-term care sector. Kitwood's theory on personhood has worked to remove "socially debilitating obstacles", thereby improving the "sense of present wholeness that might otherwise have eluded someone with dementia" (Davis, 2004, p.377). In many ways, the focus on the dining experience of residents in SFAC offered the ideal setting to examine these critical interactions between residents and staff, as one's relationship to food and the sharing of meals with others serve as a microcosm of overall social hierarchies and power dynamics (Counihan & Van Esterik, 1997). While the political nature of identity (de)construction within the social context is not explicitly addressed by Kitwood (further discussion in following subsection), the theory of personhood provides language to discuss the interpersonal relations and how one is perceived in their social context - essential aspects for understanding the holistic dementia experience (Bartlett & O'Connor, 2007).

The findings of this study suggest that there is a continual negotiation that occurs during mealtimes by residents and care staff. Evidence of both a "malignant social psychology" and "positive person work" were observed in SFAC through social interactions and the manipulation of the physical dining environment. It should be stated that "even the kind and well-intentioned" staff gave in to care that was task-oriented and disconnected, however, were never carried out with malice (Kitwood, 1997, p.14). Indeed, it is not only the nature of person-centered care during mealtimes that should be examined, but also the ongoing struggle for its definition and meaningful implementation that warrants further attention (Hung & Chaudhury, 2011).

### **Affirming Personhood through Person-Centered Care at Mealtimes**

The majority of care staff at SFAC had a clear understanding of the essence of person-centered care. As discussed in much of the literature examining the delivery of

this form of dementia care, “the meaning and uses of [person-centered care] on the ground-level remain nebulous, especially for nursing aides” (Doyle & Rubinstein, 2013, p.953). Although some staff members struggled to articulate a definition for their care philosophy, they could identify the most salient elements of meaningful care during meals, reflective of those practices proposed by Kitwood. Emphasis on knowing the resident (connecting), gaining trust (respect), patience and flexibility (relaxed pace), effective communication (inclusion), and understanding the neurological impairment (empowerment) contributed towards the person-centered environment staff assisted in creating within the cottages (Kitwood, 1997; Kitwood & Bredin, 1992a). From a staff’s perspective, affirmation of the benefits of providing person-centered care came in the form of satisfaction from watching residents enjoy their meals, develop and invest in genuine relationships with residents, and self-satisfaction in knowing they performed their job well (Barbosa, Sousa, Nolan & Figueiredo, 2014).

Examination of the physical environment’s role is also warranted to contextualize the residents’ experience during mealtimes. Consistent with the literature (Haroldlas & Lawrence, 2015; Hung et al., 2015; Chaudhury & Cooke, 2014; Lee, Chaudhury & Hung, 2014; Chaudhury et al., 2013), findings in this study suggest the physical environment assisted the care staff in the delivery of person-centered care by supporting the residents’ abilities to navigate their way in the dining environment. The dining area and kitchen were located as key focal points in the physical layout of Willow Way and Maple Lane cottages. The central location and the homelike quality of the dining spaces in these small scale units emphasized the important ritualistic functions of dining – easy access to dining areas, enjoyment of food, the importance of nutrition, and opportunities for social interaction. Dark wood furniture, ceramic dinnerware, contrasting colour schemes, and a full kitchen contributed to creating a familiar homelike atmosphere. Adequate natural lighting, glare-reducing surfaces, relaxing music, and intimate seating arrangements provided a calming and less distractive environment that allowed staff to attend to individual resident needs. The non-institutional milieu of the dining space was also noted as a cue to staff members that the cottages were, in fact, a home for these residents.

## **The “Balancing Act” of Person-Centered Care during Mealtimes**

Numerous instances of person-centered care practices were accounted for in SFAC’s two cottages. Care staff made genuine and concerted efforts to connect with the residents to make mealtimes a pleasant experience. Staff in these cottages identified the importance of providing residents with choice, with the understanding among some of them that “every effort must be made to involve them in decision-making processes” (Baldwin, 2008, p.224). Nevertheless, situations where residents’ personhood was undermined were observed throughout the duration of fieldwork. Evidence of what Kitwood assigned as a ‘malignant social psychology’ took the form during mealtimes as outpacing, disrespect, distancing, disempowering, and ignoring (Kitwood & Bredin, 1992a). For example, opportunities to socialize with residents who required eating assistance were often overlooked when staff were preoccupied with socializing amongst themselves. Residents’ reactions to such circumstances were to retreat into their bedrooms, to verbalize their displeasure or disagreement, push food away, leave the dinner table, ignore care staff’s requests and questions, or simply remain silent at the table.

Mealtime rituals were at times masked as “routine recurrences”, “skewed by the [care staff’s] need to establish an agenda based on physical tasks that their job requires” (Davis & Pope, 2010, p.37). Mealtime routines that were presented as ‘person-centered’ became dubious when “patterns of communication behaviours, assumptions, stereotypes”, and belief systems surfaced to reveal an undercurrent of oppressive biomedical mentality (Davis & Pope, 2010, p.37). A handful of care staff explained their understanding of the residents’ dementia progression as a deficit, what has been coined as “elderspeak” (infantilizing communication) (Williams, Herman, Gajewski & Wilson, 2008). Staff attributed residents’ behaviour patterns and tendencies that were viewed as “difficult” as a result of their “second childhood”, identifying the various stages as “teenager phase” or “infant stage” (Williams et al., 2008). Other instances during meals where the “discourse of efficiency” precluded any kind of social talk was when individual residents were differentiated by care staff based on their physical limitation: the term “feeders” was often used to describe residents who required assistance with eating, and

those residents who needed alterations to food texture were referred as either “pureed” or “minced” in place of their names (Davis & Pope, 2010).

Aspects of the physical environment played into these masked person-centered mealtime routines, where person-centeredness, became a superficial performance or “act”. The kitchen areas in both cottages remained off-limits to residents – both physically and psychologically. In Maple Lane, swinging gates were installed at each entrance to the kitchen, with bolt locks located at the top and bottom of the gates – out of reach of residents. When residents were seated for their meals, these gates would be open for staff to enter and exit the kitchen as they pleased. However, at all other points during the day, these gates remained shut. No physical barriers were installed in Willow Way’s kitchen to regulate users, however, instances where residents entered the kitchen to assist with clean up were responded to by staff as being an inconvenience to their own clean up routine. Staff rationalized, what can be considered an abuse of their power, as efforts to keep residents out of kitchens for reasons of “safety and security” in order to suffice food safety protocols around kitchen cleanliness. The kitchen’s function primarily served as pseudo-symbols of a person-centered care environment, providing the illusion of a home within the restrictions of an institution.

## **Linking the Personal and Political: Citizenship**

In understanding the residents’ experience at SFAC, it is critical to recognize the social environmental factors that influence mealtimes, one of which is the influence the person with dementia has on their interpersonal and social relationships. In a recent study by Abbot and colleagues (2015), the majority of interactions (68%) observed within an SCU occurred between residents and staff, however, one quarter of daily interactions were among residents themselves. Observations in SFAC cottages during mealtimes indicated a complex social system where residents were capable of navigating and influencing their social context in their own unique ways. This included communicating their needs, wants, and preferences to staff and other residents using verbal and non-verbal communication, depending on progression of their dementia. Acknowledgement of a resident’s agency over their mealtime was recognized by those staff who refrained from assuming a resident’s loss of abilities and personhood (Doyle & Rubinstein, 2013).

For instance, some staff made the presumption that Norm was unable to indicate his preference to eat more or less of his meal because he communicated mostly non-verbally, and so he was often overfed. Other examples of reciprocal interactions include residents offering each other food, assistance with eating, clearing the table, rinsing dishes, and telling jokes. Kitwood's (1997) definition of personhood – a status that is “bestowed upon one human being, by others” (p.8) – suggests that the person with dementia is “passively dependent upon others for affirmation” (Bartlett & O'Connor, 2007, p.110). Observing these residents' interpersonal interactions brings into question Kitwood's uni-directional understanding of personhood, one that fails to account for the dynamic and interactive nature of these residents with agency within their sociocultural context (Bartlett & O'Connor, 2010; Bartlett & O'Connor, 2007).

To capture the dementia experience, the person with dementia must be accurately situated within their social and political location in order to extend and develop the culture of dementia care (Bartlett & O'Connor, 2010; O'Connor, Phinney & Hulko, 2010). Since the conceptualization and development of personhood, and subsequently, person-centered care, a growing awareness of the under-theorization of dementia as a disability – a “disadvantage or restriction of activity” as a result of the “contemporary social organization” – has elicited the need to position persons with dementia within their social context in an effort to draw outstanding prejudices to the surface (Baldwin, 2008, p.223). One such movement advanced by authors such as Bartlett and O'Connor (2007) advocate for the application of ‘citizenship’ as a means promoting the status of this discriminated group as ones entitled to the same power as others – recognition as a person with agency. The citizenship model focuses on issues such as social inclusion, power dynamics, and citizenship as practice so as to identify contexts that ultimately lead to the social exclusion and dehumanization of persons with dementia (Baldwin, 2008; Bartlett & O'Connor, 2007). In order to move towards a model of citizenship, identifying the social context of the person with dementia would include accounting for interactions between their subjective experience, the interactional environment (i.e., relationships with residents and staff, and the physical dining space), and the sociocultural context (i.e., social location, organizational dining policies, societal discourse on cognitive functioning) (Bartlett & O'Connor, 2010). During mealtimes, the application of citizenship would encompass care practices, policies, and guidelines that

ensured the resident with dementia would “retain status as an active partner” (Bartlett & O’Connor, 2010, p.25); in other words, assuming a resident’s personhood but also highlighting their sets of “rights and responsibilities associated with that status” – or lack thereof, so that the resident may reposition themselves as an active and important member at the table (Bartlett & O’Connor, 2010, p. 38).

