

**'Here Comes the Sun':
Enriching Lives and Reducing Agitation for Residents with
Dementia in Long-Term Care Homes**

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Abstract

This study sought to investigate the consequences of offering socially derived programs geared to reduce agitation in residents of a secure dementia unit in a LTC home. Data were collected through the generation of field notes based on observations of unit activities and through semi-structured interviews conducted with five staff members of a LTC home in Ontario. Discussion focuses on findings from both observations and qualitative interviews. Situating the discussion within the context of a social constructivist framework, this study offers an understanding of the effects of providing meaningful activities to persons with dementia in the LTC context as a means to reduce agitation and improve quality-of-life. My thesis provides insights into the effectiveness of social programs to reduce agitation in persons with dementia in the LTC context and has implications for future care in a LTC setting.

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Chapter One: Introduction and Literature Review

Little darling, it's been a long cold lonely winter. Little darling, it seems like years since it's been clear. Here comes the sun. Here comes the sun, and I say it's alright. (George Harrison 1969)

In research and practice regarding dementia and the care and services for seniors with dementia, the predominant approach has for the most part been based in a biomedical model, which assumes that the behaviours of persons with dementia are a direct result of disease processes and changes in the brain (Clarke 1999; Russo-Neustadt & Cotnam 1997; Sweet et al. 1997). Problem and deficit based approaches to the care of individuals with dementia and the resulting stigmatization of their behaviours causes a great deal of unnecessary suffering (Dupuis, Wiersma & Loiselle 2012a: 162). For example, persons with dementia are thought to become anxious and/or prone to displays of agitation late in the afternoon, a condition frequently called “sundowning” (McLean 2007: 29). The term “sundowning” objectifies the person with dementia and implies that their behaviours are symptoms of the disease. As such, those with dementia are often understood and treated not as persons in their own right, but solely on the basis of their dementia related behaviours. These biomedically based assumptions and resulting care practices lead to negative consequences for persons with dementia. Thus, it has been “a long cold lonely winter” for those with dementia. But, traditional assumptions and care practices are currently being challenged. Without suggesting that all is sunshine from this point forward, there is reason to suspect: “here comes the sun.”

This study seeks to add to a small but growing body of literature that examines the social context in which people with dementia are situated, and the positive changes

that can happen when they are not treated as “empty shells” (Scholl & Sabat 2008). Using qualitative methods, I examine the effectiveness of social programs geared to reduce agitation in residents of a secure dementia unit in a Long-Term Care (LTC) home, focusing on the consequences for residents and staff.

This chapter begins by situating my research within the context of literature about the current status of Canadians with dementia and the predominant methods of research in the field of care for seniors with dementia. This is followed by a discussion of studies relating to research on dementia and typical behaviours for people with dementia, including agitation. I then discuss person-centered care, and conclude the literature review with a closer look at some current studies relating to agitation in persons with dementia in the LTC context and a discussion of the problems with existing research.

The Canadian population is aging (Chappell, McDonald & Stones 2008: 27). This being said, advancing age remains the single strongest risk factor for developing dementia and prevalence rates are expected to increase significantly in the coming years (O’Rourke, Bédard & Bachner 2007: 256). As such, research on dementia and the care of persons with dementia is becoming more important to many Canadians (Rockwood & Keren 2010: 878). The increase in rates of dementia have significant implications for the provision of care in both long-term and community care settings (Sachs, Shega & Cox-Hayley 2004). According to the Canadian Institute for Health Information (CIHI), in 2010 approximately 57% of persons living in LTC had a diagnosis of Alzheimer’s disease or a related dementia. This indicates there are more persons living in LTC with dementia, and these numbers are expected to increase. Furthermore, changes in entrance requirements for LTC in Ontario, as outlined in the 2007 Long-Term Care Homes Act,

requires persons to have more complex care needs than in previous years to be considered for placement in LTC. This means people in Ontario are less likely to enter LTC until they have advanced dementia. Also, the LTC sector is facing substantial changes pressured by increased demand to meet the care needs and ensure a high quality-of-life for the growing number of older adults, particularly those living with dementia (Miller, Booth & Mor 2008; Gibson & Barsade 2003; Stevens 2001). A report prepared by The Conference Board of Canada for the Ontario Long-Term Care Association (OLTCA) outlined that Ontario's capacity to provide affordable, accessible, and high quality care in LTC settings is in jeopardy and will not meet future needs without significant innovation and transformation (2011).

As indicated by Dupuis et al. (2014), these growing demands on service providers in the LTC sector have resulted in increased case loads, conflicts between front-line and supervisory staff and a focus on task-oriented approaches to care. It is also suggested that these pressures have contributed to low morale in LTC staff members, low job satisfaction, high turnover rates and absenteeism, and difficulty recruiting and retaining skilled professionals and strong leaders in LTC. Furthermore, Dupuis et al. state:

These issues, which directly impact the provision of quality care, are exacerbated in the context of dementia care because of the misunderstandings and stigma associated with the disease (2014: 2)

Clearly there is a growing demand for service providers in the LTC sector to meet the challenges of an aging population, and these challenges are further complicated by the prevalence of dementia and misconstructions of the disease.

Predominant Views and Practice in Dementia Studies and Dementia Care

In North America, dementia continues to be mainly understood within biomedical/pathophysiological and psychological/psychosocial models of illness and disease (Clarke 1999). Within biomedical approaches, persons with dementia are viewed through the lens of illness and sickness, which sees their behaviours as a direct result of disease processes and changes in the brain (Davis 2004; Russo-Neustadt & Cotnam 1997; Sweet et al. 1997). From this perspective, dementia has been understood as a disease with a trajectory of irrevocable decline resulting primarily from neurodegenerative changes in the brain (O’Conner et al. 2007: 122). As a result, most research and practice in the field of dementia assumes that the actions of persons with dementia are not under their control and are simply symptoms of the disease, which leads to persons with dementia being viewed as “robots controlled by forces beyond their reach” (Shillings 2005: 44).

Because of biomedically based understanding, many psychological approaches focus on managing behaviour of persons with dementia, and some of these approaches attempt to link behaviours to psychiatric disorders in order to identify pharmacological treatments (Volicer & Hurley 2003; Tariot 1999). In biomedically based approaches, behaviours of persons with dementia are conceptualized at the individual level, and the broader social contexts that shape human actions are rarely considered. As Dupuis et al. state:

Guided by such a micro lens, it is not surprising that identifying clinical interventions to manage individuals displaying the behaviour has been a large focus of research and practice in this area (2012a: 163).

How we frame the behaviours of persons with dementia influences our decisions and actions (Hantikenen 2001; Gubrium 1986). Dominant discourses shape how behaviours are understood in the dementia care context, and subsequently influence the approaches used to respond to behaviours (Dupuis et al. 2012a: 163). These approaches can cause much unnecessary suffering for persons with dementia, affecting how they perceive themselves, how they are perceived and judged by others, and the choices and opportunities made available to them (Kontos 2005; Fazio, Seman & Stansel 1999). Individuals with dementia come to be defined by misunderstood behaviours, such as a “sundowner,” “wanderer”, “screamer”, or “exit seeker” (Dupuis 2010). Even though the actions of a person with dementia may be appropriate and completely legitimate in a given circumstance, the behaviours and consequently the individuals are often labeled as abnormal or deviant because broader social contexts are rarely considered (Dupuis et al. 2012b).

From the biomedical perspective, typical behaviours of persons with dementia, such as displays of agitation, are viewed as a direct result of the disease, especially in moderate to advanced stages (Sink et al. 2004: 1277). Behaviours that are commonly understood as being related to dementia, such as physical attacks towards family and friends, lack of interest in daily activities, incontinence, overeating, screaming or yelling without apparent reason and wandering or getting lost (O’Rourke et al. 2007: 263), are primarily understood as biologically determined. As a result of this biomedical understanding of dementia and agitation, behaviours of persons with dementia are mostly seen through the lens of pathology and all actions are attributed to the condition (Downs, Clare & Mackenzie 2006: 240). This medical gaze views the “patient as the rediscovered

portrait of disease. He is the disease itself, with shadow and relief, nuances and depth” (Foucault 1973: 15). Hence, complex behavioural phenomena “must be reduced to organic principles to be understood or ignored” (McLean 2007: 31). Furthermore, because of this medical gaze, persons with dementia are not “seen as people within their own right, as individuals with normal responses and emotions to situations” (Dupuis et al. 2012a: 163).

Persons with dementia come to be viewed as a significant “burden,” and behaviours become things that need to be “managed” and “controlled” rather than understood (Volicer & Hurley 2003). As McLean explains:

Biomedically oriented care assumes a model that prioritizes the body over the person’s experiences, attempts to control or suppress symptoms and behaviours rather than try to understand them, and objectifies the person in order to carry out care tasks (2007: 34).

For persons with dementia, especially in the LTC context, “controlling” or “managing” behaviours often leads to the use of restraints (McLean 2007: 22). Restraints can include physical things such as bed rails or straps to prevent residents from falling out of bed, or pharmacological restraints such as anti-psychotic medications. (Mortenson et al. 2012; Ray, Bernard & Phillips 2009). Because of the predominance of this biomedical approach to the management of behaviours of persons with dementia, and despite the use of pharmacological restraints being associated with adverse health outcomes such as cerebrovascular adverse events (CVAs) or death, the use of medication to reduce behaviours in residents of LTC with dementia is commonplace in LTC facilities in Ontario (Stones 2010; Feng et al. 2009). The use of pharmacological restraints, commonly referred to as “pacification” (Butler 1975), often results in the overuse or

misuse of medication for the purpose of reducing agitation in residents of LTC with dementia as a substitute for humane attention (Stones 2007; Honeyman & Van Maanen 1991).

A recent case study by Sabat and Lee examines the “social relatedness” of persons with dementia in an adult day centre utilizing secondary data from standard tests and clinical examinations (2012). “Social relatedness describes the way in which one person can connect meaningfully to another and can include how one interprets the environment, the actions of others, and other elements” (Medeiros, Saunders & Sabat 2011: 283). Through a constructionist method of investigation and analysis, Sabat and Lee point out that often the staff in care facilities for persons with dementia rely on standardized assessments to frame their understanding of residents’ behaviours, potentials and limits (2012). These standardized tests provide a distorted and potentially inaccurate context from which staff form expectations about the abilities of persons with dementia. Sabat and Lee further explain how there is evidence that persons with dementia possess cognitive abilities that are not assessed or appear dysfunctional or non-existent based on standardized testing. As such, Sabat and Lee suggest that staff in care facilities who work with persons with dementia should not form expectations based on these tests, but rather seek to know and understand residents for the people they are in the social world (2012).

A Social Constructionist Perspective on Dementia Behaviours

Though most research and practice surrounding dementia and behaviours viewed as being associated with dementia come from a biomedical perspective, O’Conner et al. state:

Growing evidence suggests that the performance and behaviours of persons with dementia are not exclusively determined by neuropathology, but are also influenced by personal histories, social interactions and social contexts (2007: 121).

In contrast to the predominant biomedical approach, a social constructionist perspective stresses that the self is not dissolved during the progress of dementia and the behaviours of others can to some extent impact the degree to which the self is diminished (Arseneau 2009; Dorenlot 2005; Holst & Hallberg 2003; Bond & Corner 2001; Sabat et al. 1999). Sabat and Harré (1992) explore issues pertaining to dementia from a social constructionist standpoint by analyzing the book *Alzheimer's Disease: The Loss of Self* by Cohen and Eisdorfer (1986) and data collected from a dialogue exchange between a person diagnosed with dementia and a person without a diagnosis of dementia. Based on this research, Sabat and Harré suggest that people diagnosed with dementia can engage in conversation showing that they are aware of their environment and capable of working towards sustaining their presented selves. Arseneau (2009) drew similar conclusions based on her research involving conversations with people with advanced dementia.

