

**THE IMPACT OF THERAPEUTIC DESIGN ON SOCIAL
ENGAGEMENT AMONG RESIDENTS WITH DEMENTIA
DURING PROGRAMMED ACTIVITIES IN DEMENTIA
CARE UNITS**

by

Krista D. Frazee
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Name: Krista Frazee
Degree: Master of Arts (Gerontology)
Title of Thesis: THE IMPACT OF THERAPEUTIC DESIGN ON
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DEMENTIA DURING PROGRAMMED ACTIVITIES IN
DEMENTIA CARE UNITS

Examining Committee:

Chair: **Dr. Barbara Mitchell**
Professor & Graduate Program Chair, Gerontology, SFU

Dr. Habib Chaudhury
Senior Supervisor
Associate Professor, Gerontology, SFU

Dr. Sharon Koehn
Supervisor
Adjunct Professor, Gerontology, SFU

Dr. Elisabeth Drance
Supervisor
Clinical Associate Professor, Geriatric Psychiatry, UBC

Dr. Barbara Purves
External Examiner
Associate Professor, School of Audiology & Speech
Sciences, UBC

Date Defended: December 6th, 2010 _____



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ABSTRACT

Growing evidence suggests that therapeutic physical and social environments in dementia care units can enhance residents' quality of life. A therapeutic milieu can be created within smaller units that have a homelike ambience, increased wayfinding, and regulation of sensory stimulation. Organizational philosophies can also reflect a holistic model of care that values personhood, fosters relationship building, and provides meaningful activity programming. While the body of literature on therapeutic design in dementia care has been expanding steadily since the early 1980's, little is known about the design of activity spaces, particularly what environmental features are conducive to successful activity programming and positive resident outcomes. This study explored the nature of residents' engagement during group activities in two dementia special care environments purposively selected for their contrasting physical environments. Findings shed light upon the complex interactions between physical, organizational, and social environmental factors that shape residents' experiences during group activities.

Keywords: Dementia; Personhood; Quality of Life; Therapeutic Design; Activity Programming

To Fannie and Stirling Frazee,

...who in good health instilled in me the virtues of hard work, dedication, and tenacity,

... who in sickness taught me that despite the ravages of dementia, the person within always remains,

...who in memory have been the source of my inspiration every step of the way.

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CHAPTER 1: INTRODUCTION

Cognitive impairment related to Alzheimer's disease and other dementias is pervasive in long-term care settings (Proctor & Hirdes, 2001). Projections indicate that upwards of one million Canadians could be diagnosed with dementia within the next 25 years (Alzheimer Society of Canada, 2009), the majority of whom will require 24-hour nursing care at some point during the disease trajectory. Disease stage and severity of negative responsive behaviours are strong determinants of placement in long-term care (Hébert, Dubois, Wolfson, Chambers, & Cohen, 2001), indicating that over the coming years, care providers will experience a significant increase in the number of residents in mid to late stages of dementia who require highly specialized 24-hour care.

Ongoing efforts are being made to improve best practices in dementia care, working towards a model of care that ultimately values and respects residents' personhood and maximizes their overall quality of life (QoL). The number of research studies, best practices documents, and design guidelines on the topic of QoL in dementia care has risen exponentially in the last twenty years (Cantley & Wilson, 2002; Day, Carreon, & Stump, 2000; Holmes, Teresi, & Ory, 2000; Kitwood 1997). Quality of life is an intricate concept; it is multifaceted, subjective, and determined by complex interactions between individual and environmental factors that, for residents with dementia, include aspects of the social, organizational, and physical environments which constitute the long-term care setting (Lawton, 1994; Weisman, Cohen, Ray, & Day, 1991).

Investigating the impact of the built environment on resident outcomes has become an important priority in environment-behaviour research in gerontology. This growing body of literature has been the impetus for the development of Special Care Units (SCU) in the 1990s, and more recently, freestanding Special Care Facilities (SCF), around the world. Broadly, these facilities attempt to maximize QoL by supporting residents' physical and psychosocial well-being in smaller, family-oriented, homelike settings with meaningful activity programs, better trained and qualified staff, and an appropriate balance of privacy and opportunity for social interaction (Volicer, 2000; Zeisel, Hyde, & Shi, 1999). As interventions in dementia care continue to be implemented, the challenge before researchers is to determine whether they are indeed effective in helping to maintain or improve QoL for residents, as well as care providers and family members.

Currently, the majority of SCUs are retrofitted environments located within or adjacent to older, traditional long-term care facilities that reflect a medical rather than holistic model of care. Often, the physical environments of these SCUs are modified to the extent possible in keeping with the latest design guidelines, but modifications are inevitably constrained by the existing building structures. As Reimer and colleagues (2004) note, fixed environmental characteristics such as long, double-loaded corridors, limited access to outdoor areas, and large-scale, over-stimulating social spaces can limit the full therapeutic potential of retrofitted environments. Conversely, newly constructed SCUs and purpose-built SCFs are likely to be based on cutting-edge architectural design recommendations that reflect a more holistic approach to residents' QoL.

Such design recommendations are also inclined to take into account staff outcomes and how the physical environment impacts the quality of care provided.

According to Weisman et al. (1991), when studying resident outcomes in dementia care, researchers must consider how multiple environmental systems interact to influence QoL. Consequently, associations between resident outcomes and the physical environment must also take into consideration the impacts of social and organizational factors (Schwarz, Chaudhury, & Tofle, 2004; Weisman et al., 1991). From an organizational perspective, dementia care has traditionally been delivered under a medical model of care, which is reflected in traditional nursing home environments. This type of environment has hospital-like characteristics that prioritize residents' physical health considerations at the expense of personhood (Kitwood, 1997), resident choice and autonomy (Reimer, Slaughter, Donaldson, Currie, & Eliasziw, 2004), and psychosocial well-being (Moore, 1999; Kane, 2001). In addition to having many physical design modifications, SCUs and SCFs often adopt the philosophy of person-centred care, offer meaningful activity programs, and encourage formation of strong social relationships between staff, residents, and families.

Positive engagement in group activities is a critical component of good QoL for residents with dementia in long-term care; it helps prevent social isolation, withdrawal, and can assist in exercising remaining cognitive and social skills. While the body of literature on therapeutic design in dementia care has been expanding steadily since the early 1980's (Day et al., 1999), there is lack of research on the role the physical environment plays in the success of group activity programs. Little is known about the features of activity spaces that make them conducive to successful activities. This study seeks to examine the impact

of factors within the physical, organizational, and social environments on residents' QoL by focusing on the nature of residents' engagement during programmed group activities. In particular, this research will explore how different physical environments and holistic models of care impact the nature of residents' engagement in activities. A second goal of the research will be to examine how these factors support or hinder staff members' efforts to provide successful activity programs.

CHAPTER 2: LITERATURE REVIEW

The literature review for this study presents an in-depth look at “quality of life” (QoL) from a multidimensional perspective that pertains specifically to persons living with dementia. Following this is a comprehensive look at how aspects of the physical, organizational, and social environments in long-term care work in concert to influence residents’ QoL. Specifically, research findings on activity programming and physical design will be discussed in relation to the impact they have on social engagement and QoL. Finally, because subjective assessments can be difficult to obtain from residents in advanced stages of cognitive impairment, the literature review also presents a summary of existing research on care provider and family caregiver perceptions of the physical, organizational, and social environments of SCUs and SCFs in relation to residents’ QoL.

2.1 Quality of Life in Dementia

Resident’s QoL should be at the forefront of all long-term care policies and procedures. Historically, care providers have held a somewhat limited view of what constitutes QoL for elderly residents. The role of long-term care has primarily been to eliminate or reduce physical discomfort, to maintain physical health through proper nutrition and hygiene, and to insure physical safety until the resident dies (Kane, 2001). Traditionally, these goals have superseded any efforts to provide psychosocial care, yet we know that QoL is not determined

merely by the absence of physical ailments or adverse events (Coons, 1991; Kane, 2001). Another common misconception has been that QoL for residents with dementia could not be improved short of the discovery of a medical breakthrough (Kitwood, 1997). The following paragraphs describe a much more holistic, multidimensional approach to QoL proposed by Lawton (1991, 1994) that includes physical, psychological, and environmental determinants, including dementia-specific elements of QoL that must be considered in the delivery of quality person-centred care.

Powell Lawton's conceptualization of QoL is widely cited in Gerontological research: "Quality of life is the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of the individual in time past, current, and anticipated" (Lawton, 1991, p.6). Lawton classifies four distinct domains of QoL: (a) behavioural competence, (b) psychological well-being, (c) objective environment, and (d) perceived QoL (Lawton, 1991, 1994). Behavioural competence denotes an individual's ability to function physically, cognitively, and socially as assessed by social-normative criteria. It includes biological health, ability to perform activities of daily living (ADL), memory, creativity, time use, and social interaction; all of which are areas of functioning that decline as Alzheimer's disease and other dementias progress.

Perceived QoL is the subjective or intrapersonal assessment of life experiences. Each person possesses a collection of unique interests, tastes, standards, memories, and coping styles that shape behavioural responses and subjective QoL. Details of subjective experiences are not always easily obtained from cognitively impaired individuals who experience difficulties generating insight, retrieving memories, and communicating feelings (Cotrell & Schulz, 1993;

Lawton, 1994; Reimer et al., 2004). However, the perceptions of pleasant versus unpleasant, comfort versus pain, and happy versus sad are thought to be retained well into the later stages of the disease (Kitwood, 1997; Lawton, Van Haitsma, & Perkinson, 2000). Therefore, residents with dementia do experience QoL (Phinney & Chesla, 2003), which can be evaluated by others even well after the point where it may be clearly articulated (Lawton et al., 2000).

Psychological well-being is the outcome or product of both one's behavioural competence and one's subjective evaluation of everyday life. The environment plays a key role in determining psychological well-being through support of functional abilities and maintenance of self-esteem; the provision of safety, security, and privacy; opportunities to engage in social relationships and meaningful activities; and through freedom to exercise independence and choice (Kane, 2001). The second dimension of psychological well-being derives from how one perceives the quality of these environmental attributes in terms of meeting their individual needs and desires. Depression, which is common among residents with dementia in long-term care (Slone & Gleason, 1999), is related to a variety of unmet psychological needs including occupation and companionship (Hancock, Woods, Challis, & Orrell, 2006).

Of particular importance to the present research is the dimension of QoL determined by the reciprocal relationship between individuals and their environments, namely what Lawton refers to as the "person-environment system". Environmental factors influence QoL insofar as they either facilitate or impede behavioural competence. Lawton argued that behaviour could be conceptualized as a function of the 'person', the 'environment', and the 'person-environment system', as best illustrated by his ecological equation $B=f(P, E,$

PxE) where '*PxE*' represents, "the internal representation of the external environment" (see Moore, 2005). Healthy individuals have the capacity to process, reflect upon, and then actively shape their environments to meet their individual needs and abilities. However, the neuronal damage brought upon by dementia causes impairments to the higher-order cognitive processes responsible for identifying specific environmental stressors and manipulating them accordingly (Zeisel, 2006). Prosthetic physical environments in dementia care settings are meant to compensate for cognitive losses (Zeisel, 2006) and restore balance in the '*PxE*' system (Lawton & Nahemow, 1973).

A considerable increase in dementia-specific QoL research has occurred since Lawton (1994) noted, "Quality of life is a concept much in the forefront of Gerontological research but is neglected for the most part in patients with Alzheimer disease" (p.138). Since then, several researchers have offered insights into 'dementia-specific' indicators of QoL. Lawton highlighted five QoL domains specifically relevant to persons living with dementia, including self-esteem, satisfaction with health care, spare time, meaningful time use, and social engagement (Lawton, 1997, as cited in Brod, Stewart, & Sands, 1999). Brod et al. (1999) identified aspects of aesthetics, positive and negative affect, self-esteem, and feelings of belonging as being salient aspects of dementia-specific QoL. Dröes et al. (2006) identified similar domains through interviews with both community-dwelling and nursing home residents with dementia, although a few additional domains were identified including sense of attachment, security and privacy, self-determination and freedom, and spirituality. These findings emphasize the necessary components or goals of therapeutic interventions, and identify specific targets within the physical and organizational environments that

can be modified to improve and maintain residents' QoL. This study will focus on the social-normative evaluation of residents' engagement experiences during social activities as one potential contributor to residents' overall QoL.

2.2 Dementia Special Care Units

Special care environments for persons with dementia were designed with the intent to create "a prosthetic physical environment and a supportive social environment [which] would reduce excess disability and improve QoL" (Albert, 2004; Reimer et al., 2004). There are a number of characteristics that distinguish SCUs from other types of facilities, although the variability between SCUs on the quantity and quality of these therapeutic features is widespread (Chappell & Reid, 2000; Day et al., 2000; Gerdner & Beck, 2001; Zeisel et al., 2003). SCUs generally limit admission criteria to persons with Alzheimer's disease or a related dementia. Units that are attached to larger long-term care or acute care facilities are typically segregated and ideally self-contained with their own kitchen and dining room. Wandering from the unit is avoided by keeping exit doors locked at all times, with on-off access limited to staff and family caregivers who are given security access. Ideally the number of residents per unit is eight to twelve; groups that are sometimes referred to as 'families' or 'clusters'. More than one 'family' may share common spaces such as living rooms, wandering circuits, and therapy gardens. However, some traditional units can provide care for to up to 40 residents. To various degrees, features of the physical environment are modified to create a non-institutional or homelike atmosphere, support functional abilities, and promote social interaction.

Preferably, SCU staff would consist of interdisciplinary teams of health care practitioners who are specially trained to understand the specific needs of residents with dementia in various stages of the disease (Gerdner & Beck, 2001). The ratio of direct-care staff to residents is generally higher than in most traditional facilities (Reid & Chappell, 2003). Specially trained activity staff and/or direct-care staff offer dementia-specific activity programs that are designed to stimulate and support, but not overwhelm, residents' remaining skills and abilities.

Purpose-built SCFs are the newest development in specialized dementia care, incorporating the latest principles of therapeutic design for dementia through each phase of development, construction, and organizational planning. The purpose and goals of SCFs are generally the same as SCUs, however these facilities tend to be newer, freestanding buildings with more substantial improvements to the physical environment (Slaughter, Calkins, Eliasziw, & Reimer, 2006). Freestanding SCFs are more likely to function as independent organizations with higher levels of autonomy. In contrast, most retrofitted and even newly constructed SCUs remain part of or linked to larger residential care facilities. This may limit the extent to which a truly therapeutic milieu can be fully achieved as organizational policies, care philosophies, and resource allocations are dependent upon factors within the larger organization.

Finally, some studies indicate that, on average, residents in SCUs and SCFs are further along in the disease trajectory than most residents with cognitive impairment in integrated settings (Teresi, Morris, Mattis, & Reisberg, 2000; Van Haitsma, Lawton, & Kleban, 2000). Individuals who exhibit responsive behaviours – physical or emotional reactions to unmet needs or environmental

stressors (Dupuis & Luh, 2005; Speziale, Black, Coatsworth-Puspoky, Ross, & O'Regan, 2009) – may be more likely to be admitted or transferred to a SCU because they are difficult to integrate with non-cognitively impaired residents (Volicer, 2000). In sum, the primary goal of SCU and SCF care is to improve residents' QoL by supporting their physical and psychosocial health, addressing the most common causes of responsive behaviours through person-centred care practices, modifications to the physical environment, and activity programming.

2.2.1 Activity Programming

Kitwood (1997) suggests that there are five key psychological needs that contribute directly to the maintenance of personhood and QoL for individuals with dementia: the need for comfort, attachment, inclusion, occupation, and identity. These core psychological needs are closely interrelated, and each one can be addressed through positive social relationships between residents, staff, and family caregivers. To a certain extent, social relationships develop naturally in dementia care settings (McAllister & Silverman, 1999). However isolation, apathy, and withdrawal are commonly reported among residents who are not encouraged to engage in social activities (Moore & Verhoef, 1999; Schreiner, Yamamoto, & Shiotani, 2005).

Occupation through meaningful activities is a critical component of specialized dementia care (Moore & Verhoef, 1999; Volicer, 2000). Kitwood describes occupation as, "being involved in the process of life in a way that is personally significant, and which draws on a person's abilities and powers" (Kitwood, 1997, pp. 83). Occupation through appropriately planned activities contributes to sensory and cognitive stimulation, exercises both the brain and the

body, and promotes continuity with the past when residents' individual interests are incorporated. It is strongly associated with physical and psychological well-being for all human beings, and perhaps especially so for individuals with dementia (Bowlby Sifton, 2000). Group activities have been found to contribute to community formation, social bonding, and a sense of inclusion (McAllister & Silverman, 1999). The need for occupation and inclusion may be particularly strong among people with dementia, and if unmet, may trigger a variety of responsive behaviours (Kitwood, 1997).

According to the Need-Driven Behaviour Model (NDB; Algase et al., 1996), negative responsive behaviours can be interpreted in terms of unmet needs or goals. The NDB model maintains that negative behavioural symptoms, whether passive or aggressive (e.g. physical aggression, pacing, repetitive or inappropriate vocalizations, agitation, withdrawal; Algase et al., 1996), represent needs that the resident is unable to communicate or goals that the resident is unable accomplish. It explains behaviours and their underlying need states as expressions of ongoing interactions between background factors and proximal factors. Consistent with Lawton's conceptualization of the person-environment system, the NDB model suggests that individual factors interact with physical and social environmental factors, along with need states, to produce patterns of adaptive or maladaptive behaviour. Activity interventions based on this comprehensive framework aim to restore congruency between the residents' need states and their environments by interpreting behavioural patterns and developing appropriate activities to meet the resident's individual background characteristics, current health status, and cognitive abilities. Wherever possible,

appropriate modifications are also made to the resident's proximal environment in order to create a balance of both support and demand.

The literature on activity programming in dementia care suggests that activity-based interventions are effective in improving residents' QoL; the consequences of boredom and social withdrawal, and the benefits of engagement in meaningful activities have been well documented. In the absence of occupation, some residents become agitated, anxious, and restless, while others become apathetic, which may result in more rapid functional decline (Bowlby Sifton, 2000). Lack of appropriate stimulation contributes to conflict between residents (Buettner & Kolanowski, 2003; Morgan & Stewart, 1999). Moore (1999) found that residents in one SCU spent over 60 percent of their time unengaged in social interactions or goal-directed activities. He argued that this time spent unoccupied was directly related to an increase in responsive behaviours such as wandering and agitation as the hours progressed, a behaviour often referred to as "sundowning" (Kutner & Bliwise, 2000). Similarly, Cohen-Mansfield, Werner, & Marx (1992) found that residents with dementia who were prone to agitated behaviours were unoccupied 63 percent of the time.

Conversely, Kutner and Bliwise (2000) found a significant decrease in agitated behaviours such as sundowning among SCU residents who participated in social groups during the day. Martichuski, Bell, and Bradshaw (1996) found a reduction in physical and chemical restraint use in the three months following implementation of a small group activity program in three SCUs. Meaningful activities can also help reduce or prevent passivity (Buettner & Kolanowski, 2003) and depression (Slone & Gleason, 1999), and the sensory stimulation and

exercise gained through activities are beneficial for residents' physical and cognitive functioning (Bowlby Sifton, 2000).

Many family caregivers consider activity programming to be an important component of good quality dementia care. Although best practices guidelines emphasize the importance of providing consistent dementia-specific activity programming, family members often report being dissatisfied because of the lack of opportunities for social and cognitive stimulation in SCUs (Kelley, Swanson, Maas, & Tripp-Reimer, 1999; Maas et al., 2004; Morgan & Stewart, 1997; Parker-Oliver, Aud, Bostick, Schwarz, & Tofle, 2005; Specht et al., 2000). Family members who feel their spouse or parent is receiving adequate stimulation through meaningful activities feel a sense of relief that their relatives are not alone, disengaged, or unattended to in their absence (Morgan & Stewart, 1997; Piechniczek-Buczek, Riordan, & Volicer, 2007).

Based on a review of existing literature, Moore and Verhoef (1999) identified three key contributors to positive social interaction in long-term care settings: (a) the type of activity, (b) with whom the interaction takes place, and (c) the physical environment in which the activity takes place. The physical environment has significant potential as a psychosocial intervention by the degree to which it fosters both naturally occurring and programmed social interaction to occur: what Lawton referred to as an environments' "social affordance" (Lawton, 1987, as cited in Moore & Verhoef, 1999). Positive social interaction is more likely to occur in environments where residents feel at home, comfortable, independent, and oriented to time, place, and others. Therefore, theoretically, both the overall ambiance of a unit, as well as the discrete aspects

of a space in which activities take place, could contribute to the quality of residents' social interaction during programmed activities.

