

Dead Space

Observing the Physical Environment of Residential Facilities for Seniors

Living with Dementia

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ABSTRACT. As people age, the incidence of having a cognitive impairment like dementia rises and the need for quality care becomes fundamental in maintaining health, personhood and culture towards end-of-life. Assisted living, retirement or extended care facilities are alternatives to living at home when it becomes too difficult to manage one's health. The aim of this exploratory study is to highlight and compare the social, physical, psychological and culturally dead and alive spaces of four case studies. Hopefully, this will show how the physical environment either contributes to or hinders the health of seniors living and dying with dementia in a residential facility that is a part of the British Columbia healthcare system.

KEYWORDS: dead space, seniors, dementia, facility.

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Sincerely, Natalie

1) Introduction.

Today people are living longer and are facing an ever increasing chance of being diagnosed with a cognitive impairment such as dementia towards end-of-life. Personal interest in seniors living with dementia in residential facilities, as part of the British Columbia healthcare system was the topic of choice. This was incited by previous observations while working in residential facilities in the province that the idea was first considered. For many years, it was pondered if the physical environment's space had an impact on health. This led to the original research question being posed,

“Within residential facilities for those living with dementia, are there specific areas of the physical environment that have dead space?”

The rationale for this enquiry aims to identify specific areas of the physical environment that have *dead space* which might answer the underlying question as to why seniors living with dementia don't engage with certain places in residential facilities. It is hypothesized that for those living with dementia, *dead spaces* may be hard to physically reach, cognitively difficult to interact with or the space has no purpose or function. Dementia and end-of-life research has never looked at how space, either *dead* or *alive*, can alter the behavior of those living with dementia as they near death. To date, there is no literature and dead space. In this contextual framework, it is argued that exploring how space may contribute to or hinder the health, personhood and culture of seniors living with dementia in residential facilities,

the gap in the literature becomes visible. Attention will be brought to an area of enquiry that has never been proposed, specifically, highlighting the conceptualization of *dead spaces* that resulted from this research.

Juxtaposed with *dead spaces*, an analysis of *alive spaces* will define areas where seniors living with dementia are engaged with the physical environment. This study may provide future researchers something new to investigate and also, for health professionals another way to incorporate space that will engage seniors from the understanding of how the physical environment, *dead* or *alive*, can effect this population. Together, these two fundamental aspects of this research are to bring awareness allowing for new policies in end-of-life care to come to fruition.

In the following chapters it will become apparent as to why there is an interest with respect to seniors living with dementia in British Columbia's residential facilities. Highlighting how various types of spaces can impact the lives of seniors when living out their last years, months or days. In chapter two, '*Setting the Stage*' important background information will be outlined to establish a working knowledge of the key concepts as they relate to the overall study. Including a definition of Alzheimer's disease and dementia; a discussion about personhood as it relates to the notion of home and self; cultural theory; an introduction to the newly developed concepts of *dead* and *alive space*.

In chapter three, '*Methodology*', the rationale of the study will be discussed further, as will the sampling frame, types of methods used in the field of enquiry and the research design. In chapter four, '*Dead and Alive Space*' an exploration of the research findings from four residential facilities will be applied to specific categories and themes. A question and answer approach will try and uncover whether or not,

dead or alive space exists in physical environments where seniors living with dementia reside. In chapters five and six, '*Conclusions and Postscript*' will conclude what the research findings contributed to the social sciences and it will allow for an opportunity to reflect on what was learned from conducting qualitative research.

2) Setting the Stage.

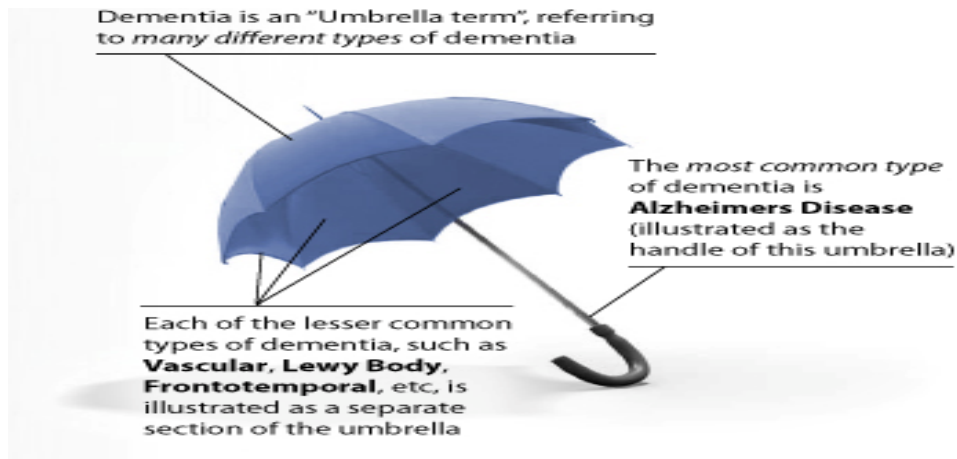
As people age, the development of a cognitive impairment is an ever increasing threat to the health, personhood and culture of seniors towards their end-of-life. A large volume of literature has been dedicated to the topic of seniors living with dementia but not from this contextual framework with respect to *dead* and *alive* space. By exploring how the physical environment may have areas that have *dead space* is a necessary addition to the literature on death and dying. Observing how space relates to the engagement or disengagement of seniors within British Columbia residential facilities will be shown.

Engagement occurs in a multitude of ways in many spaces and places. With respect to this study it refers to how seniors with dementia participate, interact and enjoy activities in the physical environments where they reside; while disengagement is the opposite. Now is the time to define important variables of the study.

Alzheimer's disease. Living with dementia and having a high level of engagement contributes to health, personhood and culture. A worsening of the symptoms of dementia occurs if there is a low level of participation, interaction and enjoyment in activities of daily living. With respect to this research, a cognitive impairment includes Alzheimer's disease or dementia but the idea of senility needs mention.

“Senility is a term used by the general public to describe the severe mental deterioration displayed by some older adults; as used by the common person in everyday discussions, senility is nearly identical in meaning to the medical term dementia” (Hoyer *et al.* 1999, p.82).

It is important to define what it means to be diagnosed with Alzheimer's disease or dementia. Alzheimer's disease is the most common form of dementia that is found in the Canadian society, as illustrated by the *Umbrella Diagram* courtesy of the British Columbia Alzheimer's Societies website <http://www.alzheimerbc.org/> (2009).



Many people are diagnosed with Alzheimer's disease which is the most devastating form of dementia (Hoyer *et al.* 1999, p.81). It is "a degenerative brain disease that is the...common cause of cognitive failure ... [which] makes remembering, recognizing and reasoning difficult" (*ibid.* p.82). In the Canadian context, this means that sixty-four percent of all dementias are Alzheimer's disease (British Columbia Alzheimer Society 2009).

One of the main reasons why seniors are moved into a residential facility towards end-of-life is because of the profound physical and mental disabilities that develop as people age (*op. cit.* p.82). An example of a physical disability for someone with dementia could be difficulty with bathing oneself; while an example of a mental disability could be disorientation with respect to day and time.

[Symptoms of Alzheimer's disease](#): Memory loss that affects job skills, difficulty performing familiar tasks, problems with language, disorientation with time and

place, poor or decreased judgment, problems with abstract thinking, misplacing things, changes in mood, behavior or personality and a loss of initiative (*ibid.* p. 85).

Types of Dementias: There are other types of dementia including vascular dementia, mixed dementia, Creutzfeldt-Jakob disease, Aids dementia complex, focal brain damage, Parkinson's disease, depressive pseudo dementia (*ibid.* pp.94-97), Frontotemporal, Lewy Body dementia and mild cognitive impairment (British Columbia Alzheimer's Society 2009). This list is growing as more scientific information becomes available.

Epidemiology & Incidence of Dementia: "Epidemiological research estimates that worldwide 24 million people live with dementia and this number is forecast to be 81 million by 2040" (Small *et al.* 2007, p.4). The incidence rate doubles every five years after the age of sixty-five, contributing to sixty-three percent of seniors living in residential homes (Johnston 2006, p. 9). Thus, the increase in numbers of seniors with dementia contributing to a demand for residential facilities in Canada and beyond. Canada is experiencing an alarming shift in population demographics due in large part because our society is aging (Alzheimer Society of Canada 2009).