Kontos conducted an ethnographic study of selfhood in a LTC facility in Ontario, which involved participant observations of persons with moderate to severe dementia (2004). Kontos argued that the presumed erosion of the self for persons with dementia is not only not based in their “neuropathology,” but is to a large extent the result of predominant attitudes or “philosophical inheritance” (p. 830). The “philosophical inheritance” Kontos refers to is the deeply entrenched biomedical assumption that cognitive impairment of persons with dementia inevitably ensures a loss of personhood (p. 830). In contrast to this assumption, Kontos found that research participants

demonstrated awareness of their surroundings and actively engaged with others with definite purpose and meaning, which suggests the “self in dementia is guaranteed through social interactions” (p. 846). Furthermore, based on inferences from her ethnographic study, Kontos indicates that residents with dementia in an Ontario LTC setting “generally observed the manners prescribed by social convention for interaction with others” (2010: 132). This suggests that when persons with dementia are afforded opportunities to engage with others in a social setting, they may be less likely to display agitation or socially inappropriate behaviours.

McLean investigated the impact that a person-centered model of care for persons in a LTC context with dementia had in terms of allowing residents to maintain the self and improve their quality-of-life (2007). In this research, McLean compared two divergent approaches to care in the same LTC facility in identically designed special care units that provided care for persons diagnosed with dementia and who were exhibiting disturbed behaviours. The approach to care on one of the units was person-oriented (Snow 2) and the other focused on a biomedically based task-oriented care model (Snow 1). McLean suggests that the “dramatic differences in outcomes in the six case studies provided affirmative evidence of the superiority of intersubjective person-oriented care over instrumental task oriented care” (2007: 199). McLean further explains:

The Snow 2 staff involved in their care was also committed to trying to understand and satisfy the elder’s own perceived needs and the meaning of their disturbed behaviours as caregiving proceeded. In contrast, elders from Snow 1 were viewed as if they were irrelevant to their care and as if their own perception of their needs did not matter. The exceptionally positive outcomes for the residents from Snow 2 case studies demonstrated the value of engaging the person in the care-giving transaction. In contrast, the negative outcomes for residents from Snow 1 offered evidence not only of the limitations, but also the injury that can result from instrumental caregiving that ignores the person (p.199-200).

In a recent cluster-randomized trial by Chenoweth et al., the “Caring for Aged Dementia Care Resident Study” (CADRES), “person-centered” care was shown to be an effective means of reducing agitation in persons with dementia and offered hope for a better quality-of-life for persons with dementia in residential care (2009). Another recent study by Terada et al., utilized a questionnaire to evaluate “person-centered” care and to assess “person-centered” care and quality-of-life of elderly patients with dementia in both geriatric health service facilities (such as LTC homes) and hospitals. This study indicated that dementia care characteristics and quality-of-life are significantly inter-related (2013: 103).

The shift from a biomedical view of dementia (American Psychiatric Association 1994) to a focus on individuals’ interaction and social context (Hughes, Louw & Sabat 2006; Kitwood 1997; Sabat & Harré 1992) has emphasized that dementia care and research cannot be explained based solely upon the view that dementia concerns “a person whose brain is failing” (Kitwood & Bredin 1992: 273). Rather, research and care should encompass the needs of the person (Goyder 2009, Wilkinson 2002; Kitwood 1997). Furthermore, adopting holistic and individually focused understanding, that considers both the social contexts and the uniqueness of every individual, promotion of the now well-established concept of “personhood” (Kitwood 1997) appears pivotal (Nowell, Thorton & Simpson 2011: 394-395).

“Person-centered” approaches to care and research, which conceptualize dementia and the behaviours of persons with dementia as dependent on not only pathological processes but also the social psychology of the person affected, are receiving much attention and are being used and tested throughout the world (Stein-Parbury et al. 2012;

Edvardson, Winbald & Sandman 2008; Kitwood 1993). In the field of dementia care, “person-centered” care has become more valued (Murray & Boyd 2009), and there is considerable evidence of continuing personhood in dementia (Arseneau 2009; Scholl & Sabat 2008; Sabat 2002; Kontos 2004; Kitwood 1997). Furthermore, recent research suggests that although it may change, identity is sustained among persons living with dementia (Sabat & Lee 2012; MacRae 2010; Beard, Knauss & Moyer 2009; Harris & Keady 2009; Harris & Sterin 1999). It is clear that persons with dementia remain people, and efforts made to treat them as persons have resulted in positive changes in care and practice.

Person-Centered Care

The philosophy of “person-centered” care, first proposed by Kitwood, regards the behaviours of persons with dementia as dependent on both the pathological processes and the social psychology of the individual affected, and strives to maintain an individual’s sense of “personhood” throughout the progression of cognitive decline (1997). There is no consensus regarding the concept of “person-centered” care, but there are a few commonalities in its approach, such as: striving to maintain personhood in spite of declining cognitive abilities; collecting and using the personal experience of life and relationships to individualize care and the environment; prioritizing relationships as much as care tasks; and involving family members in care while offering shared decision making (Terrada et al. 2013: 104). As stated by Kelly, “A person-centered approach to dementia care has at its core the goal of maintaining the personhood of people with dementia” (2010: 104). All in all, a “person-centered” approach to care views the

contexts of individuals and their social environments as the primary focus for providing quality care to persons with dementia.

In a recent three-year multi-method observational study, involving non-participant observation and recording field notes that explored the “social worlds” of 14 people with dementia in continuing care (such as a LTC facility or hospital), Kelly (2010) found that recognizing and supporting selfhood during interactions with residents can lead to qualitatively different staff behaviours and consequences for the well- or ill-being of persons with dementia. Furthermore, Kelly explains:

By integrating the person-centered and selfhood approaches throughout the data collection and analysis, a deeper understanding of the operational elements of interaction and well-/ill being were identified, as well as operational elements of the participants self expression (2010: 120).

By utilizing an approach that considers the social context of the person with dementia and their individuality throughout the research process, Kelly’s study demonstrates that when the behaviours of persons with dementia are not reduced to an understanding that assumes they are merely symptoms of the disease, it can result in a broader understanding of the implications of other social factors that may significantly influence their actions.

There are some psychologically-based, quantitative studies that recognize the utility of social interventions for influencing the behaviours of persons with dementia, and these studies show promising results in terms of the potential to reduce agitation while improving happiness and quality-of-life for person with dementia in the LTC context (Stones in press; Rocha et al. 2013; Terrada et al. 2013; Crooks et al. 2008; Bohlmeijer, Smit & Cuijpers 2003; Rattenbury & Stones 1989). However, these studies are based in a biomedical/psychological framework, so that the behaviours of persons

with dementia are primarily understood as co-morbidities of the disease. Consequently, this research does not adequately attend to the significance of social factors in producing overall well-being.

Social Interaction/Activities and Leisure

The benefits of social interaction and friendships, including the ways this contributes to overall health and well-being, have been well described (Giles et al. 2005; Kurer et al. 2000; Berkman et al. 2000; Williams & Roberts 1995). The importance of companionship, social integration and meaningful activity for contributing towards quality-of-life and well-being for persons with dementia has been documented in other research (Mitchell, Jonas-Simpson & Dupuis 2006; Chung 2004; Raynes 1999; Murphy, Glover & Davis 1996). Studies have shown that even something as simple as “meals eaten with others provide people with dementia a sense of belonging, comfort, and familiarity” (Genoe et al. 2012: 174). Furthermore, mealtimes have been identified as important occasions for building caring relationships in LTC (Amella 2002; Kayser-Jones 1997).

Phillips, Reid-Arndt and Pak investigated the impact of “creative expression interventions” which are socially derived programs geared towards persons with dementia that emphasize the uniqueness of persons, enabling them to feel included, supported, and valued such as performing or writing music. Phillips et al. used a quasi-experimental, two-group, repeated measure design to compare persons with dementia receiving creative expression interventions (n=28) with persons receiving no interventions (n=28) across nine different LTC facilities in the United States. This study suggests that the individuals who were given an opportunity to engage in social programs

showed increased expressions of pleasure and better communication as compared to individuals who were not provided similar interventions (Phillips et al. 2011).

Dupuis et al. (2010) interviewed persons living with memory loss in both community and LTC settings, and found that persons with memory loss seem to seek ways to express themselves, find meaning in their lives, and look for a range of experiences in their leisure that allow them to continue to “live” and even celebrate life despite dementia. Subsequently, Genoe and Dupuis further commented:

More specifically, they look for opportunities in their leisure to: have fun, make a difference, seek freedom, be with [others], be me [themselves], find balance, and grow and develop (2014: 34).

Another qualitative study based on interview data collected from persons with dementia in the community and LTC contexts suggests that enjoyable activities provide a way of feeling “alive” and connected to the world (Phinney, Chaudhury and O’Conner 2007). Indeed, there is considerable research to indicate that leisure plays an important role in supporting identity (Kleiber, Walker & Mannell 2011; Genoe 2010; Kleiber 1999; Haggard & Williams 1992) and can be of particular importance when a person experiences a traumatic life event, such as the onset of an illness like dementia (Reynolds & Prior 2006; Reynolds & Prior 2003; Hutchinson et al. 2003; Kleiber, Hutchinson & Williams 2002). Findings from an interpretive phenomenological study of four persons living with dementia conducted by Genoe and Dupuis revealed that leisure served as an important space to uphold the identity of a person with dementia and allowed them to remain engaged in life (2011: 423). As succinctly stated by Beard, Knauss and Moyer (2009: 227), “Engaging in leisure helps persons living with dementia to cope with the changes they experience.”

Based on her extensive experience working in the field of aging and dementia studies (2009), Basting discusses useful interventions to augment quality of life for persons with dementia. She examines different socially based programs and interventions such as sharing stories, singing and performing live music and plays, and different art projects and ventures. Though different activities require different levels of functionality for various persons with dementia, overall, most of the programs suggested by Basting require minimal abilities. Furthermore, programs and activities can be adjusted to fit the capabilities of a given person with dementia, and as previously discussed, merely affording the opportunity for social engagement and interaction for a person with dementia is beneficial. Basting suggests that offering these activities provides:

a way to open those avenues for meaning-making between people who cannot communicate through traditional, rational language. Music and songwriting, dance, non-linear storytelling, poetry, open conversation, painting, sculpting, responding to art: all of these give us ways to connect with each other, express who we are and what we believe. They can put meaning back into what we fear are meaningless lives (p. 164).

Basting continues:

We need research that convinces policy makers that training care partners to foster meaningful moments with people with dementia might work better than pills, and without side effects. Meaning-making might even work to reduce stigma and fear, something a pill can never do (p. 164).

As this research has shown, clearly persons with dementia seek ways to maintain and uphold their identities, and socially derived activities and opportunities for leisure have significant positive implications to this end. Furthermore, investigations that consider the social contexts and the individuality of every person show promise for future improvements in research methods and the quality-of-care that we provide to persons with dementia.

Improving Research and Practice

O'Rourke et al. (2007) attempt to quantify "behavioural disturbances" and compare the likelihood and severity of said instances between institutionalized persons with dementia and those in the community. In this research, they assume that these behaviours are simply a result of the dementia, and consequently pay little attention to the potential social cause(s) of "behavioural disturbances." As a result, some very significant questions are not considered, such as: What was the person with dementia's relationship with the caregiver? What were the social conditions and available resources of the ones being cared for or providing care? Were regular care hours and/or routines maintained? Was the person with dementia sad, depressed, lonely, bored, uncomfortable, tired, or in pain when the "behavioural disturbance" occurred? What is the quality of care like? Did the resident have a visitor that day? By not taking social considerations into account, the picture that is painted is not only incomplete, but also suggests that the reported behaviours are simply a result of the dementia.

An exploratory descriptive study conducted by Rocha et al. (2013) that looks into the activities and participation of 393 people with dementia across 40 different LTC facilities indicates that residents in this context have significant disability and cognitively related limitations. Although the study suggests that participation in activities "seems to be crucial" (p. 1508) for the LTC population of residents with dementia in terms of rehabilitation, there is limited consideration of the social factors associated with the ability to participate in available activities. Many environmental and social factors are not investigated. For example, because this study tries to fit social factors into quantitative categories for analysis, the researchers consider variables such as the marital

status of the participants, but fail to consider whether the resident's spouse or significant other was in the facility with them, or in the same room. Additionally, other crucial questions were not investigated, such as:

- How many friends did they have in the building?
- What was the size of the unit, or the building?
- What services were available?
- Were residents offered indoor or outdoor activities?
- What time did activities occur and how often, daily, weekly, monthly?
- Did the resident have choices as to what activities were offered?
- Were participants always on the unit?
- Did some have regular family visits and/or outings? Which volunteers were involved with which residents?
- Did they speak the same language or have different cultural values and norms?