## **Limitations**

This research study had several limitations that should be acknowledged. Kitwood (1997) explained the dementia experience as the exchange between a person’s personality, physical health, life history, neurological impairment, and psychosocial environment. More recent literature has proposed additional dimensions be incorporated when attempting to understand the experience (Baldwin, 2008; Bartlett & O’Connor, 2007). In order to keep this study in a manageable scope, emphasis was placed on the delivery of person-centered care by care staff; I did not investigate other impacting factors, such as the life history of the individual residents, relationships with family and friends, gender differences between care staff, organizational climate, and health system factors that played significant roles in the delivery of person-centered care during mealtimes. Furthermore, drawing explicit linkages between these multi-level factors is a complex undertaking, and beyond the scope of this study. I acknowledge this as a study limitation, and propose that future research continues to explore the dynamic environment within which dementia care is provided.

The conceptual orientation of this study guiding data collection and data analysis involved application of sensitizing concepts based on Kitwood’s (1997) person-centered care philosophy. As such, it is possible that there were instances where I imposed exogenous meanings, potentially distorting “local meanings” and framing “events as what they are not” (Emerson et al., 2011, p.131). Although I made efforts to utilize the three safeguards as discussed previously, in addition to applying both deductive and inductive processes to my analysis, it is plausible that other aspects to this phenomena were overlooked.

## **Implications for Future Research**

Meals and the dining experience are unquestionably an integral component of reinforcing connections – for the individual and their relationship with food rituals, and for interpersonal relations amongst residents and staff. Continued exploration of mealtimes for residents with dementia living in care facilities will lead to improving what is confirmed in this study and many others, as a critically important aspect of maintaining personhood and quality of life. The following are suggestions future research.

### **Including Perspectives of Persons with Dementia**

Up until more recently, people with dementia have been perceived as incapable of expressing their subjective experiences because of issues around communication and progressive memory deficits (Nygård, 2006). Findings in this study add to the evidence verifying the significant role residents with dementia played in expressing their experience of mealtimes in an SCU and the nature of their interpersonal relationships. Understanding that communicative efforts other than verbal ones is critical to capturing the experience of these individuals, especially as they are at greatest risk of not being heard and marginalized in the process. While this study's focus was on the delivery of dementia care, more research is needed to include the "voices" and perspectives of persons with dementia. Institutional research ethics boards could consider examining current guidelines to make more informed suggestions to researchers, ones that protect vulnerable populations without indirectly preventing their participation. In addition, research methods most conducive to understanding the experience of persons with dementia, such as focused ethnographies, should be explored and utilized to address applicability and any prejudices that exist around research data collection processes. If we are to improve the lives of residents with dementia in a meaningful way, it is imperative that future developments in dementia care are informed by a richer and deeper understanding their lived experiences.

## **Addressing the Socio-Political Climate of Dementia Care**

There has been a notable and unrelenting movement since Kitwood first put forth his concept of personhood. Researchers and theorists engaged in this movement have worked to reposition the concept of personhood into the realm of political discourse (Doyle & Rubinstein, 2013; Bartlett & O'Connor, 2010; Behuniak, 2010; Davis & Pope, 2010;; Baldwin, 2008; Bartlett & O'Connor, 2007) that is, to contextualize the dementia experience through a multidimensional lens. In doing so, issues surrounding the delivery of dementia care extends beyond the individual to one that recognizes multi-level intersecting factors that contribute to, for example, the delivery of person-centered care during mealtimes in an SCU. Future research, especially studies implementing and examining dementia care interventions, can adopt a more comprehensive and conscious approach so that the larger Canadian socio-political climate can be actively accounted for when attempting to implement a person-centered care philosophy.

## **Translating Person-Centered Philosophy into Practice**

Defining and implementing person-centered care is difficult. Findings in this study point to mixed understandings of the care philosophy, and a lack of ongoing education on its practical, day-to-day application for residents with late-stage Alzheimer's disease. This confirms in many ways, that perhaps person-centered care cannot be precisely defined, as care that is truly person-centered is one that is reflective of that resident's own preferences, needs, wants, fears, in addition to the nature of their relationship with care staff. As such, it is important that those involved with adopting this care philosophy, be better equipped with pragmatic implementation processes that address the macro-level barriers and facilitators in socio-political system, in addition to care staff belief systems, physical environment, and organizational climate (Keller, Beck & Namasivayam, 2015; Vikström et al., 2015; Keller et al., 2014). In order to produce knowledge that is meaningful to users at the outset, collaborative activities between researchers and knowledge users – referred to as integrated knowledge translation (iKT) – has been identified as a plausible solution in order to address the “knowledge to action gap” (Bowen & Graham, 2013, p.17). For instance, to improve the mealtime experience for residents with dementia at SFAC, iKT emphasizes the reciprocity between

researchers and knowledge users (care staff, management, health authority representatives) to identify together the research questions, research methodology, data collection and analysis processes, and the interpretation and dissemination of findings (Kothari & Wathen, 2013; CIHR, 2012).

## **Conclusion**

Care staff attempted to balance the facility's philosophy on person-centered care against their own perceptions, their own capacities as care providers, the physical environment, and organizational resources and restrictions. The findings of this study indicated a genuinely caring environment, where residents' personhood was honoured through meaningful social interactions and a supportive dining environment. At the same time, tendencies that perpetuated stifling and oppressive environments were also observed. As with any institution, SFAC care staff "are not free to fulfill a moral obligation to the [resident] without considering organizational and professional implications" (McCormack, 2004, p.34). Ignoring the socio-political context within which dementia care is provided denies the implicative power dynamics between care staff (powerful) and resident (powerless) (Bartlett & O'Connor, 2007). The balancing "act" that ensues within each cottage necessitates a continuous negotiation between personhood, care staff abilities and resources, overarching policies, and social stigma's attached to cognitive decline (Ducak, Keller & Sweatman, 2015). Instances where stability cannot be achieved results in a "domino effect" between macro and micro, where the personhood of the resident is ultimately compromised (Koehn, Kozak & Drance, 2011). The reality of everyday challenges faced by care staff within facilities embedded in a biomedical system means that pursuing an ideal of person-centeredness may be futile. Instead, those concerned with creating person-centered care environments should strive for a "constant state of 'becoming more person-centered'" in practice (McCormack, 2004, p.37).

## References

- Abbot, K. M., Sefcik, J. S. & Van Haitsma, K. (2015). Measuring social integration among residents in a dementia special care unit versus traditional nursing home: A pilot study. *Dementia*. Advanced online publication. doi: 10.1177/1471301215594950
- Allard, J.P., Aghdassi, E., McArthur, M., McGeer, A., Simor, A., Abdoell, M... Liu, B. (2004). Nutrition risk factors for survival in the elderly living in Canadian long-term care facilities. *Journal of the American Geriatrics Society*, 52, 59-65.
- Amella, E. J. (1999). Factors influencing the proportion of food consumed by nursing home residents with dementia. *Journal of the American Geriatric Society*, 47, 879-885.
- Alzheimer Society of Canada. (2010). *Rising tide: The Impact of dementia on Canadian society*. Retrieved from [http://www.alzheimer.ca/~media/Files/national/Advocacy/ASC\\_Rising\\_Tide\\_Full\\_Report\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/Advocacy/ASC_Rising_Tide_Full_Report_e.pdf)
- Alzheimer Society. (2011). *Guidelines for Care: Person-centered care of people with dementia living in care homes*. Retrieved from [http://www.bccare.ca/wp-content/uploads/culture\\_change\\_framework\\_e.pdf](http://www.bccare.ca/wp-content/uploads/culture_change_framework_e.pdf)
- Aghdassi, E., McArther, M., Liu, B., McGeer, A., Simor, A., Allard, J.P. (2007). Dietary intake of elderly living in Toronto long-term care facilities: comparison to the dietary reference intake. *Rejuvenation Research*, 10(3), 301-309.
- Amaral, T.F., Matos, L.C., Teixeira, M.A., Tavares, M.M., Álvares, L., Antunes, A. (2010). Undernutrition and associated factors among hospitalized patients. *Clinical Nutrition*, 29, 580-585.
- Baldwin, C. (2008). Narrative(,) citizenship and dementia: The personal and the political. *Journal of Aging Studies*, 22(3), 222-228.
- Barbosa, A., Sousa, L., Nolan, M. & Figueiredo, D. (2014). Effects of Person-Centered Care Approaches to Dementia Care on Staff: A Systematic Review. *American Journal of Alzheimer's Disease & Other Dementias*. Advanced online publication: 10.1177/1533317513520213

- Bartlett, R. & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, 21(2), 107-118.
- Bartlett, R. & O'Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship*. Chicago, IL: University of Chicago Press.
- Batstone, E. (1983). The hierarchy of maintenance and the maintenance of hierarchy: Notes on food and industry. In Murcott A. (Ed.), *The sociology of food and eating* (pp.45-53). Aldershot, Hampshire: Gower.
- Beard, R. L. (2004). In their voices: Identity preservation and experiences of Alzheimer's disease. *Journal of Aging Studies*, 18(4), 415–428.
- Behuniak, S. M. (2010). Toward a political model of dementia: Power as compassionate care. *Journal of Aging Studies*, 24(4), 231-240.
- Berg, G. (2006). *The Importance of Food and Mealtimes in Dementia Care*. London, UK: Jessica Kingsley Publishers.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice Hall.
- Boström, A. M., Van Soest, D., Kolewaski, B., Milke, D. L. & Estabrooks, C. A. (2011). Nutrition status among residents living in a veterans' long-term facility in Western Canada: a pilot study. *Journal of the American Medical Directors Association*, 12(3), 217-225.
- Bowen, S., & Graham, I.D. (2013). Integrated knowledge translation (pp. 14-23) in Straus, S., Tetroe, J., & Graham, I. D. (Eds.). *Knowledge translation in health care: moving from evidence to practice*. John Wiley & Sons.
- Bowman, J. & Keller, H. (2005). Assessing nutritional risk of long-term care residents. *Canadian Journal of Dietetic Practice and Research*, 66(3), 155-161.
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: SAGE Publications Ltd.
- Brawley, E. C. (2006). *Design innovations for aging and Alzheimer's: creating caring environments*. Hoboken, N.J: J. Wiley.
- Briller, S. H., Proffitt, M. A., Perez, K., Calkins, M. P. & Marsden, J. P. (2001). Maximizing cognitive and functional abilities. In: Calkins, M. P. (Ed.), *Creating Successful Dementia Care Settings, Volume 2*. Baltimore MD: Health Professions Press.
- British Columbia Ministry of Health. (2012). *Best Practice Guidelines for Accommodating and Managing Behavioral and Psychological Symptoms of Dementia in Residential*