Canadian Context: As Debbie Benczkowski from the Alzheimer Society of Canada explains, "Alzheimer's disease and related dementias are a rising concern in this country, an epidemic that has the potential to overwhelm the Canadian healthcare system if changes are not made today" (*ibid.* 2009). Statistics Canada reports that already there are 4.3 million Canadians are over age of sixty-five meaning that one in seven of us are now senior citizens; by 2015 this estimation is expected to reach 5.4 million (*ibid.* 2009). Across Canada, one in eleven Canadians over the age of

sixty-five has the disease, while 71,000 people are under this age; with 50,000 under the age of sixty (British Columbia Alzheimer Society 2009).

Provincial Context: In British Columbia, more than 70,000 people live with Alzheimer’s disease or dementia, 10,000 of these people are under age sixty-five (*ibid.* 2009). Understanding how the physical environment can hinder health, personhood and culture is an important cause for concern when considering seniors living with dementia when they move into a residential facility.

Aging Population: “Alzheimer’s disease is not a new disease but it is becoming more common as the population ages” (Johnston 2006, p.9). In the following diagram, information courtesy of the ‘*Alzheimer Flame of Hope*’ highlights the incidence rate compared to age (*ibid.* p.9).

65	1% of the population.
70	2% of the population
75	4% of the population
80	8% of the population
85	16% of the population
90	32% of the population
95	64% of the population

Besides age, gender, education level, family history and stroke are all major risk factors for getting dementia (*ibid.* p.12). Interestingly in Canada, “women represent seventy-two percent of all Alzheimer’s disease cases” (Alzheimer Society of Canada 2009). The entire reasoning why women are at an increased risk of being diagnosed with dementia when compared to males is not fully understood. For women life expectancy is eighty-two while for men it is seventy-six (*op. cit.* p.12). For example, “people with a grade four education have twice the incidence of having Alzheimer’s disease compared to those individuals who have a grade ten education” (*ibid.* p.12). It should be noted that having “higher levels of education do not give additional protection [from being diagnosed with the disease]” (*loc. cit.* p.12). “There is a familial incidence of Alzheimer’s disease in [people] where the disease started before age sixty, [however] if the disease started after age sixty-five, there is no increased incidence” (*ibid.* p.12). Having diabetes, high blood pressure, increased cholesterol and triglyceride levels are also risk factors for developing dementia (*ibid.* pp.12-13). To date, there are no definitive causes for having this disease but many hypothetical debates exist with respect to developing dementia.

Part of living with a diagnosis of dementia means that family members, friends and health professionals will observe changes in the senior’s personality and interests. More than just observing, people must be committed to the implementation of programs by responding to the need for change. In the following paragraphs, a discussion highlights the importance of maintaining personhood in the face of such a degenerative disease.

Personhood.

Discussing personhood would not be complete without acknowledging Tom Kitwood’s influential contribution to “the development of our thinking on the nature

and process of dementia, the experience of dementia and the development of person-centered care” (Baldwin and Capstick 2007, p.173). “For Kitwood, personhood lies at the meeting point between three discourses: transcendence, ethics and social psychology” (*ibid.* p.175).

“From the discourses of transcendence [Kitwood] takes the idea of being-in-itself, a sense that life is sacred; from ethics, the Kantian principle that persons should always be treated as ends in themselves...never as [a] means to some other ends; and from social psychology, an understanding that individuals exist within a network of relationships” (*ibid.* p.175).

The largest contribution Kitwood and his associate Kathleen Bredin developed in the late 1980's, was '*Dementia Care Mapping*' that is a practical methodology that allows individuals to assess the quality of care provided within residential facilities (University of Bradford 2009).

[Dementia Care Mapping](#): In the beginning stages of the proposal, employing this methodology was considered. Dementia Care Mapping is

“a method designed to evaluate quality of care from the perspective of the person with dementia...used in formal settings... [that] is based on the philosophy of person centered care... [that] promotes a holistic approach... that upholds the personhood of the [individual] with dementia (*ibid.* 2009).

Since Kitwood first introduced his ideas about personhood and dementia, many scholars have challenged the ideas by criticizing his theory as falling short of critical commentary (*op. cit.* p.181). Kitwood's conceptualization of personhood however, allows other researchers the ability to contribute to the literature by filling

the gaps in the further development of his theory after he suddenly died in 1998 (*ibid.* p.xv). O'Connor *et al.* of the University of British Columbia's 'Centre for Research on Personhood and Dementia' provide further developments in Kitwood's theory that are of interest to this research, specifically on home, self and dementia.

“Just as personhood can be embodied, or established in relationships with others, so, too, it can be regarded as being founded, undermined or supported by our relationship with place[s], particularly our sense of home” (*ibid.* p.186).

This type of environment contributes to how we contextually understand our life experiences. How we have a relationship with our homes by providing a place of refuge, sense of belonging, social status and self-identity (*ibid.* p.186). This establishes “affective relationships with our homes, as well as other personally meaningful places” (*ibid.* p.186). This notion of ‘home’ remains in the minds of those living with dementia.

While this scholarly research has contributed to the notion of personhood, little research has been done in the conceptualization between *dead* and *alive* spaces. By observing how the physical environment has *dead space*, it is argued that this conceptual framework will complement existing literature. Next, part of understanding a physical environment where seniors living with dementia reside, a discussion regarding culture must be included.

Culture.

Belonging to a particular society or group is a learned phenomenon that begins in early childhood and continues right into old age (Bailey and Peoples 2002,

pp.15-16). Including a cultural context defines the way of life for some human groups that has a unique distinctive aspect to living (*ibid.* p.26). With respect to this study, the population of seniors who live with dementia is the culture under observation. Culture is the shared experiences, learned knowledge and patterns of behavior that some group within society expresses (*ibid.* p.26).

“Cultural knowledge is not true in the objective sense, but it must at least allow a society to persist in its environment... [allowing] people to interact appropriately and meaningfully” (*ibid.* p.26).

Maintaining culture is essential for sustaining human life in the areas of the physical environment for seniors living with dementia in residential facilities because it is what is familiar to them. When seniors are removed from their homes and placed into a residential facility, the physical environment must be, in some form or another, represent their cultural background. Also, professionals should have some understanding of an individual's culture because it helps provide appropriate activities and services. This will create important relationships between residents and staff who look after them.

Turning back to the original question, “*Within residential facilities for those living with dementia, are there specific areas of the physical environment that have dead space?*” Most importantly, defining the types of spaces that exist in the physical environments under observation will be discussed next.

Types of Spaces.

Space includes having a collective and individual modality that contributes to making a space an identity (Auge 1995, p.51). In this context, seniors living with

dementia in a residential facility who share similar experiences remain unique but can contribute diversity to a group within specific social realms (*ibid.* p.51). As abstract as that notion is regarding collectivity and space, it is through an analysis of residential living that later findings will show how space can be dead, dependent upon a group's identity with it.

It is the organization of space and the creation of places inside a social group that gives purpose to those that live within the boundaries that have been built for seniors (*ibid.* p.51). An example of the organization of space is the idea of commensality which refers to the sharing of meals, where a family sits around a dinner table and discusses what has gone on during the day (Seale 1998, p.157). This has long been recognized as a type of membership ritual where the sharing of meals is a reciprocal exchange of food constituting the confirmation of a bond (*ibid.* p.157).

Low and Lawrence-Zuniga explain that the ways people engage with a physical environment occur in three categories of space: fixed, semi-fixed and dynamic (2003, p.61). Fixed space refers to walls and territorial boundaries; semi-fixed space refers to furniture and other items that can be applied to a space but can be easily removed; dynamic space refers to cultural attributes given to a place (*ibid.* p.61). This is particularly important to this study of *dead space*, as it will be shown in the following chapters. Moving from the background variables, the next question “*what does it mean when space is referred to as being dead*” will be answered in the following paragraphs.

a) *Dead Space.*

This new concept comes from the idea that a physical environment has spaces that lack purpose and function. In the context of seniors living with dementia in a residential facility, means that an area of the physical environment has *dead space* that hinders health, personhood or culture. The generated categories from the research are *socially, physically, psychologically* and *culturally dead spaces*. Next, each type of *dead space* will be defined.