Altogether, Rocha et al.'s quantitative approach to the collection and explanation of their data overlooks important social factors that contribute significantly to the question of whether residents with dementia participate in activities, what the resident's possible limitations are, and what benefit these activities provide.

Don't Let The Sun Go Down

Stones and his students at Lakehead University in Thunder Bay, Ontario investigated the impact of Life Enrichment Programs in terms of reducing agitation for residents of a secure dementia unit in a LTC facility (in press). Activities were provided to residents on Wednesdays, Thursdays and Saturdays from 3:15 p.m. – 4:15 p.m. during the shift change for staff as it was believed that this was a time during the day that

residents tended to display instances of agitation. Designated frontline staff members were asked to complete a chart with a brief description of any event that they deemed as being agitation, reporting on the time intervals of 2:00 p.m. – 2:30 p.m. and 3:45 p.m. - 4:15 p.m. Monday through Saturday. Although the intent of this study was to obtain data for a one-month period for six days per week, due to a virus outbreak at the facility only 11 days were observed and 17 report forms completed. Despite the setback, quantitative data collected suggested that the Life Enrichment program routinely offered at the home did lower the number of reports of agitation on this secure dementia unit.

Attention to the qualitative context was lacking in this research, but such attention could facilitate a clearer understanding of the value of Life Enrichment activities designed to reduce agitation in residents with dementia. For example, it would be helpful to have a description of the unit, who participated in activities and how, and/or to what benefit. Also, important questions that relate to social factors could be considered, such as:

- How did providing an activity to residents with dementia change their behaviours?
- What activities were offered on what days?
- What kind of barriers did residents encounter in terms of their ability to participate?
- How many staff/volunteers/guests provided activities?
- What kind of activities worked best or allowed for the greatest level of inclusion?
- What other consequences did offering these programs have?

This study views the behaviours of “severely demented” residents as co-morbidities of dementia and as something that need to be “managed” (Stones: in press), thereby furthering the biomedical approach to research and care of persons with dementia. Furthermore, as Dupuis et al. (2014) suggest based on their qualitative investigation into quality care provisions in LTC and the changing culture of care to reflect more client-driven and relationship-centered models, studies that rely on clinical outcome measures “inadequately reflect client experiences and fail to use these experiences to inform effective care decisions” (p. 3). But, “here comes the sun.”

My study aims to more fully capture the consequences of programs designed to reduce agitation in residents of LTC with dementia by utilizing qualitative methods of inquiry and incorporating a sociological perspective, which views the actions and behaviours of persons in this context as not determined only by their pathology, but as significantly shaped and influenced by their social context.

Conclusion

Canada has an aging population and more people will require health and social services in older ages. Despite this, there are decreasing resources available in the LTC sector. A significant concern for our aging Canadian population is the prevalence of dementia. For the most part, biomedical models remain dominant in terms of our approach to research and the care of persons with dementia. However, there is recognition on the margins that person-centered care is important and the importance of leisure, social activities and social interaction for persons with dementia. The aim of my study is to show the importance of offering socially derived activities to persons with

dementia in a LTC home and to demonstrate the positive impacts that can result from not understanding their behaviours as artifacts of their disease.

I began this chapter by situating my research within the context of literature about the current status of Canadians with dementia and the predominant methods of research in the field of care for seniors with dementia. This was followed by a discussion of studies relating to research on dementia, typical behaviours for people with dementia, and agitation. I then briefly discussed person-centered care, and concluded the literature review with a closer look at some current studies relating to agitation in persons with dementia in the LTC context and a discussion of the problems with existing research. The literature review will be followed by a discussion and justification of the methodology I utilized in my study in Chapter 2, and the results from the observations and interviews that I conducted in Chapters 3 and 4. I will end my research report and make final conclusions in Chapter 5.

Chapter 2: Methods

Research about dementia continues for the most part to be framed and understood within the context of biomedical models of illness and disease (Dupuis et al. 2012a: 163). In contrast to reliance on a biomedical model, I bring a “sociological imagination” (Mills: 1959) to bear on my own research about dementia, and seek in this study to offer a different perspective regarding agitation shown by persons with dementia. In this study I consider the social and situational contexts for individuals living on a dementia unit at a long term care (LTC) home, and does not assume that their various behaviours are simply a result of the disease process of dementia.

My goal with this case study is to examine the effectiveness of socially derived programs geared to reduce agitation in residents of LTC with dementia, by using qualitative methods to examine the consequences for residents and caregivers. In this chapter I begin with a discussion of my social location to situate myself in the research, followed by an explanation and justification of the methods used in this study. This is followed by a description of the setting where I conducted my research, the process of observations, how I recruited interview participants, the interview process itself, and how I went about interpreting and analyzing the data I collected.

A Reflexive Note

As a researcher, it is important that I practice reflexivity to identify the ways in which my social location affects my interpretations and perceptions of the social world (Bourdieu 2004). Not only does my social location affect how I perceive individuals and

environments, but also, in terms of race, class, gender, or age, my social location has an impact on what people will say to me and how they will interpret my actions (Manderson, Bennett & Andajani-Sutjahjo 2006). As a white, middle class male in my mid-thirties, I think residents and staff are comfortable with my presence. I look non-threatening, and my appearance is consistent with what most residents and staff would expect in this context, as most of the people who work in this LTC home are white, and most are mostly in their thirties and forties. I have very good interpersonal and communication skills, and in combination with my social location this helps me to establish credibility in what I have to say.

I bring to this research many years of experience in a LTC environment as a volunteer and as a visitor. For most of my life, I have been exposed to older people in the LTC context and I grew up with family and friends who are involved with the homes and services for seniors' sector. As such, I feel that high standards in the quality and appropriateness of care for seniors is very important. In the LTC context, I have been involved with many residents with dementia, and I believe that they should be treated as persons and with the respect and dignity that they deserve as persons. I am familiar with the particular LTC home where I conducted my research, and over the years have spent time doing activities and being involved in various programs with many of the home's residents both on and off the secure dementia unit. I have not worked with any of the current residents of the secure unit. I have not met all of the staff members of the home, but I am familiar to most, and I have friendships with various staff members across all departments from food services to nursing. Though I did not have previous friendships with any of the interview participants, or staff members who worked in the secure

dementia unit at this LTC home, my access to the LTC home and my resulting comfort level in this environment was indeed developed through prior experiences at this home.

In a different context, I have spent time with my own family members with dementia. I am therefore sensitive to the challenges created by different social contexts, such as living in a facility that cares for older people. Thus, I bring to this research the strong conviction that there is a need to change our approach to the care of people with dementia. I believe there is a need to shift to a model that identifies residents of LTC with dementia as persons whose actions have meaning beyond a response to the disease, and recognizes the impact that their social context has on their behaviours.

Despite bringing some experience in the context of LTC and with persons who have a diagnosis of dementia to my research lens, I do not know what it is like to live in a LTC home, nor do I know what it is like to experience dementia in older age. Though I am limited in my understandings of what it is like to be a person with dementia in this circumstance, I hope with this study to describe the behaviours of persons with dementia appropriately by considering their social context and not necessarily equating their various behaviours to symptoms of dementia.

Research Design and Data Collection

With this research I aim to examine the impact of social programs to reduce agitation for residents of a secure dementia ward in a LTC home. To this end, I used qualitative methods to establish a clear picture of how these programs impact the residents, staff, and volunteers. I used a qualitative case study approach, as this method of inquiry incorporates multiple data sources and seeks to provide an in-depth understanding of a specific case (Creswell 2013: 98). Furthermore, case study research

investigates a bounded system in time and space in a particular physical and sociocultural context and is conducted using a variety of methods and data sources, such as observations and interviews (Silverman 2011: 16).

To get first-hand experience with residents of the secure dementia unit, I needed to spend time in the LTC home observing the residents and ward activities for the purpose of discovering underlying meanings and patterns of relationships (Babbie 2009: 527). Observation is one of the key tools for collecting qualitative data, and is the act of noting phenomena in a field setting through the five senses of the observer, often with an instrument, and recording it for scientific purposes (Angrosino 2007). I also wanted to observe residents in their regular day-to-day environment and did not want to have my presence as an observer affect their behaviours. As such, I chose to be a “non-participant observer” (Creswell 2013: 167), taking field notes and recording data without direct interaction with residents and without participating in the activities offered to them during the study period. I designed a chart for recording observations according to whether activities were offered and how residents responded (see Appendix A). I did not want to rely on reports from staff (as previous studies had done), based on my intent to improve upon previously utilized research methods and to form my own impressions of the value of social programs for residents with dementia in the LTC context. As well, I was concerned that staff members and I might have different interpretations of residents’ behaviours and did not want to be constrained by their understandings.

In order to count the instances of agitation among the residents on the dementia unit, I used an “operational definition” (Bouma, Ling & Wilkinson 2009: 50) of “agitation” as consisting of any actions of a resident that I perceived to be an indication

of experiencing distress or discomfort. Such indications included visible/audible discomfort, visible/audible confusion, visible/audible frustration, visible/audible anger, visible/audible sadness, yelling, screaming, wandering, exit seeking, and violent or sexually inappropriate behaviour. Based on my fairly intimate knowledge of the residents that I have developed over years of exposure in this particular LTC environment, I planned to rely upon my own discretion and judgement regarding whether to classify behaviour as an instance of agitation. For example, if a resident was walking down the hall, this would only be counted as an instance of agitation if I noticed signs of angst compared to their regular demeanour, or if I thought their actions were particularly unusual, such as the resident uncharacteristically walking around in circles, walking back-and-forth, or walking in and out of rooms that were not theirs.

I planned to observe the residents and ward activities from the nursing station of the secure dementia unit located in the center of the ward (see Diagram 1 in the next section). From there, I would be able to view part of the circular hallway surrounding the nursing station, (the hallway contains the resident's rooms on the outside walls and bathroom facilities in the center past the nursing station), and all of the dining/common room and television sitting areas. I chose this location because it was only partially visible to the residents of the unit so they were unlikely to behave based on being influenced by my presence. I also planned to collect observational data from conversations with staff and from documents, which would provide some information as to the behaviours of those not readily visible during my observations.

Though I made every attempt to make observations as accurately as possible, I was not expecting to be able to directly or indirectly observe every instance of agitation

that occurred on the unit. Furthermore, because I was the only one recording observational data, I cannot test for “inter-coder reliability” (Singleton & Straits 2010: 136). Those these factors limit the generalizations that may be inferred from the data I collected, results from my observations are only meant to be indicative and/or illustrative of the consequences of offering socially derived programs to persons in a LTC dementia unit.

I also sought input from staff members to get different opinions about what I observed, learn their feelings about different phenomena, and gain insight as to how they made sense of residents’ behaviours (Silverman 2011: 131). During the observation period, I identified a purposive sample of prospective participants based on my judgement as to which staff members would provide the most useful and representative interview feedback (Babbie 2009: 207). I sought to interview differently situated staff members who were involved in daily interactions with residents of the secure dementia unit and were on-site during the observation period. During the observation period I was able to build rapport with these staff members at the facility, which increased the likelihood that they would agree to an interview and disclose detailed perspectives (Creswell 2009: 154). I was interested in gaining insight into the cultural frames people use to make sense of their social worlds (Silverman 2011: 131). I also sought to conduct interviews individually rather than in a focus group so that participants would not feel constrained or influenced by the power differentials amongst participants, as this could be a consequence of interviewing in focus groups (Nicholas et al. 2010).