*Care: A Person-Centered Interdisciplinary Approach*. Retrieved from <http://www.health.gov.bc.ca/library/publications/year/2012/bpsd-guideline.pdf>

- Brodsky, H., Draper, B., & Low, L. F. (2003). Nursing home staff attitudes towards residents with dementia: strain and satisfaction with work. *Journal of Advanced Nursing*, 44(6), 583–590.
- Brooker, D. (1995). Looking at them, looking at me. A review of observational studies into the quality of institutional care for elderly people with dementia. *Journal of Mental Health*, 4(2), 145-156.
- Brooker, D. (2003). What is person-centered care in dementia? *Reviews in Clinical Gerontology*, 13(3), 215-222.
- Brooker, D. (2005). Dementia Care Mapping: A Review of the Research Literature. *The Gerontologist*, 45(suppl 1), 11-18.
- Brownie, S. (2011). A culture change in aged care: The Eden Alternative. *Australian Journal of Advanced Nursing*, 29(1), 63-68.
- Calkins, M. P. Dining room design. In *Dementia Design Info*. Retrieved from [https://www4.uwm.edu/dementiadesigninfo/data/white\\_papers/Dining%20Room%20Design.pdf](https://www4.uwm.edu/dementiadesigninfo/data/white_papers/Dining%20Room%20Design.pdf)
- Campo, M., & Chaudhury, H. (2011). Informal social interaction among residents with dementia in special care units: Exploring the role of the physical and social environments. *Dementia*, 11(3), 401–423.
- Canadian Institute for Health Information. (2010). *Analysis in Brief: Caring for Seniors with Alzheimer's Disease and Other Forms of Dementia*. Retrieved from [https://secure.cihi.ca/free\\_products/Dementia\\_AIB\\_2010\\_EN.pdf](https://secure.cihi.ca/free_products/Dementia_AIB_2010_EN.pdf)
- Canadian Institute of Health Research (2012). *Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches*. Retrieved from [http://www.cihr-irsc.gc.ca/e/documents/kt\\_lm\\_ktplan-en.pdf](http://www.cihr-irsc.gc.ca/e/documents/kt_lm_ktplan-en.pdf)
- Carrier, N., West, G. E., & Ouellet, D. (2007). Cognitively Impaired Residents' Risk of Malnutrition Is Influenced by Foodservice Factors in Long-Term Care. *Journal of Nutrition For the Elderly*, 25(3-4), 73–87.
- Charmaz, K. (2002). Qualitative interviewing and grounded theory analysis. In J. F. Gubrium & Holstein, J. A. (Eds.), *Handbook of interview research* (pp.675-694). Thousand Oaks: Sage Publications Ltd.
- Chaudhury, H., Hung, L., & Badger, M. (2013). The Role of Physical Environment in Supporting Person-centered Dining in Long-Term Care: A Review of the Literature. *American Journal of Alzheimer's Disease and Other Dementias*.

- Chaudhury, H., Hung, L. & Keller, H. (2014). *Dining Environment Audit Protocol*. Unpublished document, Department of Gerontology, Simon Fraser University, Vancouver, Canada.
- Chaudhury, H. & Cooke, H. (2014). Design matters in dementia care: The role of the physical environment in dementia care settings. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care* (2<sup>nd</sup> Edition). UK: Open University Press.
- Clarke, A. (2000). Using biography to enhance the nursing care of older people. *British Journal of Nursing*, 9, 429-433.
- Cohen-Mansfield, J., & Bester, A. (2006). Flexibility as a Management Principle in Dementia Care: The Adards Example. *The Gerontologist*, 46(4), 540–544.
- Counihan, C. & Esterik, P V. (Eds.) (1997). *Food and Culture: A Reader*. New York: Routledge.
- Cotelli, M., Manenti, R., & Zanetti, O. (2012). Reminiscence therapy in dementia: A review. *Maturitas*, 72(3), 203–205.
- Cruz, E. V. & Higginbottom, G. (2013). The use of focus ethnography in nursing research. *Nurse Researcher*, 20(4), 36-43.
- Curle, L., & Keller, H. (2010). Resident interactions at mealtime: an exploratory study. *European Journal of Ageing*, 7(3), 189–200.
- Davis, B. H. & Pope, C. (2010). Institutionalized ghosting: policy contexts and language use in erasing the person with Alzheimer's. *Lang Policy*, 9, 29-44.
- Davis, D. H. H., (2004). Dementia: sociological and philosophical constructions. *Social Science & Medicine*, 58(2), 369-378.
- Day, K., & Cohen, U. (2000). The Role of Culture in Designing Environments for People with Dementia: A Study of Russian Jewish Immigrants. *Environment and Behavior*, 32(3), 361–399.
- Denney, A. (1997). Quiet music: an intervention for mealtime agitation? *Journal of Gerontological Nursing*, 23(7), 6-23.
- Devine, C. M. (2005). A Life Course Perspective: Understanding Food Choices in Time, Social Location, and History. *Journal of Nutrition Education and Behavior*, 37(3), 121–128.
- Dewing, J. (2002). From Ritual to Relationship: A person-centered approach to consent in qualitative research with older people who have dementia. *Dementia*, 1(2), 157-171.

- Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*, 6(11), 11-25.
- DeWalt, K. M. & DeWalt, B. R. (2010). *Participant Observations: A Guide for Fieldworkers*. Walnut Creek and New York: AltaMira.
- Donini, L.M., de Felice, M.R., Savina, C., Coletti, C., Paolini, M., Laviano, A... Cannella, C. (2011). Predicting the outcome of long-term care by clinical and functional indices: the role of nutritional status. *Journal of Nutrition Health & Aging*, 15(7), 586-592.
- Douglas, J. W. & Lawrence, J. C. (2015). Environmental considerations for improving nutritional status in older adults with dementia: A narrative review. *Journal of the Academy of Nutrition and Dietetics*. Advanced online publication. doi: 10.1016/j.jand.2015.06.376
- Douglas, M. (1975). Deciphering a Meal. In Counihan, C. & Esterik, P V. (Eds.) (1997). *Food and Culture: A Reader* (36-54). New York: Routledge.
- Doyle, P. J., de Medeiros, K., & Saunders, P. A. (2011). Nested social groups within the social environment of a dementia care assisted living setting. *Dementia*, 11(3), 383–399.
- Doyle, P. J. & Rubinstein, R. L. (2013). Person-Centered Dementia Care and the Cultural Matrix of Othering. *The Gerontologist*, 54(6), 952-963.
- Ducak, K., Keller, H., Sweatman, G. (2015). Dining Culture Change in Long-Term Care Homes: Transitioning to Resident-Centered and Relational Meals. *Annals of Long Term Care*, 23(6), 1-14.
- Durnbaugh, T., Haley, B., Roberts, S. (1996). Assessing problem feeding behaviors in mid-stage Alzheimer's disease. *Geriatric Nursing*, 17, 63-67.
- Edvardsson, D., Winblad, B., & Sandman, P. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology*, 7(4), 362–367.
- Emerson, R. M., Fretz, R. I. & Shaw, L. L. (1995). *Writing Ethnographic Fieldnotes* (2<sup>nd</sup> ed.). Chicago, IL: The University of Chicago Press Ltd.
- Evans, B. C., Crogan, N. L., & Shultz, J. A. (2003). Quality Dining in the Nursing Home. *Journal of Nutrition For the Elderly*, 22(3), 1–17. doi:10.1300/J052v22n03\_01
- Evans, B. C., Crogan, N. L., & Schultz, J. A. (2005). Innovations in long-term care. The meaning of mealtimes: connection to the social world of the nursing home. *Journal of Gerontological Nursing*, 31(2), 11–17.

- Fjellström, C. (2004). Mealtime and meal patterns from a cultural perspective. *Scandinavian Journal of Nutrition*, 48(4), 161-164.
- Flick, U., von Kardoff, E. & Steinke, I. (2004). *A Companion to Qualitative Research*. California: Sage Publications Ltd.
- Fischler, C. (1988). Food, self and identity. *Social Science Information*, 27(2), 275–292.
- Franskowski, A., Roth, E. G., Eckert, J. K., & Harris-Wallace, B. (2011). The Dining Room as a Locus of Ritual in Assisted-Living. *Generations*, 35(3), 41–46.
- Geboy, L. (2009). Linking person-centered care and the physical environment: 10 design principles for elder and dementia care staff. *Alzheimer's Care Today*, 10(4), 228-231.
- Gibbs-Ward, A. J. & Keller, H. H. (2005). Mealtimes as Active Processes in Long-Term Care Facilities. *Canadian Journal of Dietetic Practice and Research*, 66(1), 5-11.
- Gilmore-Bykovskiy, A. L., Roberts, T. J., Bowers, B. J. & Brown, R. L. (2015). Caregiver Person-Centeredness and Behavioral Symptoms in Nursing Home Residents with Dementia: A Timed-Event Sequential Analysis. *The Gerontologist*, 55(S1), S61-S66.
- Goffman, E. (1959). *The presentation of self in everyday life*. New York: Doubleday.
- Goffman, E. (1962). *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Chicago: Aldine Pub. Co.
- Golafshani, N. (2003). Understanding Reliability and Validity in Qualitative Research. *The Qualitative Report*, 8(4), 597-607.
- Guest, G., Bunce, A. & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82.
- Gray, D. (2004). *Doing Research in the Real World*. Thousand Oaks, California: Sage Publications Ltd.
- Hellström, I., Nolan, M., Nordenfelt, L. & Lundh, U. (2007). Ethical and Methodological Issues in Interviewing Persons with Dementia. *Nursing Ethics*, 14(5), 608-619.
- Henderson, J. N. (2003). Alzheimer's Units and Special Care: A Soteriological Fantasy In Stafford, P. B. (Ed.). (2003). *Gray areas: ethnographic encounters with nursing home culture* (1st ed.) (153-172). Santa Fe : Oxford: School of American Research Press ; James Currey
- Hesse-Biber, S. N. & Levy, Patricia. (2006). *The Practice of Qualitative Research*. Thousand Oaks, CA: Sage Publications.