- 1) *Socially Dead Space*: Refers to how individuals use space that disengages, lacks social interaction and has little cognitive or sensory stimulation in a physical environment that hinders health, personhood or culture. For example, a senior sitting in the same place doing nothing for long periods of time with no activity or engagement.
- 2) *Physically Dead Space*: Refers to how a physical environment is made up of fixed, semi-fixed and dynamic items including elements like furniture, lighting, mementoes, pictures, artwork and food that lack a purpose and function which hinders health, personhood or culture.
- 3) *Psychologically Dead Space*: Refers to how spaces within a physical environment can contribute to the disempowerment, depersonalization and de-humanization. Including the actions, feelings and reactions expressed by people that hinders health, personhood or culture.
- 4) *Culturally Dead Space*: Refers to how an individual's religion, beliefs, customs, traditions and ways of life are altered, discouraged or non-existent in areas of the physical environment that hinders health, personhood or culture.

Also, this research generated the concept of *alive space*, when juxtaposed with *dead space* creates a picture of the whole physical environment that blend together to establish a new theoretical perspective that will be proposed in the coming sections.

b) *Alive Space.*

This new concept comes from the idea that a physical environment has spaces that have a purpose and function. In the context of seniors living with dementia in a residential facility, it is the positive aspects of a space that contribute to health, personhood or culture. The generated categories from the research are *socially, physically, psychologically* and *culturally alive spaces*. Next, each type of *alive space* will be defined.

- 1) *Socially Alive Space:* Refers to how residents are engaged, have the ability to interact with one another by participating in a variety of activities that include cognitive and sensory stimulation in a physical environment that contributes to health, personhood or culture.
- 2) *Physically Alive Space:* Refers to how a physical environment is made up of fixed, semi-fixed and dynamic items including elements like furniture, lighting, mementoes, pictures, artwork and food. That has a purpose and function which contributes to health, personhood or culture.
- 3) *Psychologically Alive Space:* Refers to how a physical environment contributes to empowerment, personalization and humanization of people

including the various actions, feelings and reactions that contributes to health, personhood or culture.

- 4) Culturally Alive Space: Refers to how an individual's religion, beliefs, customs, traditions, and ways of life are encouraged, accepted and practiced in a physical environment that contributes to health, personhood or culture.

Now that *dead* and *alive space* has been defined, it is important to discuss the types of residential facilities that chose to participate in this research.

Facilities.

Woods (1989) suggests that when moving a senior from their known home to an institution, one must consider the pros and cons of such a decision (p.84). Including how the location, physical features, atmosphere, adequate staffing and services, various activities and visitation allowance impact and contribute to the lives of those seniors affected by dementia (*ibid.* pp.184-185). Also in this decision making process, the level of cognitive disability, how clean the establishment is, if it is too clinical or has a homelike feel along with activities that provide cognitive and social stimulation should be considered (*ibid.* pp.184-185).

When evaluating types of activity programs a facility has, this must, to some degree, be of interest to the person with dementia and culturally appropriate, task oriented and fun to participate in (*ibid.* p.185). These suggestions should aid family, friends and health professionals in making appropriate decisions for the person who will be moving into a residential facility. Let's now look at the four case studies.

- a) Case Study (CS1), Retirement Home:

CS1 is a retirement facility primarily for senior's independent living. The creation of retirement homes for seniors over age sixty-five was for people who wanted to be amongst others for social engagement. Most seniors at this stage in life usually need little medical or other types of attention, however over the years, as one staff member explains,

"The residents who choose to live here are seen as having an increased need for some level of support as they are using walkers more... which in the past was never the case, now, outside home support comes to visit residents that need extra care. There are residents who are in the beginning stages of dementia which also was never the case. If a resident can manage living with the disease with little or no care given then they can remain at this facility but that is on an individual basis" (pers. comm., 29 June 2009).

The philosophy of living as independently for as long as possible is what CS1 maintains. When a resident's cognitive impairment becomes too difficult to manage or when living independently is not an option, the decision to move a resident to a more appropriate facility may be made. CS1 has the most independent seniors than the three other facilities, but this does not mean that they are as engaged as one may expect for retirement living. Even in this physical environment, it was observed that *dead space* existed.

b) [Case Study \(CS2\), Assisted Living:](#)

Assisted living refers to "maintaining as much freedom and independent living as possible... [that] brings direct intervention and services to the elderly" (Hoyer *et al.* 1999, pg 207). There are three floors at CS2 but the study focused on the third floor where seniors living with dementia reside. The goal of the third floor is the

development of a '*reminiscence neighborhood*' that uses reminiscence therapy in artificially created spaces in the physical environment. This type of therapy refers to having

“sensitivity to the life memories of older persons in institutions... [that] encourage[s]... [them] to remember their past and reflect on their own unique... memories and experiences” (*ibid.* p.188).

Within this physical environment it includes areas that are for cognitive and sensory stimulation and memory recall.

Later it will be shown that regardless of the homelike ambiance that so many researchers argue is necessary for quality of life, this does not mean the physical environment is free of *dead space*.

c) *Case Study (CS3), Extended Care:*

CS3 is an extended care facility that looks after the needs of seniors who are either semi-independent or dependant and cognitively impaired. The entire facility has a hospital-like setting. It will be shown that the second floor has little to keep residents engaged. Just as in CS1 and CS2, CS3 could not escape having a physical environment that has *dead space*.

d) *Case Study (CS4), Retirement Home:*

CS4 is a retirement facility for independent, semi-independent or dependant seniors; respite and short stay also provided. Unlike CS1, this retirement facility was purposely built from an existing housing structure re-designed to become a retirement home. It has many of the original features along with some room

extensions to facilitate resident's rooms and living quarters. The facility's philosophy with respect to seniors living with dementia is that by keeping them as independent and semi-independent as possible, this will contribute to health, personhood and culture. A similarity with CS1 is that those living with dementia can stay living at CS4 until such time as more care is needed. The aim is for each resident to live out their last days, months, possibly years here without moving elsewhere at the end-of-life. Unlike the other three case studies, CS4 does not have *dead space* in the physical environment.

In subsequent sections, health, personhood and culture will be developed further as it relates to each case study. Various examples of *dead* and *alive space* will be shown. It is now time to comprehend the reasoning and purpose of the study, what the sampling frame was, the types of methods employed in the field and the research design in chapter three.

3) Methods.

a) Reasoning and Purpose:

This is a qualitative research project that was created from personal interests with respect to the sixty-five plus cohort who live with dementia in residential facilities in British Columbia, Canada. It was important to conduct research here because this is where, I as the researcher, reside. The aim was to bring to light what is *dead* or *alive* with respect to the purpose and function of a space in residential facilities that are built for cognitively impaired seniors. Ultimately the reasoning for this research is to see how residential facilities enrich seniors' lives, so that no person is simply stigmatized, de-humanized or forgotten at their end-of-life.

The intended audience may include professionals, researchers or students interested in the topics of sociology, anthropology, death studies and gerontology. It may interest family or friends of someone that has dementia.

The Sample: Searching on the internet for residential facilities where seniors living with dementia reside was easier than going into the community to ask in person.

This was a convenience sample done through email correspondence to over fifty

residential facilities in British Columbia, Canada. Only those websites that stated they have seniors living with dementia were contacted. Here is a portion of the email that was sent to all of the residential facilities on 19 April 2009.

“Good day, my name is Natalie Gauthier...I will be returning to British Columbia...in mid June to do my MSc dissertation and would love to be able...to conduct observational research with your permission...I am doing my dissertation on space, cognitive impairments, reminiscence, seniors and end-of-life care... that needs participants from long term care, retirement living, assisted living and special care neighborhoods that are all sought for this study...”

With ten positive responses wanting to participate, it was decided that four case studies would be more realistic due to time constraints. In British Columbia, there are five health authorities that divide the province into regions including Vancouver Coastal Health, Fraser Health, Vancouver Island Health, Interior Health and Northern Health. At first, it was thought that by covering each health region, it would garner a cross-cultural sample, however only three of the five regions were covered. Cross cultural analysis was sought because it might possibly uncover issues with respect to observing if each residential facility is heterogeneous or homogeneous in nature across the province. When it came time to finalize dates to go to the interior and northern sections of British Columbia, there was no communication back after initial contact.