2.2.2 Physical Environment

While the body of literature on therapeutic design in dementia care has been expanding steadily since the early 1980's (Day et al., 1999), there has been surprisingly little research conducted on the role the physical environment plays in the success of activity programs. Given the contribution of meaningful activities and positive social engagement to residents' QOL, this is an important direction for environment-behaviour research. The following paragraphs describe the fundamental principles of therapeutic design that contribute to overall supportive living environments for residents with dementia, and that may be used to guide research focused on activity spaces in particular.

Ideally, dementia care environments should consist of a balance of both demand character and support character. Just as environments can impose excess challenges for aging individuals, an overly prosthetic or sterile environment can also threaten QoL by contributing to boredom, excess disability, or dependency. This is referred to as a *disability gap*, denoting the difference between an individual's potential and his or her actual performance under the circumstances (Bowlby Sifton, 2000). The progression of dementia compromises one's ability to process, comprehend, and then purposefully or actively modify the environment according to need states. Therefore, the congruence or 'fit' between the person with dementia and their environment is strained (Lawton & Nahemow, 1973). Together, physical design modifications can help reduce environmental

press while adequate activity programming can add positive stimulation, which in combination can defend against excess disability.

As Zeisel (2006) notes, the fundamental goal of therapeutic design is to help residents remember who they are and where they are. The ability to perceive, encode, and store new information about the environment is lost as the neurons responsible for these complex functions are destroyed (Zeisel, 2006). Lack of awareness of time, place, self, and others can lead to disorientation, fear, and anxiety (Zeisel, 2006; Zeisel et al., 2003). The therapeutic attributes of SCUs and SCFs are designed to create comfortable, homelike atmospheres much like residents' previous home environments, while the prosthetic aspects of SCUs are designed to lessen the degree of dependency, risk, and disorientation (Brawley, 1997).

Results of empirical studies examining the success of dementia design interventions in achieving positive resident outcomes are mixed (see Day et al., 2000). Zeisel and colleagues (2003) found that after controlling for individual resident characteristics (e.g. gender, length of institutionalization, functional abilities) and organizational attributes (e.g. facility size, profit/non-profit status, staff to resident ratios) resident behaviours were associated with numerous aspects of the physical environment. In particular, resident aggression was related to levels of sensory comprehension, residential as opposed to institutional ambiance, and degree of privacy and personalization. Social withdrawal was associated with quality of common spaces throughout the facilities, and reduced depression scores were associated with greater camouflaging of exits. Reimer et al. (2004) found that over a one-year period, SCF residents maintained competence in performing ADLs longer, exhibited less anxiety and fear, and held

more interest than residents in traditional facilities. However, measures of cognitive functioning, social behaviours, and social withdrawal failed to differ from other traditional facilities.

While improving resident outcomes is the primary goal of therapeutic care environments, these settings must also function well for staff, and must be appealing to family members. Morgan and Stewart (1997, 1999) found that staff and family caregivers identified both supportive and non-supportive aspects of a newly constructed SCU (post-relocation). Supportive aspects included a more homelike environment, reduced agitation, increased sense of privacy and ability to personalize private rooms, and more appropriate dining areas with enough seating for all residents. Non-supportive features included difficulty for staff to monitor residents due to layout, and inadequate levels of sensory and social stimulation. Staff members in a study by Schwarz et al. (2004) felt that design modifications including decentralization of dining and activity spaces, development of residential "clusters", renovation of the institutional nurses station, and construction of aviaries improved resident-resident and resident-staff social interactions.

Parker-Oliver et al. (2005) found that family caregivers were pleased by the cleanliness and attractiveness of SCU décor, but were less satisfied with opportunities for sensory stimulation. Greater availability of equipment, added safety and security features, and a layout that improved ease of resident monitoring were some of the reasons why care providers in an Australian SCU felt they provided better quality care than in their previous environment (Cioffi, Fleming, Wilkes, Sinfield, & Miere, 2007). Family members in the same study reported being pleased with the bright, homelike atmosphere of a newly

constructed SCU, and attributed the layout, design of the dining room, and access to outdoor spaces to improved resident outcomes. Furthermore, these family members felt the new environment improved the quality of their visits and, as a result, felt more confident in their decision to have their loved ones in care.

Finally, Morgan and Stewart (1999) describe how staff and family caregivers perceive the interaction between physical and social environments in relation to resident social behaviours. Participants in this study described how residents relocated to a larger unit with fewer residents (from a smaller, higher social density SCU) were less likely to demonstrate negative responsive behaviours; a change which they attributed to an overall reduction in negative stimulation from noise, agitation, and aggressive contact between residents. However, other residents demonstrated a marked decline in social engagement because fewer residents were dispersed over a larger physical space in the new environment, limiting opportunities for informal interaction to occur.

Several studies point to a disconnect between physical design modifications and organizational change, which may help explain some of the mixed results found in the literature in relation to the efficacy of therapeutic physical design. As Van Hattis et al. (2000) demonstrate, segregation of residents and modifications to the physical environment in the absence of complementary program and policy changes do not improve resident outcomes. In a state-wide survey of SCU and non-SCU facilities in Arkansas, Gerdner and Beck (2001) found the differences between the policies and practices in SCUs compared to traditional facilities were negligible. Similarly, Chappell and Reid (2000) found that while SCUs in British Columbia were more likely to have modified physical environments, these facilities did not outperform traditional

facilities on a number of other important best practice recommendations such as flexible care, staff education, and use of restraints.

Schwarz et al. (2004) found that while decentralization of activity areas and construction of aviaries attracted residents to spend time in these areas, the lack of programmed activities offered in these spaces meant residents were left to instigate their own activities and interactions with others. According to staff, this meant that many residents remained passive throughout the day. Morgan and Stewart (1999) reported that elimination of the Activity Aide position in a newly constructed SCU left staff and family caregivers concerned about the boredom due to lack of stimulation in the new unit. Thus, mixed messages regarding the efficacy of physical design interventions in SCUs and SCFs in improving resident outcomes is confounded by lack of evidence suggesting that these interventions are indeed being accompanied by the recommended changes in organizational policies and care practices. Further understanding of how the physical environment in activity spaces can support positive social engagement also requires examination of associated care philosophies, organizational policies, and activity programming.

Through this literature review, one begins to realize the sheer complexity of the 'person-environment system' of a resident with dementia in long-term care. The resident brings to the environment their own uniqueness as 'persons' through their personalities, histories, preferences, and need states. The physical environment can be unfamiliar, institutional, and disorientating or homelike, supportive, and comforting. Organizational policies and procedures determine the overall climate of the unit through respect for residents' personhood, staffing, activity programming, and family involvement. Together, all of these factors

influence patterns of social behaviour and QoL. The following chapter presents a conceptual framework developed to guide this study, which takes into account the multiple subsystems that constitute the 'resident-environment system'. This framework broadly demonstrates why, theoretically, these environmental subsystems work in concert to improve or detract from residents' QoL through the quality of engagement during programmed activities.

CHAPTER 3: CONCEPTUAL FRAMEWORK

The conceptual framework guiding this inquiry builds upon a combination of Lawton's (1991, 1994) notion of the 'person-environment system', Personhood Theory (Kitwood, 1997), the Need Driven Behaviour Model (Algase et al., 1996), and Weisman et al.'s (1991) framework for environments for people with dementia. This conceptual framework (Figure 1) focuses on the individual with dementia and illustrates how the resident-environment system (broken arrows), and interactions that occur *within* and *between* each of its subsystems (solid arrows), function interdependently to impact the quality of engagement during programmed activities, which is key to supporting residents' QoL. The conceptual framework encompasses the resident (including background factors and personal capacities) and the proximal environment (including the physical, organizational, and social environments). For this study, engagement during programmed activities is the therapeutic goal of interest, which, with support from the physical environment (e.g. activity spaces) and organizational environment (e.g. programming and resources), contributes to residents' QoL.

The framework begins with the resident and his or her background factors that contribute directly to personal capacities (e.g. need states), help shape activity programs (e.g. previously enjoyed hobbies), and influence factors in the proximal environment. Note that the relationship between background factors and other subsystems is not reciprocal as are the relationships between other components of the framework because background factors represent historical or

enduring personal characteristics that are unable to be modified through interventions. However, knowledge of these background factors can help practitioners personalize the resident's environment and can contribute to more individualized care practices, the central tenet of person-centred care.

Personal capacities, or what Lawton referred to as “behavioural competence”, impacts and is impacted by therapeutic goals and the aspects of the proximal environment. For example, disease stage, concurrent medical conditions and/or physical impairments, and remaining functional abilities should determine the sorts of tasks that are chosen for programmed activities. Dementia-specific, failure-free activities maintain personhood by reinforcing confidence and self-esteem, and in turn enhance residents’ capacities by supporting remaining cognitive and social skills, creativity, and time use. Group activities also encourage residents to exercise their social skills, through which a positive social environment is created.

Therapeutic goals, represented here by activity programming, should be determined through ongoing care planning that incorporates the unique backgrounds, needs, abilities and preferences of each resident, as well as their personal capacities. Under a holistic model of care, preservation of personhood would be a key therapeutic goal achieved in part through activities that are meaningful to the residents, respect for individual choices, and involvement in decision-making. The NDB Model also emphasizes a reduction of responsive behaviours and elimination of restraint use as goals that can be achieved through individualized activity-based interventions. These goals, in turn, shape the policies and procedures that determine the social, organizational, and physical contexts. Moreover, a positive social and physical environment is reinforced and

enhanced when the frequency and duration of negative responsive behaviours such as repetitive vocalizations, aggressions, and agitations are reduced.

Proximal factors represent features of the physical, social, and organizational environments. Through an iterative process, press – environmental characteristics, whether supportive or demanding, which induce a behavioural response (Lawton & Nahemow, 1973) - can impact residents' cognitive and social capacities. Over time, changes in these capacities should influence modifications to the environment and therapeutic goals. For instance, organizational issues such as rigid routines detract from person-centred care, contribute to responsive behaviours, and may increase the rate of functional decline. Conversely, the social environment can be enhanced through organizational policies that encourage family involvement. For example, positive family-staff relationships can improve quality of resident care, which in turn improves resident outcomes. Family members' input into activity programming can help activity staff tailor activities for each resident according to past hobbies, interests, and preferences that make the activities more meaningful and enjoyable.

Finally, the physical environment can be a critical element in supporting personal capacities. Institutional characteristics such as loud speakers and alarms, glare-producing flooring, poor lighting, large over-stimulating social spaces, and disorienting layouts contribute negatively to physical, cognitive, and social functioning. As a result, many residents withdraw from the social environment as a means of coping with the frustration and over-stimulation. Others lash out by exhibiting combative or aggressive behaviours such as hitting,

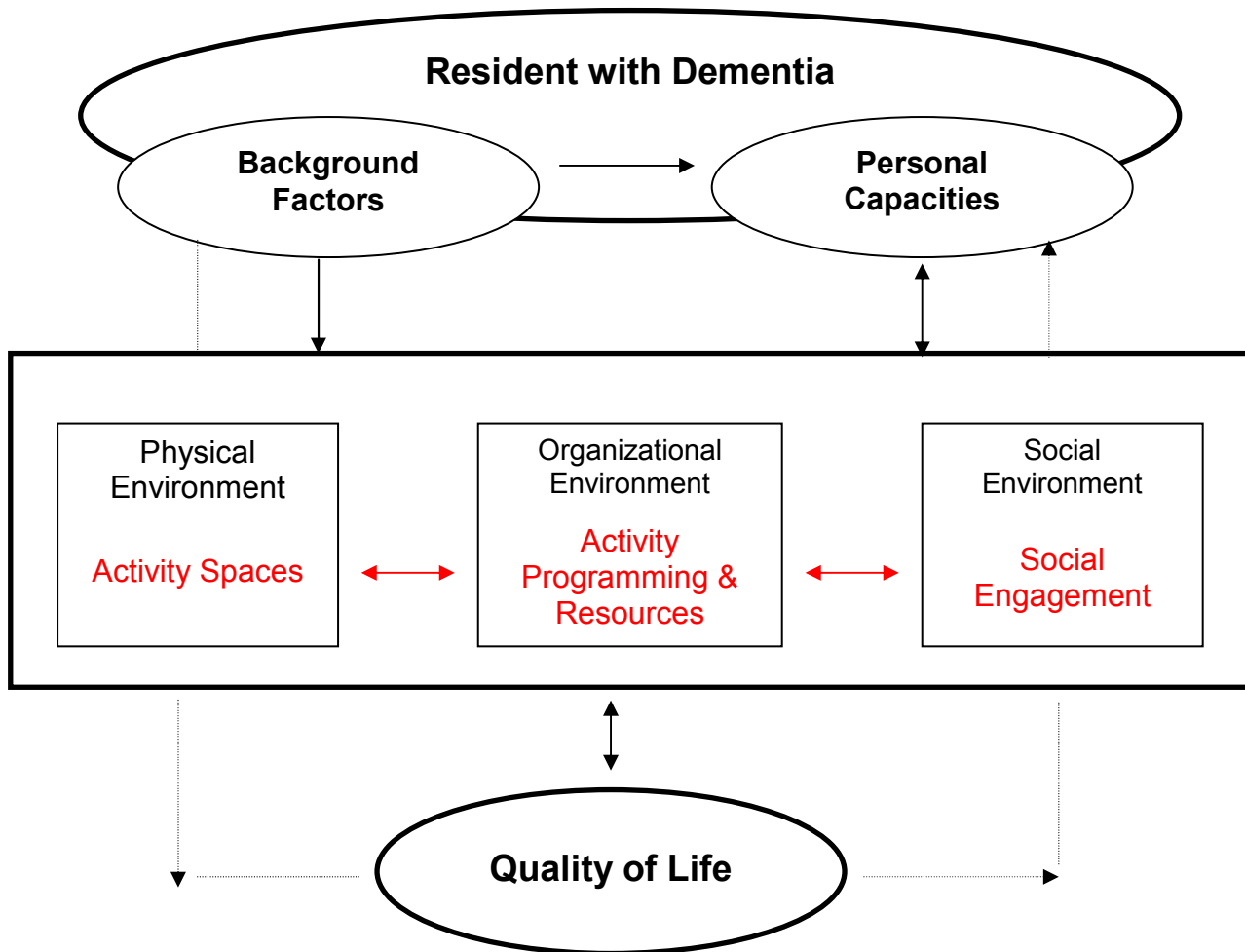
screaming, and pacing, which increases the likelihood of them being forced away from group activities (Buettner et al., 1996).

As highlighted in the figure below, the goal of this study is to learn more about the more direct relationships between the physical environment (activity spaces), the organizational environment (activity planning and resources), and the social environment (residents' engagement) and how these relationships influence residents QoL. In theory, an overall reduction in environmental press (or greater resident-environment fit) should contribute to more positive social interactions during programmed activities by: (a) alleviating burden on cognitive resources, freeing the resident to be more present in the activity and the other participants involved; (b) by reducing stress and contributing to more positive mood states before and during activity groups; (c) by providing opportunities for activities that are meaningful to the residents; and (d) by providing added attention by staff and family caregivers to individual preferences.

3.1 Research Questions

- 1) How do aspects of the physical, organizational, and social environments of dementia special care environments impact the quality of residents' engagement during programmed activities?
- 2) How do activity spaces help or hinder staff members' abilities to provide successful group activities?

Figure 1. Conceptual framework illustrates the complex, reciprocal relationships between individual and environmental factors that interact to influence positive social engagement during programmed activities, which contributes to QoL.



CHAPTER 4: METHODS

Guided by the conceptual framework, the primary objective of this study was to explore how aspects of the physical, organizational, and social environments in different types of dementia special care settings influenced residents' engagement in programmed group activities. *Focused ethnography* (Knoblauch, 2005; Morse & Field, 1995; Muecke, 1994) was chosen as the most appropriate method for this exploratory study. Focused ethnographies differ from more traditional or classic ethnographies in that the researcher pre-selects a topic of inquiry and explores this topic within a "discrete community or organization" (Muecke, 1994, pp. 199). The nature of the inquiry is problem-focused and context-specific. The purpose of focused ethnographies is typically to evaluate or improve some aspect of health services provision (Morse & Field, 1995).

Within focused ethnographies, a mixture of data collection techniques is used to "solve the ethnographic puzzle" (Morse & Niehaus, 2009, pp. 141). Different data collection techniques yield different perspectives of a phenomenon under study. Mixed method approaches reveal multiple perspectives, and then, as Denzin and Lincoln (2000) suggest, researchers can stitch the various pieces of reality together to create a more comprehensive view of the social world. This approach, also referred to as triangulation, adds to scientific rigor (Patton, 2002), and is particularly suitable for studies involving interpretation of behavioural patterns in dementia care settings (Moore, 2005).

This study involved focused ethnography employing a qualitatively-driven mixed method design (Morse & Niehaus, 2009) using resident observations, field notes, floor-plan analyses, open-ended questionnaires, and in-depth interviews as primary sources of data collection. Quantitative methods, including structured environmental assessments and closed-ended survey questions, supplemented qualitative data sources by contributing to a more comprehensive description of the physical and cultural contexts of each facility. Focused ethnography, using a primarily qualitative mixed method design, was most appropriate for this study because the topic of inquiry required an exploration of specific subcomponents of the SCU/SCF environments (e.g. the physical, organizational, and social environments) in order to paint a comprehensive picture of each resident's 'person-environment system'. All study participants and facility names were replaced with pseudonyms to ensure the privacy and anonymity of all residents and staff who participated in this study.

4.1 Facility Selection

Two residential care facilities in the Lower Mainland of British Columbia were purposively selected to represent optimum variation in the physical environment. Emory Lodge is a freestanding SCF, constructed in 2007, purposely designed according to the 'cluster' model with three secure, self-contained neighbourhoods of 12 residents each (See Fig 2.). Beachwood Residence is a segregated SCU located on the second floor of a larger multi-level campus of care. Beachwood Residence was constructed in 1980 as supportive housing for independent seniors and has since been retrofitted with security mechanisms on all stairway exits and elevators. It has a standard L-

shaped design with one large dining room/common space at the end of a long double-loaded corridor (See Figure 3.). Data collection took place over a 10-week period, four days a week, alternating one week at Emory Lodge and the next at Beachwood Residence for a total of five weeks of data collection per site.

4.2 Ethics Approval

Ethical approval for the study was granted by the Office of Research Ethics at Simon Fraser University. Because Emory Lodge is classified as “owned and operated” by the Fraser Health Authority (FHA), the proposal underwent a separate ethics review by the Fraser Health Research Ethics Board (FHREB). All research studies conducted within the FHA’s owned and operated institutions require: 1) a Co-Investigator employed by the FHA; 2) a Principal Investigator with Affiliated Researcher Status through FHA; and 3) an official Sub-Agreement signed between FHA and the educational institution underlining the terms and conditions of the research collaboration. To meet these requirements, Dr Fabio Feldman, Manager of the Seniors Falls and Injury Prevention Program with FHA was approached and agreed to join the study as a Co-Investigator. Dr Habib Chaudhury, the Senior Supervisor for the study, was named Principal Investigator and granted Affiliated Researcher Status with FHA. Finally, an official Sub-Agreement between the FHA and SFU went into effect in April of 2010, upon which time the FHREB granted ethical approval of the study.

Beachwood Residence is operated by a non-profit society, and as such did not require a separate Health Authority ethics review. However, the proposal was presented to the senior management team and approval was granted in accordance with the conditions outlined by the Office of Research Ethics at SFU.

4.3 Facility Profiles

4.3.1 Structured Environmental Assessments

A number of assessment instruments have been developed by environment-behaviour researchers to assist in measuring the quality of physical environments in long-term care (see Lawton et al., 2000). Over the years, these instruments have been conceptually refined to apply specifically to the environments of people living with dementia. For this study, two structured environmental assessment instruments were used to develop a global profile of each facility: the Therapeutic Environment Screening Survey for Nursing Homes (TESS-NH; Sloane, Long, & Mitchell, 2000) and the Professional Environmental Assessment Protocol (PEAP; Weisman, Lawton, Calkins, & Sloane, 1996).

The TESS-NH contains descriptive information about the unit as well as information relating specifically to SCU quality assessment. Six therapeutic goals are represented in the TESS-NH: a) safety and security, b) orientation, c) privacy, control, and autonomy, d) positive and negative stimulation, e) positive social milieu, and f) personalization and familiarity. The TESS-NH uses direct observation and ratings of discrete environmental attributes such as exit camouflage, handrails, maintenance and cleanliness, lighting, visual access to outdoors, opportunities for tactile stimulation, and homelikeness. Thirty-one items are scored using either binary (0 = no, 1 = yes) or categorical (0 = low quality, 3 = high quality) values. The instrument concludes with a 10-point Likert scale capturing the rater's overall impression of the environment (1 = distinctly unpleasant, negative, and non-functional to 10 = quite pleasant, positive, and functional). Embedded within the TESS-NH is a summary scale called the

Special Care Unit Environmental Quality Scale (SCUEQS), which consists of 18 TESS-NH variables reflecting measures of maintenance, cleanliness, safety, lighting, physical appearance/homelikeness, orientation/cueing, and noise.