- Hicks-Moore, S. L. (2005). Relaxing music at mealtime in nursing homes: effects on agitated patients with dementia. *Journal of Gerontological Nursing*, 31(12), 26-32.
- Hoeffler, B., Talerico, K. A., Rasin, J., Mitchell, C. M., Stewart, B. J., McKenzie, D., Barrick, A. L., Rader, J. & Sloane, P. D. (2006). Assisting cognitively impaired nursing home residents with bathing: effects of two bathing interventions on caregiving. *Gerontologist*, 46(4), 524-532.
- Hopper, T., Clearly, S., Baumbach, N. & Fragomeni, A. (2007). Table Fellowship: Mealtime as a context for conversation with individuals who have dementia. *Alzheimer's Care Quarterly*, 8(1), 34-42.
- Hubbard, G., Cook, A., Tester, S. & Downs, M. (2002). Beyond words: Older people with dementia using and interpreting nonverbal behavior. *Journal of Aging Studies*, 16, 155-167.
- Hubbard, G., Downs, M. G., Tester, S. (2003). Including older people with dementia in research: Challenges and strategies. *Aging & Mental Health*, 7(5), 351-362.
- Hubbard, G., Tester, S. & Downs, M. G. (2003). Meaningful social interactions between older people in institutional care settings. *Ageing and Society*, 23, 99-114.
- Hung, L. & Chaudhury, H. (2011). Exploring personhood in dining experiences of residents with dementia in long-term care facilities. *Journal of Aging Studies*, 25(1), 1-12.
- Hung, L., Chaudhury, H. & Rust, T. (2015). The effect of dining room physical environment renovations on person-centered care practices and residents' dining experiences in long-term care facilities. *Journal of Applied Gerontology*. Advanced online publication. doi: 10.1177/0733464815574094.
- Iizaka, S., Okuwa, M., Sugama, J., Sugama, S. H. (2010). The impact of malnutrition and nutrition-related factors on the development and severity of pressure ulcers in older patients receiving home care. *Clinical Nutrition*, 29, 47-53.
- Jayasekara, R. S. (2012). Focus groups in nursing research: Methodological perspectives. *Nursing Outlook*, 60(6), 411-416.
- Kayser-Jones, J. & Schell, E. (1997). The effect of staffing on the quality of care at mealtime. *Nursing Outlook*, 45(2), 64-72.
- Kayser-Jones, J. (2003). Continuing to conduct research in nursing homes despite controversial findings: Reflections by a research scientist. *Qualitative Health Research*, 13(1), 114-128.

- Kehyayan, V., Hirdes, J. P., Suzanne, L. T. & Stolee, P. (2015). Residents' Self-Reported Quality of Life in Long-Term Care Facilities in Canada. *Canadian Journal on Aging*, 34(2), 149-164.
- Keller, H., Beck, A. M. & Namasivayam, A. (2015). Improving Food and Fluid Intake for Older Adults Living in Long-Term Care: A Research Agenda. *Journal of the American Medical Directors Association*, 16(2), 93-100.
- Keller, H., Carrier, N., Duizer, L., Lengyel, C., Slaughter, S. & Steele, C. (2014). Making the Most of Mealtimes (M3): Grounding Mealtime Interventions With a Conceptual Model. *Journal of the American Medical Directors Association*, 15(3), 158-161.
- Keller, H. H. & Chaudhury, H. (2014). Mealtime Scan for Long-Term Care. Unpublished document, Department of Gerontology, Simon Fraser University, Vancouver, Canada.
- Keller, H. H., Gibbs, A. J., Boudreau, L. D., Goy, R. E., Pattillo, M. S. & Brown, H. M. (2003). Prevention of Weight Loss in Dementia with Comprehensive Nutritional Treatment. *Journal of the American Geriatrics Society*, 51, 945-951.
- Kitwood, T. (1997a). The experience of dementia. *Aging & Mental Health*, 1(1), 13–22.
- Kitwood, T. (1997b). *Dementia reconsidered: the person comes first*. Buckingham [England] ; Philadelphia: Open University Press.
- Kitwood, T. (1998). Toward a Theory of Dementia Care: Ethics and Interaction. *The Journal of Clinical Ethics*, 9(1), 23–34.
- Kitwood, T., & Bredin, K. (1992a). *Person to Person: A Guide to the Care of Those with Failing Mental Powers*. Essex: Gale Centre Publications.
- Kitwood, T., & Bredin, K. (1992b). Towards a Theory of Dementia Care: Personhood and Well-being. *Ageing and Society*, 12(03), 269.
- Knoblauch, H. (2005). Focused Ethnography. *Forum Qualitative Sozialforschung*, 6(3), 1-11.
- Koehn, S. D., Kozak, J-F. & Drance, E. (2011). 'The problem with Leonard': A critical constrictionist view of need-driven dementia-compromised behaviors. *Dementia*, 11(6), 725-741.
- Kontos, P. C. (2005). Embodied selfhood in Alzheimer's disease, Rethinking person-centered care. *Dementia*, 4, 553-570.
- Koren, M. J. (2010). Person-Centered Care for Nursing Home Residents: The Culture-Change Movement. *Health Affairs*, 29(2), 312-317.

- Kothari, A., & Wathen, N. (2013). A critical second look at integrated knowledge translation. *Health policy*, 109(2), 187-191.
- Kreuger, R. A. (1994). *Focus Groups: a Practical Guide for Applied Research*. Thousand Oaks, CA: Sage Publications.
- Lam, I., & Keller, H. H. (2012). Honoring Identity Through Mealtimes in Chinese Canadian Immigrants. *American Journal of Alzheimer's Disease and Other Dementias*.
- Lawton, M. P. (1989). Behavior-relevant ecological factors. In K. Schaie & K. Schooler (Eds.), *Social structure and aging: Psychological processes* (pp. 57-78). Hillsdale, NJ: Lawrence Erlbaum.
- Lawton, M. P. & Nahemow, L. (1973). Ecology and the aging process. In C. Eisdorfer & M. P. Lawton (Eds.), *Psychology of adult development and aging* (pp. 619-674). Washington, DC: American Psychological Association.
- Lee, S. Y., Chaudhury, H. & Hung, L. (2014). Exploring staff perceptions on the role of physical environment in dementia care setting. *Dementia*. Advanced online publication. doi: 10.1177/1471301214536910
- Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic Inquiry*. London, UK: Sage Publications.
- Long, T. & Johnson, M. (2000) Rigour, reliability and validity in qualitative research. *Clinical Effectiveness in Nursing*, 4(1), 30-37.
- Marsden, J. P. (2005). *Humanistic Design of Assisted Living*. Baltimore, MD: John Hopkins University Press.
- Manias, E. & Street, A. (2000). Rethinking ethnography: reconstructing nursing relationships. *Journal of Advanced Nursing*, 33(2), 234-242.
- Manthorpe, J., & Watson, R. (2003). Poorly served? Eating and dementia. *Journal of Advanced Nursing*, 41(2), 162–169.
- Marsden, J. P. (2005). *Humanistic design of assisted living*. Baltimore: Johns Hopkins University Press.
- McCormack, B. (2004). Person-centredness in gerontological nursing: an overview of the literature. *International Journal of Older People Nursing*, 13(3a), 31-38.
- McDaniel, H. H, Hunt, A., Hackes, B. & Pope, J. F. (2001). Impact of dining room environment on nutritional intake of Alzheimer's residents: A case study. *American Journal of Alzheimer's Disease & Other Dementias*, 16(5), 297-302.

- McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2009). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19, 1935-1943.
- Mead, M. (1970). The Changing Significance of Food. In Counihan, C. & Esterik, P V. (Eds.) (1997). *Food and Culture: A Reader* (11-19). New York: Routledge.
- Moore, K. D. (1999). Dissonance in the Dining Room: A Study of Social Interaction in a Special Care Unit. *Qualitative Health Research*, 9(1), 133–155.
- Morgan, D. L. (1996). Focus Groups. *Annual Review of Sociology*, 22, 129-152.
- Morgan, S., & Yoder, L. H. (2012). A Concept Analysis of Person-Centered Care. *Journal of Holistic Nursing*, 30(1), 6–15.
- Murrinen, S., Savikko, N., Soini, H., Suominen, M. & Pitkälä, K. (2015). Nutrition and psychological well-being among long-term care residents with dementia. *The Journal of Nutrition Health and Aging*, 19(2), 178-182.
- Nolan, B. A. & Matthews, R. M. (2004). Facilitating resident information seeking regarding meals in a special care unit: an environmental design intervention. *Journal of Gerontological Nursing*, 30(1), 12-16.
- Neal, M. & Barton Wright, P. (2003). Validation therapy for dementia. *Cochrane Database System Review*, 1.
- Nijs, K. A., de Graaf, C., Kok, F. J., van Staveren, W. A. (2006). Effect of family style mealtimes on quality of life, physical performance, and body weight of nursing home residents: cluster randomized controlled trial. *British Medical Journal*, 332 (7551), 1180-1184.
- Norbergh, K. G., Hellzén, O., Sandman, P. O. & Asplun, K. (2002). The relationship between organizational climate and the content of daily life for people with dementia living in a group-dwelling. *Journal of Clinical Nursing*, 11(2), 237-246.
- O'Connor, D., Phinney, A. & Hulko, W. (2010). Dementia at the Intersections: A unique case study exploring social location. *Journal of Aging Studies*, 24(1), 30-39.=
- O'Connor, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry, J., ... Beattie, L. (2007). Personhood in dementia care: Developing a research agenda for broadening the vision. *Dementia*, 6(1), 121–142.
- Odlund, O. A., Koocheck, A., Ljungqvist, O. & Cederholm, T. (2005). Nutritional status, well-being and functional ability in frail elderly service flat residents. *European Journal of Clinical Nutrition*, 59(2), 263-270.
- Patton, M. Q. (2015). *Qualitative Research & Evaluation Methods*. Thousand Oaks, CA: Sage Publications Ltd.