For CS1, the dates were 24 June and 8 July; For CS2, the dates were 22/23 June; For CS3, the dates were 29/30 June; For CS4, the dates were 8/9/10 July. Included in this study are the Vancouver Coastal, Vancouver Island and Fraser

Health authorities. Due to ethical considerations, the regions will not be discussed further to keep anonymity, privacy and confidentiality that three out of the four facilities requested. This study included one assisted living, two retirement and one extended health care facility. It was decided that by using three different kinds of facilities, this would provide a good understanding of the types of spaces that could be observed in the physical environment where seniors living with dementia reside.

b) Methods Employed:

Originally, '*Dementia Care Mapping*' was considered but could not be employed due to the lack of training in this methodology. At the University of Bradford, England, courses are being taught on the proper implementation of this strategy. The '*Bradford Dementia Group*' teach these courses within the School of Health Studies; they explain that there is a large interest in using this method for research purposes but stresses that training must take place "to ensure a thorough understanding...[of the] ethical issues involved" (University of Bradford 2009). It was decided early on in the development of the dissertation proposal that participant observations and informal interviews would be sufficient for this study.

"Ad libitum sampling [is an] observational sampling method in which there are no systematic constraints on what is observed and when" (Lee 2000, p.143).

Allowing the researcher to note what is visible, accessible and relevant as it occurs was pertinent to this study (*ibid.* p.143). It allowed for myself as a researcher to sit, stand and move anywhere in the residential facilities physical environment. I was

able to interact with residents, staff and visitors in a relaxed manner. Being able to be as natural without looking or acting like a researcher was important to me when in the field.

This type of research environment, keeps reactivity, meaning that the chance for alterations in participants behavior because of the researchers presence is minimized (*ibid.* p.47). This does not mean that some participants are not affected by the movement of researchers around them or that they don't in some way alter their behavior because of this, it just means that it is minimized and not a huge detriment to the study (*ibid.* p.47). In any field research, the qualitative nature of observational methodology lends well to the exploration and development of concepts which this particular study generated.

Bronislaw Malinowski, an anthropologist, helped popularize a way of gathering information that requires fieldworkers to take up residence with the people under study to learn their culture (Bailey and Peoples 2002, p.63). Participant observation was utilized in this research because it allowed for social interaction with people in the field. This method allows the researcher to be inconspicuous when needed and to have an insider and outsider role. The researcher can have pertinent background knowledge of the research foci in some form or another before entering the field. Also, the researcher can interact, socialize and try to live the culture of some group that is different than their own. This method gives flexibility in the roles that a researcher can use, going between being a complete observer to a total participant.

It was also decided that by using informal interviews, valuable data may provide some interesting findings with respect to the research question. Together,

these methods were appropriate strategies to use because it contributed to the understanding of how space can be *dead* or *alive* in a multitude of ways.

c) *The Design:*

The 'case study' design was practical, easy to employ and an appropriate design for exploratory research of this type and scale. Early on in the development of this research design, it was expressed that covering too many residential facilities would generate a large volume of data. Also, it is unrealistic to think that a Master's dissertation that was to be done in a short three month period could be executed through ethnography. Along with *Dementia Care Mapping*, this study was originally going to be ethnographic in nature, but the word limit and timeframe did not lend well to a full scale ethnographic study. Employing that method usually takes months or years to conduct. Using case studies unveiled the answers to the original question "*Within residential facilities for those living with dementia, are there specific areas of the physical environment that have dead space?*" in a concise manner.

A new theoretical perspective with various concepts of *dead* and *alive space* with certain themes contributed to making sense out of social processes that could not otherwise be determined by employing different types of qualitative methodology. The strengths of using case studies, although concise, allowed for a total of ninety-six hours of observations to be carried out in a short three week period. The time frame chosen to conduct the research was to include two twelve hour shifts which would oversee both the day and night shift. In total, completing twenty-four hours at each residential facility provided an overall understanding of what goes on in the spaces at all hours of the day.

One of the most important limitations of this design was that the findings could not be generalized to the larger population of residential facilities where seniors living with dementia reside. Also with respect to this study, it can be further appreciated that it may not have internal generalization either. Any project of this design and methodology has limitations that cannot be avoided. For example, observing a residential facility for only two twelve hour shifts does not show what I have missed on different days of the year.

When in the field, it is next to impossible for a researcher to replicate the study in the same manner because they may experience a totally different set of circumstances. As a researcher, I may interpret, see, hear, smell, touch and feel much differently in the physical environment than someone else. Researchers who employ participant observation, like myself may differ in personality, gender, interests, social background and skill, which in turn could make the findings much different than the original observations (*ibid.* p.64). Now that it is understood how this study was conducted, it is important to analyze what was found by going into four residential facilities for seniors living with dementia in British Columbia, Canada.

4) Dead Space.

“Within residential facilities for those living with dementia, are there specific areas of the physical environment that have dead space?”

The answer to this question will now be explored through four case studies referred to as CS1, CS2, CS3 and CS4 from a theoretical and reflexive viewpoint. The categories of health, personhood and culture are at the heart of the following discussions that will answer the question through the use of various thematic examples generated by the research. For residents living with a cognitive impairment like dementia can be difficult at the best of times regardless of where seniors reside, however family, friends and carer’s are all affected by a person living with dementia. For example this could lead to caregiver stress because of difficulty looking after a person.

For seniors living in a residential facility that has dementia, they need an environment that fosters health, personhood and culture. In the following

paragraphs, research findings will highlight specific areas of the physical environment that has *dead space* juxtaposed with *alive space*. How health, personhood and culture are maintained in the physical environment will be analyzed with respect to the level of engagement. Let's begin by looking at the findings generated from the first residential facility observed in the study, CS1.

Case Study 1: Retirement.

The initial observation was the facility was visually impressive as you enter. It has just undergone a major remodeling project to make part of the space more modern and accessible for residents, staff and visitors.

Front Lobby/Piano/Television Room: The furniture that fills the spaces in proximity to the front door and lobby are pleasant to observe, however as one resident explains,

“This new furniture replaced comfortable and yes old couches and chairs. But this new furniture is not being used as much as the old stuff because it is not as comfortable or good for making friendships...it has replaced the space we once thoroughly enjoyed” (informal comm., 29 June 2009).

Although this remodeling project changed the entire front lobby areas, the purpose and function of the physical environment is not *physically, psychologically or culturally dead space*. This is an example of *socially dead space* because when a group of seniors sat down to converse with one another, it was overheard that their known way of life has been depleted for some time. While others said it had been altered to the point they will not come to the space anymore. It is argued that living in a retirement facility means that seniors need to self engage in activities with no

initiation by staff, the choice is theirs to make. Possibly over time these seniors will engage with the area when activities are done regularly. Making this part of the physical environment a familiar place to once again enjoy.

When you move away from the areas that have been beautifully remodeled, the physical environment has a 1970's and early 1980's themed décor. There are crooked pictures hanging on all the walls, some brass mirrors that are being held together with tape and dusty artificial plants on each of the three levels. The brown carpet is in good condition considering the age. At the end of each hallway there is a space that has a couch with a table and or, with a chair. It was pondered if these areas that are located at the ends of hallways on each floor should be considered *dead spaces* because no senior was observed engaging at all in these areas.

This retirement facility prides itself on how health, personhood and culture are promoted in a nonthreatening and warm homelike environment. It is argued that this residential facility does not have a homelike environment because the spaces within the physical environment's ambiance do not have that appeal. This does not infer that the facility is distasteful, ugly or dirty. It just means it does not look homelike. This is not a huge issue for residents living here because most are not cognitively impaired.

There are some residents that do have mild cognitive impairments that live here, but they are treated as if they don't have an illness making it difficult to acknowledge them in this environment. Keeping an individual thinking and behaving as though they have a cognitive impairment de-humanizes and depletes a person's health, personhood and culture. The facility's philosophy of making the lives of seniors the first priority as they live out their last years, months and days was

apparent. While observing the physical ambiance, a question came to mind with respect to the porcelain figurines that were in the hallways outside resident rooms on each floor.

“Are these porcelain figurines or animals placed outside resident rooms to help orientate them?” This was best answered by a staff member, who explained,

“The residents place those figurines of animals and other such items outside their doors so that they can remember where they live, making it easier for them to orientate themselves back home (pers. comm., 29 June 2009).”

This was an interesting finding because for the most part, this residential facility does not have many residents with dementia that would benefit from memory aides such as these figurines. Overall there was not much to observe on both twelve hour shifts at this facility because most of the residents remain in their rooms. This brings us back to the original question,

“Within residential facilities for those living with dementia, are there specific areas of the physical environment that have dead space?”