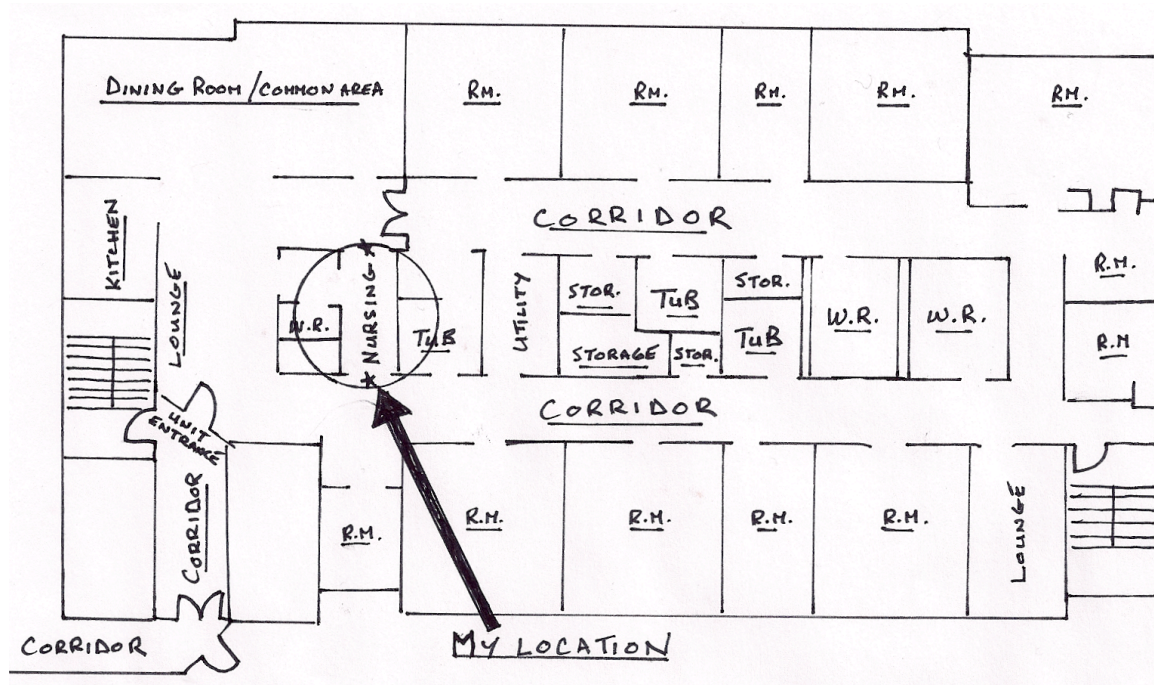
The Setting

I conducted research on the secure ward of a LTC home, hereafter referred to as LTC Ontario (LTCO), which houses and provides care for 28 residents with dementia in an area that is separated from the rest of LTCO's population. The following diagram of the first floor of LTCO shows the layout and the location of the *nursing* station in the secure dementia ward from where I planned to do my observations (see Diagram 1).

Residents live in close proximity to each other, interact on a regular basis, and are limited in their abilities to move to different areas of LTCO or access services and activities that may be provided to the rest of the population.

The secure dementia unit in this home typically has one to two Registered Practical Nurses (RPNs) on site who are responsible for administering medications to the residents, two to three Personal Support Workers (PSWs) who are responsible for the general care of the 28 residents, such as bathing and toileting, a Registered Nurse (RN) who moves between the dementia ward and other areas of the home and is responsible for any residents' wound care and the management of their care plans, and a fluctuating number of visitors and/or volunteers, typically no more than two to three at a time. Also, Life Enrichment Services provides one or two Recreational Therapists to run activities and/or programs with the residents on Monday, Wednesday and Saturday afternoons from 2:15 to 3:15 p.m. during shift change for the nursing staff, and on Monday and Tuesday evenings from 6 to 7 p.m. I was able to observe and conduct research in a relatively contained social environment without being intrusive to the lives of the residents who live there and staff who work there.

Diagram 1



Observation Process

I began collecting observational data after receiving ethical approval from Lakehead University's Research Ethics Board. I conducted observations on Mondays, Tuesdays, Wednesdays, and Thursdays from 6-8 p.m. during a four-week period starting on October 7th 2013. On Mondays and Tuesdays, a Recreational Therapist from LTCO's Life Enrichment Services provided activities to the residents of the secure ward for one hour from 6-7 p.m., but did not provide activities on Wednesdays and Thursdays during my observational period. I collected data by making field notes about my observations of the residents and staff members of the secure dementia ward, by engaging in informal conversations with staff members, and by documenting any form of agitation that I observed during the study.

Dividing my observational time into 10-minute intervals, I documented what I considered to be instances of agitation displayed by residents every 10 minutes from 6-8

p.m. with a maximum assignment of one per 10-minute interval per resident. Thus, if a resident during one 10-minute period was yelling one minute and crying the next, I counted this as one instance of agitation. But if the same resident continued the same behaviour into the next 10-minute period, I counted this as a new instance of agitation.

I made no attempt to grade or scale these variables, as this was not the focus of the study. The quantitative measures I chose to conduct this study were meant only as a guide towards showing some correlation between agitation displayed by residents and whether or not there was an activity offered that day which may have contributed to a reduction in displays of agitation.

In total I was there for 16 days of observations (Monday to Thursday from 6-8 p.m.) starting on October 7th and concluding on October 31st, which included observations of the residents, staff, volunteers and visitors during 8 hours of planned activities (Mondays and Tuesdays from 6-7 p.m.) and 8 hours immediately after activities had occurred (7-8 p.m. Mondays and Tuesdays). On Wednesdays and Thursdays for the month of October, I collected observational data from 6-8 p.m. (when planned activities did not occur) for a total of 16 hours. I decided not to collect observational data on Fridays, Saturdays and Sundays because different staff members would be on-site those days as compared to Monday through Thursday, and there was less consistency in the day's events and planned activities for residents. Also, Friday through Sunday, based on my previous knowledge of what occurs at this home, are days on which residents are more likely to have visitors, which could impact the number of persons that I could observe and the number of residents who could participate in activities. In total, I

collected data over 32 hours of observations on Monday through Thursday in the month of October 2013.

Process of Recruiting Participants

In order to gather a range of perspectives about the behaviours of residents, I selected participants using “purposive sampling” (Babbie 2009: 206). During the observation period, I approached differently situated staff members including personal support staff members, recreational staff members, and nursing staff members, and gave them an information letter about the study (see Appendix C), and invited them to participate in a semi-structured interview. Five staff members agreed to participate in an interview and signed a consent form (see Appendix D) prior to beginning the interview.

Interview Process

In November 2013, I conducted five semi-structured interviews with staff members who were working on the secure unit during the observational period. I conducted interviews in each participant’s home and tape-recorded the interviews. All interviews took place in the early afternoon at the convenience of the interview participants and on days when they did not have scheduled work at LTCO. Upon arrival to interviews I received a warm reception. Conversations began with a polite exchange and I was invited into the staff member's home.

I explained the format of the interview as a discussion with a series of questions with no right or wrong answers and I explained that the participants’ identities would not be linked to their responses. I asked participants if they had any questions before the interview began and at the end of the interview I asked if I could contact them again in

case further questions or clarification of their responses was required. Using a semi-structured interview guide (see Appendix B), I asked participants to discuss:

- how to reduce and/or deal with responsive behaviours and/or agitation;
- if they had any thoughts as to what might be the best methods for reducing and/or dealing with responsive behaviours and/or agitation;
- what kind(s) of programs they felt were the most beneficial to residents with dementia;
- what benefits they felt were gained from offering various social programs to residents with dementia and who benefited (staff, residents or both) and how they benefited;
- what kinds of challenges and/or limitations they foresaw in terms of administering programs and activities for residents with dementia;
- whether they had observed any changes in the behaviours of residents with dementia when the programs/activities were offered in the evenings; and
- what they would like to see change in terms of their opportunity to engage with residents and their role(s) within the home and what changes they would like to see occur.

Given that I had spent a significant amount of time observing participants in their work environment and had already established a good rapport with them, the interviews proceeded smoothly. I followed the interview guide (see Appendix B) relatively closely, and all interviews were asked the same questions in the same sequence with little veering off topic. I took minimal notes so that I could closely focus on what was being said, and because interviews were recorded for later transcription and further review. Interview

participants appeared to easily understand the questions I was asking. They seemed very comfortable responding and eager to share their opinions. I got the impression that the topic of reducing agitation for residents of LTCO was very important to interview participants.

Each interview lasted between 15 and 40 minutes as some participants had more or less to say about the topic than others. Some interview participants were more outspoken, while others were more reserved in their responses. At the end of each interview, I thanked the participant for agreeing to participate in the study and for welcoming me into their home. I also gave each participant a small token of appreciation (Tim Horton's gift card for ten dollars).

Data Analysis and Interpretation

I organized the data I collected from my observations into days when activities occurred and did not occur and counted the numbers of instances of agitation that I had observed each day. I also looked at my observation data for possible social considerations that may have had a bearing on the behaviours of the residents.

I compared the total number of behaviours recorded between 6 p.m. and 7 p.m. for Mondays and Tuesdays (when activities were provided) against the same time period on Wednesdays and Thursdays (when activities were not provided) to see whether there was a reduction in agitation. I did the same for the hour after activities had occurred from 7pm to 8pm on Mondays and Tuesdays and when they had not occurred on Wednesdays and Thursdays during the same time frame, to investigate whether there were possible lasting effects of the programs to reduce agitation in residents after the activity sessions had concluded, and to compare this with what happened on days when no activity was

offered. I then compared the total number of recorded instances of agitation over the two-hour time period between 6pm to 8pm on Mondays and Tuesdays (when activities were provided) against Wednesdays and Thursdays (when activities were not provided) over the same duration. I did this to get an overall picture of the differences in recorded behaviours between evenings when activities had occurred and when they had not occurred. Additionally, I wrote comments regarding notable events and occurrences to better describe the possible reasons for behaviours of residents.

After transcribing interviews, I read through each transcript multiple times and spent considerable time soaking in the data to become familiar with it. When I was reviewing the interview data, I was looking for a way to organize and make sense of what participants had to say. I hand coded interview data by first comparing and contrasting interviewee responses for each specific question I asked, and then as a whole document looking for consistencies and differences in what the staff members had to say. I came to identify the following thematic categories as capturing participant responses and concerns: The Significance of Social Interaction, Activities and Consequences, Communication and Information Sharing Amongst Staff Members, and Challenges: Time Constraints/Job Responsibilities and Respect. I discuss these themes and utilize direct quotes to illustrate the attitudes and opinions of interview participants relating to the different categories at length in the interview results chapter.

Conclusion

This chapter began with a discussion of my social location and was followed by an explanation of how I developed my research design and went about collecting the data for my case study. After this, I discussed the LTC setting where I conducted research and

the process by which I collected observational data. This discussion was followed by an explanation of how I recruited participants for interviews and the interview process, and concludes with an explanation of how I analyzed and interpreted the data I collected. The next chapter will discuss the results of my 4 weeks of observations conducted at LTCO and will be followed in Chapter 4 with a discussion of the results of the five interviews that I conducted with the staff of this unit.

Chapter 3: Observation Results

In this chapter I discuss the results of my observations of 28 residents and ward activities over a four-week period at LTCO's secure dementia unit. I begin with a discussion of the daily routines of residents and the activities on the unit. This is followed with a presentation of the number of instances of agitation I observed. I then conclude by considering these observations in relation to what activity was facilitated for the residents, how residents participated in different activities, and which staff members were involved.

Typical Daily Activities for Residents

Throughout a typical day, residents in the secure dementia ward have various scheduled events such as breakfast, lunch, dinner and snack time. These events provide residents something to look forward to and an opportunity for social interaction. Even the most basic and essential scheduled events give residents something to keep them occupied, which tends to reduce incidents of agitation. Dinner is usually served at about 5:30 p.m. nightly, and after that, residents are typically left to keep themselves occupied until a brief snack is provided at 7 p.m. After this snack, residents are again left to themselves until bedtime (except for when medical care and/or assistance with personal care and toileting is provided) which may occur anytime from 8 p.m. to 1 a.m. depending on which staff members are working at that time and the usual bedtimes of the various residents.