- Pearson, A., Fitzgerald, M. & Nay, Rhonda. (2003). Mealtimes in Nursing Homes: The Role of Nursing Staff. *Journal of Gerontological Nursing*, 29(6), p.40-47.
- Pelto, P. J. (2013). *Applied Ethnography: Guidelines for Field Research*. Walnut Creek, CA: Left Coast Press Ltd.
- Penrod, J., Yu, F., Kolanowski, A., Fick, D., Loeb, S., & Hupcey, J. (2007). Reframing Person-Centered Nursing Care for Persons With Dementia. *Research and Theory for Nursing Practice: An International Journal*, 21(1), 57–72.
- Perivolaris, A., LeClerc, C. M., Wilkinson, K. & Buchanan, S. (2006). An enhanced dining program for persons with dementia. *Alzheimer's Care Quarterly*, 7(4), 258-267.
- Plummer-D'Amato, P. (2008a). Focus group methodology Part 1: Considerations for Design. *International Journal of Therapy and Rehabilitation*, 15(2), 69-73.
- Plummer-D'Amato, P. (2008b). Focus group methodology Part 2: Considerations for analysis. *International Journal of Therapy and Rehabilitation*, 15(3), 123-129.
- Quandt, S. A., Arcury, T. A., Bell, R. A., McDonald, J., & Vitolins, M. Z. (2001). The social and nutritional meaning of food sharing among older rural adults. *Journal of Aging Studies*, 15(2), 145–162.
- Ragneskog, H., Kihlgren, M., Karlsson, I. & Norberg, A. (1996). Dinner music for demented patients: Analysis of video-recorded observations. *Clinical Nursing Research*, 5(3), 262-282.
- Ramage-Morin, P. & Garriguet, D. (2013). Nutritional risk among older Canadians. *Health Reports*, 24(3), 3-13.
- Reed, P. S., Zimmerman, S., Sloane, P. D., Williams, C. S., & Boustani, M. (2005). Characteristics Associated With Low Food and Fluid Intake in Long-Term Care Residents With Dementia. *The Gerontologist*, 45(Supplement 1), 74–81.
- Reimer, H. D., & Keller, H. H. (2009). Mealtimes in Nursing Homes: Striving for Person-Centered Care. *Journal of Nutrition For the Elderly*, 28(4), 327–347.
- Reisberg, B., Ferris, B., deLeon, S. H. & Crook, M. J. (1982). The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*, 139, 1136-1139.
- Roberts, E. (2011). Six for lunch: a dining option for residents with dementia in a special care unit. *Journal of Housing For the Elderly*, 25(4), 352-379.
- Roper, J. M. & Shapira, J. (2000). *Ethnography in Nursing Research*. Thousand Oaks, California: Sage Publications.

- Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data* (2nd ed.). Thousand Oaks: Sage Publications Ltd.
- Sabat, S. R. (2005). The Self in Dementia In Johnson, M. L. (Ed.). (2005). *The Cambridge handbook of age and ageing* (332-337). Cambridge ; New York: Cambridge University Press.
- Sandelowski, M. (1995). Qualitative Analysis: What It Is and How To Begin. *Research in Nursing & Health*, 18, 371-375.
- Saunders, P. A., de Medeiros, K., Doyle, P. & Mosby, A. (2011). The discourse of friendship: Mediators of communication among dementia residents in long-term care. *Dementia*, 11(3), 347-361.
- Savage, J. (2000). Education and debate: Ethnography and health care. *British Medical Journal*, 321(2), 1400-1402.
- Savage, J. (2006). Ethnographic evidence: The value of applied ethnography in healthcare. *Journal of Research in Nursing*, 11(5), 383-393.
- Savishinsky, J. S. (2003). "Bread and Butter" Issues: Food, Conflict, and Control in a Nursing Home. In Stafford, P. B. (Ed.). (2003). *Gray areas: ethnographic encounters with nursing home culture* (1st ed.) (103-120). Santa Fe : Oxford: School of American Research Press ; James Currey
- Schwarz, B., Chaudhury, H. & Tofle, R. B. (2004). Effect of design interventions on dementia care settings. *American Journal of Alzheimer's Disease and Other Dementias*, 19(3), 172-176.
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, 63-75.
- Sitter, M. & Lengyel, C. (2011). Nutritional status and eating habits of older Manitobans after relocating to a personal care home. *Canadian Journal of Dietetic Practice and Research*, 72, 134-39.
- Simmons, S. F., Osterweil, D. & Schnelle, J. F. (2001). Improving Food Intake in Nursing Home Residents With Feeding Assistance: A Staffing Analysis. *Journal of Gerontology: Medical Sciences*, 56A, M790-M794.
- Slaughter, S., Cole, D., Jennings, E. & Reimer, M. A. (2007). Consent and Assent to Participate in Research from People with Dementia. *Nursing Ethics*, 14(1), 27-40.
- Sloane, P. D., Hoeffler, B., Mitchell, C. M., McKenzie, D. A., Barrick, A. L., Rader, J., Stewart, B. J., Talerico, K. A., Rasin, J. H., Zink, R. C. & Koch, G. G. (2004). Effects of person-centered showering and the towel bath on bathing associated aggression,

agitation, and discomfort in nursing home residents with dementia: a randomized, controlled trial. *Journal of the American Geriatric Society*, 52(11), p.1795-804.

Sloane, P. D., Ivey, J., Helton, M., Barrick, A. L., & Cerna, A. (2008). Nutritional Issues in Long-Term Care. *Journal of the American Medical Directors Association*, 9(7), 476–485.

Soeters, P., Reijven, P., Vanbokhorstdevanderschueren, M., Schols, J., Halfens, R., Meijers, J., & Vangemert, W. (2008). A rational approach to nutritional assessment. *Clinical Nutrition*, 27(5), 706–716.

Stafford, P. B. (Ed.). (2003). *Gray areas: ethnographic encounters with nursing home culture* (1st ed.). Santa Fe : Oxford: School of American Research Press; James Currey.

Stanner, S. (2007). Older people with dementia: Eating and drinking healthily. *Nursing & Residential Care*, 9(1), 18-21.

Sturges, J. E. (2004). Comparing telephone and face-to-face qualitative interviewing: a research note. *Qualitative Research*, 4(1), 107-118.

Talerico, K. A. (2003). Person-Centered Care: An Important Approach for 21<sup>st</sup> Century Health Care. *Journal of Psychological Nursing*, 41(11), 12-16.

Ullrich, S., McCutcheon, H. & Parker, B. (2011). Reclaiming time for nursing practice in nutritional care: outcomes for implementing Protected Mealtimes in a residential aged care setting. *Journal of Clinical Nursing*, 20(9-10), 1339-1348.

Venturato, L. (2010). Dignity, dining and dialogue: reviewing the literature on quality of life for people with dementia. *International Journal of Older People Nursing*, 5(3), 228–234.

Vikström, S., Sandman, P-O., Stenwall, E., Boström, A-M., Saarnio, L., Kindblom, K... Borell, L. (2015). A model for implementing guidelines for person-centered care in a nursing home setting. *International Psychogeriatrics*, 27(1), 49-59.

Webb, C. & Kevern, J. (2000). Focus groups as a research method: a critique of some aspects of their use in nursing research. *Journal of Advanced Nursing*, 33(6), 798-805.

Weisman, G. D., Lawton, M. P., Calkins, M, P., Norris-Baker, L. & Sloane, P. (1993). Professional environmental assessment protocol. Unpublished manuscript.

Williams, K., Herman, R., Gajewski, B. & Wilson, K. (2008). Elderspeak communication: Impact on dementia care. *American Journal of Alzheimer's Disease and Other Dementias*, 24(1), 11-20.

Whear, R., Abbot, R., Thompson-Coon, J., Bethel, A., Rogers, M., Hemsley, A... Stein, K. (2014). Effectiveness of mealtime interventions on behaviour symptoms of people with dementia living in care homes: A systematic review. *Journal of Post-Acute and Long-Term Care Medicine*, 15(3), 185-193.

Winter Falk, L., Bisogni, C. A., & Sobal, J. (1996). Food Choice Processes of Older Adults: A Qualitative Investigation. *Journal of Nutrition Education*, 28(5), 257–265.

Zgola, J. M. (2001). *Bon appetit!: the joy of dining in long-term care*. Baltimore, Md: Health Professions Press.

## **Appendix A**

### **Informational Letter to Residents, Staff, Family Members Heading for Appendix**

#### **Invitation**

As a resident, family member/friend, and staff member of the Stroud-Fung Alzheimer Centre, you are being invited to participate in this research study about residents' mealtime experiences and care interactions. Your participation in this study will help us better understand ways to improve mealtime experiences.