Answer: Simply stated, yes there are areas that have *dead spaces* that were observed here at CS1. Regardless of the remodeling project, this space is argued as being *socially dead space*. Some residents are frustrated, even saddened by the first renovation; this was disappointing to hear but could be appreciated. What residents expect from the second remodeling project will hopefully be taken into account. A resident said,

"I hope that when they get to doing the next million dollar upgrade to our home they understand I don't want it to take away what I socially enjoy by making it boring and uninviting" (informal comm., 29 June 2009).

One last point with respect to CS1 is that many hours were spent alone allowing for personal reflection. It was a very lonely place to visit but this time allowed for the development of a new theoretical viewpoint as it relates to spaces where seniors reside who have dementia. Many connections were made with respect to the conceptualization of *dead* and *alive spaces* that bridged together ideas, themes and categories that are being presented in the following residential facilities.

Case Study 2: Assisted Living.

The first impression of this facility's physical environment was that it had a bright homelike appearance. This may impress people with the decoration and layout of the floor at first glance. Looking beyond the facility's ambiance are the spaces which are argued as being dead that hinder the health of its residents. Turning to the findings, we start with observations from the *Snoezelen* room.

Snoezelen Room: The purpose is to create a multi-sensory environment that enchants, enables, enriches and engages people that "meet the needs of specific populations according to age and ability [with a] ...blend of sights, sounds, textures, aromas and motion" (Flaghouse 2009).

This is a very clean room compared to other areas of the neighborhood that will be discussed later. The room's furniture, walls and accessories are shades of brown, beige, cream and white, with the carpeting being a cool shade of green. Staff

must take every precaution to keep this room free of stained furniture, dirt and dust because it would definitely show more than if it was dark colored. When the recessed lighting is on, this room becomes too bright, however when the lights are turned off this space is soothing. There are special fiber optic lights that when turned on have white, pale red and green colors used for mood elevation, relaxation, visual and tactile stimulation (Flaghouse 2009). Music faintly played in the background while two water fountains could be seen on a bookshelf. A basket full of items including blocks, socks, balls of thread, scarves and a variety of other ornaments provide visual, tactile and cognitive stimulation.

Some questions became apparent while spending time in this space including,

- 1) *Does the auditory, visual and tactile stimulation make this area of the physical environment an alive or dead space when no one is here to experience this?*

Answer: Regardless if anyone is in the *Snoezelen* room, it may engage seniors as they pass by, making it an *alive space*. A resident may choose to come into the room to sit or they may stand near the space. The multi-sensory experience of this part of the physical environment can contribute to the cognitive and sensory stimulation of residents, giving this area a purpose and function. However, it is argued that if all of the equipment is turned off, the purpose and function of the room has been lost meaning that the area has *dead space*. To engage residents living with dementia, this part of the physical environment within the '*reminiscence neighborhood*' should always be in working order twenty-four hours a day.

One of the problems for seniors living with dementia is that they can become disoriented with time (Hoyer *et al.* 1999, p.85). For example, it was observed that some agitated residents wandered the hallways in the middle of the night. Residents may benefit from this room during times of disorientation thus contributing to health. When the purpose and function of this room is restored, it can be an *alive* space.

2) *Does the researcher's presence in this area of the physical environment make it an alive space?*

Answer: Reflecting on the experience in the *Snoezelen* room, it was a socially, physically, psychologically and culturally uplifting experience. I played with the tactile items in the basket, enjoyed the music and stared at the optical lights that were placed on the cream colored couch. It was appreciated that this room was for a different culture than mine. For example, the environment of seniors living with dementia in a residential facility. It was none-the-less culturally appropriate and enjoyable. It was also observed that when all the sensory equipment and the lights were turned off, the room was not available to enter. Everything was in darkness and covered up by a bed sheet; this was disappointing. As the following paragraphs highlight, this was not the only reason for disappointment.

While observing this space during the early afternoon, a staff member brought a potential family member into the area. This person was trying to explain the purpose and function of the *Snoezelen* room as a multi-sensory experience that their loved one would have if they decided to move them into this facility. After selling the idea of this room, they left. Five minutes later a few agitated and confused residents passed by, stopped and stood in the hallway adjacent to this room and then left.

These are common symptoms of dementia when seniors are not engaged, bored or

lack interest in daily activities. A staff member was observed walking right by these residents.

If the purpose of the *Snoezelen* room is to calm agitated residents by the use of mood elevating techniques then these seniors should have been brought here. Later that afternoon, a different staff member brought a resident who appeared calm and tired into this area. The resident was helped to sit on the couch and then the staff member said, "*Have a nice sleep*" (*informal comm.*, 22 June 2009). At that moment, this observation raised another question.

3) *As a researcher it was pondered, would residents be brought here to this space if they were not under the scrutiny of the observational study?*

Answer: It was later learnt that this particular resident is brought to the *Snoezelen* room everyday regardless of my presence. This made me realize that I had nothing to do with the resident being brought here. This example shows how the reactivity of the behavior of staff under observation were minimized (Lee 2000, p.143). There could be a multitude of reasons why this staff member brings this resident here daily. Clearly it was not to stimulate the senses or to cognitively engage them with the elements that give this room purpose and function. It is argued that the purpose and function has been lost meaning it can be considered *dead space*. Next to be discussed will be the dining room to see if there are any areas that have either *dead* or *alive space*.

Dining Room: The dining area is part of the physical environment that has the most *socially, physically, psychologically and culturally alive spaces* found on the third floor. This does not infer that there is no *dead space*. This is where residents eat their meals, have afternoon tea, night time snacks and participate in a variety of

activities. Examples observed throughout the morning, afternoon and early evening were exercise and knitting class, dancing to music, arts and crafts, visiting with family or friends during tea time, folding laundry and cleaning the dishes. Some questions that arose while observing this area are,

1) *Does broken furniture mean that it is contributing to dead space?*

Answer: It was noticed that some broken chairs are situated in places within this area of the physical environment where residents are unable to use them. Any semi-fixed piece of furniture that is in disrepair is considered *physically dead space* because it can hinder the health of residents. For example, if a resident sits on one of these broken chairs and it falls apart, this could cause harm making it not only a dangerous space but *dead space*.

While observing the dining room, many pictures are fixated on the walls that are mainly of current residents, however a few are of past residents. The purposes of pictures are for ambiance, visual and cognitive stimulation, along with memory recall. It was pondered,

2) *Can pictures be considered alive spaces in the physical environment?*

Answer: Simply stated, yes. The pictures in the dining room appeared as though they were taken recently. For example, the pictures showed residents gardening, having tea socials and doing activities on the third floor. The purpose of pictures is to highlight the activities that residents participated in, both as a group and individually for memory recall. Pictures also function as a way to give meaning to past experience which can engage residents with visual and cognitive stimulation. Pictures can contribute to personhood because they transcend time by providing

memory stimulation for the resident at various times and places. Staff may also provide a storyline to pictures contributing to further understanding of the contexts of pictures which was observed. This is what makes this part of the physical environment an *alive space*. On several occasions, residents were observed looking at pictures hanging on the walls in the dining room. One resident was overheard saying,

“I don’t know these people but they sure look like they are having fun doing that together. I just know they are there to have fun, look at all the people, how nice” (informal comm., 22 June 2009).

Reflecting on this further, it can be argued that this contributed to the residents’ health, personhood and culture because it was observed that they were engaged with the spaces unlike the next area.

Baby and Children’s Area: The purpose and function of this area of the physical environment is to aid the cognitively impaired resident to engage with the elements in this space for multi-sensory stimulation and memory recall.

This area has a bassinet with three realistic looking dolls that have been placed under a blanket. The dolls eyes are looking upwards at a mobile that is hanging. A rocking chair is beside the bassinet while other baby items such as a diaper bag and clothing hang from a coat hanger next to it. Across the hall, baby bottles, toys and a miniature doll carriage are noticed. While observing this area of the physical environment another question was pondered,

- 1) *Do artificially produced ‘reminiscence neighborhoods’ including the baby and children’s area, the boudoir, work bench and desk spaces that are*

strategically located throughout the physical environment here at CS2, contribute to or hinder the health, personhood or culture of residents?

Answer: The creation of these types of reminiscence areas in the physical environment of CS2 can hinder the health, personhood and culture of residents. For example, it can never be assumed seniors had children, liked playing dress up or enjoyed working at a bench or typewriter. When professionals consider the design and decoration of reminiscence neighborhoods, the cultural audience should be considered.

