

**An Evaluation of a Dementia Care Unit**

**by**

**Dulce Santos**

**A Thesis submitted to the Faculty of Graduate Studies of**

**The University of Manitoba**

**in partial fulfilment of the requirements of the degree of**

**MASTER OF SOCIAL WORK**

**Faculty of Social Work**

**University of Manitoba**

**Winnipeg**

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## **ABSTRACT**

Little is still known regarding the effect Dementia Care Units (DCUs) have on the quality of life (QOL) of their residents. This study evaluated a DCU, focusing on the impact it had on residents' QOL, responsive behaviours and family member's level of satisfaction. It compared the residents living on a DCU to those living on a "traditional" unit. Multi-variance and bi-nominal logistic regression procedures along with qualitative methods of analysis were used. Although, no significant differences were found between the units, level of education and regular family contact were found to affect residents' QOL. Furthermore, family members did find value in the physical and social environments of the units and in primary care.

Although findings cannot be generalized the ultimate goal was to expand on the research findings related to DCUs. Based on findings of this study, implications for social work practice and recommendations for future research were developed.



## TABLE OF CONTENTS

<b>Acknowledgements.....</b>	<b>i</b>
<b>Abstract.....</b>	<b>ii</b>
<b>Table of Contents.....</b>	<b>iii</b>
<b>List of Tables and Graphs.....</b>	<b>x</b>
<b>Chapter One – Overview.....</b>	<b>1</b>
Statement of the Problem.....	1
Incidence of Dementia and Development of Dementia Care Units.....	2
Relevance to Theoretical Development.....	5
Relevance to Extension of Empirical Knowledge.....	6
Relevance to Social Work.....	8
<b>Chapter Two – Review of the Literature.....</b>	<b>10</b>
Defining Constructs.....	10
Dementia.....	10
Dementia Care Unit.....	12
Quality of Life.....	15
Models of Care.....	17
Integrated versus segregated.....	17
The Medical Model.....	19
Environment-Behaviour Models.....	21
Ecological Perspective – Person-Environment Fit.....	21
Progressively Lowered Stress Threshold.....	23
Person-Centred Model of Care.....	24

Review of the Empirical Literature.....	29
Research Findings.....	29
Methodology.....	47
Limitations.....	47
Identification of the Theoretical, Empirical and Methodology Gaps.....	55
<b>Chapter Three – Research Design.....</b>	<b>56</b>
Research Site.....	56
Research Questions and Hypothesis.....	62
Research Design, Sample Definition and Recruitment.....	64
Measurements.....	67
Quality of Life.....	68
Reactive Behaviours.....	70
Family Members’ Level of Satisfaction with care and the unit.....	70
Cognitive Level.....	71
Environmental Changes.....	72
Sample Description.....	74
Residents.....	74
Family Members.....	74
Staff Members.....	74
Data Collection.....	75
Data Analysis.....	77
Quantitative Data.....	77
Qualitative Data.....	78

Review of the Empirical Literature.....	29
Research Findings.....	29
Methodology.....	47
Limitations.....	47
Identification of the Theoretical, Empirical and Methodology Gaps.....	55
<b>Chapter Three – Research Design.....</b>	<b>56</b>
Research Site.....	56
Research Questions and Hypothesis.....	62
Research Design, Sample Definition and Recruitment.....	64
Measurements.....	67
Quality of Life.....	68
Reactive Behaviours.....	70
Family Members’ Level of Satisfaction with care and the unit.....	70
Cognitive Level.....	71
Environmental Changes.....	72
Sample Description.....	74
Residents.....	74
Family Members.....	74
Staff Members.....	74
Data Collection.....	75
Data Analysis.....	77
Quantitative Data.....	77
Qualitative Data.....	78

<b>Chapter Four – Research Limitations</b> .....	80
Quantitative Analysis.....	80
Internal Validity.....	80
Construct Validity.....	84
External Validity.....	84
Qualitative Analysis.....	85
<b>Chapter Five – Results</b> .....	87
Overview.....	87
Description of the Two Units.....	87
Quantitative Analysis.....	93
Preliminary Analysis.....	93
Descriptive Analysis.....	100
Differences Between Residents on the Two Units.....	103
Hypothesis Tests.....	106
Quality of Life.....	106
Reactive Behaviours.....	111
Additional Findings.....	113
Qualitative Analysis – Family Interview.....	117
Overview.....	117
Family Members’ Description of the Unit.....	118
Physical Factors.....	119
Dementia Care Unit.....	119
Traditional Unit.....	121