We obtained your name because you were identified by the Stroud-Fung Alzheimer Centre as a resident (or substitute decision-maker), family member, and/or staff member who lives/visits/works in [*insert Cottage A/B*]. This study is being conducted by a graduate student researcher from Department of Gerontology at Simon Fraser University as part of her graduate thesis requirement.

#### **Background**

Mealtimes are an important part of quality of life for residents living in long-term care facilities. Important aspects of mealtimes are social interactions, quality of food served, and the physical dining environment. The aim of this study is to understand how mealtimes can be a more person-centered and enjoyable experience for the residents.

#### **Participation**

If you choose to participate, the researcher will observe you immediately before, during, and immediately after mealtimes. She will be looking specifically at social interactions, care interactions, and interactions with the physical dining environment. The researcher will spend time observing from the perimeter of the dining area, and also amongst residents and care staff. She may also engage in casual conversation and exchanges.

You will be observed a maximum of twelve times during mealtimes in your cottage's kitchen, dining, and immediate surrounding area. You will not be observed anywhere else within the cottage. The researcher may also observe family member/friend visits during mealtimes.

If you are interested in learning more about the importance of this research study, please contact the study's Co-Investigator:

Sarah Wu, M.A. Candidate

Phone: xxx-xxx-xxxx Email: xxxxxxxx@sfu.ca

The Co-Investigator will contact you within 2 weeks to ask whether you are interest in participating in the study, and to provide you with further information. If you have any

questions before or after being contacted, please feel free to call or email the investigator at any time.

## Appendix D

### Participant Observation Guidelines

Not Patient-Centered Oriented	Patient-Centered Oriented
<i>Outpacing</i> – Acting or speaking in a manner that is too fast for residents to understand or react (i.e., rushing or ignoring residents requests for help)	<i>Relaxed Pace</i> – Acting or speaking in a manner (i.e., slowing down tasks to accommodate resident’s preferences)
<i>Withholding</i> – Disregard for a resident’s evident need (i.e., refusing to answer resident’s questions)	<i>Holding</i> – Provision of safety, security, and comfort to a resident (i.e., using reassuring words, answering resident’s questions)
<i>Stimulation (too little; too much)</i> – The level of stimulation that is either too little or too much that does not allow residents to function independently to the best of their ability (i.e., noise level of staff talking during mealtimes)	<i>Stimulation (appropriate level)</i> – The optimal quality of stimulation provided to residents that allows them to function independently to the best of their ability (i.e., baking cinnamon buns for breakfast)
<i>Disrespect</i> – Acting or speaking in a disrespectful manner (i.e., patting residents on the head; assembly-line feeding assistance)	<i>Respect</i> – Treating residents as valued members of the family unit (i.e., serving and preparing meals based on individual resident’s preferences)
<i>Invalidation</i> – Failing to acknowledge resident’s realities (i.e., what they might be feeling)	<i>Validation</i> – Exercising empathy to recognize the reality of the resident (i.e., trying to understand how the person feels and needs)
<i>Distancing</i> – Creating a psychological distance with residents (i.e., staff speaking in an authoritative tone; ignoring presence of residents)	<i>Connecting</i> – Working to build a sense of togetherness within a relationship (i.e., use of hugs to establish connection with residents)
<i>Disempowerment</i> – Failing to support residents use their remaining abilities (i.e., using physical objects to block residents from going certain places)	<i>Empowerment</i> – Relinquishing control over residents; instead supporting abilities and skills (i.e., changing food arrangement on the plate in order to make residents feel comfortable)
<i>Ignoring</i> – Social situations that fail to acknowledge the presence and feelings of	<i>Inclusion</i> – Social situations that actively include residents with social conversations

the resident (i.e., laughing at or ignoring feelings of residents)	and activities (i.e., authentic attention to give a resident social confidence)
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## Appendix E

### Informed Consent Form for Participant Observations (Care Staff)

Principal Investigator: Dr. Habib Chaudhury  
Professor and Chair  
Department of Gerontology  
Simon Fraser University Vancouver  
#2800-515 West Hastings Street  
Vancouver, BC V6B 5K3  
Phone: xxx-xxx-xxxx  
Email: xxxxxxxx@sfu.ca

Co-Investigator: Sarah Wu, BA, BHS, M.A. Candidate  
Department of Gerontology  
Simon Fraser University Vancouver  
#2800-515 West Hastings Street  
Vancouver, BC V6B 5K3  
Phone: xxx-xxx-xxxx  
Email: xxxxxxxx@sfu.ca

Dear *[insert name of staff member]*,

As a staff member working in the Stroud-Fung Alzheimer Centre, you are invited to take part in a research study. **Your participation in this study is entirely voluntary, therefore it is up to you to decide whether or not to take part.** Before you decide, it is important for you to understand what the research involves. This consent form will give you information about the study, why the research is being done, what will happen during and after the study, as well as any possible benefits, risks, and/or discomforts.

If you wish to participate, you will be asked to sign this consent form. If you do decide to take part in this study, you are always free to withdraw at any time, without giving any reason for your decision. Your decision to participate in this study will have **no effect** on your job or your relationships you have with residents, other staff, management, or resident's family members. All information will be kept strictly confidential and will only be used for the purposes of this study. No information obtained in this study will be connected to your personal information. All names will be replaced with ID numbers and pseudonyms in any databases, papers, reports, or presentation that are produced from this research.

**Please take time to read the following information carefully before you decide to give your consent.**

### **Who is conducting the study?**

This study is being conducted by Sarah Wu under the supervision of Dr. Habib Chaudhury, as part of a Masters of Arts thesis in Gerontology at Simon Fraser University.

### **What is the purpose of the study?**

The purpose of this study is to learn more about how we can improve the dining experiences of residents living in long-term care facilities by exploring the impacts of the social and physical dining environments. Mealtimes are an important ritual of daily life, and offer opportunities to not only maintain physical health, but also to engage in meaningful social interactions with other residents and staff members.

The goal of this research is to learn how care staff administer person-centered care practices during mealtimes, and how the physical dining room impacts the ways in which staff and residents are able to interact with one another. In order to do this, we would like to observe care staff approaches and interactions with residents and other staff members during mealtimes.

### **Who can participate in this study?**

You can participate in this study if you are a full or part-time employee who has been employed at the Stroud-Fung Alzheimer Centre for at least three months, and are directly involved in facilitating and/or providing care for residents with a diagnosis of Alzheimer's disease or other dementia.

### **What does participation involve?**

In order to gain a better understanding of the complexity of mealtimes from a care staff perspective, as well as the mealtime experience of residents, a technique called "participant observations" will be used. Observing staff administer care during meals will provide a better understanding of person-centered care practices for residents with dementia. No clinical determinations will be made on the quality of care provided to residents.

For this study, care staff will be observed during mealtimes in order to gain a better understanding of how staff deliver care, socially engage and interact with residents and other staff, and how the physical environment of the dining space impacts mealtimes. To do this, the observer will sit to the side of the dining area where she can clearly observe care staff's facial expressions, verbal and non-verbal communication, and physical movements, but will not be a participant in dining. The observer will not have any physical contact with staff or residents. However, she will speak with staff in instances where clarification about a matter is needed, or if staff choose to engage with her.

Your participation in this research is entirely voluntary. You may withdraw from this study at any time. If you decide to enter the study and to withdraw at any time in the future, there will be no penalty or loss of benefits to which you are otherwise entitled. The study investigators may decide to discontinue the study at any time, or withdraw you from the study at any time, if they feel that it is in your best interests. If you choose to

enter the study and then decide to withdraw at a later time, all data collected about you during your enrolment in the study will be retained for analysis.

**What are the possible harms and side effects of participating?**

There are no known risks to participating in observations. Again, you are free to withdraw your participation at any time.

**What are the benefits of participating in this study?**

Information obtained through this research study will enhance our current knowledge of dementia care and dementia care environments, and may contribute to advancements in future care for people with dementia.

**What happens after the study is finished?**

Information collected from these participant observations and informal interactions between the researchers and participants will be analyzed and discussed in Sarah Wu's MA thesis, along with any subsequent publications and presentations. Again, all names and data will be kept strictly confidential and anonymous by using pseudonyms and by presenting data in group form. No information that discloses your identity will be released or published. All data will be stored on a password-protected computer and/or locked cabinet at Simon Fraser University. At the end of the study, all data will be destroyed accordingly.

**What will the study cost me?**

You will not incur any personal expenses as a result of participating in the study. You will not be paid for your participation in this research study.

**Who do I contact if I have questions about the study during before or after I consent?**

If you have any questions or desire further information about this study before or during participation, you can contact:

**Sarah Wu at xxx-xxx-xxxx or xxxxx@sfu.ca**

**or**

**Dr Habib Chaudhury at xxx-xxx-xxxx or xxxxx@sfu.ca.**

**Who do I contact if I have any questions or concerns about the residents' rights as a participant during the study?**

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, contact the [Health Authority] Research Ethics Board co-Chair at xxx-xxx-xxxx and/or Dr. XXXX XXXXXXXX, Director, Simon Fraser University, Office of Research Ethics at xxxxxxxxx@sfu.ca or xxx-xxx-xxxx.

*Please retain this document for your own records.*

## **Person-Centered Care and Mealtimes in Residential Care Units**

### **CONSENT TO PARTICIPATE**

I have read and understood the information and consent form.

I have had sufficient time to consider the information provided and to ask for advice if necessary.

I have had the opportunity to ask questions and have had satisfactory responses to my questions.

I understand that all of the information collected will be kept confidential and that the results will only be used for the research objectives.

I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or to withdraw from this study at any time.

I understand that I am not waiving any of my legal rights as a result of signing this consent form.

I understand that there is no guarantee that this study will provide any benefits to me.

I understand that if a situation occurs that may be/is harmful to residents and/or staff (i.e., verbal, emotional, psychological, physical, or sexual abuse), this interaction will be reported to the director of care.

I have read this form and I freely consent to participation in this study.

I have been told that I will receive a dated and signed copy of this form.