The time after dinner until bedtime is the longest period of time when residents are typically provided little or nothing to do, which could lead to a greater possibility of residents displaying signs of agitation. Providing planned activities after dinner in the evenings gives residents something to do and opportunities to engage socially with others, which reduces the likelihood that these individuals will display signs of agitation. Indeed, as shown later in this chapter, on days when activities were provided to residents in the evenings, there was a substantial reduction in recorded behaviours as compared to days when no such activity was provided, although there were differing rates of participation.

Occasionally, various staff members and/or volunteers would come into the unit to assist some of the residents to attend an event that was happening in an area away from the secure unit in the main home. When an event was happening off the unit, typically one particular volunteer and one or two Recreational Therapists would assist in moving residents from one area of the home to another and supervising. Though this volunteer did not have a set schedule, he had an existing relationship with a few residents and those particular residents were the most likely to be involved with that volunteer in off-site activities. Also, the residents taken to events off the unit tended to be higher functioning cognitively, had better mobility, and were more communicative as compared to some of the other residents of the unit. Though the residents selected for participation in off-site events were typically more cognitively intact than others on the unit, they seemed equally prone to displaying agitation. Furthermore, if any of the residents from the unit displayed agitation while off the unit they would be returned by either the volunteer or one of the other staff members.

On days when activities were not provided, every evening after dinner between 6 and 7 p.m., at least five residents wandered around the unit or paced around the halls in different fashions. One individual pushed her roommate in a wheelchair around the circular hallway and would continue to do this until snack time around 7 p.m. unless there was a visitor or an off-site event. Some residents would spend this time either walking in and out of other people's rooms, collecting objects like pieces of garbage or anything left out on the dining room tables or on other residents' walkers or wheelchairs, or moving furniture. On days when activities were provided none of these residents displayed any of these behaviours.

Some residents typically spent Wednesdays and Thursdays between 6 and 7 p.m. trying to open locked doors. Most of the residents of the dementia unit wore a bracelet called a "wander guard," which would sound an alarm anytime someone was too close to the exit door or attempted to open the door. Some residents would sit near the exit door and attempt to get out when someone entered or exited. This would result in the exit door alarm going off every night at least a few times on evenings when no activity was provided. Some of the residents would try to enter locked rooms, attempt to open locked control panels, or try to enter the nursing station. Again, all of these behaviours ceased on days when an activity was provided in the evening.

On evenings when no activity was offered some residents would yell or scream, as if to express anger, discomfort or pain. Upon staff intervention these instances of agitation would often slow for a few minutes, but rarely stop altogether. Some residents would get very confused or frustrated and talk rudely or use crude language with staff members and/or other residents. On one occasion a resident became very agitated, as

they believed they had just come from their spouse's funeral and wanted to go back home with their son, though their son and significant other had both long passed. This person was obviously very confused and upset. Though not all instances of agitation such as yelling, displaying visible confusion, frustration, sadness, or anger were completely eliminated on days when social programs were offered, the likelihood of these types of instances of agitation were drastically reduced on program days.

Observations of Agitation

Table 1 (below) offers a quantified representation of my observations of instances of agitation among 28 residents of the secure dementia ward. As discussed in Chapter 2, I documented observations of agitation on both activity and non-activity days, with a maximum assignment of one per ten-minute interval per resident. Activities were offered by various recreation staff members and/or volunteers on Mondays and Tuesdays from 6 to 7 p.m., while at 7 p.m. every day residents were offered an evening snack, which provided them with an opportunity for some social engagement and kept residents occupied.

Table 1: Observed Instances of Agitation

<u>Date:</u>	<u>6pm – 7pm</u>	<u>7pm – 8pm</u>	<u>Total</u>
(*) Monday Oct 7	2	0	2
(*) Tuesday Oct 8	4	2	6
Wednesday Oct 9	23	10	33
Thursday Oct 10	17	12	29
(*) Monday Oct 14	7	3	10
(*) Tuesday Oct 15	5	10	15
(#) Wednesday Oct 16	8	4	12
Thursday Oct 17	22	9	31
(*) Monday Oct 21	2	2	4
(*) Tuesday Oct 22	0	1	1
Wednesday Oct 23	28	17	45

Thursday Oct 24	27	20	47
(*) Monday Oct 28	2	0	2
(*) Tuesday Oct 29	13	2	15
Wednesday Oct 30	28	14	42
Thursday Oct 31	21	18	39
<hr/>			
(*) Total Mon/Tues	35	20	55
(*) Ave. Mon/Tues	4.375	2.5	6.875
Total Wed/Thurs	174	104	278
Ave. Wed/Thurs	21.75	13	34.75

(*) = Activity Occurred (#) = Unscheduled Activity Occurred

Several patterns jump out from this table. First, there was clearly less agitation displayed by residents on Mondays and Tuesdays (M/T) – the days when activities were offered from 6 p.m. to 7 p.m. – than on Wednesdays and Thursdays (W/Th) when activities were not provided. For M/T, I observed a total of 35 instances of agitation during the hour when activity was offered (6 to 7 p.m.). This compares with my observation on W/Th of a total of 174 instances between 6 and 7 p.m. Furthermore, even after recreational activities were finished there was a substantial reduction in agitation as compared to days when such activities did not occur at all: 20 instances between 7 p.m. and 8 p.m. for M/T, versus 104 instances during the same time period on W/Th. Care must be taken, however, in crediting the reduced instances of agitation between 7 p.m. and 8 p.m. solely to the provision of recreational activities, as residents were always provided with a snack at 7 p.m. each evening.

Agitation tended to decrease between 7 and 8 p.m. regardless of whether recreational activities had taken place the previous hour. One of the exceptions when observed instances of agitation increased between 7 and 8 p.m. on Tuesday October 15th is likely due to the fact that nine residents were off the unit between 6 and 7:30 p.m. attending a function in the main home's dining area and there were only three residents

on the unit who were participating in activities between 6 and 7 p.m. The rest of the residents on the unit were either in their rooms, being assisted with personal care, or sitting in the lounge or dining area and not involved in the activity. Though most of the residents who were off of the unit at the time were fairly high functioning, a few of those persons tended to be more prone to displaying agitation than others who were taken off the unit, and upon their return I noted multiple instances of agitation in those individuals. Another exception was on Tuesday October 22nd. On this day (Oct. 22), one of the residents was yelling and complaining of being in pain and wanting to go to bed closer to 8 p.m., which for this particular resident was close to their regular bedtime.

A final comment regarding what I observed is about the events of Wednesday October 16. This was originally supposed to be a day when recreational activities would not take place, but on this Wednesday one of the Recreational Therapists and a volunteer took 13 residents out of the secure unit from 6:00 p.m. to 7:30 p.m. to go for refreshments in the LTC facility's main dining hall. This activity was likely the reason for a relatively low number of recorded instances of agitation (only 12 total), which is much lower than the next lowest total of 29 on non-activity days and could account for the substantial difference compared to any of the other non-activity days.

Altogether, I observed significant reductions in displays of agitation on days when activities were provided compared to days when residents were not provided with any activity. Indeed, there were overall decreases of approximately 500%.

Special Activities on Mondays and Tuesdays

Activities offered to residents on Mondays and Tuesdays from 6 p.m. to 7 p.m. included: passing/throwing a beach ball around and listening to music with a group of

residents (Oct 7, Oct 21), going outside the dementia ward (assisted by a volunteer) to participate in bingo or watch a live musical performance (Oct 7, Oct 15, Oct 21); playing bowling on Nintendo Wii and playing cards (Oct 8); helping to make and then eat pumpkin pie (Oct 14); doing puzzles (Oct 15); making hot chocolate while watching television as a group (Oct. 22); listening to guitarist/singer brought into the unit to perform for the residents (Oct 28); and eating ice-cream while watching movies (Oct 29). Different activities had different levels of participation and different effects on the residents who observed and/or participated in them.

On the day (Oct. 22) that residents were assisted in making hot chocolate and watched movies I observed only one noted instance of agitation between 6 and 8 p.m., the fewest for all the days in the study. The day (Oct. 28) that a live musician was brought into the unit to perform for the residents had the greatest number of residents participating and also had only two instances of agitation between 6 and 8 p.m. On one of the program days (Oct. 7) residents were offered the activity of playing with a beach ball as a group and listening to music, while others were taken off-site to the LTCO's main dining area for bingo. On this day, I observed only two instances of agitation between 6 to 8 p.m. On another day (Oct. 21), residents were offered the same activity of playing with a beach ball and listening to music in a group. On this day (Oct. 21) I noted only four instances of agitation, and the same group of residents was taken off-site to the home's main dining area to listen to live music.

There were also only six noted instances of agitation on the day (Oct. 8) residents played bowling on Nintendo Wii and played cards. There were ten noted instances of agitation on the day (Oct. 14) the activity was making pumpkin pie, fifteen when

residents were playing with puzzles while some went off-site with a volunteer for music (Oct. 15), and fifteen on the day (Oct. 29) residents were given ice-cream and watched movies. Altogether, on days when activities were provided I never saw more than 15 instances of agitation, and this happened on two separate occasions as previously mentioned.

The residents who were the most mobile and high functioning in terms of communication and cognitive abilities were the most likely to participate in activities, although many participated in different ways. For example, the day (Oct. 8) that residents played bowling on Nintendo Wii, which requires fine motor skills to press buttons on the controller and coordinate movements with the motion sensor, only six residents were able to play the game, but five others either watched, or engaged socially with other residents and/or with the Recreational Therapist facilitating the activity. Though not all residents participated, or in the same way, I observed few instances of agitation on this occasion, which suggests that simply providing and facilitating an activity for people in this context is of substantial benefit.

Usually, between eight and 20 residents participated in various activities. Some activities provided to the residents were more conducive than others for large group participation, such as joining a group to listen and sing along with a live musician, compared to throwing a beach ball around in a small group. Regardless, all activities substantially reduced instances of agitation among the residents. Furthermore, though the residents who were most likely to participate in activities were the most mobile and high functioning, on days when activities were not provided even these residents were as

likely to display agitation. Clearly, the provision of activities for residents from 6pm to 7pm on Mondays and Tuesdays changed or eliminated signs of agitation.

Who Provides Activities

On-site activities were usually provided by one Recreational Therapist and began as a permanent program for residents of LTCO on Monday and Tuesday evenings from 6 to 7 p.m. starting on October 7th, 2013.

Staff members' involvement and interaction with various residents during regular hours, and during those which activities are offered, was in many ways dictated by their role within the institution. Also, the involvement of staff members with residents was impacted by differing personalities and relationships.

Depending on which staff member(s) and/or volunteer(s) facilitated activities, there was a substantial impact on how many people participated and the number of displays of agitation. The day (Oct. 22) with the lowest total of noted instances of agitation occurred on the day that Recreational Therapist "A" was running the program. Furthermore, every time "A" facilitated activities I observed very few instances of agitation and a greater level of participation from residents. "A" seemed very good at communicating with the residents while making a conscious and constant effort to engage with the residents and encourage their participation in the activities being offered.

The activity days with the highest reports of agitation and/or responsive behaviours occurred when Recreational Therapist "B" facilitated the program. On all the days that "B" was responsible for running the program, "B" was late starting and spent less time involved in activities. Also, "B" appeared to have much more difficulty

communicating with residents and did not do as effective a job recruiting participants or staying engaged with residents during activities.

All in all, Recreational therapist “A” facilitated the activities for residents of LTCO five times (Oct. 7, Oct. 8, Oct. 21, Oct. 22, and Oct. 28) and Recreational Therapist “B” three times (Oct. 14, Oct. 15, and Oct. 27). The average number of occurrences of agitation I documented amongst residents of LTCO on days when Recreational Therapist “A” was running the programs was three. The average number for Recreational Therapist “B” was 13.3. This indicates that I observed an average of slightly more than four times the number of instances of agitation when Recreational Therapist “B” ran the activity as compared to Recreational Therapist “A.”