Social Factors.....	123
Dementia Care Unit.....	123
Traditional Unit.....	124
Family Members' Satisfaction with the Level Care and Unit Staff.....	126
Dementia Care Unit.....	126
Traditional Care Unit.....	128
Social Life on the Unit.....	130
Activity Programs.....	130
Dementia Care Unit.....	130
Traditional Unit.....	132
Opportunity for Socialization.....	133
Dementia Care Unit.....	133
Traditional Unit.....	134
Meal Program.....	136
Dementia Care Unit.....	136
Traditional Unit.....	137
Family Relations with Unit Staff.....	138
Level of Involvement with Care Related Decisions.....	139
Dementia Care Unit.....	139
Traditional Unit.....	140
Level of Support Offered to Family Members.....	141
Dementia Care Unit.....	141
Traditional Unit.....	142

Unit Effect on Residents.....	143
Unit Benefit.....	144
Dementia Care Unit.....	144
Traditional Unit.....	145
Unit Effect on Residents' Quality of Life.....	147
Dementia Care Unit.....	147
Traditional Unit.....	149
<b>Chapter Six – Discussion.....</b>	<b>151</b>
Overview.....	151
Unit Effect on Quality of Life for Residents.....	151
Unit Effect on Reactive Behaviours Presented by Residents.....	159
Unit Effect on Family Members' Perception.....	160
Care Provided to the Residents.....	161
Physical and Social Environments.....	164
Summary.....	168
Implications.....	170
Implications for Future Research.....	170
Implications for Social Work Practice.....	172
Implications for Personal Care Homes.....	174
Conclusion.....	176
<b>References.....</b>	<b>179</b>

<b>Appendices.....</b>	<b>186</b>
Appendix A – Philosophy of Care at Holy Family Home.....	186
Appendix B - Dementia Care Units –Admission and Discharge Criteria..	187
Appendix C - Holy Family Home - Philosophy of Dementia Care.....	188
Appendix D – Consent Form – Resident.....	189
Appendix E – Consent Form – Family Members.....	192
Appendix F – Consent Form – Staff Member.....	195
Appendix G – Executive Director’s letter to Resident and Family.....	198
Appendix H - Executive Director’s letter to Staff Members.....	199
Appendix I – Quality of Life–Alzheimer’s Disease Survey-Residents....	200
Appendix J-Quality of Life–Alzheimer’s Disease Survey–Instructions..	201
Appendix K - Quality of Life – Alzheimer’s Disease Survey – Staff.....	204
Appendix L – Family Interview Questions.....	205
Appendix M – Data Sheet.....	206

## LIST OF TABLES AND GRAPHS

### TABLES

Table 1.1	Summary of Reviewed Studies.....	40
Table 3.1	Examples of Qualitative Analysis Method.....	79
Table 5.1	Comparison of Unit Characteristics.....	89
Table 5.2	Normality Distribution of Independent Variables.....	95
Table 5.3	Kolmogorov-Smirnov Values for the Transformations of the Variable Reactive Behaviour.....	100
Table 5.4	Description of Residents.....	101
Table 5.5	Normality Distribution for Dependent Variables.....	106
Table 5.6	Linear Regression – Testing for Unit Differences.....	109
Table 5.7	Linear Regression – Testing for Differences.....	116

### GRAPHS

Graph 5.1	Histogram of Length of Time Living on the Unit.....	96
Graph 5.2	Histogram of the Log Transformation of the Variable Length of Time Living on the Unit.....	96
Graph 5.3	Histogram of the Variable Reactive Behaviours.....	97
Graph 5.4	Histogram of Log Base 10 Transformation of Variable Reactive Behaviours.....	98
Graph 5.5	Histogram of the Inverse Transformation of Variable Reactive Behaviours.....	98
Graph 5.6	Histogram of the Square Root Transformation of Variable Reactive Behaviours.....	99