## Appendix F

### Informed Consent Form for Participant Observations (Substitute Decision-Makers)

Principal Investigator: Dr. Habib Chaudhury  
Professor and Chair  
Department of Gerontology  
Simon Fraser University Vancouver  
#2800-515 West Hastings Street  
Vancouver, BC V6B 5K3  
Phone: xxx-xxx-xxxx  
Email: xxxxxxxx@sfu.ca

Co-Investigator: Sarah Wu, BA, BHS, M.A. Candidate  
Department of Gerontology  
Simon Fraser University Vancouver  
#2800-515 West Hastings Street  
Vancouver, BC V6B 5K3  
Phone: xxx-xxx-xxxx  
Email: xxxxxxxx@sfu.ca

Dear *[insert name of substitute decision-maker]*,

As a resident living with dementia at the Stroud-Fung Alzheimer Centre, your family member is being invited to participate in a research study. **Participation in this study is entirely voluntary, therefore it is up to you to decide whether or not your family member should take part.** Before you decide, it is important for you to understand the purpose of the research and what participation in the research involves. This consent form will tell you about the study, why the research is being done, what will happen during and after the study, as well as any possible benefits, risk, and/or discomforts.

If you are a substitute decision-maker for someone who may take part in this study, permission from you and the agreement and the assent (agreement) of the potential research participant may be required. When we say “you” or “your” in this consent form, we mean the substitute decision-maker; “we” means the research staff.

If you wish to provide consent for your family member to participate, you will be asked to sign this form. If you do provide consent for your family member to take part in this study, you will be free to withdraw your family member’s participation at any time during the study and without giving any reasons for your decision. Your decision to involve your family member in this study will have **no effect** on the care *he or she* receives in this facility, nor will it have any effect on the relationships you or your family member have with the staff or administration of this facility. All information will be kept strictly confidential and will only be used for the purposes of this study. This will be done by replacing all names with ID numbers and pseudonyms in any databases, papers, reports, or presentations that are produced from this research.

**Please take time to read the following information carefully before you decide to give your consent.**

**Who is conducting the study?**

This study is being conducted Co-Investigator Sarah Wu, under the supervision of Dr. Habib Chaudhury, as part of a Masters of Arts thesis in Gerontology at Simon Fraser University.

**What is the purpose of the study?**

The purpose of this study is to learn more about how we can improve the dining experiences of residents living in long-term care facilities by exploring the impacts of the social and physical dining environments. Mealtimes are an important ritual of daily life, and offer opportunities to not only maintain physical health, but also to engage in meaningful social interactions with other residents and staff members.

The goal of this research is to learn how care staff administer person-centered care practices during mealtimes, and how the dining room impacts the ways in which staff and residents are able to interact with each other. In order to do this, we would like to observe residents and their interactions during mealtimes.

**Who can participate in this study?**

Any resident who has been diagnosed by a physician as having Alzheimer's disease or a related dementia (e.g. vascular dementia or Lewy body dementia), and who has lived in at the Stroud-Fung Alzheimer Centre for at least 3 months.

**What does participation involve?**

As individuals with dementia sometimes are unable to communicate their likes, dislikes, feelings, emotions, and preferences through verbal communication, researchers will often use a technique called "participant observations" to gain insight into an experience. Observing a resident during mealtimes interacting with others and their physical environment allows for a more comprehensive and richer understanding of their experience.

For this study, residents will be observed during mealtimes in order to gain an understanding of how residents interact amongst themselves and with care staff. To do this, the Co-Investigator will sit to the side of the dining area where she can clearly observe the resident's facial expressions, verbal exchanges, and physical movements, but will not be a participant in dining. The Co-Investigator will not have any physical contact with the residents in the group. However, she will interact verbally and non-verbally with the residents if they initiate interactions or ask questions.

Your family member's participation in this research is entirely voluntary. You may withdraw your family member from this study at any time by contacting the Co-Investigator via phone or email. If you decide to enter your family member in the study, and then withdraw them at any time in the future, there will be no penalty or loss of benefits to which your family member is otherwise entitled. The study investigators may

decide to discontinue the study at any time, or withdraw your family member from the study at any time, if they feel that it is in your family member's best interest. If you choose to enter your family member in the study and then decide to withdraw at a later time, all data collected about your family member during their enrolment in the study will be retained for analysis.

**What are the possible harms and side effects of participating?**

There are no known risks associated with participant observations of residents with dementia. However, if at any time a resident appears to be upset by the presence of the Co-Investigator, she will discontinue the observations and exit the room until the resident is comforted. Observations will only continue if all residents in the group appear uninfluenced by the presence of the Co-Investigator.

**What are the benefits of participating in this study?**

Information obtained through this research study will enhance our current knowledge of dementia care and dementia care environments, and may contribute to advancements in future care for people with dementia.

**What happens after the study is finished?**

Results of the observations will be included in Sarah Wu's MA thesis, along with any subsequent publications and presentations. Again, all names and data will be kept strictly confidential and anonymous by using pseudonyms and by presenting data in group form. No information that discloses a residents' identity, or your identity, will be released or published. All data will be stored on a password-protected computer and/or locked cabinet at Simon Fraser University. At the end of the study, all data will be destroyed accordingly.

**What will the study cost me?**

Neither you nor your loved one will incur any personal expenses as a result of participating in the study.

**Who do I contact if I have questions about the study during before or after I consent?**

If you have any questions or desire further information about this study before or during participation, you can contact:

**Sarah Wu at xxx-xxx-xxxx or xxxxxx@sfu.ca**

or

**Dr Habib Chaudhury at xxx-xxx-xxxx or xxxxxx@sfu.ca.**

**Who do I contact if I have any questions or concerns about the residents' rights as a participant during the study?**

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, contact the Health Authority Research

Ethics Board co-Chair at xxx-xxx-xxxx and/or Dr. XXXX XXXXX, Director, Simon Fraser University, Office of Research Ethics at xxxxxx@sfu.ca or xxx-xxx-xxxx.

*Please retain this document for your own records.*

## **Person-Centered Care and Mealtimes in Residential Care Units**

### **CONSENT TO PARTICIPATE**

I have read and understood the information and consent form.

I have had sufficient time to consider the information provided and to ask for advice if necessary.

I have had the opportunity to ask questions and have had satisfactory responses to my questions.

I understand that all of the information collected will be kept confidential and that the results will only be used for the research objectives.

I understand that *[insert name of resident here]*'s participation in this study is voluntary and that I am completely free to refuse their participation or to withdraw their participation from this study at any time without changing in any way the quality of treatment or care that *[insert name of resident]* receives.

I understand that none of *[insert name of resident here]*'s legal rights are waived as a result of signing this consent form.

I understand that there is no guarantee that this study will provide any benefits to me or my relative.

I understand that if a situation occurs that may be/is harmful to residents and/or staff (i.e., verbal, emotional, psychological, physical, or sexual abuse), this interaction will be reported to the director of care.

I am satisfied that the information contained in this consent form was explained to my family member to the extent that he/she is able to understand it, that all questions have been answered, and that *[resident's name]* assents to participating in the research.

## Appendix G

### Participant Observation Consent Letter

Dear [insert name of visitor],

As a visitor of a resident living at Stroud-Fung Alzheimer Centre, you are invited to take part in a research study. **Your participation in this study is entirely voluntary, therefore it is up to you to decide whether or not to take part.** Before you decide, it is important for you to understand what the research involves. This consent form will give you information about the study, why the research is being done, what will happen during and after the study, as well as any possible benefits, risks, and/or discomforts.

You will be approached again by the Co-Investigator 15 minutes after the receipt of this letter to determine whether you would like to participate or not; additional time to review the information will be provided if needed. No data about you will be gathered until oral consent is obtained.

Your participation in this research is entirely voluntary. You may withdraw from this study at any time, without giving any reason for your decision, by indicating to the Co-Investigator you wish to no longer participate either in person, by email, or over the phone. If you decide to enter the study and to withdraw at any time in the future, there will be no penalty or loss of benefits to which you are otherwise entitled. Your choice not to participate will have **no effect** on your relationship with your resident family member/friend or their level of care. The study investigators may decide to discontinue the study at any time, or withdraw you from the study at any time, if they feel that it is in your best interests. If you choose to enter the study and then decide to withdraw at a later time, all data collected about you during your enrolment in the study will be retained for analysis. All information will be kept strictly confidential and will only be used for the purposes of this study. No information obtained in this study will be connected to your personal information. All names will be replaced with ID numbers and pseudonyms in any databases, papers, reports, or presentation that are produced from this research.

**Please take time to read the following information carefully before you decide to orally give your consent.**

#### **Who is conducting the study?**

This study is being conducted by Co-Investigator Sarah Wu, under the supervision of Dr. Habib Chaudhury, as part of a Masters of Arts thesis in Gerontology at Simon Fraser University.

#### **What is the purpose of the study?**

As individuals with dementia sometimes are unable to communicate their likes, dislikes, feelings, emotions, and preferences through verbal communication, researchers will often use a technique called “participant observations” to gain insight into an experience. Observing a resident during mealtimes interacting with others and their physical

environment allows for a more comprehensive and richer understanding of their experience.

For this study, residents will be observed during mealtimes in order to gain an understanding of how residents interact amongst themselves, with care staff, and visitors. To do this, the Co-Investigator will sit to the side of the dining area where she can clearly observe the resident's facial expressions, verbal exchanges, and physical movements, but will not be a participant in dining. The Co-Investigator will not have any physical contact with the residents in the group. However, she will interact verbally and non-verbally with the residents if they initiate interactions or ask questions.

There may be instances when family and friends come to visit and assist with a resident's mealtime. Sharing a meal with loved ones is an important and comforting event, and therefore would be considered an important aspect of the resident's mealtime experience to capture during observations.