Regardless of the emotions that can be evoked by these types of spaces in the physical environment, it is argued that areas can become *psychologically dead spaces* if they hinder health, personhood or culture. An example of *psychologically dead space* may be that a resident had an inability to conceive or there could have been a death of a child. This could lead to increased agitation, uneasiness and sadness for some residents leading to a bereaved state that can go unnoticed. Although it is appreciated that negative emotions or responses are better than no response, it still can hinder health if no attention is given.

While here at CS2, no staff member was observed engaging residents with the elements of this baby/children's area. It is argued that regardless of the various emotions that may be produced by these types of artificially created environments, it is the responsibility of staff members to stimulate conversation, engaging the space with residents. The function of the space has been lost in the everyday business of looking after the activities of daily living including dressing, bathing and cooking. A possible explanation for this may be insufficiently trained staff in the use of reminiscence neighborhoods. Staff may need to develop the necessary and

appropriate skills on how to engage residents with these areas that are specifically designed for people that live with dementia.

Living Room: While observing the living room, this area is a *socially, psychologically, physically and culturally alive space* where approximately twenty of the residents spend a large amount of time. There are twenty-nine residents who reside here. Many of the residents are brought here by staff members, so no particular person or personality chooses to be here.

Old black and white movies and programs play on the large screen television throughout the day and night. When the television was turned off, other activities took place that engaged residents more. For example, a sing-along one afternoon had everyone singing and laughing. The residents who were here in the living room participated equally, making this a rewarding experience for all. Culturally appropriate songs were sung, memories were evoked and people were engaged collectively. This is the purpose and function of these types of activities that contributed to the health, personhood and culture of residents. To answer the original question regarding *dead space*, no area in the physical environment of the living room was observed.

Right Hallway Area: The initial observation of this area is that the furniture is soiled and smells of urine. This made it rather embarrassing for me to sit down and conduct research in this space. It was very quiet here because many residents were attending the arts and crafts activity in the dining room which means they are being engaged. The armoire, three chairs, ottoman, two side tables and a rocking chair are all strategically arranged for social engagement, however over the two twelve hour shifts, no residents were observed using this space. It is understood residents

do walk by this area on their way to their rooms, however this does not mean they engage in this space.

It can be argued that this area of the physical environment has *physically dead space* because the furniture is dirty, functionally difficult to sit on because two of the three chairs had missing cushions and the obvious smell of urine. These examples plus many others observed can hinder the health of residents.

Left Hallway Area: This space is *socially, physically, psychologically and culturally dead* because residents do not walk this far just to sit down and have a conversation. There are two chairs and one side table with a lamp. The functional placement of this furniture in this area fills the corner space at the end of a long hallway. The purpose of this area gives residents an opportunity to sit, relax and have a conversation with someone, but no resident was observed in this small area. As one staff member explained,

“Many find it too far to walk to, so they simply avoid going down there. Only residents who have their rooms in that area pass by” (pers. comm., 22 June 2009).

While walking around CS2, a resident was overheard explaining,

“I don’t like it down there, it scares me to death. Oh my goodness what is down there, it looks dark, why go there, oh my goodness. Who is down there...I don’t know them” (informal comm., 22 June 2009).

One of the reasons why this area may scare residents is because they are unfamiliar with the space and do not interact there. In earlier discussions about home and

familiarity it was shown that by engaging residents with the space in the physical environment, troublesome symptoms of dementia can be decreased.

With respect to the original question, “*Within residential facilities for those living with dementia, are there specific areas of the physical environment that have dead space?*”

Answer: This residential facility for the cognitively impaired senior does have areas in the physical environment that are considered *dead space* by the examples given, however it is also appreciated that there are *alive spaces*.

Case Study 3: Extended Care.

The first impression was that it was institutionalized, unimpressive, dirty and dilapidated. For example, the walls and flooring had large cracks, the furniture was broken, paint was coming off the walls and the foundation of the building looked very unstable. The second floor south wing was used for the purpose of this study because the residents all have dementia. As one staff member explains,

“This residence needs a serious overhaul and more activities for seniors living here at this place are seriously needed. I hope this research that you are conducting will provide this facility with some eye opening information” (pers. comm., 24 June 2009).

This is not an exaggeration about how this facility is in such disrepair. Observing how resident’s living with dementia move through this physical environment was heartbreaking. There is one main dining and activities area, two long corridors and one middle connecting hallway, a nursing station, a library/television area and a palliative room that make up the physical environment.

Dining/Activities Area: The dining and activities area is where most of the residents spend much of their time. It is argued that for seniors living here, they have little activity to engage in. For the time spent observing this facility, residents watched television or sat alone for hours doing absolutely nothing to stimulate them. Although people were sometimes placed in front of the television after a meal was finished, little interest was taken. The residents were observed sleeping with their heads turned back, drooling, crying or screaming at each other. It is as though these seniors are just waiting to die because they are bored to death. There were activities being done on the first floor but no resident from this area attended. This raised questions as to why they are not being included. It is argued that people regardless of their physical and mental disabilities need social engagement.

The dining room is always busy, meaning that residents, staff, visitors and family members are always moving around this space. Meals are regimented to keep everything on schedule. Another aspect to this area is that residents are placed at tables, with their names written on pieces of paper placed above 'their' spot. It is argued that although this helps aid in memory recall, it depersonalizes them, depleting the sense they can choose where to sit and whom to converse with. This is considered *psychologically dead space* hindering health, personhood and culture.

Here at CS3, many pieces of furniture have no purpose and function because either they were placed very far away from all of the commotion that occurs or it was broken which is considered *physically dead space*. Many of the residents sit in their wheelchairs while others sit in one place most of the day and night if they are not in their rooms. The lighting is very bright in some areas while in others it is dark. Just

like the example from the end of the left hallway in CS2, CS3 has dark and frightening areas that are avoided by residents. Seniors can be observed as being agitated and confused in spaces like these. The furniture is very uncomfortable and many of the residents choose to sit on the side table. One resident explained, "*I find those chairs uncomfortable and hard, I would rather sit here on this table*" (informal comm., 24 June 2009). Another resident said in response, "*Who chooses to use those old, hard, dirty things anyway, I sure don't*" (informal comm., 24 June 2009)?

There are a couple of couches and plenty of uncomfortable chairs lining the two larger hallways which are not used. It was pondered if these chairs are ever used by anyone because they look so awful. The entire physical environment for these residents living here at CS3 is very depressing and de-humanizing. A senior's health, personhood and culture are hindered because the level of disengagement and amount of *dead space* observed was overwhelming. Old furniture in need of replacement is *physically dead space*. It is also argued that personhood is lost in the place of institutional spaces because it does not have a homelike environment which is so important for seniors living with dementia.

The Hallway Corridors: The right, middle and left hallways are the only corridors that residents can access at CS3, even though there is another floor in this facility. The right and left hallways is where resident's rooms are located. Resident's go back and forth either by foot or wheelchair from their rooms to the middle hallway or main dining area. It was observed that the middle hallway connects the two larger ones and is an area of the physical environment where a lot of sitting, reading of newspapers and communication with staff, residents and visitors occurs.

On the wall in the middle hallway is an activities board and calendar that had out of date information posted. For example, the *'what's on'* activity sheet had information from weeks earlier. On the calendar, the date was wrong and the season said it was spring when it was actually summer. Part of the purpose of this space on the wall is to orientate residents to time, place and season which clearly it did not provide. The function of this space was also dead because when residents read what was on the boards that became agitated and confused. One resident expressed, *"Is it still springtime because it feels like summer to me"* (informal comm., 24 June 2009)? This resident was correct it was summer and not spring as the calendar showed. It was also observed that the calendar said the current day's weather was sunny, hot and beautiful. It was felt that by re-orientating the resident to the correct information would help in some positive way.

Part of the problem here at CS3, for example is that there was also another space near this calendar and activities board towards the nurses' station that did have the correct date written on a chalkboard. The incorrect information provided by the calendar in the middle hallway it is argued, contributed to this resident's agitation and confusion. As this example shows,

"I don't know what day it is, I looked over to that place and it says that it is June, my goodness, I am so confused and muddled up that I don't know where I am anymore" (Resident, informal comm., 24 June 2009).

This disorientation was sad to observe because it was unnecessary agitation and confusion. It is argued that this area is *socially* and *psychologically dead space* because it hinders health, personhood and culture. It is a result of disengagement and little attention being paid by staff members to change the space.