## **CHAPTER ONE - OVERVIEW**

### **Statement of the Problem**

Dementia affects many lives, those living with the illness, their families, friends and communities. The need for effective programming and care for these individuals is a growing need since the incidence of dementia continues to rise (Alzheimer Society of Canada, 2003). Dementia affects each person differently depending on the degree of impairment, his or her life experience, personality and environment (Kitwood, 1997). For some of these individuals extended care is required which usually means placement in a personal care home (PCH). Some of these PCHs have “traditional” units that mainly follow a medical model of care delivery (focus placed on illnesses, losses and routine). This philosophy of care does not recognize the uniqueness of each individual and therefore their unique need. It does not recognize that an individual’s personality can continue to shine through, regardless of how progressed the dementia has become.

As a social worker who works with individuals living with dementia and their family members, I questioned if there was a better way in which care could be delivered. One where the focus is placed on the unique individual and not the illness, where emphasis is placed on quality of life and not routine, where those who have difficulty verbalizing their needs are given the opportunity to be heard and understood and where family members are included in the day-to-day care planning of their relative and viewed as part of the care team.

One response to the need to improve care for those living with dementia has been the development of special or dementia care units (DCUs) within PCHs. These units offer one or more “special” features such as smaller units (fewer than 20 residents living on a unit), staff trained in person-centred care, inclusion of family members in care

decisions, specialized environmental design or dementia-appropriate programming (Day, Carreon & Stump, 2000). This researcher questioned if these units could improve the quality of care offered to individuals living with dementia. Can these units increase quality of life for these individuals? The researcher wanted to explore the following questions:

1. Will the quality of life of residents living on a DCU be higher than those living on a “traditional” unit within the same PCH?
2. Will DCUs assist in decreasing the episodes of responsive behaviours of individuals living with dementia?
3. Do family members with relatives living on a DCU have a higher level of satisfaction with the unit and care as compared to family members of relatives living with dementia who reside on a traditional unit within the same PCH?

The opportunity to explore these questions became possible for this researcher, with the development of a DCU within the PCH employing the researcher. This provided the opportunity to identify how effective this unit would be in improving care and service delivery to those individuals living with dementia.

### **Incidence of Dementia and Development of Dementia Care Units**

The number of people living with dementia is growing since the incidence of dementia continues to rise (Alzheimer Society of Canada, 2003). One reason for the increase is the fact that the risk of dementia increases with age. Due to better medication and development of antibiotics, people are living longer lives (Alzheimer Society of Canada, 2003). One of the fastest growing age groups is 80 and over. In Canada, this

age group grew from 943, 375 in 2001 to 1, 206, 249 in 2007 (Statistics Canada, 2008). In Manitoba, those aged 80 and older grew from 44, 580 in 2001 to 50, 426 in 2007 (Statistics Canada, 2008). According to the Alzheimer Society of Canada (2008), about 1 in 13 Canadians over 65 have Alzheimer Disease or a related dementia. This grows to 1 in 3 by the age of 85. In 2007, approximately 450,000 Canadians over the age of 65 had Alzheimer Disease or a related dementia, of which 18,000 were Manitobans (Alzheimer Society of Manitoba, 2007). It is estimated that by 2011, there will be 111,600 new cases of dementia, nation wide and by 2031, over 750,000 Canadians are predicted to have Alzheimer Disease or a related dementia (Alzheimer Society of Canada, 2003).

Alzheimer Disease is progressive and as this disease progresses the ability to perform self-care functions and other activities of daily living (ADL) decreases. This creates increased stress on family members who are usually the primary caregivers. Over 70% of informal caregivers are women, mostly wives and daughters (Alzheimer Society of Manitoba, 2007). Approximately 36% of informal caregivers are over 70 years of age (Alzheimer Society of Manitoba, 2007). Predictors of placement in a PCH include increased assistance with ADLs, behavior changes (hitting out, verbally threatening, pacing, restlessness), and caregiver burnout (University of Manitoba, Centre on Aging, 1995). Approximately 50% of the people living with a dementia in Manitoba reside in an institution (Mitchell-Pedersen, 2002). Some studies have found that 65% to 90% of residents in PCHs have a diagnosis of dementia (Rabins, Morrill, Johnson, Smith & Low, 1990). The National Institute on Aging Collaborate Studies of Dementia Special Care Units found that "...almost 90% of nursing home residents were cognitively impaired, about half severely so" (Teresi, Morris, Mattis, & Reisberg, 2000, p.118).