Sloane et al. (2002) provide extensive details on the psychometric properties of the TESS-NH; the instrument has been found to demonstrate acceptable to good interrater reliability, test-retest reliability, and concurrent validity (Lawton et al., 2000; Sloane et al., 2002). In a study by Slaughter et al., (2006) comparing 45 units in traditional facilities and one SCF with six self-contained bungalows, the TESS-2+ (an earlier and very similar version of the TESS-NH) was sensitive to differences in environmental quality between the facilities. Therefore, the TESS-NH was considered an appropriate instrument to evaluate discrete aspects of environmental quality across the two facilities in this study.

The PEAP (Weisman et al., 1996) can be used alone or to augment the TESS-NH by adding a more global, detailed evaluation of similar dimensions of the physical environment (Lawton et al., 2000). It contains both discrete and global indicators of environmental quality for residents with dementia (Schwarz et al., 2004; Morgan, Stewart, D'Arcy, & Werezak, 2004). While the primary emphasis of the PEAP is on the physical environment, it does address, in more detail than TESS-NH, elements of the social and organizational contexts as well. The therapeutic goals represented in PEAP overlap with those in TESS-NH, with the addition of a domain measuring support for functional abilities. While the PEAP evaluation relies primarily on direct observations of the environment, some questions do require input from staff.

A five-point rating scale (1= unusually low support to 5 = exceptionally high support) is provided for each of the PEAP's nine assessment dimensions, along with a detailed description of what each score should represent. The original authors suggested that intermediate points be rated as + or - (e.g. a score 3+ would indicate a rating between moderate and high levels of support on a given dimension). Subsequent researchers have expanded the original scoring scheme to a 13-point scale in order to quantify intermediate points and increase variability of scores (e.g. the same 3+ rating would translate to a score of 8 out of 13; see Morgan et al., 2004). The latter method was used for this study to compute a composite score of environmental quality similar to that derived from the TESS-NH. Details of the psychometric properties of PEAP can be found in Lawton et al. (2000).

4.3.2 Staff Questionnaires

Direct-care staff who were interested in participating in the study completed questionnaires consisting of a blend of fixed-choice and open-ended questions. Eligibility was limited to full or part-time care staff, duration of employment with the facility (or on the unit) of at least three months, proficiency in reading and writing in English, and having responsibility for managing, coordinating, or providing direct care to residents with dementia.

The self-completion survey method was chosen for several reasons. First, the shortage of workers and low staff to resident ratios commonly reported in dementia care settings can pose problems for recruiting face-to-face interviews during working hours. Coverage would have been required in order for direct-care workers to leave their residents for interviews, which would have placed

additional strain on the staff resources and may have been upsetting for some residents. Instead, participants were invited to complete the questionnaires at a time and location of their convenience (within a two week period). Packages including a detailed study description, informed consent, questionnaire, and sealable envelope were available in the staff room at Emory Lodge, and in the nurses' station at Beachwood Residence. Each package contained instructions to complete the questionnaire within a two-week period and return it in the sealed envelope along with the signed informed consent. All staff members who returned completed questionnaires were compensated with a \$15 gift certificate.

Some methods experts suggest that using a mixture of qualitative and quantitative questions in a survey or questionnaire can generate the richest, most in-depth, and most accurate knowledge of the topic under investigation (Adamson, Gooberman-Hill, Woolhead, & Donovan, 2004). Using a combination of both quantitative (fixed-choice) and qualitative (open-ended) questions is a way of compensating for the limitations of single-method data collection techniques and can improve methodological rigor (Brewer & Hunter, 2006; Johnson & Turner, 2003; Patton, 2002). Adamson et al. (2004) demonstrate that quantitative and qualitative questions complement each other well in survey research. For example, including fixed-choice questions can reduce vagueness and trigger thought processes that lead to more complex responses to open-ended questions. On the other hand, open-ended questions compensate for the lack of subjectivity, richness, and contextual details captured in fixed-choice questions, and allow respondents to comment in greater detail on the uniqueness of their experiences and perceptions.

The staff member questionnaires consisted of 21 fixed-choice and open-ended questions divided into three main sections: a) Demographic and Employment Information, b) Group Activities, and c) Physical Environment. A conclusion section invited participants to add any additional information that had not been covered in the questionnaire (see Appendix A). Definitions were included at the beginning of each section to clarify the meanings of specific terminology such as "group activities" and the "physical environment".

Questions 11a through 11c were adapted from the Nursing Unit Rating Scale (NURS; Grant, 1996). In contrast to the TESS-NH and PEAP, NURS is designed to assess policy and program features of SCUs that differ from traditional facilities. Because these attributes are not measurable by direct observations, NURS contains questions that are designed for use in staff interviews. These three questions were chosen for their focus on the complexity of programmed activities. The fourth question in this series (11d) is not part of NURS, but was included in the same format to assess whether or not residents are given a choice to participate in programmed activities, a reflection of person-centred care practices. The remainder of the questions were original questions that reflect salient issues identified in the literature review. Questions pertaining to programmed group activities and family involvement were designed to capture aspects of the organizational and social environments in each facility that contributes to more comprehensive facility profiles. Open-ended questions in the latter section on the physical environment were included in the qualitative analyses. An additional open-ended question was added to the questionnaire at Beachwood Residence to capture staff members' ideas and opinions regarding an upcoming cosmetic renovation scheduled for their dining room.

4.4 Qualitative Data Generation

4.4.1 Resident Observations

Participant observation is a common method used by ethnographic researchers to develop an understanding of the interactions that naturally occur between individuals and their environments (Lofland & Lofland, 1995; Morse & Field, 1995). Researchers immerse themselves in the participants' environment over time to record and analyze naturally occurring behaviours, while being cautious not to create or impose disruptions to the natural setting (Morse & Field, 1995). Patton (2002) identifies several important advantages to conducting observational research, including (a) a deeper understanding of the context within which people interact, (b) the reduced reliance upon prior conceptualizations of behavioural settings, (c) discovery of deeply embedded behaviours that may go unnoticed by participants, and (d) opportunities to reflect upon and interpret observations using personal knowledge.

Participant observation is a suitable technique to use in efforts to understand how residents with dementia experience their physical and social worlds, as many can no longer articulate their feelings clearly and concisely during interviews (Volicer, 2000). For this study, observations were conducted 10 minutes before, during, and 10 minutes after group activities with a sample of residents in each facility to observe the nature of their cognitive and social engagement during activities in different settings, as well as factors within the physical and organizational environments that contribute to the nature of their engagement. During the five-week period at Emory Lodge, 13 observation sessions were conducted, from Tuesday to Saturday, between 11:00am and

3:30pm. Observations sessions were anywhere from 50 minutes to 80 minutes in length. The sample included 11 residents (9 female, 2 male) who were chosen—through consultation with the Social Worker and the Activity Coordinator—based on their current ability to engage in group activities. Of those 11 residents, eight were independently mobile, two required wheelchairs for mobility, and one required some assistance from staff. At Beachwood Residence, 12 observation sessions of comparable duration took place from Monday to Friday, between the hours of 9:30 am and 3:00pm. Through consultation with the Activity Coordinator and the Director of Special Care, a sample of 14 female residents was chosen based on their ability to engage in group activities. Of the 14 residents chosen, 10 were independently mobile, three required wheelchairs for mobility, and one required some assistance from staff. Neither Emory Lodge nor Beachwood Residence offered programmed activities during the evenings, and only Emory Lodge offered weekend activities.

A behavioural observation protocol (Creswell, 2003) was developed to guide participant observations for this study incorporating elements of the Observed Emotion Rating Scale (OERS; Lawton et al., 2000) and Dementia Care Mapping (DCM; Brooker & Surr, 2005) as sensitizing concepts (see Appendix B). Dementia care mapping includes an assessment of the level of residents' engagement in an activity. The DCM accounts for withdrawn, passive, and active levels of engagement (Brooker & Surr, 2005). Withdrawn behaviours are noted when the resident being observed is not exhibiting any signs of engagement in the activity or with people around them, which includes sleeping, dozing, or being socially uninvolved. Being withdrawn from an activity may indicate that the resident is uninterested in the content of the activity, or that the activity or the

environment around them is overly challenging for his or her cognitive capabilities. Passive engagement (e.g. observing but not actively engaging in the activity or with others) indicates that the resident has some level of interest in the activity and the people around them, and may have the potential to become actively engaged with some assistance. This level of engagement might also be interpreted as a warning sign that the resident may become increasingly withdrawn without further attention from care staff. Active engagement consists of interacting with others and participating in the activity through verbal and physical gestures. An additional category was added to account for solitary engagement (Moore & Verhoef, 1999), which reflects engagement in some type of motor or cognitive activity in the absence of social engagement with other residents, staff, family members, or volunteers.

The OERS, formerly known as the Apparent Affect Rating Scale, was designed on the premise that emotional displays can serve as indicators of psychological well-being, behavioural competence, and the interplay between a person with dementia and their environment (Lawton et al., 2000). When a resident displays positive emotional behaviours (both verbal and non-verbal), such as pleasure (e.g. smiling, singing, dancing) and/or interest (e.g. alertness, focused gaze or attention, active participation), these behaviours can be interpreted as signs of a good person-environment fit. Such positive displays of emotion during programmed activities can be interpreted as indicators of congruence between the residents' abilities or interests and the task at hand; positive social interactions between the resident and other residents, staff, etc; and a physical environment that is appropriately responsive to that residents' needs and abilities. On the other hand, expression of more negative emotions

such as anger (e.g. aggression, combativeness, yelling), anxiety/fear (e.g. restlessness, pacing, repetitive vocalizations), or depression/sadness (e.g. crying, sleeping, moaning) may indicate dislike of something in their environment. In particular, the activity may be too difficult or unappealing, the noise level in the room may be over-stimulating and distracting, or they may be signs of loneliness or withdrawal.

The structured observational protocol described above, which consisted of a 'checklist' of engagement levels and emotion categories with a measurement of the length of time they occurred, proved to be an unreliable tool for measuring residents' engagement. First, the tool was limited in terms of capturing the subjective nature of residents' behavioural patterns. The positive emotion indicators and behaviours included in the tool (e.g. clapping, singing, holding hands, smiling, laughing) were not representative of the manner in which many residents exhibited positive engagement in group activities. For instance, for some residents simply sitting for a sustained period of time and maintaining eye contact was demonstrative of high levels of positive engagement, which was not captured by the tool itself. Second, in some cases it was simply not in the residents' nature to hold hands, sing, or dance. Finally, the positive behaviours represented in the tool were not always appropriate for certain activities. For example, it would have been inappropriate for residents to sing, clap, or dance during a 'news and views' or 'tea party' activity. Therefore, the 'checklist' component of the tool was dropped early in the data collection period and replaced with qualitative field notes. However, the emotional and behavioural indicators were still used as a guide in the interpretation of residents' engagement experiences. Ethnographic field notes (Lofland & Lofland, 1995;

Morse & Field, 1995) were recorded directly prior to and following each observation period to capture environmental factors (e.g. lighting, temperature, ambiance), resident factors (e.g. mood state, physical health, non-verbal gestures, presence of family members) and activity details (e.g. type of activity, appropriate responses, etc) deemed pertinent to the understanding of residents' engagement in the activities. Interactions between the residents and the Activity Coordinator were also recorded. Informed consent was obtained from Activity Coordinators and volunteers present at the time behavioural observations were being conducted.

4.4.2 Field Notes and Floor Plan Analysis

While the TESS-NH and PEAP are used to guide global evaluations of SCU quality, with some attention to discrete aspects of the physical environment, they do not contain assessment questions directly related to spaces where programmed activities occur. Therefore, floor plans were used to record the design, layout, furniture configuration, and any other significant attributes of the activity spaces where resident observations were conducted. Ethnographic field notes (Lofland & Lofland, 1995; Morse & Field, 1995) were recorded each day to supplement the structured assessment instruments and floor plans. Field notes combined descriptions of the spaces and resident behaviours to augment subsequent interpretation of resident-environment interactions during activities.

4.4.3 In-depth Interviews

Both one-on-one and group interviews with staff members were conducted at various times over the 10-week period of data collection. One-on-one

interviews (N = 3) were semi-structured, loosely following items in the physical environment section of the staff member questionnaire. Interviewees – one Recreation Therapist (Emory Lodge), one Activity Coordinator (Beachwood Residence), and one Music Therapist (Beachwood Residence) were probed for details about their personal experiences offering group activities in activity spaces at their respective workplaces. Group interviews (N = 4) involved nine members of the interdisciplinary leadership and recreation teams. At Emory Lodge, group interviews (N = 3) involved the Manager, Director of Care, Occupational Therapist, Activity Coordinator, Social Worker, and Music Therapist. At Beachwood Residence, the group interview involved the Executive Director, Director of Special Care, and Director of Leisure Services. An “informant feedback” approach (Schwartz-Shea, 2006) was used to guide group interviews. According to Morse, Barrett, Mayan, Olson, & Spiers, (2002) collecting and analyzing data concurrently allows “mutual interaction between what is known and what one needs to know” (pp.12). In an iterative process, emerging themes identified from observations, floor plan analyses, and field notes were presented during group interviews to stimulate open discussion and encourage verification. Questions were also posed during the interviews that were meant to further elaborate on or clarify aspects of the data. For example, at the time of data collection, the leadership team at Beachwood Residence was in the process of transforming the ‘culture of care’ on the special care unit where data collection took place. Questions posed during the group interview probed their perceptions of the current culture of care, as well as their vision for the future. This approach to group interviews enabled validation, clarification, and expansion of ideas as they were being developed, while the representation of both leadership and

interdisciplinary team members enhanced the richness and scope of the dialogue and subsequently the data obtained. All interviews were audio recorded with permission and transcribed verbatim.

4.5 Data Analysis

The first step of the analysis was to create facility profiles by combining data from TESS-NH and PEAP assessments; floor plan analyses; and staff survey data on organizational practices, activity programming, person-centred approaches to activity programming, and family involvement in care. This initial stage in the analysis process set the stage for further analyses by providing a rich contextual background and foundation for the interpretation of qualitative data.

Theoretical thematic analysis (Braun & Clarke, 2006) was used to identify concepts and patterns that emerged across the data set from resident observations, qualitative field notes, open-ended survey questions, and in-depth interview transcripts. The qualitative software program NVivo 8 was used as a tool to help identify, cluster, and interpret recurring concepts within the various qualitative data sources. Initial coding involved an inductive exploration of the data, initial formulation of ideas based on patterns identified across the data set, and the preliminary development of a broad coding scheme. The initial coding scheme was then further developed using concepts from the literature review and conceptual framework, which helped to add meaning to the preliminary data clusters. This procedure was followed by focused coding (Lofland & Lofland, 1995); through a recursive process (Braun & Clarke, 2006), codes were further developed by reading and rereading the data and returning to the conceptual

framework until higher level themes and subthemes were identified, defined, and refined. While the larger themes were informed by concepts found in the existing literature, the names and definitions of subthemes were derived from the data. Substantive differences and similarities between concepts emerging from data generated at each facility were also examined.

An audit trail consisting of process, analytic, and topic memos was maintained throughout the coding and analysis process documenting insights, decisions, and changes to analytical or methodological approaches (Morse & Field, 1995). The final step in the analysis process involved development of a concept model and matrix illustrating the intersections between concepts; in particular the overlap that emerged in relation to Lawton's ecological equation $B=f(P, E, Px E)$ and the temporal component of the findings, namely the before, during, and after of activity spaces, activity programming, and residents' experiences.

CHAPTER 5: FINDINGS

5.1 Facility Profiles

To provide context for the qualitative findings, the following paragraphs describe of the overall physical, organizational, and social environments in each setting. The profiles emphasize qualities related to the eight specific goals of therapeutic design for dementia care identified by Weisman et al. (1996): maximization of safety and security; support of awareness and orientation; support of functional abilities; facilitation of social contact; provision of privacy; opportunities for personal control; regulation and quality of stimulation; and continuity of the self. Policies and practices related to person-centred care and activity programming are also highlighted. Table 1 provides quantitative results of the TESS-NH and PEAP assessments; Table 2 presents the results of the closed-ended staff survey questions.

5.1.1 Emory Lodge

Emory Lodge is a purpose-built, freestanding dementia care facility that is home to 36 residents with Alzheimer's disease. Residents represent a mixture of both males and females with varying levels of mobility and cognition. Residents reside in one of three self-contained 'neighbourhoods' consisting of 12 private rooms, each with its own bathroom and shower. In the interest of sample size and amount of data generated, this study focused only on the two identically

designed neighbourhoods on the left and right of the floor plan (see Figure 2), namely “Maple Grove” and “Willow Place”.

Each neighbourhood has a fully functional kitchen with both industrial (for food services staff) and residential (for residents and staff) appliances, as well as two small dining room spaces, a living room with a small television and fireplace, and a piano room for musical activities. Neighbourhoods have a homelike ambiance created by the small-scale spaces, wood trims, shelving for family pictures, artwork, and activity supplies, carpet and hardwood flooring, and mostly residential-style furniture. Furniture pieces are arranged at right angles to promote informal social interaction. Residents are welcome to bring their own furniture for their bedrooms and a chair for the living room. The neighbourhoods are open-concept; space differentiation is created through changes in floor surface, furniture, and textiles.

Figure 2. Emory Lodge Floor Plan. Blue indicates the neighbourhood activity spaces; Orange indicates the Concert Room.



The circular wandering path and open-concept design provides residents easy visual access to all social spaces from the wandering loop and facilitates staff monitoring. Exit doors are locked at all times and are camouflaged by a mural. Doors to the secure outdoor space are locked at night or during inclement weather, otherwise residents are free to move in or out as they wish. Large windows line the wandering loop adjacent to the gardens, which provides additional visual stimulation, contributes to orientation of time and season, enhances the natural light into the neighbourhoods, and enables resident monitoring (based on PEAP assessment; Weisman et al., 1996). Sheer fabric curtains provide a homelike ambiance and cover the windows at night to prevent reflections and shadows.

Staff to resident ratios during the day are: two Care Aides per cottage, one RN per 36 residents, one to three recreation staff (one full-time Activity Coordinator, one part-time Music Therapist, and one part-time Recreation Therapist) per 36 residents, plus one part-time Occupational Therapist and one part-time Social Worker. Policies and practices reflect the Eden Alternative ¹ and person-centred care. Most programmed activities take place in the living rooms or piano rooms within the neighbourhoods. Weekly concerts and intergenerational events are offered in the 'Concert Room', a large multi-purpose space located in the main section of the building, which is not a 'secured' area. Residents from all three cottages are invited to these 'community' events. Staff questionnaires indicate that activities are always carefully planned according to the residents' interests and abilities. Family members play a role in activity planning by communicating valuable information about the residents' tastes, hobbies, and preferences. Staff welcome the participation of family members in activity groups, especially events in the Concert Room. As one staff member explained:

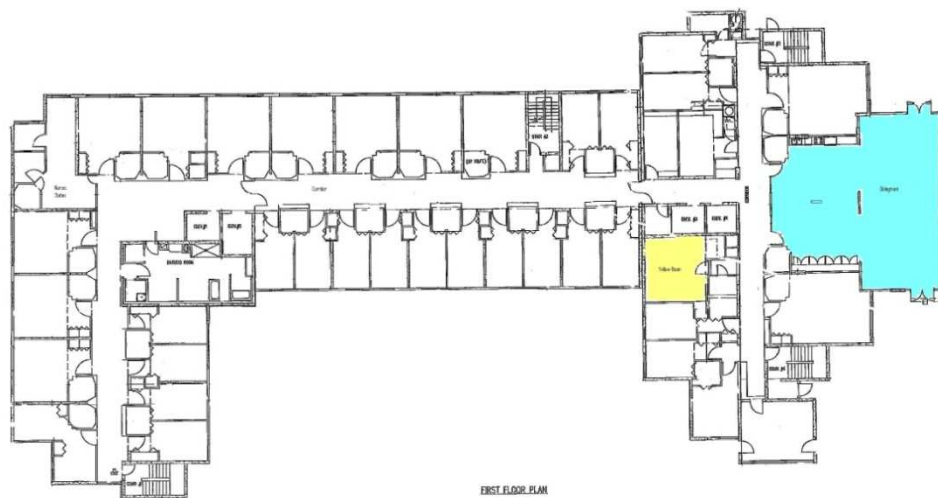
A daughter let us know that her mother played the piano beautifully. So when the piano is the main focus of any concert, she is usually one of the first to be escorted to that concert. Her enjoyment is always visible. (*Lilly, Care Aide, Emory Lodge*)

¹ The Eden Alternative is a philosophy of care that originated from the work of Dr William Thomas, which aims to eliminate boredom, loneliness, and helplessness in long-term care settings by promoting a spirit of community within habitats that promote quality of life through interactions with plants, animals, and others (Eden Alternative, 2009).