Library / Television Room: This area of the physical environment was hardly used but two residents were observed sitting watching television on different occasions. One resident who spends most of their days in this room explained, *“There is nothing else to do but sit in front of the television and waste time before I die. I am so bored, what else am I to do but wait to die you know”* (informal comm., 24 June 2009).

It is argued that the disengagement of this resident and their sentiment that they feel like they are just waiting to die is a commonly observed reaction to boredom. This was a frequently expressed theme by several residents not just at this facility but also at CS1 and CS2. The room with the most *dead space* is the palliative room, discussed next.

The Palliative Room: One staff member thought that the palliative room would be of interest. It was the hope that by observing this area of the physical environment it would have purpose and function, however this was not the case. The palliative room

“Is a room where residents, staff and family members can have an area where they can spend time in a quiet space that allows for intimacy when... residents are close to death or for family members who want a place to be together after their loved one has passed on” (Staff, pers. comm., 24 June 2009).

This staff member further explained,

“This room has not been used in a long time for bereavement or grieving. I can’t even remember when this space was used last for the purpose it was meant...it should have a bed in here but now it is just a storage space for

unwanted furniture or equipment that cannot be placed elsewhere. It is unfortunate really” (ibid. 24 June 2009).

The idea that a palliative room exists in the physical environment of CS3 was exciting to learn. It is for residents, staff, family and friends who want to spend quality time together, especially with respect to end-of-life care, in a private area. This excitement turned to disappointment afterwards when it was reflected upon.

This space is *socially, physically, psychologically and culturally dead space*. It is argued that this area could be brought back to life if the original purpose and function is re-established to allow people to use the space as it is originally intended. It should be an area where mourning can be done in a safe and comforting space. By removing the equipment and other items placed into this room and replacing that with a bed, chairs and more culturally appropriate items, this can be a great space. New furniture, a fresh coat of paint with soothing and calming colors would add life to this *dead space*, enhancing the health, personhood and culture of those who reside, visit and work here.

As the staff member also said, *“I don’t believe it will ever return back to the way it was” (ibid. 6 July 2009)*. It is argued that the reason for this could be because the physical environment is small, dilapidated and needs serious renovations in order to engage the staff. Many conversations were overheard about how staff did not like working in these horrific conditions.

With respect to the question, *“Within residential facilities for those living with dementia, are there specific areas of the physical environment that have dead space?”*

Answer: Yes there are several interesting observations that highlight *dead space* found here at CS3 that hinders health, personhood and culture. Just as in CS1 and CS2, there are areas of the physical environment that are considered *alive*. It is argued that this facility has more *dead* than *alive spaces*.

Case Study 4: Retirement.

The first impression of CS4 was that it had a homelike atmosphere with a welcoming staff. The original question “*within facilities for those living with dementia, are there specific areas of the physical environment that have dead space*” does not apply because no *dead space* was found here. This does not infer that no issues arose while conducting research. This retirement facility is the most *socially, physically, psychologically and culturally alive space* where seniors with dementia reside that was observed in this study. This is a great research finding that will highlight how the health, personhood and culture have been kept alive in the physical environment.

What is needed in today’s ever growing society of seniors living with dementia at the end-of-life is a loving, caring and trusting environment regardless of the facilities size and amount of residents. For a space to be considered entirely alive, it must have a purpose and function in the manner it was intended that engages residents that fosters health, personhood and culture. Here at CS4, the house was redeveloped into a residential home for seniors. Attention to every detail provided each rooms space with a vibrancy that residents enjoy, appreciate and live comfortably in. For example,

“This home is my home, it makes me feel comfortable, happy and it is just a wonderful place to live. The staff makes every effort to make it known that this is my home and not theirs...I have all of my favorite and familiar things here” (Resident, *informal comm.*, 8 July 2009).

Kitchen / Dining / Television Area: Analyzing how spaces are deemed alive and how they contribute to health, personhood and culture of seniors living with dementia must include a discussion with respect to the sustenance of life. Here at CS4, the dining area and the kitchen where meals are prepared does not look institutional like CS3. The philosophy is that when people come to the dining room, everyone sits around one communal table so that social engagement can occur. One particular detail is that resident’s who have a daily newspaper ordered have it placed on their chair at the dining room table just before breakfast.

The residents have their favorite spots that they sit at and everyone appears happy by this arrangement but they can change places if they want, unlike CS3. The meals are home cooked to the delight of the residents who can have their preferences known, just as in CS1 and CS2. Mealtimes provided greater insight about the resident’s likes, dislikes and interests. Residents spoke about past memories which gave them the ability to understand each other, to get to know what makes them who they are today. Many residents were engaged with one another in several interesting conversations about culture, industry, countries of origin and government. It is argued that each resident’s culture was spoken about and maintained in the facility. It was observed that there were no lapses in conversation and many residents changed the topic when the moment arose regardless of their level of cognitive impairment. Together, residents, staff, visitors and home support

employees all participated in conversations during meals and activities throughout the day. This space is *socially, physically, psychologically* and *culturally alive spaces* within the physical environment.

Living Room: Although many residents chose to stay near the dining area, sun room or in their rooms, the living room was not used as much. When the weather is not so good, holidays or when people come to visit the residents, this area of the physical environment is used. One staff member expressed,

“The living room is used on special occasions such as Christmas. We sing carols next to whoever is playing the piano. Our Christmas tree is located there as well but we also recognize different cultural events, making it special for those residents that may celebrate other holidays. This is what we use that space for primarily but residents do sit and look out the large windows which allows them to see the ocean, watch boats going by and the gardener watering the flowers, fruits and vegetables” (pers. comm., 9 July 2009).

Sun Room: Located just right of the dining area, the sun room provides many visual, tactile, olfactory and auditory stimulation. Residents can engage with books, magazines, current newspapers and one another. The white wicker furniture adds to the country themed ambiance. The décor includes drapes with a white and blue gingham design, a country themed needle point hanging on the wall and other pictures that have scenic designs of homelike environments. Just as in the living room, the sun room allows residents to look out towards the ocean, backyard where the garden is and the many goings on. There is a birdfeeder right in front of the largest window. One resident made a comment about this environment,

“Having the ability to just look out and see nature is a great experience.

Living here and not in some insane asylum is why I love being here, I feel so alive. I love this space because it makes me feel comfortable and relaxed while I look out at the birds. The binoculars are good for seeing small creatures that are in the distance” (informal comm., 9 July 2009).

One nice detail that is provided are two sets of binoculars placed on the windowsill for bird watching and to appreciate the scenery that this home’s location near the water has. A couple of times during each day spent here, along with the residents and staff members, many types of animals could be observed in the backyard including deer, hummingbirds, finches and dogs.

Hallways: The hallways are lined with eclectic pictures, mementoes and ornaments. The furniture is strategically placed for when a resident needs a rest. Residents were observed taking an opportunity to sit when they appeared fatigued and were having difficulty moving around the facility. When the resident felt better, they would get up and start moving again. On one of the walls, an interesting finding was that there were hand drawn pictures of past and current residents that an artist drew with pencil. A staff member said,

“These are pictures of residents who either still live here or who have moved or passed on to heaven. It is a nice gesture that the artist contributed to the home. I enjoy them so much that I wished that our newest residents who don’t have their portraits could have them done” (pers. comm., 9 July 2009).

The drawings gave purpose and function to the space on the wall. A resident said,

“These are people who have lived here. It is nice to remember them and I enjoyed their company when they were alive. They were like family to me but that’s how life is, we live and die” (informal comm., 9 July 2009).

It is argued that for residents who have dementia that live here, their level of cognitive stimulation is impressive with respect to memory recall. Many residents still remember others who made a difference, even for a short time that they may have known each other. Part of having dementia is the deterioration of short term memory which is one of the first signs people experience. The relationships and bonds that have been formed are obvious that it contributes to the health, personhood and culture of seniors living with dementia who live here.

Downstairs Area: On another note, there is a downstairs where some resident’s rooms are, a home support area and a small living room. The stairs leading down to this area has a railing for stability and a mechanical chairlift that can move residents up and down if mobility is an issue. Safety is a large concern for residents living with dementia because they wander, become agitated, may be unfamiliar with their surroundings and not be able to recognize people or hazardous situations.