Dementia Care Units developed from a need to improve the quality of care offered to individuals living with dementia who resided in PCHs. These units have become an alternative choice to traditional units based on a medical model of care (Leon & Siegenthaler, 1994; Manitoba Health, 1999; Maslow, 1994b). Although the numbers of DCUs are increasing, there is limited research validating their effectiveness (Kovach, 1998; Leon & Ory, 1999; Phillips et al., 1997). For instance, Leon and Ory (1999) compared special care units (SCU) to non-specialized or traditional units in PCHs, in their effectiveness in reducing physically aggressive (reactive) behaviors within six months of placement. Their results indicated that "... when difference in age and baseline levels of "disruptive" behaviors were controlled, SCU placement showed no positive or negative effect on the frequency of aggressive [reactive] behaviors" (p.270). Phillips and associates (1997) completed a study that analyzed the effects of SCU residence on the rate of decline in residents' functional status. They followed a cohort of nursing home residents in four American states at multiple points over a one year period. These residents included those admitted to a SCU, to traditional units within a personal care home with SCUs and residents admitted to units within a non-SCU facility. Results indicated "... no statistically significant difference was observed in the speed of functional decline for residents in SCUs and traditional units..." (p. 1340).

One reason for the limited research validating the effectiveness of these units may be related to the great diversity noted in the characteristics of DCUs and their definition (Day, Carreon & Stump, 2000; Gruneir, Lapane, Miller & Mor, 2008). Day, Carreon and Stump (2000) completed an empirical research review on SCU environmental designs. They found that DCUs "...are not comparable because what is considered a DCU varies

enormously” (p. 406). One of the reasons for the variation among DCUs is due to the fact that there are no national standards in Canada or in the United States established for these units (Morgan, Stewart, D’Arcy & Werezak, 2004; Parker-Oliver, Aud, Bostick, Schwarz & Tofle, 2005; Teresi, Homes & Ory, 2000). It is therefore difficult to compare these units when there are significant variations.

Not only do DCUs vary in definition and characteristics, but also so do the characteristics of the residents who reside in them. Mace (1991) found that there was considerable variation among the characteristics of the residents living on the DCUs included in her survey. Some of these units incorporated admission criteria which accepted residents who presented with behavioral disturbances that could not be managed elsewhere while others excluded residents with certain behaviours, particularly combative behaviour.

Despite these limitations, DCUs continue to develop, which leads to the following questions: Should DCUs continue to develop? If so, which DCU features are found to be effective? Although outside of the scope of this study, these are questions that future research may assist in answering.

### **Relevance to Theoretical Development**

There are a number of theories or models associated with dementia care and DCUs. A key concept that a theory linked to DCUs should acknowledge is how these units affect the individual and in turn how the individual responds to their environment. It is for this reason that the researcher wanted to focus on a theory that incorporated an ecological perspective. This perspective emphasizes “goodness of fit” between the person and the environment (Heinonen & Spearman, 2001, p. 186). It is a concept that

refers to the "... interrelationships between living organisms and their environments" (Dubois & Miley, 1992 cited in Heinonen & Spearman 2001, p. 186). It views human needs and problems as being "... generated by transactions between persons and their environment, and through a process of continuous reciprocal adaptation, humans change and are changed by their physical and social environments" (Dubois & Miley, 1992 cited in Heinonen & Spearman 2001, p. 186).

One model of care which incorporates an ecological perspective is the person-centered model of care. It recognizes the impact that the environment (physical, social, cultural and psychological) has on the individual. This is fundamental since an appropriately designed environment for people living with dementia has the potential "... to help individuals continue to function maximally, to remain aware of and enjoy their surroundings possibly to retard deterioration, and to live with dignity" (Coons, 1991, p. 21). The person-centered model also focuses on a holistic approach to care (physical, mental, social, psychological, and spiritual). Care is centered on the resident's needs and comfort. Emphasis is placed on a person's residual strengths and on QOL. This study incorporated a person-centred model of care into the evaluation of a DCU and its effect on residents' QOL and potential to decrease reactive behaviours.