One volunteer (“V”) either engaged in activities with residents, or helped the Recreational Therapist(s) take residents to various events off the ward, and “V” appeared to be very good at engaging with certain residents. “V” was regularly involved with a specific group of six to eight residents and provided them with opportunities to leave the secure unit to attend events in other parts of the facility. These residents were much more high functioning, mobile, and cognitively intact than others on the ward, and typically displayed fewer signs of agitation. There was, however, one instance when “V” took a different resident to listen to music elsewhere in the facility. Previously, this resident had consistently displayed signs of agitation and difficulties communicating with staff and/or other residents. After this resident was taken to listen to music, however, she returned to the unit in a better mood (smiling and more engaged with others), and all of their typical displays of agitation ceased for the rest of the evening.

Some of the residents have been there for longer than others, and everyone has dynamically different life histories, experiences, and abilities. Some residents and staff members have very close relationships, which have been developed over years, and others are drawn to certain individuals for one reason or another. Adversely, some staff and residents do not have strong relationships and some residents do not like having care provided or interacting with certain staff members as I have learned through watching them interact with each other and observing various residents express their like for some and disdain for others.

Conclusion

In this chapter I discussed the results of my observations of 28 residents and activities over a four-week period at LTCO's secure dementia unit. I began with a discussion of what usually happens on this dementia unit and the activities I observed. This is followed with a presentation of the number of instances of agitation I observed. I then discussed these observations in relation to what I found were the consequences of providing different activities to the residents of LTCO and the significance of who helped to facilitate these activities for residents. The next chapter contextualizes these observations with a discussion of the views of staff members of LTCO.

Chapter 4: Interview Results

This chapter discusses the results of five interviews that I conducted with the staff at LTCO. Interview participants were staff members who are involved with the daily care of residents of the secure dementia ward and were on-site during days when activities were offered to residents of the home to get their opinions about the consequences of offering activities to residents with dementia to reduce agitation. I have organized interview data according to the themes: The Significance of Social Interaction, Activities and Consequences, Communication and Information Sharing Amongst Staff Members, and Challenges: Time Constraints/Job Responsibilities and Respect.

The Significance of Social Interaction

All interview participants commented on the importance of identifying each resident as an individual, and argued that this is the primary element to providing quality and appropriate care. One of the interview participants summarized the importance of taking “different approaches for different residents” by explaining “when you know your resident, you know which approaches are good for certain people, no two residents are alike, everybody is different.” The importance of knowing intimate details about each resident and tailoring care to their needs was further explained by another interviewee who suggested that “a lot depends on the resident, because they respond differently depending on their interests and what they are able to do.”

Interview participants felt that providing opportunities for residents to engage socially with each other and various staff members and/or volunteers is extremely important for overall quality-of-life and happiness. One of the interview participants

suggested that residents seemed to be in a better frame of mind during and after activities were offered at the home. This interviewee felt there were reduced instances of agitation when residents were engaged socially in activities or programs because it gave residents something to do. The staff member elaborated, “because they [residents of the secure dementia ward] were bored all of the time, or they appear to be bored” having an opportunity to be with other people made them less likely to be agitated. This interview participant expressed sadness when they commented on their feeling that residents had been “living busy lives and then all of a sudden they expect them to just sit there? And not talk to anyone?” Another interviewee stated:

When you don't socialize and interact with others you become like an animal, because you don't remember how to interact with people! If you can't get people to come together they just go inward, it is a strong human need to feel included and you can't understand the meaning of a social situation without having someone else involved.

This individual felt that people need and want to engage socially with others. They felt that without feedback from other persons in a social environment that residents could lose the ability to act in socially appropriate ways and become more withdrawn.

All staff members indicated the importance of identifying each resident as an individual with different needs. Furthermore, staff members clearly indicated that they felt providing opportunities for social interaction was crucial for the overall well-being of residents with dementia.

Activities and Consequences

All interview participants agreed that offering activities to residents of the secure dementia unit provided substantial benefits, and that similar programs should be incorporated and maintained as an important and necessary means to reduce agitation and

promote better quality-of-life. One participant offered the following description of consequences:

It seemed to set up a new environment on the unit for the rest of the evening. The activities would end at seven p.m. and they [residents of the unit] seemed to be in a different mindset completely, they weren't calling out, they weren't pacing and they weren't agitated! They were sitting together in closer proximity without striking out at anyone or being agitated. They seemed to have some conversations going on among themselves more so than when the activity started, it seemed to allow them to sit and calm down, and focus on being with each other in a social environment [pause] they seemed to settle much easier at night without the use of medications to help, it [providing activities in the evenings] makes a huge difference for them.

This interviewee summarized the position taken by staff members in saying:

I'd like to see an increase in the activities brought to the unit, because there are a lot of positive benefits, and by bringing these positive benefits in, it allows the staff to spend more time with residents, talk to them. We're not always there to have fun with them, we're there to make the residents do things they often don't want to do, but the staff doesn't always need to be the "bad guy", you know, but by having these different events it opens the door for staff to speak with residents in a more positive way, and you know, speak to them about things that have happened to them, or their family. It puts them [residents] in a state of mind where they don't see staff as being the meanies that are trying to provide physical care or do things to them against their will. We can speak with them like family or friends instead of the bad guy that comes in all the time.

Another interview participant further elaborated on the position of staff members about the benefits of providing social activities to residents at LTCO, and described how providing activities creates a:

more appropriate environment and more opportunity to slow things down and spend more time with residents. Offering activities makes our jobs not just nursing, but considers the social part, not as just a task.

All interview participants agreed that providing activities to residents gave staff members more opportunities to interact with residents as friends or family, instead of only having time to do care tasks required of their various roles within the home.

A few of the staff members felt that one of the most significant consequences of providing activities to residents was a reduction in the use of medication and need for medical intervention. As stated by this interview participant referring to who benefits from these activities and how:

Oh everyone! Staff, residents, families, the facility. Yeah, I mean, it's obvious that when there is different activities going on for them [residents of the ward] that there is less agitation on the unit, less wandering, there's less PRN medications that are used for agitation. Less Ativan, and a lot less receive Habitol and different PRN medications that we used to use on a regular basis when they have these activities going on.

Some activities were considered by different staff members of LTCO to be more beneficial to residents and more inclusive of a greater number of participants. Though not all activities have the same number of residents included, the social nature of the activities also tended to draw other residents to be involved, which further promoted inclusion in the day's activities and reduced agitation for more than the direct or initial participants. As this interviewee explained:

I haven't noticed too many behaviours when I was working those evenings [when activities were provided], I found that everybody sort of participated, one resident came out of their room and was sort of yelling, like talking away, and then they calmed down when they saw people and joined the group. Whatever program was running and the residents joined in, and I think a lot of the time just residents observing made a big difference in their agitation.

This interviewee felt that one of the reason residents sometimes got agitated was because residents were rarely afforded a chance to be themselves and have fun with other residents and/or staff members. They suggested residents looked for ways to be part of something and were drawn to social activities. As they explained,

I think sometimes it's just being by yourself. I remember when an activity started maybe I'd see four or five people and next thing you know there would be eight or ten! Because the residents are just coming out of their rooms and looking for something to do.

When music was provided as some part of the programming, interview participants all felt that this was one of the best activities that could be offered to residents. One of the interviewees stated:

I think music is probably number one (activity to reduce agitation and improve quality of life). Definitely! It doesn't matter if they (residents with dementia) have dementia, Alzheimer's, had a stroke or can't communicate. Music always seems to calm them down.

Another interview participant suggested that the residents of LTCO liked music and, "they don't care what it is, we've had like [pause] rock stations on to classical, it doesn't seem to matter." Though all interview participants agreed that providing any form of music in general to residents of the secure dementia ward had some benefits, one of the interviewees suggested that "appropriate" choices of music, like pieces from the resident's past or in the style they prefer, promoted a sense of choice and agency, promoted more social engagement, improved communication and cognition, improved quality-of-life and the ability for residents to express themselves, and reduced agitation among residents of the ward. Furthermore, this interviewee felt that some staff members would put on "children's shows and music" for the residents and that they felt this was inappropriate. They felt that residents should not be treated like children and that putting on "kids shows" was disrespectful.

Sometimes residents were taken off the dementia ward to a different part of the LTC home for activities. Although some residents were not included in off-site activities, because of their differing health and cognitive status and because some staff members felt the change in environment would likely lead to increased agitation, there was a consensus among interview participants that off-site activities and programs offered to residents of

the secure dementia ward were beneficial to those who could participate. One interview participant explained with regard to off-site activities:

I find them [the residents who return from off-site activities] a little bit calmer, a little more relaxed, and maybe it even...I don't know, I hate to say it this way but tires them out a bit more if they were agitated, but it seems to work really well, and sometimes I don't think it does, depending on what the activities are and who is doing it, that makes a huge difference too. Sometimes the programs are really good for them and sometimes they are not. And I don't mean that in a bad way, I just mean that sometimes, depending on how bad they are sundowning, they just agitate them more. And I also think that staff should be asking, is it okay to take so and so tonight, they look pretty agitated? And we've asked that in the past; please don't take certain people off the unit, because they come back and are wound up tighter than a yo-yo. And now we're [staff] having problems trying to complete our job because the resident was already in a mood before they went off the floor and now they've come back and they've escalated ten times what they were, and it makes it hard for everybody.

Though this staff member indicated the benefit of having residents of LTCO participate in events outside of the unit, they also felt that sometimes taking certain residents off the unit for activities would cause those residents to become agitated because of the change in environment, especially if those residents had displayed signs of being agitated throughout the day. This staff member also felt that sometimes differently situated staff members would not communicate effectively, and as a result certain residents who they felt should not be taken off of the unit were taken to different events against this staff member's recommendation.

Interview participants clearly described what they felt were the significant benefits of offering socially derived activities to residents of LTCO. Staff members suggested that providing activities to residents of LTCO promoted a positive social environment. Also, interviewees felt providing meaningful activities for residents to reduce agitation changed the way they were able to interact with the residents and their relationships with them. Staff members felt providing activities to the residents of LTCO

allowed them a better opportunity to focus on the residents as individuals and in less task-oriented ways. Interviewees also felt that persons with dementia were drawn to social activities and enjoyed being part of something and having fun with others. Staff members all felt that various forms of music are very effective for reducing agitation, but some felt that different types of music or socially based activities in general were more or less appropriate than others, and that effective communication among staff members was important to determine which residents should participate in what kinds of activities.

Communication and Information Sharing Amongst Staff

Different departments at LTCO have different roles and responsibilities: Nursing is responsible for the management of medical care and services for residents; the Health Care Aides (HCAs) and PSWs are responsible for general care and assisting residents with daily living needs; and the Life Enrichment services are responsible for planning and facilitating activities and programs for residents of the home. All interview participants felt that it was extremely important to sustain and maintain open and effective communication between different staff members and across different departments with regard to the various statuses of residents, and this was a key factor in delivering appropriate social activities to residents. One interviewee commented that it would be helpful to talk about appropriate interventions to calm residents, and differently situated staff members should respect insight from each other:

Sometimes I think because staff, whether it be from a different department, they just don't want to hear it, or they do listen but they don't go forward with it, they say, oh yeah well try that! And then sometimes it just never proceeds the way it should. It would be nice if all departments communicated better and more! Instead of just coming in and saying, oh we're going to do this today, these guys should come and say, what are the residents like today? What are their moods? Should we have something a little quieter today, or should we have something noisier or fun? So I feel it would be smoother offering programs if they started

talking with staff, just to see what mood the floor is for that day. Because, you know, like full moons play a part in everybody's moods not just the residents and I don't know how true this is. But if they're [residents] bouncing off the walls, we should switch it up and try something instead of following what the calendar [activities planned for that day] says.

Some interview participants felt that there was difficulty in getting all staff members to respect the importance of each other's role. As this interviewee expressed:

It is important to educate staff about each other's role. We're all part of the unit and have to work together, because I can't do their job, it's important that we work together, I don't care what you do in here, I don't care what it is we all need to work together. It's respect for the other person's job. We don't know how difficult it is either, they are all important, everyone! And a lot of the time we need each other.