Here at CS4, the philosophy to allow residents the ability to move in and out of the areas of their home as they want fosters health and personhood. It must be understood that this depends on the level of cognitive impairment that the home’s residents have. At CS2 and CS3, the doors remain locked and the residents may not leave the floor unattended. This is not what the staff believes is necessary here at CS4. It is argued that although this could potentially cause concern, the staff can watch the residents more closely than the other residential facilities because there are fewer of them. The physical environment including the furniture, lighting,

mementoes, artwork, food and people all contribute to health, personhood and culture of the residents. Every element had a purpose and a function, if it didn't it was removed, altered or manipulated to give it meaning.

Culturally, every resident is allowed to participate in any belief, religion, custom, ritual while each individual livelihood is fostered. It is argued that by highlighting each resident's culture, the facility has maintained a large portion of personhood. There are many examples highlighting how this home is *socially*, *physically*, *psychologically* and *culturally alive*, these are just a few. This ends the chapter with respect to the research findings. In the following chapter, conclusions and inferences will be drawn from this discussion of *dead* and *alive space*.

5) Conclusions.

As people age, the likelihood that seniors will move into a residential facility like assisted living, retirement or an extended care facility rises if a diagnosis of dementia is made. As the incidence rates of diseases such as dementia increase as prognosticated in Canada, it is proposed that in the coming years and decades, a decision about moving into a residential facility will have to be made. Especially when living in the home becomes too difficult because of cognitive dysfunction and disability results.

If seniors live past the expectancy rate, for women eighty-two and men seventy-six, living becomes increasingly more difficult towards end-of-life (Johnston 2006, p.9). Moving into a residential facility may be an option for seniors who have dementia. There is a growing societal concern about the amount of residential beds, rooms and homes in British Columbia, Canada, because people are living longer. Even when a decision is made about moving a senior into one of these residential facilities, the likelihood that they will be put on a waiting list is probable, especially for publicly funded, governmentally run facilities. This may be different for privately funded residential facilities however. Currently there is an economic downturn in British Columbia, making it increasingly difficult to afford privately owned residential facilities. For example, there are available rooms in CS1 and CS2 because, as one staff member explained, "... nobody can afford it" (*pers. comm.*, 29 June 2009).

More residential facilities, '*reminiscence neighborhoods*' and culturally appropriate healthcare are needed in the face of such devastating degenerative diseases like dementia. That is why in the beginning, my aim in conducting this research was to identify areas of the physical environment in residential facilities for seniors living with dementia that have *dead spaces* that hinder their health, personhood and culture. It is my hope that this research will raise awareness about the levels of engagement that seniors living with dementia have in residential facilities with special regard to *dead and alive space*.

Changes in social and health policies, along with architectural developments are needed for the future care of the cognitively impaired. By changing physical environments like CS1, CS2 and CS3 that have *dead spaces* in residential facilities, it is argued that this will, to some degree, hopefully contribute to the positive health, personhood and culture of seniors. It can be concluded that if a debate about *dead space* occurs between social scientists, professionals that care for seniors living with dementia along with family and friends, the implementation of changes in the physical environments of residential facilities can begin. These changes can evolve into *socially, physically, psychologically and culturally alive spaces* for seniors living with dementia in residential facilities within the Canadian healthcare system.

When entering the field, it was never assumed that this research would make it possible to observe spaces considered dead. It was anticipated that no *dead space* would be found. If there are areas in the physical environment that did have *dead space* it might mean that health, personhood and culture were being compromised. It can be concluded that clearly the answer to the original question,

“Within residential facilities for those living with dementia, are there specific areas of the physical environment that have dead space?”

Is yes, *dead space* is unfortunately alive and well within residential facilities for seniors who have dementia in British Columbia, Canada. It was also highlighted that in CS4, there are no areas in the physical environment where *dead space* exists.

It can also be concluded that many interesting themes from this research were generated. This project emphasizes how the physical environment has *dead space* within the subcategories of *socially, physically, psychologically* and *culturally dead spaces*. It is argued that the success of developing new concepts such as *dead* and *alive space* will allow researchers the chance to think outside the box of conventional thinking. This theoretical viewpoint about *dead space* can be applied to many other areas of enquiry beyond death studies. It was the conceptualization of terminology that made this research so exciting because that is the goal of doing research, to make a valuable contribution; this research did just that.

Further exploration: By conducting this qualitative, exploratory and observational study, although interesting, many ideas were not possible to include in this analysis. This is unfortunate because it would have complimented this work. For example, the idea of *spiritually dead* or *alive space* was pondered. Phenomenon's such as having some form of a God, Deity, ghost or life form existing in an area of the physical environment was not possible in a small scale study as this. The notion of *spiritually dead space* is worthy of a whole new study just on that concept because of growing interest in the metaphysical world.

It is exciting that this research generated many new ways of understanding our social world that hopefully, researchers in the future take interest. One of the

largest areas that have not been covered here which need further analysis is the concept of *dying space*. It was considered in the development of the thesis proposal and then dismissed as thinking way too outside the box of conventional thinking. It is argued that the process of *dying space* is a phenomenon that does exist at some point along the continuum of *dead* and *alive space*. Just as there is a process of dying that people experience there has to be a process of dying with respect to space.

The ideas of *spiritually dead space and dying space* needs more developmental research to create further understanding. What might be of interest to social scientists is to apply the concepts of *dead* and *alive space* to other environments, theories and genres. Some examples include family homes, hospitals or educational establishments. The theory of *dead space* can be applied from different worldviews including a positivist or phenomenological perspective from disciplines like thanatology or sociology. Exploring these ideas further, it may prove beneficial in establishing cause and effect relationships about how *dead* or *alive spaces* contribute to or hinder health, personhood and culture. For example, through the use of different cultural groups of people living and dying with different diseases other than dementia.

It could be argued that this may be a rewarding and productive research project for professionals or graduate students interested in understanding how *dead space* evolves. What the reasons are for *dead space* by identifying the areas of the physical environments that have it and what the social implications might be for these places. Observing and identifying different types of *dead spaces* is crucial to

comprehending, even changing the problematic spaces where people reside, work or study; making these *dead spaces* come back to life or dispose of altogether.

6) Postscript.

This is an opportunity to reflect upon what was learned by conducting this dissertation. Any scientist who studies a social phenomenon in the field, must be open-minded when communicating with potential research sites about what will be required if they participate. It was paramount that I was honest about what the study entailed with the managers, directors of care and proprietors with respect to death studies and how this will benefit the larger social world. This was crucial in gaining access to the sites that participated, they, just as I, wanted to make a difference for seniors that are living and dying with a cognitive impairment like dementia.

When I think about what makes a good researcher, at first, I thought it was someone who is unbiased. Although I tried very hard to keep certain biases out of this research, it could not be eliminated completely. Having a well rounded knowledge base with respect to the field of enquiry is how I can accept my own bias. Critically analyzing who I am, where I have worked and what I believe in that ultimately shaped this research. I was open to learning new ideas about seniors living with dementia in residential facilities in British Columbia, Canada.

I had two researcher roles, the first, was an insider because I have a working knowledge of the settings that participated in this research including an assisted

living home and various extended care facilities, and second, I was definitely an outsider because I was a student researcher observing the physical environment. Staff, family, even residents, regardless of being a participant observer took notice at varying times throughout the study that I was a researcher. This did not affect the findings or the conclusions. I had no hidden agenda other than presenting a new way of understanding a physical environment. People living with dementia is my topic of choice so making a difference in the lives of seniors was important. In addition, the development of social programs that engage seniors living in residential facilities is also my hope. I have observed what living without appropriate care and programs can accomplish.

Being a participant observer contributed to making theoretical connections that otherwise may not have been made if a different methodology was employed. Being just a total observer it is argued, does not allow the researcher to obtain a thoroughly descriptive set of field notes that can allow for a deeper understanding of the larger social world. Conducting death research at the best of times is a difficult theme to study, especially in the environments I was studying. It was a complicated study to explain to people because of the sensitive nature that death research presents, however it was well worth the effort to demystify the concept. It was both uplifting and informative for all who spoke on such an important subject with me.

Otherwise, one of the biggest issues in this study is that many new ideas have come out of this research that could not be included in this dissertation. I do wish that I could have included more examples that highlighted how *socially, physically, psychologically* and *culturally dead space* was in more areas than I could include. Time spent in the field was limited in scope which made it difficult to make inferences

to the larger social world but it is a start. In the end, most importantly, this experience was full of many *unforgettable* moments.

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