### **Relevance to Extension of Empirical Knowledge**

Past research on the effectiveness of DCUs has primarily focused on benefits in behaviour management as well as maintaining or improving the individual's functional and cognitive status. Evidence of effectiveness in these areas is inconsistent (Gruneir et al., 2008; Leon & Ory, 1999; Phillips et al., 1997; Ross, 1999). Some of the research shows effectiveness in the management of certain behaviours such as agitation and

increased socialization (Bellelli, Frisoni, Bianchetti, Boffelli, Guerrini, Scotuzzi, et. al., 1998), while others show no effectiveness (Leon & Ory, 1999). The differences in results are likely related to the variation in the types or characteristics of the DCUs that have developed. A limitation of some studies is related to the fact that a description of the unit, philosophy, and or theoretical perspective is not included. This makes it difficult to compare results as well as to generalize findings.

Another limitation of the research is related to QOL. There is a limited amount of research that includes the effect of DCUs on the QOL of its residents. This research is however growing (Cioffi, Fleming, Wilkes, Sinfield & Le Miere, 2007; Day, Carreon & Stump, 2000; Reimer, Slaughter, Donaldson, Currie & Eliasziw, 2004). Are DCUs effective in increasing a resident's QOL? A further limitation of the research is related to family members' perspective on the benefits of DCUs. Do family members feel that their relatives have benefited from living on a DCU as compared to a traditional unit? As the literature on effects of DCUs on the QOL of its residents grows, so does the literature on family members' perspectives in regards to these units (Cioffi et al., 2007; Donovan & Dupuis, 2000; Maas et al., 2004; Parker-Oliver et al., 2005).

In an attempt to address some of the limitations outlined above, the present study provides a description of the two units involved (a DCU and a traditional unit) and a measurement of how they placed on a continuum between specialized care and general care. This research focuses on QOL of individuals diagnosed with dementia living in a PCH. It attempts to identify differences between the QOL of residents on a DCU compared to those on a traditional unit within the same PCH. It also includes family members' perspectives and satisfaction with the unit and the care. It is the hope of this

researcher that further research related to DCUs and dementia care will continue to build on existing findings including those of this study, in order for improvements to continue to occur in the lives of individuals living with dementia.

### **Relevance to Social Work**

The current research on the effectiveness of DCUs is primarily found in the medical and nursing fields, with few studies within the field of social work. A further dimension can be added to these studies with the inclusion of social work and the ecological perspective. The focus can include psychosocial components rather than only behavioural, functional, and cognitive aspects of the individual. There is also a lack of research into the effectiveness of DCUs on the QOL of its residents. Only part of the person is being considered when focusing solely on the cognitive, functional and behavioural aspects of an individual. If the focus continues to remain limited to these areas, “dementia care” cannot be considered holistic.

Gerontological social workers have played a significant role in the area of dementia care, such as in developing theories and care models. For instance, validation theory was developed in the 1960s by Naomi Feil. This led to a shift towards “... feelings and emotions, and a realization that there might be general therapeutic psychological outcomes in dementia” (Kitwood, 1997, p. 56). Emily Brody in the 1970s used empirical research designs to develop a systems approach to individualized care of elders presenting with “excess disability” (Morton, 2000; Lacey, 1999). The term excess disability refers to an individual presenting with increased disability that is due to factors unrelated to their diagnosis of dementia, such as the environment, infections, metabolic changes and discomfort (Martichuski & Bell, 1993).



Social work plays an important role in client advocacy and ensuring that quality care is offered to this group of individuals. Further research on DCUs will increase knowledge on the effectiveness of this concept which will assist in the development of standards. Social work has and needs to continue to play a role in this area in order to ensure that focus on the person and psychosocial needs are included in the development of new theories, practices and policies.

## **CHAPTER TWO – REVIEW OF THE LITERATURE**

The following chapter will focus on defining constructs and reviewing the theoretical literature regarding dementia care and dementia care units (DCUs). It will also include a summary of empirical findings and methodologies. It will conclude with a discussion on the limitations found in past studies.