A few of the interview participants suggested the route to improved consistent communication would be achieved through better documentation and filing of reports, yet others felt that there was already too much time spent documenting and not enough time spent with individual residents. One interviewee explained:

What I find with a lot of staff is that the techniques that they use that work with certain residents to deal with agitation are not always documented in the care plan. So even though it's [a given intervention or technique] very effective for that resident, yet for the staff, a lot of it is not widely expressed among, you know, others on different shifts in different groups, so it can be kind of a setback. And so, I think documenting is important, some staff aren't expected to document but they are the first line of defense so to speak and there needs to be more time spent educating them, so they feel comfortable with documenting, and I think if the staff did that more it would highlight different techniques that they use to deal with their residents different problems.

Though documenting information about different residents is a significant duty for some staff within the home, those who provided direct care had fewer requirements to document information and felt time was better spent working directly with residents than in filling out paperwork. Some staff members felt it would be too great a compromise to

spend more time completing forms at the expense of less time directly with residents. As this interviewee explained:

There is already so much paperwork, I'd love to be able to sit down and spend more time with residents and not be rushed, and I would love for management to not be on our ass all the time, like this isn't done or your paperwork isn't complete, well I'm sorry! But sometimes the resident comes first! Everything is already a big rush and it's not fair to anybody!

Interview participants had a range of concerns about how information was shared across different departments. Some staff members felt that their roles were more or less respected and valued than others. Staff members all agreed that effective information sharing was very important to provide individually appropriate care for the residents of LTCO, but staff members suggested different ways they felt would improve communication between different departments.

Challenges: Time Constraints/Job Responsibilities and Respect

All interview participants felt that managing their time at work and the responsibilities of their position was a difficult task. Even though they thought it was important to be socially engaged with residents, it was extremely difficult to spend what they felt was an appropriate amount of time socially engaging with residents. One interviewee stated:

Because we are so busy with our own job we don't have a lot of time to interact with the residents. I'd like more time to interact with residents, it gives them self-worth, and some of their family members don't come that often, so they are even more withdrawn, and those ones, when I've got the spare time, I'll go and interact with, because they don't have any family interaction.

Furthermore, some interview respondents commented that the workload of staff members has increased over the years. As this interviewee explained:

Like ten, what twenty years ago now? We were able to have our care done and spend time with residents and visit with them when they had more staffing and with the cutbacks in staff we don't have that anymore.

Another interviewee further explained:

The expectations have always been the same for staff and now there is less staff on the floor so you can't spend as much time with individual residents and the workload is too big. But the care level has changed. I find that people who are coming in now require more help than they did five years ago. They stay at home longer and their disease is much worse.

This staff member also described, as most of the other interviewees identified, that the residents of LTCO and those entering similar LTC homes, required greater levels of care than in earlier years, which made the staff members' jobs more challenging.

Staff members identified the importance of having time to be socially engaged with residents, but felt that they were unable to spend as much time with residents as they would like because of work responsibilities and time restraints. Staff members also felt that the amount of work has increased and there were less staff members available. Furthermore, some staff members suggested that persons in LTC with dementia, and those soon to be entering LTC homes, required a greater level of care than in years past.

Conclusion

In this chapter I discussed the results of five interviews that I conducted with staff members of LTCO. I began this chapter with a presentation of interview responses that I categorized to reflect the themes: The Significance of Social Interaction, Activities and Consequences, Communication and Information Sharing Amongst Staff Members, and Challenges: Time Constraints/Job Responsibilities and Respect. In "The Significance of Social Interaction" section I discussed how staff felt it was important to provide opportunities to residents to be socially engaged and that each resident should be treated

as an individual. I followed this in the section “Activities and Consequences” with a discussion of what staff members felt were the consequences of offering different types of socially based activities to residents. I then discussed staff members concerns about the importance of effective information sharing across departments to provide appropriate care to residents with dementia in the section “Communication and Information Sharing Amongst Staff Members.” I concluded this chapter with the section “Challenges: Time Constraints/Job Responsibilities and Respect,” wherein I discussed some of the challenges staff members felt impacted their ability to provide the quality-of-care for residents that they would like to be able to. The following and final chapter will discuss conclusions based on the results of the observations and interviews that I conducted.

Chapter 5: Conclusions

Little darling, it's been a long cold lonely winter. Little darling, it seems like years since it's been clear. Here comes the sun. Here comes the sun, and I say it's alright. (George Harrison 1969)

This chapter begins with a discussion of the ways my study has challenged the biomedically-based approach to research and care of persons with dementia. By utilizing a “sociological imagination” (Mills 1959) in my research, which considers the social and situational contexts for persons and does not assume their behaviours are a result of dementia, I add to a small but growing body of literature that examines the social context of persons with dementia and the positive changes that can happen when they are not treated as “robots controlled by forces beyond their reach” (Shillings 2005: 44). I conclude this chapter with a discussion of the limitations of my research at LTCO, and a call for further sociologically framed inquiry in the field of dementia and the behaviours of persons with dementia in the LTC context.

Contributing to the Literature: “Here comes the sun”

My study used a qualitative case study approach (Silverman 2011: 16) to investigate the effectiveness of social programs geared to reduce agitation in residents of a secure dementia unit in a LTC home. Similar to the results from Stones' study (in press), my study affirms that there is a significant reduction in instances of agitation when meaningful activities are offered to residents with dementia in a LTC setting.

My case study research incorporated multiple data sources and sought to provide an in-depth understanding (Creswell 2013: 98). As such, inferences that can be drawn

from this method are rich and descriptive. Also, in contrast to research that views agitation as a co-morbidity or symptom of dementia, I viewed the behaviours of persons with dementia as “not exclusively determined by neuropathology, but are also influenced by personal histories, social interactions and social contexts” (O’Conner et al. 2007: 121). I did not rely only on quantitative data or clinical outcome measures, which according to Dupuis et al. (2014) can lead to an “inadequate reflection of the residents’ experiences and fail to use these experiences to inform effective care decisions” (p. 3). Rather, my study utilized methods similar to those used by Kelly (2010), whereby a person-centered and selfhood approach was taken throughout the data collection and analysis, and as such my study provides a deep understanding of the operational elements of interaction and well-/ill being, as well as operational elements of the residents’ self expressions (p. 120). By utilizing a “social constructionist” perspective, which stresses that the self is not dissolved during the progress of dementia and behaviours are shaped and influenced by other persons and the social context (Arseneau 2009; Dorenlot 2005; Holst & Hallberg 2003; Bond & Corner 2001; Sabat & Harré 1999), my study adds to a growing body of literature which adopts a holistic and individually focused understanding of the behaviours of persons with dementia (Nowell et al. 2011). Finally, this study contributes to the considerable evidence of continuing personhood in dementia given and active, robust and engaging social environment (Arseneau 2009; Basting 2009; Scholl & Sabat 2008; Sabat 2002; McLean 2007; Kontos 2004; Kitwood 1997).

Most studies that have investigated behaviours and agitation of persons with dementia have done so from a medically based perspective and understanding (Stones in press; Rocha et al. 2013; O’Rourke et al. 2007). This leads to seeing the actions of

persons with dementia as being determined by the illness. In contrast to this approach, my study clearly indicates that behaviours of persons with dementia are strongly associated with their social environment and the opportunities afforded (or not afforded) to residents to interact with others and express themselves.

Observation and Interview Conclusions: “It’s alright”

My study has significant findings in terms of the impact of social activities provided to residents of LTCO. When activities were provided to residents of LTCO there was a substantial reduction in agitation as compared to days when no activities were provided. Furthermore, because of the qualitative multi-method approach I took to investigate the impact of social programming to reduce agitation, this study sheds light on some of the consequences of activities and opportunities for social engagement provided to persons with dementia and staff in the LTC context.

One of the findings in my study was: regardless of whether an activity was offered on a given day or not, the number of recorded instances of agitation reduced substantially in the evenings at 7 p.m. when a snack was provided to the residents at LTCO. This finding is complimentary to research from Genoe et al. (2012), wherein they suggest meals eaten with others provide persons with dementia a sense of belonging, comfort and familiarity (p. 174). During snack time each evening at LTCO, most of the residents were in the dining room socializing and enjoying some type of food and beverage in a group. Some residents were talking with other residents and/or staff members, and some were either eating alone or sitting in the lounge area watching television. All in all, the simple occasion of eating and facilitating an opportunity for residents to socialize and engage with other residents and various staff members

significantly reduced instances of agitation among residents at LTCO. Also, staff were able to spend more time engaging socially with residents outside of their regular task-oriented encounters, (like medical treatments and personal support services), and were able to focus on building relationships with residents. This finding is also similar to results found in Amella (2002) and Kayser-Jones' (1997) studies, which identified mealtimes as an important occasion for building caring relationships in the LTC context.

Residents of LTCO who participated in activities and even those who watched, or were on the unit when activities were provided, were encouraged to be part of the group, were helped in their efforts to participate in various activities, and were typically treated as persons with value by the RTs and/or volunteers who facilitated any given activity. Complimentary to my findings, the study by Phillips et al. (2011), indicates that residents who were given the opportunity to engage in social programs showed increased expression of pleasure and better communication. For example, on a few occasions, residents of LTCO who did not normally speak or communicate at all began to sing along with music or engage in a given activity, and were even able to talk to other residents and staff. Some residents of LTCO who seemed depressed, or were generally socially disengaged, showed signs of happiness such as smiling and sitting up in their chairs actively participating when an activity was provided.

On days when activities were provided to residents the overall environment of LTCO felt more positive. Residents were smiling and talking and engaged in activities and with each other and staff. The staff had more time to do their required job, but they also were able to spend more time with residents and even get involved in some of the activities. The benefits of offering activities to residents at LTCO were substantial and

positively affected their relationships with other residents and staff members. Clearly, providing an opportunity for these individuals to enjoy life and express themselves has great benefits in terms of reducing agitation and improving quality-of-life. Residents of LTCO seemed happier and better able to express themselves and their needs on days when activities occurred at the home. Furthermore, interview participants indicated there was a smaller need for medications to manage agitation on days when activities were offered to residents of LTCO, which furthered residents' abilities to communicate and not be treated as objects (McLean 2007).

The benefits of providing opportunities for residents of LTCO to be involved in activities and social events goes beyond simply reducing agitation, but also promotes personhood and quality of life. By providing activities to residents of LTCO, there was a reduction in the use of antipsychotic or behaviour management medications on days when activities were provided, and activities improved the residents' opportunity to express themselves, their interactions with others, and their overall quality-of-life.

During activities residents of LTCO were having fun and enjoying being together as a group interacting. When activities were provided to the residents at LTCO, they were often smiling and engaged with each other and the RTs and/or staff and volunteers who were facilitating the activities. Residents at LTCO laughed and joked with each other and staff/volunteers/visitors during activities, and demonstrated signs of happiness and fulfillment. Similar to findings by Dupuis et al. (2014), Genoe and Dupuis (2011), Dupuis et al. (2010), and Phinney et al. (2007), my study indicates that persons with dementia use various opportunities to engage in leisure and social activities to have fun, seek freedom, be with others, express themselves, feel "alive", feel connected to the

world, and remain engaged in life. Furthermore, complimentary to Kontos' ethnographic research (2010), residents of LTCO when given an opportunity to be involved with others during group activities generally acted in socially appropriate ways, indicated in part by the substantial reduction in agitation I observed on days activities were offered.

Similar to results found in other research (Giles et al. 2005; Kuner et al. 2000, Glass et al. 2000; Williams & Roberts 1995), my study has clearly shown the benefits of social interaction and opportunities to engage in socially derived activities for the residents of LTCO, and implies that similar interventions for persons with dementia in the LTC context would bring similar benefits. In terms of reducing instances of agitation, and promoting opportunities to improve quality-of-life through social involvement and facilitating the ability to express personhood, this study has identified many benefits that are derived from various Life Enrichment services offered to the residents of LTCO. Furthermore, complimentary to findings of many other studies (Michell et al. 2006; Chung 2004; Raynes 1999; Murphy et al. 1996), my study has clearly shown the importance of social integration and meaningful activity to quality-of-life and well-being for persons with dementia.