5.1.2 Beachwood Residence

Beachwood Residence is a retrofitted SCU on the second floor of a larger multi-level complex care facility. The SCU is home for 34 residents with a wide variety of different types of dementia. Residents are predominantly female with varying levels of mobility and cognition. The unit is a standard L-shaped design with all private rooms of various sizes, some with private and some with shared half-baths. There is one central tub and shower room².

Figure 3. Beachwood Residence Floor Plan: Cyan indicates main dining and activity space; yellow indicates the “Yellow Room” activity space.



The hallway has two separate uncamouflaged elevators: one for visitors, one for service staff. The hallway is well-lit and well-equipped with handrails and plenty of seating for residents to rest or converse with others. However, the ambiance is highly institutional with glossy flooring, very little variation in paint

² This description of the unit reflects the décor, ambiance, and atmosphere at the time of the data collection. It is worth noting that extensive cosmetic renovations were planned for the dining room and kitchen area in the months following this data collection. Residents' rooms were also gradually being redecorated with warm paint colours and colour contrasting to support functional abilities.

colours, and limited opportunities for sensory stimulation. All residents' doors display their names in large lettering; some doors also display a current photograph of the resident. Residents are encouraged to bring their own personal furniture, photos, and other cherished belongings to decorate their bedrooms.

At the end of the main hallway is a large dining room where residents spend the overwhelming majority of their awake time. The dining room has a small kitchen area with a sink, fridge, and microwave. Meals are delivered on trays from the kitchen on the main floor, however some juices and snacks are available in the kitchen area. Residents have access to two washrooms within the dining room. At the time of data collection, the dining room had a very institutional and sterile ambiance. Residents were spread out over a wide area; they sat at dining room tables, on matching dining room chairs or in wheelchairs throughout the day. There was no designated living room, den, or lounge area on the unit where residents could have their 'own' chair or display personal belongings. Although the area was very large, and group activities or 'down-time' tended to take place more on the south side of the room, with the exception of a piano and a wall-mounted television, there was no clear differentiation of space. The acoustics in the room are very poor.

Large windows give visual access to the sky, surrounding buildings, and to the well-designed and well-maintained secure outdoor patio and garden. However, the windows at the time were bare, which contributed to the institutional ambiance and created difficulties in terms of controlling light, temperature, and glare. The patio garden is accessible from either side of the dining room, however for safety and monitoring reasons, the doors remain locked

the majority of the time. The overall layout of the unit creates great difficulty for resident monitoring. At the opposite end of the hallway is a traditional nurses' station with an adjacent social space off the hallway that has capacity for five to seven residents, with a flat-screen television for movies or concerts.

Programmed activities take place primarily in the dining room, however some regular events (e.g. Tuesday morning sensory stimulation group) and some special events (e.g. special lunches) are held in a small multi-purpose space called the "Yellow Room". The Yellow Room has an interesting history. It began as an office space for leisure staff. Several years ago, it was completely transformed into a dark Snoezelen room meant to provide a soothing and comforting experience for agitated residents. However, the effort was largely unsuccessful, so the room was re-painted a warm, light yellow colour. At the time of the data collection, the "Yellow Room" as it is now known, was being re-designated as an office space/conference room. However, leisure staff had negotiated access to the space at certain times for small group activities.

Staff to resident ratios fluctuate during the day according to rotations and mealtimes. During peak hours, the unit has anywhere from four to seven Care Aides; one LPN; and one RN per 34 residents. One part-time Activity Coordinator is available from Monday to Friday for six hours per day to organize and provide activities for residents within the SCU; a full-time Music Therapist spreads his time throughout the multi-level campus of care. Like Emory Lodge, the organization has adopted the principles of Eden Alternative and person-centred care. At the time of data collection, the leadership team was in the process of working towards a new 'culture of care' within the unit. The following quote from

the Director of Care at Beachwood Residence provides a snapshot of the leadership team's vision for culture change, specifically in relation to staff collaboration, psychosocial care, and resident QoL:

Well, in the traditional model in the sense that...there are actually a lot of people up there who could potentially be engaging within, even within their work roles, in social aspects or...but who don't see it as part of their role. So you'd still have, you'd have one person who is designated leisure, who is charged with that job, and that's where you get the silos of 'who does what', right? And so...getting past that in a sense where everybody is thinking differently, even... a housekeeper or, everybody, that we're all there to support these things. (*Jennifer, Director of Special Care, Beachwood Residence*)

Many staff members maintained that activities were organized in a person-centred manner with input from family members as well as direct care staff. As one Care Aide explained,

Family's input and inclusion of each resident's family is important to be able to know [about] their past interest and etc. Knowing their past interest will give leisure and staff the idea what kind of activities [are] suited for her/him. (*Tammy, Care Aide, Beachwood Villa*)

However, despite having provided a clear definition of "programmed group activities" at the beginning of the survey, a number of staff at Beachwood Residence confused their responses about 'group activities' with 'one-on-one' activities or ADLs. This could reflect question composition, comprehension issues resulting from language differences, or lack of awareness and knowledge of that aspect of care provision. The latter explanation coincides with what Jennifer describes as the "silos of who does what".

Table 1. Structured Environmental Evaluation Scores

	Emory Lodge	Beachwood Residence
PEAP Score (max score 117)	98	56
Sample Items:		
Maximize Safety & Security	11	8
Maximize Awareness & Orientation	12	5
Facilitation of Social Contact	12	7
TESS-NH		
SCUEQS total score (max score 38)	36	21
Sample Items:		
Light Intensity: Activity areas	2 – Ample	2 – Ample
Homelike atmosphere	3 - Very homelike: 75% or more of public areas are "residential"	0 – Less than 25% of the public spaces are "residential"
Kitchen on the unit	2 - Kitchen available for use	1 – Select kitchen appliances available for use
Personalizing residents' rooms	3 - 75% or more of the residents have at least 3 personal pictures and/or mementos in their rooms	3 – 75% or more of the residents have at least 3 pictures and or mementos in their rooms
Resident appearance	2 - Extensively (75% or more of residents are well groomed)	2 – Extensively (75% or more of residents are well-groomed)
Global Evaluation Score (max score 10)	9	5

Table 2. Staff Questionnaires

	Emory Lodge (N = 10)	Beachwood Residence (N = 10)
Activities are simplified to meet residents' abilities % Always % Usually	60% 30%	30% 60%
Activities are held in small groups to reduce over-stimulation % Always % Usually	10% 60%	30% 50%
Activities are kept short to hold residents' attention % Always % Usually	20% 70%	10% 70%
Residents are given a choice whether or not to participate in activities % Always % Usually	80% 10%	90% --
Activities are planned so they focus on what residents can do, not what they can't % Yes	100%	100%
Activities are planned so they appeal to residents' unique characteristics, tastes, and interests % Yes	100%	90%
Family members are invited to participate in programmed activities with their loved one % Yes	100%	80%

5.2 Qualitative Findings

The following sections present key themes identified through thematic analysis across all qualitative data sources. The themes of *Comprehensibility*, *Inclusion*, *Autonomy*, and *Community* represent the products of 'P x E' interactions (1986, as cited in Moore, 2005) whereby personal factors (e.g. background factors and/or personal competencies) interacted with proximal factors (e.g. size and location of activity spaces, unit design, resources, and staff collaboration) to either support or detract from residents' experiences during

group activities, and thus their QoL. Within each theme, the impacts of resident, physical, and organizational environmental factors are described in detail and supported with quotes from in-depth interviews, field notes, and staff-member questionnaires. Interwoven within each of the themes is a temporal dimension of the findings that distinguishes 'P x E' interactions that occur in the before, during, and after activity groups.

Table 3. Themes and Subthemes

Theme	Definition	Subtheme	Definition
Comprehensibility	Aspects of the sensory environment that support or detract from residents engagement experiences.	Spatial Familiarity	Having a sense of command of or orientation to the physical attributes of a 'space'.
		Place Rules	A recognition and awareness of the socially shared understandings of 'place', including its purpose and expected behaviours.
Inclusion	Including or being included in activity groups, either physically or verbally, regardless of functional capacities.	'Self' vs. 'Staff' Inclusion	Including oneself in activity groups versus being included by staff.
		The Captive Audience	Inadvertently being included in activity groups merely because of one's presence in the space prior to the activity.
Autonomy	Exercising self-determination and choice as to if, when, where, or for how long one engages in activity groups.	'Come and Go' Participation	Having the freedom and the opportunity to join groups late, leave groups early, or come and go during group activities.
		'From a Distance' Participation	Having the freedom and the opportunity to participate in activities groups from a location outside of the main group formation.
Community	The interconnectedness and bonding between residents, staff, and family members at Emory Lodge.	Neighbourhoods as Communities	Each neighbourhood of 12 residents as its own community.
		"The County Fair"	The coming together of all communities for special events in the Concert Room.

5.2.1 Comprehensibility

According to Zeisel et al., (1999), sensory comprehensibility derives from environments that are familiar, comforting, and understandable, yet not overly sterile. Because neurodegeneration related to Alzheimer's disease and related dementias can impede cognitive processes such information processing, comprehension, attention, and formulation of goal-directed behaviours, the physical environment needs to present clarity and familiarity. As Zeisel (2006) notes:

The greatest environmental challenge people living with Alzheimer's face is that they lose certain types of spatial processing abilities and memories while others remain...If an environment requires a person to use all his spatial processing and memory functions to figure out "Where am I?", "Where have I been?"..."Where am I going?"...whatever remaining memory functions he has are effectively disabled. It is too much to ask a [person's] brain to process (pp. 371).

As Zeisel points out, spaces that are not purposely designed to compensate for the cognitive losses associated with dementia often impose excess sensory demands. This overload or surge of information creates a 'cognitive noise' in the brain, which reduces the resident's ability to master a particular task or social situation. On the other hand, supportive environments where sensory stimulation is regulated, wayfinding is facilitated, and behavioural cues are readily available can help residents to process information more effectively and respond more appropriately.

In this study, comprehensibility was a precondition for positive engagement during group activities, particularly with respect to the location of programmed activities, the cognitive demands imposed by moving from one space to another and the presence of behavioural cues. The extent to which

residents were able to effectively deal with a variety of environmental stimuli and focus their attention on activities was affected by both physical and organizational factors. Two subthemes further explain the relationship between environmental attributes, comprehensibility, and engagement in group activities: *Spatial Familiarity* and *Place Rules*. Both concepts relate to how environmental factors made it easier or more difficult for residents to 'make sense' of their situations and thus engage accordingly. However, whereas *spatial familiarity* relates to having a sense of orientation to the physical attributes of a 'space' (e.g. "Where am I?" "How do I get home?"), *place rules* represents a recognition and awareness of the socially shared understandings 'place' (e.g. "What is expected of me here?", "How should I behave?").

5.2.1.1 Spatial Familiarity

Spatial familiarity was a theme that initially emerged during observations and interviews at Emory Lodge where it not only played a key role in residents' engagement, but also in how activity staff planned and organized group activities. Residents experienced the greatest amount of *spatial familiarity* in the neighbourhoods. The small-scale, homelike ambiance of the neighbourhood environments provided a sense of safety, security, and comfort for residents. In this respect, the sense of being 'at home' in environments they were cognitively oriented to, and felt comfortable in, reduced uncertainty and anxiety, enabling them to engage in group activities in a more positive way. Therefore, activity staff at Emory Lodge emphasized the cognitive and social benefits of taking activities 'to' the residents in their familiar, homelike environments:

I'm in the house with the residents living in their environment, playing in their environment, helping them to control or be part of their environment. I'm not moving them from it. So that's their house, and at your house you feel quite safe, I'm sure. And so if you had people helping you, you'd feel safe. And I think by being there, they feel comfortable and safe. *(Neil, Recreational Therapist)*

Larger or more formal group activities took place in the Concert Room.

The consensus among all staff members was that activities in the Concert Room provided invaluable opportunities for residents to experience the normalcy and excitement of 'going out' for special events. On occasion, staff had also used the Concert Room for smaller, more focused group activities for residents with similar interests and abilities (e.g. baking, art therapy). However, the disorientation and anxiety caused by the move away from home to an unfamiliar space with unfamiliar people meant that, for some residents, it was more difficult to relax and fully enjoy the activity. For others, the change of space and additional sensory demands resulted in a compression of their attention spans or a constant need for reassurance from activity staff.

...when you take them out and try and do an activity, say in the kitchen in the Concert Room they're like "Am I going home? Do you know the way home?" Because like, just that, as soon as you take the familiarity away, then the function in the kitchen, the skills that they are really able to do diminish... I mean, and I think that is part of the reason that the environment [in the neighbourhoods] is designed the way it is, why we have a kitchen for food and nutrition and why we have, you know, a stove and fridge and all of those other things so that people can have that normalcy, right? *(Lauren, Occupational Therapist)*

Consistent with many other findings in this study, the issue of *spatial familiarity* was relevant to some residents more than others depending on disease stage and expression of symptoms. Certain residents appeared to have more difficulty adjusting to unfamiliar surroundings, which impacted the quality of their engagement experiences. For example, individuals who experienced paranoia as a result of their dementia appeared to have a particularly difficult time adapting to large group activities in the Concert Room.

Many care staff at Emory Lodge felt that certain residents - in particular those who had more remaining cognitive abilities and those who verbalized their desire to 'go out' more often - should be given more opportunities to leave their neighbourhoods for activities. Care staff did acknowledge the potential disorienting effects of taking residents out of their home environments into unfamiliar spaces. However, they felt that the residents' abilities to concentrate on and enjoy activities also depended upon key factors other than *spatial familiarity*, including the 'meaningfulness' of the experiences and situational factors (e.g. mood, physical health, pain, etc).

I feel we could benefit from having a few different rooms to go do activities such as a woodwork room, library room, painting or artsy room. I think a cooking room would benefit the residents, where they can smell the food cooking, the hovering over the stove, around the kitchen area would be more homey. (*Leah, Care Aide, Emory Lodge*)

Thus both activity staff and care staff valued the 'going out' aspect of activity programming. However, the transition from one space to another, and the increase in sensory information in the Concert Room, had noticeable effects on certain residents' engagement. Consequently, activity staff seemed to favour the

neighbourhood activities as they did not disturb residents' *spatial familiarity*, and resulted in more positive engagement. On the other hand, care staff, who spent many hours per day in the neighbourhoods with the residents, saw the loss of *spatial familiarity* as something that was manageable if the 'activity', the 'space', and the 'person' were the right 'fit'.

This finding underscores the sheer complexity involved in organizing and delivering person-centred activities for such a vastly diverse population of residents, and the vital role the physical environment plays in the process. Whereas there was already a high level of 'person-environment fit' in the neighbourhoods, hosting group activities outside of the neighbourhoods necessitated additional planning, organization, and coordination in order to compensate for the increase in environmental demand. As Lauren explains, restoring 'person-environment fit' in unfamiliar spaces is not always easily achieved considering the diversity of needs and many constraints imposed by limited time and scarce resources:

And if you look at it even from a resource perspective, when you think about the allocation of scarce resources, you have 36 people, right? ...so even though it takes you, between the planning and the getting the groups, say it takes you three hours to reach four residents, right? It might be half your day. So I'm not saying that it's not important to meet everyone's needs, and make sure that you can meet their needs, but at the same time you also have a lot of needs to meet. (*Lauren, Occupational Therapist, Emory Lodge*)

At Beachwood Residence, the relationship between *spatial familiarity* and engagement in group activities presented itself much differently. In contrast with Emory Lodge, residents at Beachwood Residence spent the majority of their

awake time in the dining room: a space that compares in scale, and at any given time occupied a comparable number of residents and staff, as the Concert Room during special events. In this sense, the effects of relocation for large group activities were reduced. In fact, for many residents it was merely a matter of moving from one side of the room to the other, which decreased disorientation and virtually eliminated the worry and anxiety of “getting home” during the activities. Because residents were already familiarized with the space, large group activities such as music therapy, news and views, and ball tosses were successful in engaging residents for a sustained period of time, despite the greater scale and sensory stimulation. The following field notes describe one resident’s participation during a ‘news and views’ activity:

Lucille was a bit feisty when Natalie turned her chair around to participate. She seemed slightly agitated by being moved, but luckily she didn’t have to move far. The event was interrupted by a routine test of the fire doors (with a big bang), and housekeeping activities were loud in the background. But Lucille never moved her body or head the entire time – only her eyes moved from Natalie’s face to the newspaper and back to Natalie. She displayed a high level of active engagement and responded verbally and appropriately to Natalie’s comments and questions. Her attention to the activity never wavered despite all the background noise.
(Excerpt from field notes)

In contrast to Emory Lodge, where residents were relocated from small-scale, homelike environments to larger spaces for special events, Beachwood Residence offered some special events (e.g. special lunches), as well as certain regular activities (e.g. sensory stimulation groups) in the smaller “Yellow Room”. As a result, relocating residents from one space to another, although disorienting at first, had an opposite effect on residents’ engagement in the activities. The

reduction in size and sensory stimulation meant that there was less information to 'become familiar with' in the new environment of the Yellow Room; once residents became oriented within their new surroundings, they had fewer stimuli competing for their cognitive processes. For some residents, particularly those in earlier stages of dementia, an improvement in social skills and communication was notable during activities in the Yellow Room, and the change in space seemed to have a positive effect on their attention spans. Natalie, Beachwood Residence's Activity Coordinator, felt that although residents often needed some time to become familiar with the new space, the Yellow Room provided a more "normalized" environment that facilitated an awareness of "the self" during the special lunches, which was otherwise impeded in the large dining room, especially during mealtimes:

...because, as I said earlier, you take people that are institutionalized and you put them in a normalizing situation, its awkward, its all of a sudden, there is a total awareness of self, which is huge...So, I mean, so their memory just appears all of a sudden? No, the situation makes the memory happen. (*Natalie, Activity Coordinator, Beachwood Residence*)

What Natalie so vividly describes is an emergence, or re-emergence, of self-awareness and social skills resulting from a reduction in 'cognitive noise' imposed by the physical environment. In other words, *spatial familiarity* and 'person-environment fit' was easier to achieve in the Yellow Room.

The initial period of awkwardness that Natalie describes was related to the change in physical space, but was also the result of an awareness of being part of an intimate and unfamiliar social situation. Because residents spent the majority of their time spread out over a large area, there appeared to be a brief

period of uncertainty that occurred in the Yellow Room before activities began that was directly related to the social intimacy of the space. The following excerpt from field notes describes observations of Christina's experience adjusting to the Yellow Room before a sensory stimulation group:

Christina was the first resident to be brought into the Yellow Room. She appeared to go through a period of adjustment to her new surroundings. She had a puzzled look on her face as she looked around the room. I was there to engage her in conversation, which seemed to make things better, but her facial expressions suggested confusion, uncertainty, and sympathy as Paul and his volunteer continued to bring in other residents who were clearly more 'advanced' in terms of physical and cognitive decline. I wondered what must have been going through her mind at the time. Was she thinking, "Who are these people?" or "Why was I invited here?" or "Why were they invited here?" or "What is wrong with them that they are so sick?" or "Will that happen to me?" It made me wonder if there might be a more sensitive 'order' in which to bring people into such an intimate space that might minimize that confusion and uncertainty for the residents who are more aware of their surroundings. She was fine once the activity started. She was very alert, very attentive with eye contact, smiled, sang along, and watched Paul intently. (*Excerpt from field notes*)

In sum, *spatial familiarity* meant that residents had greater command or control of environmental stimuli before activities began, and as such, their cognitive abilities were freed to process information about the activities and others involved. In other words, *spatial familiarity* indicated a good degree of 'person-environment fit'. For some residents the experience of relocating to unfamiliar environments resulted in a sensory overload that caused anxiety and made it difficult to relax and attend to the activities. However, the effects of relocation were remarkably different when residents moved from smaller, more

home-like environments to larger, less controlled environments and vice versa. Relocation to the smaller space of the Yellow Room for special lunches required an initial period of adjustment, but the intimate and controlled nature of the space eventually facilitated an emergence of cognitive and social skills that were otherwise encumbered in the larger dining room during mealtimes. In contrast, relocation from smaller, more homelike settings to a large, relatively uncontrolled space at Emory Lodge was cognitively taxing for some residents, resulting in a general sense of unease and a compression of their attention spans.

5.2.1.2 Place Rules

According to Canter (1991), interactions between people and their environments can be understood in large part by what he terms 'place rules': socially shared understandings of the purpose(s) of a place and appropriate behaviours within it. This approach to environmental cognition suggests we continually refer to our cognitive representations or schemata of 'places' to help guide our actions, as well as our evaluations of what may or may not be appropriate conduct for others. In everyday life, some place rules are communicated explicitly through signage or verbal directions (e.g. a '*please wait to be seated*' sign in a restaurant), whereas others are implicit and learned through years of socialization and experience (e.g. respect for personal space). Both the physical environment of a setting, and the language we use to describe the setting, give it meaning and provide cues for the purpose of the space and the corresponding rules of engagement. When uncertain, place rules may be learned by observing the interactions of others, both within the space and with each other.