### **Defining Constructs**

#### **Dementia**

Dementia is a syndrome of symptoms, which results in progressive deterioration of the brain. This leads to a loss of cognitive ability, sufficient to interfere with an individual's physical function, social and occupational life (Molloy & Caldwell, 1998). The most common type of dementia is Alzheimer disease, which makes up about 64% of all dementias (Alzheimer Society of Manitoba, 2007).

Memory is always affected, but some of the other cognitive skills that could be impaired include judgment, abstract thinking, insight, problem solving, language recognition and inhibition (Molloy & Caldwell, 1998). Reactive behaviours that are difficult to manage can develop as a person's cognitive level decreases. These behaviours are at times the result of a struggle between a person's diminished capacities and the inability to understand the demands of the environment (Alzheimer Society of Canada, 1991). Some of these behaviours include pacing, restlessness, suspiciousness, catastrophic reactions, eating difficulties, hitting and calling-out (Alzheimer Society of Canada, 1991). Although there are some losses with dementia, the ability to appreciate,

respond to, and experience feelings remains intact (Alzheimer Society of Manitoba, 2001).

As the disease progresses, due to the decline in cognition and possibly sensory deficits, individuals begin to require assistance in making sense of their environment. They come to require assistance with orientation to their surroundings and cueing to complete activities of daily living, such as getting dressed, eating, and toileting (Jones, 1999). Basically "... confusion and disorientation can alternatively be exacerbated or helped by environmental interventions" (Teresi, et al., 2000, p.417).

The design of the environment is being recognized as an important component of caring for people living with dementia. Reimer, Slaughter, Donaldson, Currie and Eliasziw (2004) stated that reactive behaviours, which are found to occur in up to 90% of persons living with dementia, can be minimized through environmental modifications and caregiver skill. Environments that are confining or confusing may lead a person living with dementia, to experience excess disability (Reimer et al., 2004). Essentially the environment (which includes the physical and social) needs to become a prosthetic device, a structure that substitutes for or supplements an individual's deficits (Jones, 1999). In this case it would compensate for limited cognitive and physical capabilities. A prosthetic environment for people living with dementia would include features such as way-finding signs or cues to identify living spaces or expected behaviors, for instance the smell of cooking and tables being set to identify it is meal time. This could assist individuals living with dementia in remaining as functionally independent as possible (Coons & Mace, 1996). In an attempt to create this type of environment and meet the needs of these individuals, some PCHs began to develop specialized units such as DCUs.

## Dementia Care Units

Dementia care units (DCUs) “... were developed on the conviction that a prosthetic physical environment and a supportive social environment would reduce excess disability and improve quality of life” (Reimer et al., 2004, p.1086). With the development of these units the focus of care began to incorporate a person-centred approach and a move away from a medical model.

There are many variations on the definition of a DCU found in the literature. The difficulty in precisely defining a DCU lies in the fact that they are so diverse. Leon and Siegenthaler (1994) define them as “... programs and physical [segregated] environments designed to meet the specific needs of residents with dementia” (p. S58). In her report to the Winnipeg Regional Health Authority, Lynne Mitchell-Pedersen (2002) identified the mandate of these units by stating that they serve a

clearly defined population, that is, they care for residents with a particular combination of characteristics, that is, who are ambulatory, who almost universally suffer from dementia of some sort and who manifest a particular range of behaviours not easily managed in a regular PCH unit (p.18).

One reason for the diversity of these units could be related to the variation in theoretical frameworks and philosophies guiding the development of these units (Morgan, et al., 2004; Parker-Oliver, et al., 2005). Using a non-random sample of sixteen DCUs, Ohta and Ohta (1988) identified three types of DCUs based on the unit’s goals and philosophies. They included,

- Units that have as their primary goal to meet residents’ physical care needs

- Units that have as their primary goals to maintain residents' ability to perform activities of daily living to the greatest extent possible and to minimize memory impairments and behavioural symptoms, and
- Units that have as their primary goals to maintain residents' quality of life, while also maintaining their ability to perform activities of daily living and minimizing their memory impairments and behavioural symptoms.