### **What are the possible harms and side effects of participating?**

There are no known risks associated with participant observations of residents with dementia. However, if at any time a resident and/or visitor appears to be upset by the presence of the observer, she will discontinue the observations and exit the room until the either party is comfortable with continuing. Observations will only continue if all residents in the group appear uninfluenced by the presence of the observer.

### **What are the benefits of participating in this study?**

Information obtained through this research study will enhance our current knowledge of dementia care and dementia care environments, and may contribute to advancements in future care for people with dementia.

### **What happens after the study is finished?**

Results of the observations will be included in Sarah Wu's MA thesis, along with any subsequent publications and presentations. Again, all names and data will be kept strictly confidential and anonymous by using pseudonyms and by presenting data in group form. No information that discloses a residents' identity, or your identity, will be released or published. All data will be stored on a password-protected computer and/or locked cabinet at Simon Fraser University. At the end of the study, all data will be destroyed accordingly.

### **What will the study cost me?**

Neither you nor your loved one will incur any personal expenses as a result of participating in the study.

### **Who do I contact if I have questions about the study during before or after I consent?**

If you have any questions or desire further information about this study before or during participation, you can contact:

**Sarah Wu at xxx-xxx-xxxx or xxxxx@sfu.ca**

or

**Dr Habib Chaudhury at xxx-xxx-xxxx or xxxxxx@sfu.ca.**

**Who do I contact if I have any questions or concerns about the residents' rights as a participant during the study?**

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, contact the Health Authority Research Ethics Board co-Chair at xxx-xxx-xxxx and/or Dr. XXXXX XXXXXX, Director, Simon Fraser University, Office of Research Ethics at xxxxx@sfu.ca or xxx-xxx-xxxx.

### **CONSENT TO PARTICIPATE**

I have read and understood the information and consent form.

I have had sufficient time to consider the information provided and to ask for advice if necessary.

I have had the opportunity to ask questions and have had satisfactory responses to my questions.

I understand that all of the information collected will be kept confidential and that the results will only be used for the research objectives.

I understand that my participation in this study is voluntary and that I am completely free to refuse their participation or to withdraw their participation from this study at any time without changing in any way the quality of treatment or care that my relative receives.

I understand that none of my legal rights are waived.

I understand that there is no guarantee that this study will provide any benefits to me or my relative/friend.

I understand that if a situation occurs that may be/is harmful to residents and/or staff (i.e., verbal, emotional, psychological, physical, or sexual abuse), this interaction will be reported to the director of care.

**By reading and understanding the information provided, you have agreed to participate in mealtime observations unless otherwise specified.**

## **Appendix M**

### **Resident Participant Observations Information and Assent Form**

Dear SFAC Resident,

As you are a resident living at the Stroud-Fung Alzheimer Centre, you are invited to take part in a research study. This study is trying to understand your dining experiences in order to improve mealtimes. It is your choice whether or not you would like to participate. Your participation in this study may help other residents, like yourself, to better enjoy their dining experience.

#### **What are we doing in this study?**

This study will try and understand how to improve mealtimes at this facility.

#### **What will happen in this study?**

If you agree to be in this study, a researcher will observe you during mealtimes over a month and a half (12 visits). She will be there at selected breakfasts, lunches, and dinners. You are free to speak with the researcher if you would like to make any comments or have any questions.

#### **Who is doing this study?**

Dr. Habib Chaudhury and Sarah Wu from Simon Fraser University will be doing this study. They will answer any questions you have about this study. You can telephone them xxx-xxx-xxxx or speak the Sarah Wu in person.

#### **Can anything bad happen to me?**

Nothing bad will happen to you in this study. Sometimes people do not like being observed during mealtimes. If you feel uncomfortable for any reason by the researcher, you can let her know. You can also let a staff member and your family member know you are feeling uncomfortable. You are free to leave this study at any time.

#### **Is my participation voluntary?**

Your participation is entirely voluntary. You can decide not to participate in the study at any time, for any reason, and your level of care will not change in any way. Let the Co-Investigator, staff member, and/or family member know when you would like to stop participating.

**When do I have to decide?**

You will have as much time as you need to think about this study, to ask questions, or talk about your concerns with the Co-Investigator, family member, and/or staff member. If you decide to participate, you are welcome to ask questions at any time until you receive an answer you are happy with. You are also encouraged to talk to your family members and friends about this study.

**Who will know I am in the study?**

All the information collected about you in this study will be kept secret. When the study is finished, the Co-Investigator will write a report about what they learned. This report will not say your name or that you were in the study.

**Who Do I Talk to if I Have Concerns or Questions?**

If you feel uncomfortable for any reason, you are encouraged to speak to any of the staff members, your family, and/or friends to ask for assistance or information. Sarah Wu is also available to answer any of your questions at any point.

*Please keep a copy of this for your records.*

**Person-Centered Care and Mealtimes in Residential Care Units  
Resident Assent to Participate Process – Documentation Form**

Resident participate assent was gained from \_\_\_\_\_

Name of participant

on \_\_\_\_\_ by \_\_\_\_\_.

Date

Co-Investigator

Assent was expressed in the following ways:

## Appendix N

### Protocol for Assent to Participate Process (Residents)

1. Substitute decision-maker has been contacted prior to the assent/dissent process with residents to provide information and gain consent
2. If consent is gained from the substitute decision-maker, the Co-Investigator will approach care staff in order to gain background information so as to become aware of any triggers that change well-being specific to that individual, as well identify how the individual would communicate assent or dissent through literal, implied, or non-verbal means.
3. Initial assent will be performed by going through the following points, using verbal or visual methods of explaining the research that is most appropriate for that individual:
  - I have understood the information and assent form.
  - I have had enough time to think about participating in the study
  - I have had enough time to ask questions and have understood the responses to my questions
  - I understand that all of the information collected will be kept a secret and will be only be used for this study
  - I understand that my participation in this study is voluntary and that I can leave at any time with out it affecting my level of care
  - I understand that none of my legal rights are waived.
  - I understand that there is no guarantee that this study will provide any benefits to me
  - I understand that if a situation occurs that may be harmful to me or to staff, that this will be reported to the director of care
4. Regardless of whether consent is obtained from the substitute decision-maker, if the resident expresses dissent towards participating, they will not be included in the study.
5. Ongoing assent will be monitored throughout the 12 participant observation visits in order to determine whether the individual wants to continue participation.
6. Evidence demonstrating that assent was obtained and continually monitored via an audit trail in the Co-Investigator's field notes

# Appendix O

## Care Staff Interview Guide

### Introduction

I'm interested in learning about what it is like to provide person-centered care to older residents with dementia in this care facility during mealtimes. I'm also interested to know how the physical environment affects how you provide care and how the residents experience mealtimes.

#### **A. Questions posed to staff during participant observations will focus on the following themes:**

1. Tailoring care delivery based on individual resident's preferences.
2. Knowledge and ability to administer mealtime care.
3. Role of individual characteristics of residents (physical and cognitive abilities) during mealtimes.
4. Interacting with the physical environment, which includes tableware, tables and chairs, ambiance, lighting, noise, etc.
5. Challenges and barriers at various levels (i.e. individual, management, and organizational culture).
6. Social interactions between staff and residents.
7. Social interactions between residents.

#### **B. Questions posed to staff during one-on-one scheduled interviews:**

##### ***Potential Questions***

##### **QUESTION 1:**

Let's begin by talking about what it's like to care for older people with dementia. Can you tell me what it's like to work as a [*insert discipline*] for people with dementia during mealtimes on this particular unit?

##### Potential Probes:

- What does a typical breakfast, lunch, and dinner look like for you?
- What's the most challenging aspect of meal service?
- What is the most enjoyable aspect of mealtimes?
- What part of mealtimes do you think residents enjoy the most?

## QUESTION 2:

Person-centered care can mean a lot of different things to different people working within different organizations. I'm interested in understanding how you understand and provide person-centered care during mealtimes. What do you think makes for good quality dementia care as a *[insert discipline]*?

### Potential Probes:

- How do you define person-centered care?
- What information have you been given about person-centered care by this facility?
- What makes it challenging to provide the care you want to during mealtimes?
- What makes it easy to provide good care during mealtimes?
- How have you found the residents to respond when you provide person-centered mealtime care?
- How have you found the residents to respond when you haven't provided person-centered care at mealtimes?

## QUESTION 3:

An important aspect of person-centered care is social interaction. This can include verbal and non-verbal communication (i.e., body language, sounds, touch). Social interactions also play a big part of enjoying mealtimes. How do you as a *[insert discipline]* facilitate meaningful social exchanges between residents, and between residents and yourselves, during mealtimes?

### Potential Prompts:

- How big of an impact do you believe your care approach is on residents' mealtime experiences?
- What are some challenges you face facilitating meaningful social interactions?
- What makes it easy to facilitate meaningful interactions?

## QUESTION 4:

a) The physical dining room can have a big impact on the residents' mealtime experience, and your ability to provide quality dementia care. Are there any particular aspects of the physical dining room (i.e., positioning of tables and chairs, lighting, noise levels, colours, etc.) on this unit that make it easy or difficult to provide good care?

### Potential Prompts:

- How do you think the physical dining room affects the residents?
- What aspects of this dining space support you in providing good care?
- What aspects of this dining space make it difficult for you to provide good care?
- How do you think the physical dining room affects your ability to work with other staff?

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

Potential Prompts

- Consider the following aspects of the physical environment, such as lighting, noise, smell, and orientation.

**QUESTION 5:**

a) Reflecting on the responses you've given me so far to my questions, are there any particular aspects of this organization's care policies and procedures, scheduling, and staffing, that make it easy or difficult for you to provide person-centered care at mealtimes?

Potential Prompts:

- How do you feel the facility's policies and procedures affect your ability to work with residents?
- How do you feel management supports you in providing the kind of care you want to give residents?
- How do you feel management does not support you in providing the kind of care you want to give residents?

b) What changes would you make to any of the mealtime policies or procedures that would allow you to provide better care to residents?