In residential care settings for individuals with dementia, the interpretation and enforcement of place rules is complex. First, the purpose of a given space, and its accompanying place rules, may be evaluated in relation to the space as 'home' for the residents or 'workplace' for the staff. Second, a fundamental goal of therapeutic design is to make the nature or purpose of spaces more obvious to residents through the use of behavioural cues from the physical and social environments. Finally, certain rules of place may be relaxed or infractions tolerated in dementia care settings that would not normally be accepted in other settings (e.g. sleeping at the dining room table; having a nap in someone else's bed). Thus, place rules are emphasized and perpetuated by the supportive nature of the physical environment, as well as the organizational philosophy and staff treatment of the space as the residents' 'home'.

The notion of *place rules* playing a role in the nature of residents' engagement in group activities surfaced primarily through interviews at Emory Lodge and observations at Beachwood Residence. And as with the association between *spatial familiarity* and engagement, the relationship between *place rules* and engagement differed according to the setting and the space.

At Emory Lodge, the homelike neighbourhood atmosphere, along with the strong organizational philosophy of approaching the environment as residents' 'home', contributed to an awareness of appropriate social behaviours during group activities, both within the individual neighbourhoods as well as during community events in the Concert Room. The recognition of *place rules*, and the subsequent effect of this awareness on social behaviour, was most evident when residents had the experience of 'going out' for an activity, such as attending an

event in another neighbourhood or a larger event in the Concert Room. For residents who had less difficulty managing the loss of *spatial familiarity*, the act of 'getting ready' and 'going out' cued them to the rules of social etiquette that one would normally expect when attending a concert or gathering at someone's home. Features of the physical environment further supported this awareness. For example, the seating arrangement, stage, and presence of music playing in the Concert Room cued certain residents to put on their 'public' face, which included warmly greeting others, being very cordial, and even 'pretending' to recognize other residents from previous events. As Jane explains, 'going out' also had the potential to suspend the intolerance that certain residents had for each other at home:

But, also if you look at [The Concert Room's] activities, is it when you get those people who don't necessarily get on with one another, is it different because they are in a different social setting and they are acting differently socially? Because it does seem more like you're going out somewhere and you're in a larger setting... Yeah, the social rules of engagement, how you have to act... (*Jane, Director of Care, Emory Lodge*)

And you know how often we'll go into the Concert Room, and I'll be setting someone up to sit for an event, and I feel like it's only proper when I'm sitting them beside someone who is already there [to say], "Oh, you remember [name]" and more often than not it's, "Oh yeah, yeah...I see you all the time". It's like, "Oh, pardon me!" (*Emma, Activity Coordinator, Emory Lodge*)

Similarly, Margaret describes an experience where the physical and social ambiance of the neighbourhood setting in Maple Grove cued appropriate social behaviours on behalf of the 'guest' and the 'hosts' during a happy hour:

You know...I watched Katie from Willow Place go to Maple Grove, and then that social play that goes on. She came down with me for the pub night, and she walked in, and she was going around table to table shaking hands with people. You know, 'I'm out for the evening'...And she lined up at the bar for her [drink], she was told to! They were all, two or three of them were really concerned that she hadn't been served yet. And she had come into this social setting, so... (*Margaret, Manager, Emory Lodge*)

Residents who experienced more difficulty processing the spatial 'unfamiliarity' of the Concert Room, and those who experienced a compression of their attention spans as a result of the increase in environmental press, clearly relied on the actions of others for behavioural cues. Emma, the Activity Coordinator at Emory Lodge, nicely summarizes her experience of observing residents exhibit a sense of uncertainty and 'looking to others' for cues during events in the Concert Room:

...that's what I was saying too, kinda the same idea that at the concert, because maybe it's not home-base, you know, you're kind of here mingling with a bunch of your, you know, acquaintances, and it's not so familiar, I've seen that a lot... it's not only just the one resident getting up but then someone else is following or there is a lot of attention when that person gets up. You know, we're all making eye contact, like who is going to go and everyone is kind of on the edge of our seats, and then it doesn't take much and then if one more person also, like someone like [Celia] who sometimes has a span of about 25 minutes whereas others can last the hour. She loves it up to that point, and sometimes that's when she gets a little anxious so she'll be up. It's almost like that social norm like that everyone else sort of stirs and "I guess we should be going" and "I don't want to be rude and sit here and overstay my welcome"... But I'm sure there is a lot of that playing too, like, "Is that my group?" or "Should I be going?" or you don't really know. But then, yeah, there has to be a sense of that because in the neighbourhood you don't get that feeling of, "Oh, ok, I should be going now". They know they are home, whereas at a concert

they're like, "Oh, ok, who should I follow?" (*Emma, Activity Coordinator, Emory Lodge*)

At Beachwood Residence, the experience of attending a special lunch in the Yellow Room, and the cues within the environment, had a positive impact on residents' engagement. Once they had oriented to the new space and that initial period of social awkwardness was resolved, features in the environment like the small room size and warm paint colour, the use of table linens and real china, and the smell of food cued them as to how they should interact, largely because the space had the ambiance of a Tea Room. Residents demonstrated appropriate table manners, their voice levels lowered, they engaged in conversation about the china patterns, and often expressed concern for or lent assistance to the person sitting next to them. As Natalie, the organizer and facilitator of the special lunches explains, in the small, quiet, warm space of the Yellow Room: "That person emerges, the person that they were..." Unlike regular mealtimes in the dining room, special lunches were relaxed and intimate affairs that often involved second and third helpings along with conversation and reminiscing that, for most of the guests, lasted well into the afternoon.

However, during activities where residents were spread out across the large dining room space and the activity was not directly facilitated by the Activity Coordinator (e.g. happy hour, ice cream socials), *spatial familiarity* failed to compensate for the general sense of confusion and isolation induced by the large-scale, institutional ambiance, and general lack of 'social affordance' of the space. As the following excerpts from observational field notes during a happy hour activity illustrates:

Yolanda was in and out, up and down from seat to seat. She chose not to have any chips or drink when offered, but then picked up some from other residents. She keeps looking down the hall and around the room with a mostly null expression on her face. She was happy when a staff member interacted with her. She ate a sandwich when offered but generally seemed confused and possibly overwhelmed. Possibly she thought someone was coming to visit her.

Christina sat quietly eating chips and drinking her beverage. She seemed generally more interested in her chips than the environment or the activity around her. She continued to eat more chips as offered but did not engage with music or others. She was attentive to children as they left.

Deanna tapped and clapped to the music on and off. She talked to her friend for a great deal of the time. At times had a concerned look on her face. She seemed happier towards beginning but at then end became more anxious and agitated. Even so, she still attended to music off and on. Eventually she got up to leave, persuaded her friend to go along with her. She showed signs of anxiety and sadness. *(Excerpts from field notes)*

Beachwood Residence faced two particular challenges that resulted in place rules emphasizing space as 'workplace' as opposed to space as 'home': a) the institutional physical environment, and b) the well engrained routines of long-time employees. The 'place rules' for the unit as a whole, but particularly in the dining room, had been well established over many years by care staff in their efforts to provide the most efficient and best quality physical care to a large number of residents. Routines that revolved around mealtimes and personal care shaped the place rules of shared spaces, especially the dining room. Meanwhile, the institutional ambiance on the unit offered no behavioural cues for the staff as reminders to approach the spaces from the perspective of 'home'. New staff or

casual staff looked to more senior staff for direction, and thus followed the rules of engagement modeled by their superiors. As a result, there were no implicit or explicit rules in place to illustrate or protect the 'home' or 'social' aspects of the common spaces. The following passage is from field notes recorded after observing a special lunch in the Yellow Room:

As a mental note, the language of 'guests' as opposed to 'residents' stood out to me through watching Natalie as a hostess for the event, making sure all her 'guests' had enough to eat and drink, and thanking them for coming as they left. It was clear to me that she had put careful thought and planning into the event, and her intention was to make it a special therapeutic activity. However, at some point during the luncheon, the 'in and out' of various staff members (to get leftover food) confused the atmosphere. It changed from being a 'special space' for a therapeutic lunch activity for the residents (guests) to a space that felt like a quasi-staff room where certain residents were 'allowed' to join....Various staff members came in and out without attending to the intimacy of the space, joining the guests, or really acknowledging that this event was planned in the way Natalie had intended. (*Excerpt from field notes*)

The approach to space as 'workplace' also resulted in several observations whereby care staff inadvertently interrupted group activities to provide personal care (e.g. to put on garment protectors before lunch, to collect blood samples, to take residents for a walk or to the bathroom, etc). These interruptions had the greatest impact on residents in the earlier stages of dementia (e.g. a higher level of awareness of their surroundings) because it took their focus and attention away from the activity itself - even if the care was not being done directly to them - and in some cases created what appeared to be a sense of worry and anxiety. The following excerpt illustrates how care staff had

become accustomed to prioritizing personal care over social care, or in other words space as ‘workplace’ over space as ‘home’, and how the absence of boundaries sometimes deterred from residents’ engagement in group activities in the dining room:

A care staff came to take Daisy for a walk; furniture arrangement worked well for her to leave the group with her walker. But then the care staff came back to get another resident and take her for a walk. This resident is not feeling well and non-verbally indicates that she doesn’t want to go for a walk. Care Aide persists in trying to get her up into a “contraption” to take her out. Penny is clearly upset by the interruption (commotion) and concern for the resident who was being “cared” for. She gets out of her seat and stands in the middle of the circle, clearly wanting to help but not sure how. Penny sits back down and waits for her turn. Care Aide comes to get a third resident instead and begins to put the belt on the resident right as she is in the middle of her turn tossing the rings. (*Excerpt from field notes*)

As Natalie explained, residents who were taken out of group activities for personal care and brought back often had great difficulty re-engaging.

It’s like [Care Aide] coming to take Donna away from our lunch group. She came back a different person. Donna came back an angry, disengaged—she’d sit there with her eyes closed—disengaged person. And she was so actively engaged before. (*Natalie, Activity Coordinator, Beachwood Residence*)

The Dining room at Beachwood Residence carried the name of “dining room” because that was the primary purpose of the space, and because mealtimes provided the most structure to the residents’ days and staffs’ routines. However, in reality the space had multiple purposes and was used in multiple ways. It was a place for large group activities, small group activities, self-directed

leisure activities, one-on-one activities, down-time, mealtime, and personal or medical care. Because of this, the dining room was a confusing environment because it had few readily apparent place rules, other than one vividly obvious place rule implemented by the staff in order to streamline the process of mealtimes: *two tables are reserved on the far left side of the room for residents who required the most assistance with eating their meals*. Incidentally these residents were also the most dependent on others for ambulation, and since group activities typically took place on the far right side of the room, a considerable amount of preparation time and effort was needed to help residents move from one side of the room to the other. Many of the residents who required assistance with mealtimes were still able to get a great deal of enjoyment out of group activities, especially those involving music and the high-energy tactics of the Activity Coordinator. However, the time it took to help that many residents to the other side of the room nearly always resulted in one or more residents being left out; some facing the wall or in the opposite direction of the activity. Hence, the place rule that had been implemented to streamline mealtimes worked well as it had been originally intended. However, it made the before and during of activity groups more difficult as it required extra time and effort on behalf of activity staff, and it resulted in the unintentional exclusion of certain residents with higher-level needs.

In sum, comprehensibility describes the extent to which features of the physical environment supported residents in their efforts to effectively process and act upon environmental stimuli. Residents with dementia can experience great difficulty with sensory comprehension, especially within settings where

environmental press exceeds their available cognitive capacities. Good 'fit' between residents and their environments is achieved when sensory information is simple, familiar, and behavioural cues are readily apparent. In this study, comprehensibility - as it related to engagement in group activities - was associated with *spatial familiarity* and *place rules*. *Spatial familiarity* illustrates situations where features of the physical environment supported residents in their efforts to gain 'command' of the spatial attributes of activity spaces, which effectively reduced 'cognitive noise' and allowed them to attend to the activities and others involved. *Spatial familiarity* was largely associated with the neighbourhood activity spaces at Emory Lodge and the Yellow Room at Beachwood Residence because these spaces were smaller, more normalized environments that produced less environmental press. While relocation away from familiar, comforting environments contributed to a breakdown in *spatial familiarity* for some residents at Emory Lodge, relocation to the Yellow Room at Beachwood Residence had a positive effect on *spatial familiarity* as the 'new' space offered more support of cognitive processing.

In comparison, the clarity of *place rules* helped residents to judge what behaviour was appropriate for them in a given space and social situation. At Emory Lodge, the atmosphere of 'home', in combination with the experience of 'going out' for an activity, cued certain residents to put on their 'public face' at events in the Concert Room or in another neighbourhood. When uncertain, residents turned to others for behavioural cues. At Beachwood Residence, the ambiance created during special lunches in the Yellow Room offered similar behavioural cues. However, the physical environment and approach to space as

'workplace' at Beachwood Residence generated an institutional ambiance that created uncertainty in terms of the purpose of activity spaces.

5.2.2 Inclusion

I love the Yellow Room too...in fact I would like that to be like an activity room so when I do current events, we go there... On the other hand though, I get to involve more people in the dining room...the balance is difficult, it's a difficult thing..." (*Natalie, Activity Coordinator, Beachwood Residence*)

Social inclusion is one of the most widely emphasized aspects of person-centred dementia care (Brooker & Surr, 2005). Kitwood (1997) identified *inclusion* as one of the five main psychological needs prominent among people with dementia. Feeling accepted and valued as a worthy member of society is a fundamental characteristic of human nature that persists despite other cognitive losses. In contrast, exclusion and banishment undermine personhood and contribute to poor psychological, emotional, and behavioural outcomes (Bruce, 2004; Kitwood, 1997).

Programmed activities are a necessary catalyst for social inclusion in dementia care. Without group activities, many residents would have limited opportunities to experience a sense of social belonging, especially as many lose the capacity to initiate their own interactions with others. In this study, both organizational and physical environmental factors had a visible impact on inclusion in group activities.

Two subthemes further describe the associations drawn between the physical environment, organizational factors, and residents' experiences in group activities: *'Self' versus 'Staff' Inclusion*, and *The Captive Audience*. Brooker and

Surr (2005) define inclusion as “bringing or being brought into the social world, either physically or verbally” (pp. 95). This definition provides a particularly effective way of framing the first of the two sub-themes related to inclusion, namely ‘*self*’- versus ‘*staff*’-inclusion. *Self-inclusion* was demonstrated by residents ‘bringing’ themselves into the social realm of activity groups of their own accord, which was directly related to several key aspects of the physical environment. Meanwhile *staff-inclusion* was a much more ethically complicated, emotionally demanding, and resource-intensive procedure whereby residents were ‘brought’, either physically or verbally, into the social sphere of activity groups. The second sub-theme, *the captive audience*, relates to situations where staff felt that certain residents were inadvertently being included in groups merely as a result of their presence in the space prior to the activity taking place, perhaps to their detriment rather than benefit.

5.2.2.1 ‘Self’- versus ‘Staff’-Inclusion

Consistent with the principles of the Eden Alternative and person-centred care, staff in both settings emphasized the value of providing opportunities for *all* residents to engage in group activities, regardless of their functional capacities. When residents were dependent upon others for mobility or decision-making, staff turned to their extensive knowledge of residents as ‘persons’ (e.g. their past histories, hobbies, interests, preferences, etc) and inclusion was judged accordingly.

The residents are capable of participating in every program I lead. For example, in the dancing program, I can dance with those in wheelchairs as well as the others...the songs I sing are directed toward individuals based

on their background, origins, nationality, and gender. (*Paul, Music Therapist, Beachwood Residence*)

And that's what we do with Richard too, we know that he enjoys music, but we also know that he is not a huge group person, so he gets included in the sort of Country and Western sorts of music that he likes, but at the same time we respect the fact that he was an isolated man when he was making his own decisions. (*Lauren, Occupational Therapist, Emory Lodge*)

Although organizational policies and staff approaches were firmly focused on supporting social inclusion, the actual practice of organizing and delivering activity groups in an inclusive manner was challenging. As with many other findings from this study, multiple factors converged to create individual and situational contexts for inclusion in group activities. In particular, resident characteristics, situational factors, time pressures, and staff collaboration all played a major role in determining 'which' residents were included in 'which' activity groups. At times, features of the physical environment of activity spaces contributed to ethical dilemmas and time constraints, whereas at other times the spaces presented appropriate solutions.

In many ways, the act of *self-inclusion* exemplified autonomy in that residents 'chose' to attend activity groups, and did so quite freely when the environment 'fit' their needs. In this sense, staff valued and encouraged this type of independent engagement as it did provide a meaningful and beneficial exercise of residents' autonomy. As Jane, Care Coordinator at Emory Lodge explained, "*Everyone gains something... Residents who aren't invited can invite themselves. Team work is/should be enhanced if a resident is particularly disruptive to the detriment of others.*" Through both observations and interviews,

it became apparent that, on occasion, certain residents who included themselves in group activities did not always do so with the intention of joining the 'group' for the 'activity'. In other words, certain residents had lost their ability to interpret social situations, and as such, their intent was to fulfil their own personal need for attention, comfort, or validation from activity staff. These situations became particularly difficult for activity staff who faced the dilemma of attending to the needs of these residents while maintaining the integrity of the activity groups. As Jane explains, the organizational culture at Emory Lodge is one that promotes collaboration and teamwork, therefore activity staff had the support of direct care staff to help manage these difficult situations. However, the direct care staff at Beachwood Residence were less involved in programmed activities. Oftentimes the activities took place while direct care staff were on breaks or performing personal care. This was particularly challenging during large group activities when the Activity Coordinator was alone with upwards of 25 residents during activities in the dining room.

What happens is... I call it the group of 5, it could be the group of 10. But, I've got 34 people, and I call it the group of 5, it's the same 5 people who get the most attention, because maybe they're just higher functioning, maybe they have higher needs. But because I'm the only one there... But that's the balance, that's the difficulty of that because it's so instantaneous, like the 'five'...when they need something, they can articulate it... And the thing is, Frances slips through my fingers because she doesn't ask for anything. Umm, I don't have the time to pay attention to her, umm, aside from, "Oh, you've got your hair done, you look fantastic!" "Oh, do you think so?" "Oh yes!" You know, like, she just sort of gets lost in the crowd because everybody else emerges to the front, that

require my six hours a day. (*Natalie, Activity Coordinator, Beachwood Residence*)

When asked whether it was better to have smaller, separate, enclosed activity spaces or open-concept activity spaces, the overwhelming majority of staff in both settings felt it was necessary to have access to both. Staff felt the smaller, enclosed spaces offered a reprieve: a place where they could provide activities for smaller, select groups of residents without the threat of constant interruptions or the stress of managing the diversity of needs and abilities. However, they reiterated the need to carefully balance these occasions with opportunities for all residents to participate in group activities equally and on their own terms:

But I think sometimes, to be able to take those people to a separate space to have a 'higher-functioning', if you will, group that isn't interrupted by people calling out, by people wandering by, by people messing with them, I think that would also be beneficial to them. And I, I mean I know that we can use [The Concert Room] and stuff like that but, you know, just that thought does cross my mind sometimes, that there are times when I want the closed, uninterrupted group. Not all the time, but sometimes, right? (*Lauren, Occupational Therapist, Emory Lodge*)

Spaces like the dining room at Beachwood Residence and the Concert Room at Emory Lodge facilitated larger groups and thus were more inclusive in 'numbers'. However, inclusion involves more than just being physically present in a social setting; as Kitwood (1997) notes, people can be "left together, but profoundly alone". Just having a large group of residents in one space at one time was insufficient for supporting inclusion and engagement. Large activity groups embodied a great deal of diversity in terms of background factors (e.g. personalities, past hobbies, preferences) and personal capacities (e.g. mobility,

cognitive status, behavioural symptoms, need states). This meant that staff collaboration or volunteer assistance was essential in terms of managing the diversity of needs, interests, and abilities. One-on-one assistance was necessary to help maintain the interest and engagement of residents who required extra cueing or had to wait 'between turns'. In this sense, inclusion, to the fullest extent of its meaning, was only possible when staff collaboration occurred both before and during group activities.