During activities residents of LTCO were in a better state of mind. They were visibly happier and engaged with others. On a few occasions different residents told stories of their pasts or shared their feelings about different things with other residents and staff members. Some residents remembered their favourite song when music was played and even sang along or danced. On a few days residents played catch and/or passed around a beach ball. Each time the ball came to one particular resident, he would pass it with his head like a soccer ball while smiling and laughing. This person loved

soccer. He had played and enjoyed the game his whole life, and the person that this resident is shone through whenever this activity was offered. Every time an activity was offered at LTCO, residents showed signs of personhood, and expressed their identity in different ways.

Similar to findings of multiple qualitative studies (Klieber et al. 2011; Klieber 1999; Haggard & Williams 1992), the opportunity for residents of LTCO to be involved in activities and leisure is of great importance to developing and upholding identity. Furthermore, residents of LTCO are in a drastically different social environment compared to their previous positions in life, and are experiencing changes in their cognition as a result of dementia. For these reasons, it is extremely important that residents are offered activities as an outlet to express themselves. As studies suggest, leisure activities are of particular importance for persons who have experienced a traumatic life event, like the onset of dementia (Reynold & Prior 2006; Reynolds & Prior 2003; Hutchinson et al. 2003; Kleiber et al. 2002), and leisure activities help persons living with dementia to cope with the changes they are experiencing (Beard et al. 2009). Clearly, as outlined in Genoe and Dupuis' phenomenological study of persons living with dementia (2011), leisure serves as an important space to uphold the identity of a person with dementia and allow them to remain engaged in life.

As suggested by Basting (2009), social programs and interventions for persons with dementia provide:

a way to open those avenues for meaning-making between people who cannot communicate through traditional, rational language. Music and songwriting, dance, non-linear storytelling, poetry, open conversation, painting, sculpting, responding to art: all of these give us ways to connect with each other, express who we are and what we believe. They can put meaning back into what we fear are meaningless lives (p. 164).

Basting continues:

We need research that convinces policy makers that training care partners to foster meaningful moments with people with dementia might work better than pills, and without side effects. Meaning-making might even work to reduce stigma and fear, something a pill can never do (p. 164).

Similar to findings of multiple studies (Dupuis et al. 2014; Miller et al. 2008; Gibson & Barsade 2003; Stevens 2001), during my interviews with LTCO staff members they raised concerns as to the growing pressures of meeting the care needs of residents in LTC with dementia, both due to funding cutbacks and the rising care needs of persons in, or entering LTC. However, creative and cost effective measures, such as the social programs provided to residents with dementia at LTCO to reduce agitation, need to be considered as viable and realistic means to alleviate some of the pressures currently faced by LTC providers.

The costs associated with implementing the program at LTCO to facilitate social opportunities and activities for residents of the secure unit with dementia is very minimal, and the benefits to residents certainly seems to far outweigh the costs of implementation. Also, because of the successes of this program at LTCO, providing activities to residents of the secure dementia unit in the evening on Mondays and Tuesdays has become a permanent program and continues to reduce instances of agitation and positively impact the lives of residents and staff members alike. Other similar facilities could easily take steps to implement similar initiatives. Furthermore, the minimal costs associated with providing a similar program could be offset with involvement from students and/or the community. My study indicates that as long as there is something for residents with dementia to occupy their time in meaningful ways, they are less likely to become

agitated. This opens up nearly unlimited possibilities of social activities to offer residents with dementia in a LTC context.

Limitations and Future Research

Adopting only a scientific understanding of dementia loses the humanity of the person who is diagnosed with dementia, missing the complexity and diversity of individual social experience (Arseneau 2009: 78).

My thesis demonstrates the importance of offering regular activities and opportunities for residents of LTCO to engage socially as a means to reduce agitation, improve quality-of-life, and uphold the identities of these persons. The aim of my study was to capture the consequences of programs designed to reduce agitation in residents of LTC with dementia in a secure ward by utilizing qualitative methods of inquiry and incorporating a sociological framework, which views the actions and behaviours of persons in this context as not only determined by their pathology, but significantly shaped and influenced by their social context. Though results from my study were significant in that the reduction in agitation of the residents at LTCO on days activities were offered was drastically lower than on days when no activity was offered, further qualitative inquiry into the role of activities and social programs to improve care of persons with dementia is greatly needed.

In this study I looked at the consequences of providing socially derived activities geared towards persons with dementia in one Ontario LTC home's secure dementia unit. As such, my findings are not necessarily representative of every individual's experiences in a LTC dementia unit. Furthermore, although the costs associated with the programs offered to residents in the secure dementia unit at LTCO are minimal, for other LTC

homes to offer similar programs will require them to accept socially derived activities as an integral part of the care and overall well-being of residents with dementia.

Although my study indicates some of the benefits of offering socially derived programs to persons in LTC with dementia, future research needs to further explore the implications of offering social activities to reduce agitation in residents of secure dementia units. Future study could involve more thorough investigations into which activities have the most significant impacts, or whether utilizing volunteers or students would be as effective as using trained professionals to run programs. Other future study could consider, at a macro scale, the extent to which LTC facilities across Ontario are utilizing socially derived programs to reduce instances of agitation for residents with dementia, their regularity, their content, and with an eye to expand.

Though findings from my study are not exhaustive, they are useful in providing some insight into the impact of social programs and activities geared towards persons with dementia in the LTC context and the positive implications of approaching research investigating behaviours of persons with dementia from a social constructionist framework. We must continue to bring new ideas to the investigation of dementia and the behaviours of persons with dementia that are not limited in their scope by a biomedical model. Furthermore, we must look for new approaches that do not stigmatize persons with dementia and their behaviours resulting in unnecessary suffering (Dupuis et al. 2012b).

It has truly been a “long cold lonely winter” of negative and harmful approaches to research and the care of persons with dementia. However, my study, and others that view individuals with dementia as persons and seek alternative frameworks to understand

their behaviours, show great promise in terms of changing the culture of care for persons with dementia to one that sees them as more than “empty shells” (Dupuis et al. 2014; Scholl & Sabat 2008). There is much work yet to be done to improve research approaches and the care of persons with dementia, but “here comes the sun, and I say it’s alright” (George Harrison 1969).

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Appendix A

Observations for: Date/Time

Res.#	Agitation Y/N	Time	Description	Observations	Comments
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Appendix B

Interview Questions for “Here Comes the Sun: Enriching Lives and Reducing Agitation for Residents with Dementia in Long-Term Care.”

Protocol:

Introductions. Thank participant for allowing me into their home and/or agreeing to meet for the interview at a different location. State the interview is completely voluntary and they can end it at any time. Explain the purpose of the study and ensure that the letter of introduction is understood. Read through the consent form, ask them to sign it and provide a copy. Explain the format of the interview, a series of questions, no right or wrong answers, their identity will not be linked to their responses, at the end they will be asked if I can retain their contact information if I have any further questions or require clarification of responses. Ask them if they have any questions.

Questions:

- 1.) Let's begin with a discussion of how to reduce and/or deal with responsive behaviours and/or agitation for residents with dementia. Do you have any thoughts on what the best methods might be for reducing and/or dealing with responsive behaviours and or agitation for residents with dementia?
- 2.) What kind(s) of programs or activities do you feel are most beneficial to residents with dementia?
- 3.) Do you see any benefits to be gained from offering various social programs and/or activities to residents with dementia? Who benefits: staff, or residents or both? How does each group benefit?
- 4.) What kind of challenges and/or limitations do you foresee in terms of administering programs and activities to residents?
- 5.) Have you observed any change in the behaviours of residents with dementia when social programming/activities are offered during the evenings?
- 6.) Would you like to see anything change in terms of your opportunity to engage with residents and your role within the home? If yes, what would you like to change?

Appendix C

Information Letter

Study Title:

'Here Comes the Sun': Enriching Lives and Reducing Agitation for Residents with Dementia in Long-Term Care

Dear Potential Participant,

I am writing to invite you to participate in an interview for a study to explore the effects of 'Life Enrichment' programs designed to reduce agitation for residents in a Long-Term Care (LTC) facility with dementia. This research is being conducted for a Master's Thesis by Christopher Gash, Lakehead University Graduate Student, and supervised by Dr. Sharon-dale Stone, Lakehead University Department of Sociology.

This research aims to better understand the effects of providing entertainment and/or meaningful activities to residents with dementia in the evenings. The purpose of this study is to investigate whether offering programs will reduce observed instances of agitation among residents of a secure dementia unit, and what methods and strategies are the most effective and/or beneficial according to staff and volunteers.

My intent is to make passive observations of the 28 residents of the secure dementia unit for the month of October 2013 during the evenings from 6-9pm on Monday and Tuesday, when 'Life Enrichment' services are provided, and Wednesday and Thursday from 6-9pm when services are not provided. I would also like to interview any staff and/or volunteers involved with residents of the unit, including Personal Support Workers and Health Care Aides, Management, Nurses, Recreational Therapists and volunteers.

I would like to ask you to participate in a private interview, which would involve discussing your experiences with the care of residents with dementia and your impressions about offering programs and activities during the evenings as a means to reduce agitation and improve quality-of-life. These interviews would be scheduled sometime during the month of November 2013, and will be tape recorded with your permission. The interview will likely take approximately 30-60 minutes, during which time all answers are acceptable and valued.

All information gathered during the study, including field notes from observations and the interview transcripts would be kept strictly confidential and accessed only by the

researcher. In order to protect the anonymity of all participants and the facility, pseudonyms will be used in all notes and in written and oral reports of the project.

If you decide to give your consent to take part in this study, I will be asking you to sign a consent form. This form will state that you consent to participate in an interview. Participation in the study is completely voluntary and you may choose not to participate. You may also choose to withdraw from the study at any time.

All data from the study will be securely stored at Lakehead University for a minimum of five years. The Master's thesis will be deposited at Lakehead University library and provided to the facility after summer 2014. At that time you may request a summary of research results.

This study has been approved by the Lakehead University Research Ethics Board. If you have any questions related to the ethics of research and would like to speak to someone outside of the research team please contact Sue Wright at the Research Ethics Board at 807-343-8283 or research@lakeheadu.ca.

Should you have any questions about the study, please feel free to contact the graduate student researcher Christopher Gash at 807-343-8740 (cfgash@lakeheadu.ca), or the Faculty member supervisor for student research Dr. Sharon-dale Stone 807-343-8530 (sdstone@lakeheadu.ca).

Thank you for your interest and involvement in this project and I look forward to working with you and others at this facility.

Sincerely,

Christopher F. Gash

Appendix D

Consent to participate in an interview for the study ‘Here Comes the Sun’: Enriching Lives and Reducing Agitation for Residents with Dementia in Long-Term Care.

I have read the information letter provided by Christopher Gash describing the purpose of the study of the effects of offering Life Enrichment services to residents of a dementia ward. My consent _____ [name of participant] to participate is made under the following conditions:

1. That I have received and understood an explanation about the nature of the research project, its purpose and procedures.
2. My involvement includes participating in an interview that will take approximately 30-60 minutes to be scheduled the week of [???] at a convenient time for me during that week.
3. My participation is completely voluntary and data collected will be used solely for teaching and research purposes.
4. All information will be kept strictly confidential, accessed only by the researchers involved in the project. Pseudonyms for the facility and all participants will be used on all documents pertaining to the study and in all oral and written reports of the project. My name will not be used.
5. Questions will not be of a personal nature, and there is no apparent risk of physical or psychological harm.
6. I may withdraw from the study at any time by simply notifying one of the researchers, and I may refuse to answer any question during the interview.
7. The findings of the research will be prepared for publication as a Master’s thesis.
8. No participants will be identified in published results without their explicit consent.
9. All data will be securely stored in a locked filing cabinet at Lakehead University for a minimum of five years and then destroyed
10. At the completion of the research, I may request a summary of research results.

This study has been received by the Research Ethics Board at Lakehead University and has received ethics clearance. The Office of Research Ethics at Lakehead University is available for any concerns and comments pertaining to this study.

Consent for the Interview or to be Audiotaped

Name of Participant _____

Signature of Participant _____

Date _____

Signature of Researcher _____