...and there are people that need either cueing or need some sort of facilitation in order to participate. You think of the kids group, that, you know I try to kind of, there are certain people that I try to sort of move around the group, that you know, otherwise Chantal might sleep through the whole thing, or Grace might just keep her eyes shut through the whole thing. Whereas, you know, even Wally that day, I found that if I put his hand sort of tapping to the music then after I removed my hand then he could continue to tap and engage. I think that sometimes if you leave people, or even you know when Deborah was alive, I would go and I would sing real loud right by her until she got the song. And then she would kind of catch on and go by herself. But you kind of have to facilitate that initiation at the beginning. Even though they are in a group and there is lots of stuff going on, I think that helps. So one person and however many people, there's just no way you could get that level of participation.
(Lauren, Occupational Therapist, Emory Lodge)

Inclusion was an ethical consideration that evidently weighed heavily on the minds of activity staff and surfaced especially when activities took place in spaces other than the main common areas such as the living room or dining room. Because of the logistical challenges involved with helping residents move from one space to another, numerous factors had to be considered in the decision-making processes of activity staff: What is best for the resident? What is

best for the other residents? How big is the space and how many residents can be accommodated? How much time and staff/volunteer resources are available to help residents move from one space to another and back again? In this respect, while offering activities in separate spaces had definite advantages, the process required considerable time and effort on behalf of activity staff, as well as buy-in from Care Aides and other support staff or volunteers. The balance achieved by offering activities in shared social spaces as well as separate designated spaces helped staff to reconcile the ethical and practical challenges, and enabled inclusion of residents who otherwise might consistently be left out because of personal or behavioural reasons:

... [T]here's more to it when we're doing stuff in the neighbourhoods, not only with all those considerations for our work, but we're doing it for reasons because, like...someone like Linda...the smile on her face yesterday when she sees [volunteer] for a few seconds, or someone like Mason who, you know, he may not get chosen for that group out here [in the Concert Room], but I see how much he passively gets from things that happen there [in the neighbourhood]. And he, I hate to say it, but he isn't very active in doing a lot of things anymore, but he still really seems to like it, his eyes are bright and he likes that attraction...those things you would lose if we stopped. (*Emma, Activity Coordinator, Emory Lodge*)

The global layout of the environment, as well as the configuration of activity spaces in particular, was pivotal in determining how the process of inclusion unfolded. The open-concept, circular design in the neighbourhoods at Emory Lodge enabled and promoted *self-inclusion* for residents who were independently mobile. However, the L-shape layout at Beachwood Residence presented significant challenges for residents and activity staff. The long corridor and lack of visibility from residents' rooms into the dining room meant that

residents who were in their rooms were not always aware of an activity taking place in the dining room. As a result, activity staff were often required to 'gather' certain residents from their rooms for activities. This was a remarkably time-consuming process, and without the assistance of an 'anchor person' who remained with the group, staff often lost the attention or enthusiasm of residents while they waited for the activity to begin:

[I]f I'm doing something like a happy hour, and Penny is in her room, I want to make a point of going all the way down to her room, inviting her, and escorting her down. Because, it's happy hour, she likes her sherry...She is still with it enough to know that, 'Oh, this is the normal part of my life, I'm having a glass of sherry, there is some music playing, I can get up to dance' and she'll get up to dance... *(Natalie, Activity Coordinator, Beachwood Residence)*

Finally, the configuration of the activity spaces in the neighbourhoods at Emory Lodge, and the dining room at Beachwood Residence, enabled certain residents to enjoy activity groups from a position outside of the group itself (e.g. a dining room table). Activity staff consistently made efforts to accommodate and include these residents by taking the activity 'out' to them, either physically or verbally. Including residents along the periphery was easier to achieve and less disruptive to the remainder of the group at Emory Lodge where the small-scale, open-concept spaces meant the activity coordinator didn't have far to go to engage these residents while maintaining focus among residents in the larger group.

This morning was 'bat the balloon' in Maple Grove. We arrived at approximately 11:10, so there were some people still in the dining room just finishing breakfast/morning snack. Most of the residents were easily

moved to the lounge area for the activity. Lillian stayed back at the table, as usual, and participated from there...Two other residents also chose not to move to the lounge area. Periodically, the ball would be tossed past the couch and chairs and end up in the dining room. Emma took this opportunity to engage the residents who had chosen not to move into the lounge. Both residents were receptive and happily engaged with her...The nice thing about the dining room and lounge area being open-concept and in such close proximity is that even if the residents choose not to move, they are still able to gain some passive enjoyment - they are not just staring into space, completely unengaged - and Emma doesn't have far to go to engage them directly. (*Excerpt from field notes*)

However, at Beachwood Residence, the large-scale dining room and wide distribution of tables across the large space presented more of a challenge in this respect. In order to include residents who chose to participate from a distance, the activity coordinator required assistance from a volunteer or staff member to help maintain the focus of those in the larger group.

If I didn't have those two nursing assistants to play ball while I was over here to go to Karen, to go to Ray, they would have been left behind, because my focus would have been the circle that I had. But because the two nursing assistants helped me, engage the circle of people, I could go to Karen, I could go to Ray. And if it didn't happen, they would not have interacted, they would not have had my attention. They would not have gotten that time. (*Natalie, Activity Coordinator, Beachwood Residence*)

In sum, both *self-* and *staff-inclusion* in group activities were related to features of the physical and organizational environments. *Self-inclusion* was common when activities took place in shared common spaces like the dining room at Beachwood Residence, or the lounge areas in the neighbourhoods at Emory Lodge. However, at times, self-inclusion was disruptive to the rest of the

group, and as such, activity staff valued having separate spaces where they could tailor activity groups by selecting certain residents based on personal interests and functional similarities. The ethical dilemma posed by the selection process was reconciled by maintaining a balance of activities in common spaces and separate spaces. Activities that took place in separate spaces required careful planning, additional time, and staff collaboration in order to include as many residents as possible. But the inclusion process did not end once all the residents were gathered in the activity space. During activity groups, activity staff needed to go that extra step to bring residents actively into the social world, both verbally and physically, by engaging them one-on-one or taking the activity 'out' to them along the periphery. Again, this process was more successful when the spaces were smaller and the activity staff had support from care staff or volunteers.

5.2.2.2 The Captive Audience

In contrast to the sub-theme of *self-inclusion*, a very different concern related to inclusion surfaced in both settings: Are residents being included in activity groups merely because of their presence in the room prior to the activity? Specifically, staff were concerned that certain residents who relied entirely on others for mobility and decision-making were being included in group activities simply because they were 'already there'. Primarily through interviews and questionnaires, it became apparent that bringing activity groups into common social spaces runs the risk of creating a *captive audience* of residents who perhaps are not interested in the activity or would benefit more from a tranquil, relaxed setting, but because of functional limitations are unable to act

independently on their preferences. As one staff member at Emory Lodge explained, when activities are brought into the neighbourhood TV room, *“People that want to watch TV but not participate in the activity are out of luck.”*

(Stephanie, Care Aide, Emory Lodge). Similarly, Tanya, Director of Leisure Services at Beachwood Residence explains,

I like the group space, but I think sometimes you do have people that are, in the same way that you were describing, this sensation of, ‘Ok now I’ve oriented myself to this space and now I’ve been moved to a different space and how did I get here?’, well sometimes I think people have that reaction to, ‘Ok, it was so nice and calm here, and now there is all this activity going on, how did this happen?’ *(Tanya, Director of Leisure Services, Beachwood Residence)*

Organizing and hosting group activities in the dining room at Beachwood Residence posed two particular challenges in relation to this concern: a) intense time pressures, and b) few space alternatives. Because the Activity Coordinator or the Music Therapist were often acting alone or with the assistance of one volunteer, there was very little time available to interpret residents’ non-verbal language to decide whether ‘exclusion’ may have been the best option to support their QoL. Furthermore, the number of alternative spaces to which residents could be taken was limited; the small social space by the nurse’s station was too small for many wheelchairs, and the Yellow Room posed challenges in terms of staff monitoring. Therefore, taking residents back to their bedrooms was the only alternative:

I’m saying, ‘come on, reach up, reach up your arms’ and they must be thinking, ‘you know, I’ve got a headache and this woman won’t stop talking’, right? Or ‘Hello Tina, how are you doing?’ and Julie is singing and

they're like, 'Oh please make that stop'. You know, I mean, they're just stuck there. They're just stuck there... Whatever is happening around them...They have no *out*. (Natalie, Activity Coordinator, Beachwood Residence)

Consequently, inclusion is not a 'blanket principle' of person-centred care that applies to all residents, all of the time. Activity staff and Care Aides need to communicate and collaborate in the 'before' stages of activity groups in order to determine the situational and contextual circumstances of each resident who cannot easily communicate or act on their preferences. Time and effort needs to be taken to establish who would enjoy and benefit from having an active and lively social atmosphere around them, and who would benefit more from a quiet and peaceful social setting.

5.2.3 Autonomy

Who else really can give them the most choices? I think its leisure. And that's why I totally love my job, and I really try to be better at it, because I think that dietary can't do it because if you can't chew you get minced food, and if you're diabetic you get this food and, you know, laundry is laundry, and housekeeping is housekeeping, and who else is going to meet you and give you like a total care, like total care, like every choice that you ever... everything that's been taken away from you for medical reasons, for dietary reasons, dentures...whatever, I think leisure, really, is the only one that can give you choices...to be like a 'normalized' person, right? To be like a real self-actualizing person. Because all of the other decisions are made for them. Or dictated... (Natalie, Activity Coordinator, Beachwood Residence)

In the most basic sense, autonomy stands for self-determination or the freedom to make ones own life choices. Naturally, this definition implies that the

decision-maker is cognitively healthy (i.e. capable of rational thought), informed, and able to reflect on the consequences of his or her own decisions. The expressions of autonomy revealed in this study reflect what Agich (2003) terms “actual autonomy”, which represents how acts of self-determination unfold in everyday social situations within long-term care. Agich argues that while perhaps the greatest amount of reflection and debate around the concept of autonomy in long-term care has occurred in relation to major life events or ethically complex circumstances, there is a level of autonomy rooted in everyday actions that is largely overlooked.

Supportive dementia-care environments can help facilitate self-determination and maintain residents’ involvement in daily decision-making for as long as possible (Lawton, 2001; Zeisel et al., 1999). The physical environment is a valuable tool for supporting residents’ autonomy. Increased wayfinding and visual access to a variety of space options can help residents make their own decisions about how or with whom they spend their time. In this study, staff in both settings respected and valued residents’ choices about if, how, or for how long they engaged in activity groups. Organizational expectations, such as care plans or therapeutic goals, were never given priority over residents’ right to choose whether to participate. Activity staff were mindful of ‘inviting’ residents to join activity groups, never demonstrating a paternalistic or forceful approach.

Meanwhile, the overall unit design, location of activity spaces, and furniture arrangements either supported or impeded residents’ freedom to ‘*come and go*’ from programmed activities, or to participate ‘*from a distance*’. During activity groups in both settings, ‘*come and go*’ participation was very common.

This subtheme describes how residents were free to leave groups early, join groups late, or wander in and out of groups as they wished. The second subtheme, *'from a distance'*, participation describes how some residents chose to engage passively by positioning themselves outside of the physical formation of the group, while remaining within a distance where they could still hear and see the activities. For some residents the decision to participate from a distance was related to situational factors or their dislike of crowds. However, *'safe-distance'* participation describes a unique type of peripheral or *'from a distance'* engagement observed at Emory Lodge whereby residents - primarily in early stages of dementia - chose to engage from an *'outsider'* position that appeared to reinforce their perceptions of themselves as *'different'* from the other residents.

5.2.3.1 'Come and Go' Participation

Pacing and wandering are common symptoms of dementia. While previously viewed as *'negative'* or *'challenging'* behaviours that justified a variety of behavioural interventions, a more recent approach is to design environments that support this type of activity in a safe and secure manner. Open-concept designs that are *'naturally mapped'*—*i.e.*, designed to reduce the need to remember spatial directions (Zeisel, 2006)—are key to supporting the QoL of residents' who pace and wander. Clearly visible pathways and social spaces encourage residents to come and go at their leisure without becoming *'stuck'*. Open-concept designs also enable staff monitoring of residents as they move about.

Residents who wander can find it difficult and often distressing to sit still for an extended period of time. While staff may have specific therapeutic goals in

mind for activity programs, to ask certain residents to participate in group activities from start to finish would not have a positive impact on their QoL. '*Come and go*' participation was common among residents in both settings; residents with shorter attention spans or those who spent the majority of their time 'on the move' were able to benefit from shorter periods of engagement. Features of the physical environment such as space configuration and thoughtfully planned furniture arrangements made it easy for residents to enter or exit activity groups, while minimizing disruption to others.

At Emory Lodge, the open-concept, butterfly design in the neighbourhoods supported and encouraged residents to *come and go* freely from activity groups. Because neighbourhood activities took place in the central common areas adjacent to the wandering loop, residents who paced or wandered could benefit from sporadic engagement in activities while retaining the freedom to *come and go* as they wished. Others who had had enough of the stimulation could leave when they felt the need, easily finding an exit to the wandering loop from either side of the space.

I've been noticing the open-concept/in and out, the residents like Linda or like Amelia who don't necessarily want to sit down all the time, they can come and go as they please, and they do come more often than they would if there was no activity taking place. Especially down in Willow Place, Linda comes into that space more often when there is a group activity going on than she would if there were just some residents sitting around. Sometimes she even sits down for a few seconds! (*Excerpt from memo*)

Because the open-concept design at Emory Lodge was intended to maximize visual and physical access to the central common spaces, residents had become accustomed to the constant 'flow of traffic' through the space, which reduced the impact of *come and go* participation on their ability to maintain focus on the activity despite the small space. Meanwhile the atmosphere remained inviting, and staff could continue to encourage residents to join at any time without getting the sense they were 'interrupting'. As Margaret, Manager at Emory Lodge explains:

You know that that feeling of coming into a room and interrupting versus just being able to join in where or when able. I think that the open spaces promote the 'in the moment or happenstance' engagement and involvement experiences (*Margaret, Manager, Emory Lodge*)

In contrast, supporting residents' freedom to *come and go* during events in the Concert Room at Emory Lodge required careful planning on behalf of activity staff, as well as additional support and involvement from direct care staff.

Residents who chose to leave concert events early required a staff member to monitor their whereabouts or accompany them back to their neighbourhoods. As a result, depending on the availability of staff support, activity staff were more likely to redirect residents back to the activity or take them home. Once back in their neighbourhoods, they were unlikely to have an opportunity to return. Thus, the location of the Concert Room and the fact that it was not a 'secure area' placed some limitations on residents' freedom to *come and go*. The additional 'vigilance' on the part of activity staff sometimes resonated with residents and appeared to change the emotional energy in the group from relaxed and fun to nervous and unsure.

Yeah, and I say too that the emotions are contagious. I find with the things that we do in the Concert Room, I am more 'on'. Like I'm kind of on high alert, ok who is up? You know, I can't totally relax and participate with this person because I've seen this person up and I want to make sure they don't go where it is unsafe. Whereas in the cottage if someone gets up, I don't have to...I just feel like I can be more at ease, and really give that undivided attention to someone if I need to. I don't have to be quite as cautious about what is going on. *(Lauren, Occupational Therapist, Emory Lodge)*

Although the dining room at Beachwood Residence was not purposely designed to foster this type of *come and go* participation, activity staff used their knowledge of residents as 'persons', in combination with thoughtful furniture arrangements, to accommodate and support their preferences. Organizing large group activities in the dining room required activity staff to be mindful about creating visually noticeable and physically manageable pathways for residents who chose to leave early, join late, or *come and go* at their leisure. Staff achieved this by avoiding completely enclosed circular furniture arrangements, alternating wheelchairs with residential chairs, and leaving clear visual pathways to peripheral tables, the washrooms, and the exits.

A lot of times...a lot of the independently mobile people, I'll try to have closer to the 'out', so if they do want to get up and go, they'll go. And so, the ones that don't will stay one spot, and have a clearing for the Julie's and the Penny's and the Yolanda's...If they want to get up, the Deanna's, Lori who cannot sit still at all, so as not to sort of trap them in there. Because once you get all the big chairs in a big circle, they can't get out. *(Natalie, Activity Coordinator, Beachwood Residence)*

As Natalie explained, activity staff at Beachwood Residence had to be creative with seating arrangements in the dining room in order to be inclusive as well as

supportive of residents' autonomy. With the high number of residents in one space—of which over one-third required large wheelchairs for comfort and mobility—staff were forced to put extra time and careful planning into setting up activity groups. Seating all residents in wheelchairs on the outside of a semi-circle gave the impression of an 'impenetrable barrier', thus residents on the outside, who perhaps would have joined the group a bit late, were met with what resembled a 'steel wall' that was neither inviting nor passable. Meanwhile, independently mobile residents, who typically sat inside against the wall were 'trapped' in a sense. Dina, Manager at Beachwood Residence, also expressed concern that enclosed or unwelcoming furniture arrangements that did not naturally encourage come and go participation would also deter care staff from joining activity groups, an aspect of the culture of care that their management team was eager to improve upon.

But the staff also who may come and go with more frequency than, I believe, the residents. Because they could sit for 5 minutes, but then maybe they have to get up and...there's no way they can join...it's a barrier. *(Dina, Executive Director, Beachwood Residence)*

The Yellow Room at Beachwood Residence was least supportive of *come and go* engagement. The lack of visibility to and from the main hallway meant that once certain residents were in the Yellow Room, they were less likely to leave on their own volition. As one resident explained following a special lunch in the Yellow Room, *"[I] didn't really know what was beyond the door."* Moreover, some staff members described how the location and lack of visibility also discouraged residents from entering the Yellow Room without guidance, and deterred care staff from using the space for their own activities: *"[The Yellow*

Room] is too far in the corner for elders to see” (Sheena, Care Aide, Beachwood Residence); “Access to the Yellow Room is difficult because of the entry way. It also takes you away from the majority of the residents.” (Tamara, Care Aide, Beachwood Residence). Interestingly, while these spatial attributes made the Yellow Room the least advantageous in terms of naturally supporting residents’ freedom to *come and go* as they wished, activity staff actually appreciated having less *coming and going* in that space. The small, quiet, enclosed atmosphere reduced unnecessary disruptions, improved regulation of sensory stimulation, and enabled focused attention, which improved residents’ experiences in activity groups.

5.2.3.2 ‘From a Distance’ Participation

Certain residents in both settings appeared to have an interest in engaging in programmed activities, but preferred to do so *from a distance*. For some residents, situational factors (e.g. not feeling well, having a bad day) played a role in their decisions to observe activities from tables along the periphery; some residents preferred not to move from their seats; and others chose to avoid crowds or excessive noise. Both observations and in-depth interviews indicate that residents receive a great deal of enjoyment and therapeutic benefit from passive engagement, despite not being in the ‘hub’ of the activity:

I think that sort of peripheral enjoyment, or that passive participation is a very, very important part of what we do. And you see it here on the main floor as well, where somebody, somebody who is not a joiner who doesn’t want to come close, they’ll sit at the back of the room and they’ll do exercises or they’ll tap along, so I think it’s incredibly important. *(Tanya, Director of Leisure Services, Beachwood Residence)*

Certain residents at both Emory Lodge and Beachwood Residence consistently participated in activities *from a distance* outside of the group formation; however the reasons behind their decisions appeared to be quite different. At Beachwood Residence, residents tended to engage *from a distance* primarily because they were asleep in their chairs when the activities were being organized, or they simply preferred not to move from their seats. Alternatively, 'safe-distance' participation was a type of engagement observed among a small subset of residents at Emory Lodge. These residents, who were in earlier stages of Alzheimer's disease and thus had a higher level of self-awareness, appeared to self-identify as 'different' from the other residents. As a result, they often turned down invitations to 'physically' join their neighbourhood activity groups. However, rather than abandon the area altogether, these residents sat at dining room tables adjacent to the activity space where they could overlook the activity at a 'safe distance' from the others. The following field notes describe Lillian's way of participating in a 'bat the balloon' activity from the safety of her table in the dining room.

It was interesting to me how Lillian so enjoyed this activity, which must be a brief yet amazing relief to her in her recent state of chronic frustration and paranoia. But she did not want to leave 'her table' (her choice to make), so she batted the balloon from her 'post' over the heads of the residents seated on the couch. This must be a safe place for her; to her, a place where she can be in control, or something she can be in control of.
(Excerpt from field notes)

For residents like Lillian, the configuration of space enabled participation from a more desirable 'outsider' position, while the furniture arrangement created

a physical boundary that supported and protected the social distance they perceived, and even valued, between themselves and the others. Thus, the physical environment enabled residents make autonomous decisions about where and how they participated in group activities, which preserved their self-esteem. The small-scale and open-concept design allowed these residents to benefit from engagement in the activity itself without having to cross the 'social threshold' that set them apart from the others:

Wednesday morning - sitting at a dining room table in Willow Place watching the piano player play for the residents in the piano room....Allison came and she sat down with me and she said, "I don't know why I'm here, I don't know what they think is wrong with me". But she used to be a piano teacher, so the whole time she is saying, "Why am I here? I don't know why I am here. I'm just going to go home" but she was keeping the beat, keeping the beat with the drum, keeping the beat with her piano fingers the whole time. There was this real discrepancy between her verbal language and her body language. She was really getting a lot out of listening to the music, but she was not identifying with the rest of the residents at all. She was saying things like "She acts like a baby" or "Look at her"... she was talking about the rest like they were not the same as her. And not knowing why she was there but at the same time keeping the beat on the table...it makes me think about how the space works really well to facilitate that...when they don't want to 'be' with the rest of the group, and this is a safe and comfortable zone for them, they just sit back in the dining room. But they are not missing out on the activities altogether. *(Excerpt from field notes)*

Overall, residents in both settings were fully supported by activity staff in their decisions regarding if, when, where, and for how long they engaged in activity groups. Residents were 'invited' to participate in activity groups and their responses to these invitations were always respected. Of course, mobility and

cognition determined the extent to which residents could act independently and autonomously. Secure, open-concept spaces with thoughtful furniture arrangements supported residents who were independently mobile by enabling them to '*come and go*' from activity groups at their own will and with minimal disruption. Meanwhile, the presence of tables and chairs in adjacent spaces along the periphery facilitated a form of distal engagement that was simply more comfortable for some, and for others, was a way of reinforcing a social dissonance felt between themselves and the other residents.

5.2.4 Community

I don't understand how people carry on in those environments where it's just so cold and because basically like the environment around and the team and everything has a big role, but the fact that there is no interaction and there's no social engagement at all. That's the root of it, I think, if your not going to even engage or treat the residents as another person there with you, you can't build from that...I can understand in the very traditional environments where it's like, ok, well the care staff are just doing, like taking care of this physical body, that's it, and the rec staff do that kind of stuff, but even...I just don't get, like even as rec staff, there are so many who think ok, well I'll come in at 1 o'clock and I'll do an hour of bingo, but I just don't get like, how do you think that's benefitting people when the rest of the day you don't really treat them with that ... like the reason that those things can be successful are because you develop a relationship with someone and because you treat them that way... I don't want to play bingo with Joe Blow off the street who I don't know, or who just kinda comes in like "here, here we go", you know...I don't get that, like, that whole environment and that's totally the difference here and that's what I love so much because I can go into the [neighbourhood] thinking I'm going to go in and do the balloon game, and the there's so many times when I'll go in and quite often I think there's already something going on here where they

are so well engaged that I don't want to interfere and I realize when we talk about it how lucky we are that that happens. (*Emma, Activity Coordinator, Emory Lodge*)

Although 'community' was not a concept that surfaced through resident observations, nor was it something that related directly to resident outcomes, it was a common part of the everyday vocabulary at Emory Lodge, and hints of it began to surface early on from preliminary analysis of the first group interviews. While the primary goal was not to learn about the culture as a whole or patterns of residents' or staffs' behaviour in general, the learning occurred within an overarching culture that gave direction to the research as it progressed. According to Morse et al., (2002) solid qualitative research is generated, in part, from "investigator responsiveness" whereby researchers "listen to the data" and recognize when there is a need to alter their research plans in order to secure the validity and comprehensiveness of the findings. Part way through the data collection at Emory Lodge, indications pointed towards a need to pursue the concept of 'community' with the interdisciplinary leadership team, both to get a sense of what it meant to them, and to see what, if any, impact activity programming and the physical environment had on their 'community spirit'.

A group interview with all members of the interdisciplinary leadership team was held specifically to discuss the concept of 'community' at Emory Lodge. The interview began by having everyone read the above quote from Emma, their Activity Coordinator. This quote was extracted from the first team-based interview at Emory Lodge, and was the first indication that the concept of community was not only a key element of their overall culture, but that it was intricately woven into all aspects of daily life, both as a goal and an outcome. Participants were

asked to reflect upon how that quote spoke to them about community; whether they considered each individual neighbourhood a community or family; and how they felt activities and activity spaces contributed to the overall spirit of the Emory Lodge community.

5.2.4.1 Neighbourhoods as Communities

When asked whether each neighbourhood was conceived of as a 'family' or 'community', there was strong consensus that each neighbourhood represented its own unique 'community' or 'town within a larger suburb'. However, the concept of an Emory Lodge 'community' went far beyond each of the neighbourhoods. Numerous small micro-communities (e.g. staff, family members) also co-existed within the larger Emory Lodge community, and each of these discrete communities was closely interconnected with the others in an act of unification built upon equality, shared responsibility, and mutual respect that, as a whole, encompassed the Emory Lodge community spirit.

When I read Emma's quote here, you know, I read things about respect, about it's a level playing field, I read here that she doesn't go in to provide recreation for 12 people with dementia; she goes into [neighbourhoods] with a spirit that these people, as human beings, are connected to her in a very meaningful way. That there's not that separateness, there's that co-existence that I have always enjoyed and reflected on. You know when I think about the many...I think of us as circles, we co-exist in this community in circles, but all those circles are so interwoven in such a beautiful way. *(Margaret, Manager, Emory Lodge)*

Certainly, the physical layout and design of each neighbourhood fostered a sense of community amongst residents, direct care staff, and family members. Participants also unanimously agreed that having group activities in the common

spaces within neighbourhoods (as opposed to the Concert Room) supported and helped maintain each neighbourhood's sense of community, both during and after events. For instance, eliminating the need to take residents home or move them to a different space after events meant that the positive engagement, social belongingness, and sometimes even the activities themselves, continued on well after the activity was officially over:

I had tea with a few of the ladies in Maple Grove last week, and there were four of us sitting around the table, you know, and then Lillian's at her own table, and Ruby was on the couch, but they still participated but they weren't around the table. But then when I was done, I was able to leave and I was in the kitchen talking to one of the Care Aides about an entirely different issue, and then three ladies at the table were still carrying on. Right? Two were talking and the other just stacked all the teacups up...so they're still, so had I had to move them back out of the activity room, or whatever, all of that would have stopped. (*Lauren, Occupational Therapist*)

And how many times do we see after, maybe the piano playing is done, a volunteer comes and plays the piano, and then they leave and Emma and everybody else leaves, but they [the residents] all sit in that same area, and then you go back in and they're still, they're dancing, the Care Aide has got the music on and they're all dancing together. So it didn't stop, it kept going. (*Andrew, Social Worker*)

Thus, the community spirit in each neighbourhood was fostered by the small-scale, circular design with centralized common spaces that encouraged informal social interactions, passive social engagement, and formation of group identity. Group activities held in the shared common spaces within the neighbourhoods further helped to sustain their sense of community spirit by providing opportunities for collective engagement or 'we-feeling' (Keith, 1980, as

cited in McAllister & Silverman, 1999) that resonated long after the actual activities had ended. As staff explained, if residents were relocated to a different space after activities were over, the lingering effects of social belonging and ‘wellness’ would have disintegrated.

5.2.4.2 The “County Fair”

And I always see the [Concert Room]... so we have our [neighbourhoods] and these are our different communities, and then the [Concert Room] is kind of like “Big County Fair” where all the communities come together...and they have a good time. So, I definitely think, for me, it’s a sense of community. (*Andrew, Social Worker*)

Whereas small group activities helped to encourage and sustain a sense of community within the neighbourhood settings, events in the Concert Room provided invaluable opportunities for all Emory Lodge communities to join together. These opportunities contributed to the overall sense of community spirit at Emory Lodge in several ways. First, because most care staff did not rotate between the neighbourhoods, Concert Room activities gave staff a chance to spend time with residents from different neighbourhoods whom they knew and had emotional connections with, but rarely had a chance to see. Second, because each neighbourhood is completely self-contained and separate from the other neighbourhoods, Concert Room events presented rare opportunities for care staff to perform their duties collectively and to all the Emory Lodge residents, not just those from their own neighbourhoods. Finally, members of the leadership team, in particular, valued the opportunities Concert Room events provided for family members and residents to enjoy each other’s company without the pressure of carrying on a conversation: *“I think the main thing with the*

concerts, the residents they enjoy it, but really I wouldn't say it is Emma's goal, but my goal is that family interaction it provides, it provides a focus for the family." (Jane, Care Coordinator). Activity staff used several methods to advertise concert events, including posting posters at the front door, on the fridge in the neighbourhood, and in the family communication room.

Finally, Concert Room events gave residents from different neighbourhoods a chance to see each other, to mingle amongst "acquaintances," and to feel the sense of belonging to a larger community that is so important for QoL. Thus, as Emma's quote demonstrates, the Emory Lodge community is strengthened by their dedication to residents as human beings, as persons, and as equal members of the community. Drawing from the literature on social capital, both bridging (reaching out to and bonding with different communities) and bonding (maintaining cohesiveness within communities; Putnam, 2000) can be seen as preserving and strengthening the positive social milieu at Emory Lodge. Activities that took place in the neighbourhoods strengthened the bonds between residents, staff, and family members within each neighbourhood community, while Concert Room events provided the medium for bridging between communities, which kept the overall Emory Lodge 'community spirit' alive and strong.

CHAPTER 6: DISCUSSION

This study sought to explore residents' engagement experiences during programmed group activities in two dementia special care settings purposely selected for their contrasting physical environments: one purpose-built, freestanding Special Care Facility (SCF) and one retrofitted Special Care Unit (SCU). A second goal of the study was to discover the environmental features of activity spaces that help or hinder staff members' abilities to provide successful group activities. The inquiry was guided by a multidimensional conceptual framework that integrates Lawton's (1994) conception of the Person-Environment System, Kitwood's (1997) theory of Personhood and dementia, the Need-Driven Behaviour Model (Algase et al., 1996), and Weisman et al.'s (1991) framework of environments for persons with dementia. The strength of this framework is that it takes into account the diversity of residents' backgrounds and personal capacities, and illustrates the multidimensional and interactional nature of residential care as a dynamic and complex physical and social world.

Over the past three decades, there has been a steady growth in the body of literature on dementia care and quality of life. Research has focused on a wide variety of domains, including the built environment (Day et al., 2000; Holmes et al., 2000; Reimer et al., 2004; Schwarz et al., 2004; Zeisel et al., 2003), organizational issues (Chappell & Reid, 2000; Gerdner & Beck, 2001), therapeutic interventions (Buettner & Kolanowski, 2003; Kutner & Bliwise, 2000; Martichuski et al., 1996), and the social environment (Moore & Verhoef, 1999). To

my knowledge, no other study has focused on exploring the physical environmental qualities of activity spaces in dementia care units. Furthermore, few studies looking into therapeutic physical design have adopted such a comprehensive approach to understanding the complex, interrelational nature dementia special care environments (Moore, 2005). The following paragraphs discuss why such an approach proved to be invaluable for this study; specifically how considering all aspects of 'person-environment system', rather than just the physical environment in relation to resident outcomes, enhanced our insights into the relationships between activity spaces, activity programming, and resident QoL.

Although researchers typically approach the study of dementia care in very diverse ways depending on their disciplinary orientations, we share a common goal to advance knowledge and practice in order to move towards a truly holistic model of dementia care whereby residents are fully supported in all domains of QoL, including physical, functional, psychological, and social. In theory, activity programming can effectively address and support each of these QoL domains; in practice, proper spaces and adequate resources are necessary to make it happen. The following paragraphs describe how the findings from this study contribute to a baseline understanding of what specific environmental features support the practice of activity programming and the quality of residents' engagement experiences.

6.1 The 'Person'

First, it is necessary to call attention to the tremendous diversity that exists within dementia care environments, and the challenges this diversity has for

programming and practice in the context of delivering person-centred care. Each resident possesses a unique set of characteristics that collectively shape the 'person'. These characteristics have their origins in ethnicity, culture, language, spiritual beliefs, family history, personality, life roles, values, and interests (Kitwood, 1997). Their identities, which have developed over time and through a variety of life experiences, are not lost with cognitive impairment (Lesser, 2006; Sabat, 2006). Rather they shape the subjective experience of dementia (O'Connor et al., 2007) and residents' daily lives in long-term care (Lawton, 1994). Person-centred care that is individualized—that respects the subjective experiences and perspectives of individuals with dementia (Brooker & Surr, 2005)—requires careful attention to the unique details that influence behavioural outcomes and QoL differently for each resident. Care staff are responsible for knowing and understanding each resident's needs and behaviours in the context of their unique personal identities, thereby shaping care interactions accordingly (Kitwood, 1997; Oppenheimer, 2006).

Further contributing to the vast diversity in dementia care settings is the wide range of personal capacities that correspond to each resident's specific disease type (e.g. Alzheimer's disease, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, to name only a few), disease stage, and manifestation of symptoms. These factors determine extensive variations in mobility, cognition, need states, and behavioural symptoms. Moreover, residents' conditions are ever changing as their dementia and/or other age-related impairments (e.g. vision or hearing loss) deteriorate over time. Thus, although the fabric of residents' personal identities endures, the 'person-environment system' is constantly evolving.

These realities warrant mention of an important caveat: an environment that is supportive of some residents' engagement experiences might not be equally supportive for others (Koehn, Kozak, & Drance, in press). Likewise, activities that are successful one day might not be the next. For instance, while some residents in the two facilities in this study demonstrated considerable difficulty with sensory comprehension when relocated for activities, others seemed to thrive on the experience of 'going out'. Similarly, residents whose engagement in activity groups demonstrated a form of autonomous decision-making were largely independently mobile and able to verbalize their preferences. Therefore, the themes presented and discussed in this study are not to be interpreted as 'blanket' assumptions. However, they do provide a starting point for further understanding how environmental attributes can contribute to positive engagement in group activities and how this relates to a social-normative view of residents' QoL (Lawton, 1994).

According to Lawton (1986, as cited in Moore, 2005), behaviour can be understood as a function of the person, the environment, and the complex interactions that occur between the person and his or her environment, as expressed in the ecological equation $B = f(P, E, P \times E)$. Lawton later applied this ecological equation, and the notion of 'person-environment systems', to the development of a multidimensional framework of QoL for frail elders (1991). In 1994, Lawton expanded this framework specifically to persons living with Alzheimer's disease. The findings from this study bear a striking resemblance to Lawton's ecological equation: Residents' engagement in group activities was indeed a function of the 'Person' (background factors and personal capacities as previously discussed), the 'Environment' (unit layout, size, location, and

configuration of activity spaces, behavioural cues, organizational philosophies, staff collaboration, family involvement in care), and 'Person x Environment' interactions (comprehensibility, inclusion, autonomy, and community).

The findings are also consistent with the work of Algase et al. (1996) and Weisman et al. (1991), who argue that multiple factors within the physical, organizational, and social environments of SCUs and SCFs work in tandem to determine the 'social affordance' of activity spaces, the quality and success of activity programs, and the degree to which residents' QoL is supported and enhanced by this vital aspect of care.

6.2 Physical Environment

Modifications to the physical environments of SCUs and SCFs are prime examples of therapeutic interventions aimed at improving the congruence between 'person and environment' in order to enhance residents' QoL (Zeisel et al., 1999). Small, homelike environments with enhanced wayfinding, maximization of safety and security, regulation of sensory stimulation, and opportunities for personal control are some of the many supportive features of therapeutic design (Cohen & Weisman, 1991; Sloane et al., 2000; Weisman et al., 1996). The findings from this study suggest that four key design elements can impact residents' engagement in group activities, as well as staff members' efforts to provide successful activity programs: a) global unit layout, b) scale of activity spaces, c) location of activity spaces, and d) furniture configuration.

Global unit layout was associated with residents' autonomy and inclusion, both before and during group activities. The open-concept design of the neighbourhoods in Emory Lodge enabled residents to take initiative and make

their own choices as to if, when, or for how long they engaged in activity groups. Because neighbourhood activities took place in central common spaces, residents had clear visual and physical access to and from the wandering loop, thus enabling them to join late, leave early, or come and go on their own accord with minimal disruption to the others in the group. The open-concept design also facilitated visual access to alternative spaces (e.g. the kitchen, the garden, or the alternate activity space) for residents whose attention spans or tolerance had 'run out' (Cohen & Weisman, 1991).

Meanwhile, the standard L-shape design at Beachwood Residence presented challenges in terms of inclusion. The lack of visibility from residents' rooms to the dining room impeded 'self' inclusion. Residents who spent time in their rooms or in the social space next to the nurses' station had no way of seeing, hearing, or knowing about activities taking place in the dining room or Yellow Room, unless they were 'collected' by staff members or volunteers. This put an additional burden on activity staff who were charged with gathering as many residents as possible with little assistance from an 'anchor' person to help maintain the attention of those residents already waiting for the activity to start. Although lack of visual access to the Yellow Room also inhibited many residents from 'self'-including, staff felt this was an advantage of the space as it facilitated smaller, more focused groups with greater sensory control and minimal disruption.

Staff at Emory Lodge felt that the global layout of their facility helped to foster a spirit of community, both within the individual neighbourhoods and at larger community level. McAllister and Silverman (1999) also found that activity

programming, coupled with features of the physical environment, encouraged social interaction, bonding, and the formation of communities within a purpose-built SCF with similar environmental features as Emory Lodge. The same authors noted that indications of community formation could also be seen developing among long-term care residents in a traditional comparison facility during religious activities in the dining room. However, that sense of community quickly disintegrated as residents were “wheeled out of the room into hallways, where they once again began to sit and wait” (pp. 78). In this study, activities that took place in the smaller, centrally located spaces in the neighbourhoods encouraged a sense of cohesion among residents that resonated for a period of time after the activities had ended largely because the residents were ‘at home’, eliminating the need for relocation.

Meanwhile, events in the Concert Room presented opportunities for the wider Emory Lodge community to gather together, creating an impression of belonging and contributing to a larger community. In dementia care settings, continuity with the past is a vital strategy for supporting functional and cognitive abilities, social skills, and personhood (Weisman et al., 1996). One important advantage of the Concert Room was that, for some residents, the act of ‘going out’ and engaging with people other than their immediate neighbours consistently renewed their sense of belonging to a larger community, much like they had experienced in the past. Events in the Concert Room also contributed to the Emory Lodge community spirit by providing enjoyable opportunities for family members to visit with their loved ones without the pressure of difficult conversations.

The size of activity spaces was related to both sensory comprehension and inclusion. The small-scale spaces found in the neighbourhoods at Emory Lodge, as well as the Yellow Room at Beachwood Residence, created a more normalized, intimate atmosphere that instilled a sense of comfort and maximized awareness and orientation. In other words, these small-scale spaces decreased the presence of competing environmental stimuli (cognitive noise), which appeared to reduce uncertainty and anxiety (Zeisel, 2006), and facilitated more positive engagement in the activity and with each other (Zeisel et al., 1999).

On the other hand, sensory comprehension was more challenging in the dining room at Beachwood Residence and the Concert Room at Emory lodge. The impact of these large-scale spaces on residents' engagement, however, also appeared to be associated with 'relocation' and the 'type of activity'. The key difference between the two settings was in the nature of the relocation, from a small space to a large space at Emory Lodge, and from a large space to a small space at Beachwood Residence. Because residents at Beachwood Residence spent the majority of their awake time in the large dining room, most had already achieved a level of sensory comprehension before the large group activities began. Activities that involved being physically together in a group formation, along with high levels of facilitation and direction (e.g. music therapy, ball toss) worked well in the space and fostered high levels of positive engagement. The effects of the space on attention spans and anxiety levels were more obvious, however, when residents were spread out around the dining room and the activity required a greater amount of self-directed initiation.

Inclusion was an ethical issue faced primarily by activity staff at Beachwood Residence. The Yellow Room had capacity for only seven to ten of

the 34 residents who lived on the unit. Therefore, activity staff were obligated to 'select' only certain residents to include. This was less of an issue at Emory Lodge because residents were not routinely invited from one neighbourhood to another for group activities. Moreover, the neighbourhood spaces were large enough to accommodate a small amount of 'company' from different neighbourhoods during special occasions.

Finally, although the dining room space at Beachwood Residence was not purposely designed to support or foster residents' autonomy, staff had creatively mapped-out various furniture configurations that worked well to accommodate residents who enjoyed the freedom to come and go. One of the significant challenges faced by staff at Beachwood Residence in terms of space and furniture configuration was the especially high number of residents in large, tilt wheelchairs. If not carefully planned, group formations had the potential to create an illusion of a semi-circular 'steel wall', which created an impenetrable barrier for residents and staff on the outside, and a sense of entrapment for those on the inside. The solution involved creating clearly visible and physically manageable pathways in and out of groups to welcome new members and support those who chose to leave early.

6.3 The Organizational & Social Environment

The past decade has seen a gradual movement towards adopting models of care underpinned by the philosophy of personhood. Kitwood's (1997) idea of "The Caring Organization" and Thomas' (1996) Eden Alternative model of care have set the stage for many improvements to the organization and practice of dementia care. Kitwood (1997) asserts the need for a breakdown of the "us-them

barriers” in caring organizations, to be replaced by teams of individuals who share common goals, values, and ambitions, at the core of which is the residents’ QoL. The findings from this research underscore the impact the physical environment can have in shaping staff behaviours; the benefits of family involvement in care; and the central role of team-based approaches in supporting the ‘bio’, ‘psycho’, and ‘social’ dimensions of QoL. In this study, both sides of the divide were evident: the consequences of “us-them” barriers, and the advantages of staff collaboration.

The process of achieving culture change takes a great deal of time, patience, and commitment on behalf of managers, interdisciplinary leadership teams, and direct care staff. The breaking down of barriers between care staff and activity staff, for example, requires development of a mutual respect for each others’ roles in the residents care. Second, it necessitates a knowledge and understanding, on behalf of care staff, of the widespread therapeutic benefits of group activities. Third, care staff need to become comfortable with providing social care as part of their role; traditional models of care have cultivated an attitude of ‘care staff do the personal work and recreation staff do the social work’. Breaking that tradition will require time and support from leadership, as care staff may initially feel as though they are ‘shirking their duties to have a good time’. At Emory Lodge, staff collaboration was instrumental to the success of activity programs, especially those in the Concert Room. Support from care staff was critical to help escort residents to events, to help monitor or engage residents during events, and to assist residents back home. Care staff also played an important role in creating residents’ experiences of ‘getting ready’ and

'going out' by spending extra time choosing attire, applying make-up, etc. These acts of collaboration served to improve residents' engagement experiences, and provided much needed and appreciated tangible support for activity staff.

A shift in ways of 'thinking' and 'doing' can be even more difficult to achieve when care is provided in an environment that exemplifies, and perhaps promotes, a medical model of care. The organizational philosophy may be one of person-centred care and creating a habitus of 'home', yet the rules of place may continue to prioritize the needs and routines of staff. Indeed, the findings from this study suggest that a staff approach to space as 'workplace' as opposed to space as 'home' can result in mixed messages about the purpose and corresponding behaviours of 'place'. Specifically, at Beachwood Residence, no clear rules were in place to protect the dining room or Yellow Room space as a 'social' milieu, therefore care staff were not aware of the imposition caused by interrupting activity groups to perform personal care.

The quality of residents' engagement in group activities hinges upon the staff members' knowledge of residents' unique interests, past hobbies and occupations, and personality styles; knowledge that, for some residents, can only be gained through open communication and partnership with family members. Perhaps the most valuable role family caregivers can play in the care of residents with dementia is through the communication of biographical information. Biographical knowledge is essential to the maintenance of personhood after residents lose their ability to demonstrate or communicate self-identity (Kitwood, 1997). Both organizations in this study valued communication and partnerships with family members and encouraged their ongoing participation in activity

programming and events. This finding is consistent with other studies and reports of specialized dementia care facilities that adopt more family-inclusive policies and programs whereby staff are encouraged to value family members for their knowledge and expertise and to accept them as partners in the residents' care (Cantley & Wilson, 2002; Spencer, 1991; Volicer, 2000).

6.4 Resident Quality of Life

The following paragraphs present the themes of *comprehensibility*, *inclusion*, and *autonomy* as they relate to Lawton's (1994) multidimensional view of QoL in dementia, specifically from the perspective of "*the social-normative criteria of the person-environment system*" (p.6).

6.4.1 Sensory comprehension

'Person-environment fit' represents the dimension of QoL determined by the reciprocal relationship between individuals with dementia and their environments (Lawton, 1994). Prosthetic dementia care environments consist of a balance of both demand character and support character so that residents are neither bored nor over-stimulated, as either condition can lead to detrimental consequences such as agitation or withdrawal. Lawton's notion of 'behavioural competence' alludes to how well individuals are able to function in their everyday lives (e.g. memory, creativity, time use, social interaction) given their personal capacities and presence of a variety of environmental supports or demands.

In dementia care settings, the physical environment plays a key role in supporting residents' QoL through support of cognitive and functional abilities (Zeisel, et al., 1999). Whereas healthy individuals have the capacity to actively

shape their environments to meet their individual needs and abilities, residents with dementia have great difficulties processing certain aspects of their environments, including spatial orientation and cognitive maps (Zeisel, 2006). Prosthetic physical environments in dementia care settings are meant to compensate for cognitive losses, restore balance in the person-environment system, and improve residents' abilities to perform at their best.

Sensory comprehension indicates that residents have a sense of orientation to space and place (Zeisel et al., 1999). Not surprisingly, the findings from this study suggest that sensory comprehension is essential for positive engagement in programmed activities. Staff felt that in the neighbourhoods at Emory Lodge, residents felt comfortable, safe, secure, and 'at home'. Thus, the environment afforded a high level of compensation for sensory deficits and the 'fit' resulted in greater clarity and piece of mind during activity groups. For some residents, the journey to the Concert Room, and the unfamiliar nature of the setting, made sensory comprehension difficult to attain, and thus their participation in activity groups was obscured by feelings of anxiety, insecurity, and inattention.

More optimistically, however, residents at Emory Lodge and Beachwood Residence who had fewer difficulties orienting to a change in physical space benefited from the act of 'going out'. The relocation to a different space in combination with behavioural cues from the physical environment brought to the surface a set of social skills corresponding to place rules—deeply engrained 'schemata' of how one should act in a given public setting (Canter, 1991). As Moore (2005) argues, closer examination of the discrete features of space that impact sensory comprehension, as well as the socially derived meanings of

place, can be useful for designing successful interventions aimed at improving person-environment fit. For instance, an activity room may be high in sensory control but have none of the attributes of an activity room that would cue a resident to what might be appropriate behaviours for that space. An intervention to improve resident-environment fit in this space might include the addition of appropriate activity props. In contrast, if an evaluation of the physical features of the space deemed it to be problematic in terms of sensory control, one might choose to reduce the amount of visible activity props to expose only those appropriate to the task at hand. The concept of place rules in dementia care, and their role in creating supportive physical and social environments, is a relatively new area of inquiry, and one that merits future research.

6.4.2 Inclusion

For many years, dementia care facilities have had the reputation of being socially and psychologically impoverished environments. Several researchers and scholars have alluded to the profound social isolation encountered in dementia care facilities (Bruce, 2005; Kitwood, 1997; Moore & Verhoef, 1999), due to a lack of opportunities for occupation and social stimulation (Kelley et al., 1999; Maas et al., 2004; McAllister & Silverman, 1999; Morgan & Stewart, 1997; Parker-Oliver et al., 2005; Specht et al., 2000). Sabat, Fath, Moghaddam, and Harré (1999) argue that positive social interactions preserve residents' self-esteem by reinforcing their views of themselves as being likeable and as possessing remaining strengths despite numerous losses. Group activities are one way in which residents can be included in a constructive social experience that inspires a sense of belonging and self-worth. In contrast, Kitwood's (1997)

notion of a 'malignant social psychology' and Sabat's (2006) view of 'malignant positioning' describe the physical and psychological consequences of exclusion based on an unjust and unnecessary focus on functional impairments.

In this study, social inclusion and equality were core values that shaped the practice of activity programming. Staff in both settings recognized the importance of providing opportunities for all residents to gain social, psychological, and functional benefits from participation in activity groups. Inclusion was easier to achieve in larger activity spaces or when activities were taken 'to' residents in their common social spaces. Although smaller activity spaces created a more inclusive atmosphere (e.g. more normalized, less institutional), functionally they had the opposite effect by limiting the number of residents who could participate at any one time. Activity staff were then presented with an ethical dilemma in terms of deciding which residents to include. When the layout, size, or location of the activity spaces presented logistical challenges (which meant not all residents could be included), staff fell back on their knowledge of residents as 'persons', both past and present, to support their decisions.

An interesting discovery to surface from this study relates to an issue rarely discussed in the literature on personhood or person-centred care: when is 'exclusion' from programmed activities – specifically, taking residents 'out' of the social space where activities will take place - actually the best option to support the QoL of a resident, and what criteria should this moral and ethical decision be based upon? Furthermore, what are the steps involved in the decision-making process and what types of resources are necessary to support activity staff in their efforts to do what is best for each resident? This research suggests that

bringing activities 'to' residents in their common social spaces can result in a 'captive audience' of residents whose well-being might be better supported in a more tranquil setting. However, the process of organizing activity groups is so time-sensitive and resource-intensive that activity staff rarely have the time to refocus their attention on who, if anyone, should actually be taken out of the space and why. Communication, collaboration, and teamwork would clearly offer some resolve, however the exact mechanisms involved in the process should be the focus of future research.

6.4.3 Autonomy

The literature concerning autonomy in long-term care continues to evolve on a number of different levels. On one side, the 'true meaning' of autonomy is debated within the fields of philosophy, law, and biomedical ethics (Boyle, 2008; Carter, 2002; Cayton, 2006; Hall, 2009). Such debates have important implications for capacity assessment and proxy decision-making in times of significant illness or vulnerability (O'Connor & Donnelly, 2009). Others adopt a more pragmatic approach (Kane, 2001), focusing on personal choice and independent functioning as they relate to everyday life decisions, what Agich (2003) terms "actual autonomy". Environmental design researchers tend to fall into the latter category, focusing on the preservation of personal choice and independent functioning in many facets of daily life in long-term care (Lawton, 2001; Zeisel et al., 1999).

Residents who still have the capacity to self-determine should be afforded the right to do so as long as their decisions do not compromise their safety or the safety of others. As Boyle (2008) argues, persons with dementia have a right to

be given opportunities to exercise personal choice as a fundamental aspect of human 'equality'. Indeed, such arguments have been the impetus for changes in policies and practices that deemphasize rigid institutional routines, and call into question the moral and ethical implications of restraint use (Carter, 2002).

Exercising autonomy can help maintain functional skills (Zeisel et al., 1999) and contribute positively to psychological well-being (Boyle, 2008). Institutional environments limit personal choice, while prosthetic environments can enable choice (Cohen & Weisman, 1991; Lawton, 2001). However, modifications to the physical environment without changes in organizational philosophies and care practices would offer few benefits for the preservation of residents' autonomy (McAllister & Silverman, 1999). Under a holistic model of care, residents with dementia are not viewed as patients, objects, tasks or passive recipients of care. Rather, they are supported in making their own choices within boundaries of safety and security to themselves and others.

The findings from this study demonstrate some of the ways in which residents exercise autonomy in relation to group activities, and how features of the physical and social environments support their personal decisions. Respect for residents' autonomy was evident in both settings. When residents were independently mobile and possessed decision-making capacities, open-concept spaces and thoughtful furniture configurations supported their decisions to come and go from activity groups or to participate from a distance. In some instances, the connection between autonomy and QoL was obvious; in particular when residents' choices to participate from a distance appeared to be in an effort to preserve their personal identity (Lesser, 2006). In cases where residents

perceived themselves as 'different' or 'better off' than their peers, the physical environment appeared to offer them a mechanism with which to protect themselves, enabling support for both their psychological well being and their perceived QoL. In other circumstances such as 'come and go participation', the link between freely exercising choice and QoL was grounded in the literature on social-normative appraisals of QoL in long-term care as involving self-determination and a sense control over ones personal decisions (Boyle, 2008; Dröes et al., 2006; Kane, 2001; Lawton, 1991).

6.5 Implications and Conclusion

The primary goal of this research was to discover what constitutes well-designed activity spaces from the perspectives of residents and staff. The results reveal a variety of answers that reflect the complexity and nuances of environment-behaviour interactions. Observational and interview data concerning residents' and staff members' experiences in four very different types of activity spaces reveal that each has its own distinct advantages and disadvantages. Small spaces represent more normalized environments and help residents achieve sensory comprehension, attention, and under the right circumstances can support the emergence of deeply embedded memories and social skills. On the other hand, in units with a high number of residents, small spaces present ethical dilemmas in terms of inclusion. Large spaces help solve the problem of inclusion, yet in their very nature as large spaces they can generate high levels of sensory demand that are difficult for some residents to manage. Moreover, the large spaces seem to have little effect on social inclusion if residents are spread out over a wide area with little direct assistance or support for engagement.

One particular strength of this research is that it draws from data collected in several contrasting contexts: bringing activities 'to' small homelike settings; taking residents 'out' to large, unfamiliar, less controlled settings; bringing activities 'to' residents in larger, less controlled environments; and finally relocating residents to smaller, more intimate settings. While these contrasting scenarios do broaden the scope of the findings, they further complicate any conclusions that can be drawn. Taking activities 'to' residents in their common social spaces eliminates the disorienting effects of relocation, helps support inclusion, and contributes to the prolonged after-effects of cohesiveness and belonging. Meanwhile, staff must be mindful not to include residents merely as a result of their presence in the space prior to the activity beginning. Taking residents out for activities, while disorienting and unnerving for some, offers unique advantages for others who appear to gain a great deal of benefit from behavioural cueing during the process of 'getting ready' and 'going out' in 'public'. One definite conclusion that can be drawn is this: as with other aspects of long-term care, 'cookie-cutter' policies and procedures (Kane, 1995) related to activity programming or the design of activity spaces will not be effective in supporting residents QoL.

The multiple paradoxes that surfaced in this study suggest that, until further research is conducted in this area, the focus of designers should be on *flexibility*, while the focus of practitioners should be on *person-centredness* and *collaboration*. Activity spaces need to be designed taking into consideration that SCUs and SCFs are home for a vastly diverse population of residents who possess unique interests, skills, and personalities, and whose needs are continuously evolving. Spaces should be large enough and sufficiently flexible to

accommodate walkers and large wheelchairs, while retaining the homelike qualities that provide comfort, enable awareness and orientation, and serve as reminders to staff to respect the social milieu of 'home'.

Activity staff have a high level of knowledge about residents as 'persons', and as such would benefit from having a variety of space options to meet both individual and group-level needs. Ethical dilemmas can be reconciled by having access to both larger, open-concept spaces, as well as smaller, enclosed spaces, perhaps even 'theme' rooms to serve the needs of residents with common interests. Primary activity spaces should be centralized (i.e. visible from most residents rooms), open-concept, and easily accessible. A collection of tables and chairs should be within 'close yet distant' proximity to activity groups for residents who prefer to passive engagement. Visibility and access to alternative spaces are also important to support the needs of residents who choose to disengage from the group setting all together, but prefer to remain in a public or social space.

Finally, the results of this study underscore the pivotal role organizational factors play in the relationship between the physical environment of activity spaces and residents' engagement experiences. Staff collaboration is vital during all stages of activity programming. During the before stages (e.g. planning and organizing activity groups), open communication and partnership between care staff and activity staff is required in order to make the best decisions on behalf of residents who can no longer clearly articulate their preferences; depending on personal and situational factors, this may involve including or excluding. Collaboration in the form of practical assistance with helping residents transfer from one space to another before and after events, and helping with one-on-one

engagement during activities, is necessary to engage as many residents as possible in a positive way. The barriers that have traditionally stood between care staff and activity staff need to be replaced by a focus on teamwork in a collective approach that puts the all aspects of the residents' QoL as the focal point of their efforts. Future research would benefit from taking a more in-depth look at policy issues such as staffing patterns, training, and resource allocation in relation decision-making and staff collaboration during the organization and delivery of activity programs,

This exploratory study represents the first step in developing an understanding of how the physical, organizational, and social environments of SCUs and SCFs work in concert to support residents' engagement experiences during group activities. One obvious limitation is that it draws only upon a 'social-normative' perspective of the person-environment system and residents' QoL, making inferences based on researcher observations and staff member accounts in the absence of the views of residents themselves. Interviews with residents would help expand on the 'person' aspect of 'person-environment fit' by shedding light upon the subjective experiences of engaging in social groups, and exploring how the environment could be more supportive of positive engagement experiences.

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APPENDICES

Appendix A: Staff Member Questionnaire

The Impact of Therapeutic Design on Social Engagement among Residents with Dementia during Programmed Activities in Dementia Care Units

Staff Member Questionnaire

Instructions

Please answer the following questions as best you can. Most questions provide space for you to write your answers, as well as any additional thoughts, observations, and experiences that you may wish to share. If more space is needed, feel free to write on the side margins of the page.

If you do not know the answer to a question, please say so by writing "don't know" in the space provided. If you prefer not to answer a question, you may do so by writing "refuse". Your participation in this study is voluntary, so you are free to withdraw from the study at any time.

Definitions are included at the beginning of each section to clarify certain terms used in the questions. Further instructions may be included in [brackets] after certain questions to help guide you through the questionnaire. Completed questionnaires should be sealed in the envelope provided and can be put in the tray in the staff room within 2 weeks of the day you receive it.

Don't forget to sign your name on the list when you return the questionnaire and indicate whether you would prefer a gift card from Tim Hortons, Starbucks, or Chapters! Thank you!

1. Demographic & Employment Information

1. What is your gender?

Male Female

2. Is English your first language?

Yes [Go to 3] No [Go to 2a.]

2a. If no, what is your first language? _____

3. What is your highest level of education other than training for your current position at *[name of facility]*?

- a. Less than high school
- b. High school
- c. Some college or university
- d. Completed college or university

4. How long have you worked at *[name of facility]*?

5. What is your current position at *[name of facility]*?

- e. Care Aid
- f. Licensed Practical Nurse
- g. Registered Nurse
- h. Recreational Therapist
- i. Occupational Therapist
- j. Social Worker
- k. Other _____

6. Have you worked in other dementia-care facilities prior to coming to *[name of facility]*?

Yes [Go to 6a.] No [Go to 7.]

6a. If yes, how many other facilities have you worked in? _____

2. Group activities

Definition: "Group activities" are any organized activities such as musical activities, exercise, reminiscence, crafts, movies, cooking, gardening, or special events that are meant to provide opportunities for enjoyment, socialization, and stimulation for your residents. The groups can be small (more than three residents) or larger.

8. Do residents in your care have opportunities to participate in group activities?

Yes No

9. When are these activities offered? [Check all that apply]

- a. Weekday mornings
- b. Weekday afternoons
- c. Weekday evenings
- d. Weekend mornings
- e. Weekend afternoons
- f. Weekend evenings

10. How often are these activities offered?

- a. Daily
- b. Every other day
- c. Weekly
- d. Other _____

11. How often do the following practices occur in activity programs for residents with dementia under your care: [Circle the best response]

a. Activities are simplified to meet the residents' abilities.

Always Usually Sometimes Rarely Never

b. Activities are held in small groups to reduce over-stimulation.

Always Usually Sometimes Rarely Never

c. Activities are kept short to hold residents' attention.

Always Usually Sometimes Rarely Never

d. Residents are given the choice whether or not to participate in activities.

Always Usually Sometimes Rarely Never

12. Are these activities planned so they focus on what residents can do, not what they can't do? Please explain.

Yes No

13. Are these activities planned so that they appeal to residents' unique characteristics, tastes, and interests? Please explain.

Yes No

14. Who is involved in planning and organizing these activities?

15. Are family members encouraged to be involved in planning these activities by sharing information about their loved ones' interests, hobbies, preferences, etc? Please explain.

Yes No

16. Are family members invited to participate in group activities with their loved one? Please explain.

Yes No

17. Which of the following methods are used to communicate with family members about programmed activities at your facility? [Check all that apply]

- During visits
- Care conferences
- Educational sessions
- Family council
- Newsletters
- Support groups
- Volunteer opportunities
- Phone or email
- Other _____

3. Physical Environment

Definition: For this study, the physical environment refers to aspects of the building/unit and the atmosphere within the building/unit. It includes the size, layout, décor, flooring, furnishings, lighting, noise, smells, etc. of the spaces where residents spend their awake time. For the purpose of this study, it does not include private spaces such as residents' bedrooms or bathrooms.

18. How would you describe the spaces where group activities for your residents take place (e.g. size, layout, décor, flooring, furnishings, lighting, noise, smells, etc)?

19. Are there ways in which the physical environment in these spaces helps staff to provide group activities for your residents? Please explain

Yes No

20. Are there ways in which the physical environment of these spaces makes it harder for staff to provide group activities for your residents? Please explain.

Yes No

21. In your opinion, could these spaces be improved to make the activities more successful for your residents? Please explain.

Yes No

4. Conclusion

Thank you for taking the time to participate in this study. Your help is very much appreciated. If you have any additional comments that you wish to include that were not already covered in the body of this questionnaire, or if you would like to provide feedback on the questionnaire itself, please feel free to do so in the space below.

Additional comments:

Would you like to receive a report of the findings from this study?

Yes No

Coding Instrument*

	9 Can't tell	1 Never	2 < 16 sec	3 16-59 sec	4 1-2 min	5 2-5 min
Engagement						
None						
Solitary						
Passive						
Active						
Interaction						
Talking						
Helping						
Touching						
Hand holding						
Dancing						
Pleasure						
Smiling						
Laughing						
Nodding						
Singing/humming						
Sadness						
Crying						
Moaning						
Sighing						
Head down						
Null expression						
Anxiety						
Restlessness						
Rep. vocalization						
Rep. motions						
Pacing						
Anger						
Shouting						
Swearing						
Hitting						
Pushing						
Frowning						
Scolding						

* Adapted from the Apparent Affect Rating Scale (AARS; Lawton, Van Haitsma, & Perkinson, 2000). Additional categories derived from Dementia Care Mapping (DCM; Brooker & Surr, 2005), Schreiner et al. (2005), and Wood et al., (2005).