Another reason for the diversity of these units could be due to the fact that there are no established standards in Canada as to what constitutes a DCU (Manitoba Health, 1999; Mitchell-Pedersen, 2002). There are some common characteristics to these units. In a report conducted for Manitoba Health (1999), a literature review was completed on the "special" features of DCUs, and five basic characteristics were found. Lynn Michell-Pedersen (2002) also found the same five characteristics. Variability even among these features was noted. These features included

1. Modified physical and social environments

These units were usually described as segregated and having completed some adaptations to the environment to meet residents' needs. This included exit control, way-finding décor (signage and landmarks), common activity spaces (kitchen, dinning area, activity area) access to outdoor space, homelike furnishings, controlled sensory stimulation (i.e., removal of public announcement systems) and improved lighting and contrast (to assist with depth perception and decreased sight). Most units were also found to be smaller in size (5 to 15 residents on a unit) as compared to traditional units. Some provided family style

delivery of meals instead of cafeteria style tray service and most offered the opportunity for personalization of residents' rooms.

## 2. Staff selection and training

Most units were found to provide specialized staff training in dementia care.

There was however variation as to what should be considered basic training requirements of staff working on these units. Some units had a screening process in choosing which staff members would work on these units, while others did not. Staffing ratios also varied. They were found to range from one staff per four residents to one staff per seven residents (Mitchell-Pedersen, 2002, p. 62).

## 3. Activity programming specifically designed for persons living with dementia

This was the most commonly reported feature of DCUs. Some focused on specialized small group programming designed to maximize functional, social and cognitive abilities (i.e., reminiscing, life skills such as washing dishes or cooking and woodworking), instead of focusing only on large traditional programs such as bingo and bowling. Reference to individualized one-to-one activity programming and music therapy were also commonly reported activities.

## 4. Family programming and involvement in care planning

The importance of family members' involvement in unit programming and in decisions related to their relative's care was recognized. For some units support groups or educational in-services for families were also offered.

## 5. Admission criteria of residents with irreversible cognitive impairment

A common feature of DCUs was the admission criteria of residents. Most common requirement for admission was a diagnosis of dementia. Additional

criteria that were found to be required by some DCUs, included "... age limits (i.e. residents must be 65 years of age or older), inability to manage on general personal care units, problem behaviour(s), ability to participate and benefit from group programming, thresholds on standard mental status tests, and requiring the resident to be ambulatory (Manitoba Health, 1999, p. 17). Some DCUs also had discharge criteria; however there is debate on whether or not this should be included.

These five features continue to be listed in the literature as the most commonly reported features (Morgan, et al., 2004). However due to a lack of standards these features continue to vary from unit to unit. Furthermore, a unit does not have to incorporate all of them to be considered a DCU. Regardless of the features that these units may incorporate the common reason for the development of these units is to improve the QOL for persons living with dementia (Reimer et al., 2004).

### Quality of Life

There is great controversy found in the literature on defining quality of life (QOL). The controversy is based on the fact that the meaning of QOL differs from person to person and is developed and shaped by a person's experiences and internal standards. Due to this there are a number of definitions for QOL.

Selai and Trimble (1999) identify QOL in the medical context "... as a multidimensional construct comprising physical, psychological and social well-being" (p. 102). While there is no absolute agreement about the sub-components of each domain, there is some agreement that in order to measure QOL in persons with dementia, domains

that are relevant to these individuals should be included. Brod, Stewart, Sands and Walton (1999) suggested that

[q]uality of life as a unidimensional construct would do a serious injustice to researchers' understanding of the dementia-specific influence on QOL.

Additionally, without an appreciation for this multidimensionality, the clinical understanding of disease progression and impact, development of appropriate interventions, and measurement of treatment effects would be seriously compromised (p.32).

Rabins (2000) defined dementia-specific QOL as consisting of five domains: social interaction, awareness of self, response to surroundings, enjoyment of activities, and feelings or mood. Coons and Mace (1996) identified issues that affect QOL for persons with dementia, specifically for those living in an institution. They include the following: (1) freedom of choice, (2) recognition of individuality, (3) right to privacy and a fostering of human dignity, (4) continuity with the past and of normal social roles, (5) a health-fostering, prosthetic, orienting and sensory-stimulating environment, (6) opportunity for age appropriate activities, (7) the ambiance of home, neighborhood and community and (8) the opportunity for enjoyment, fun, humour, and creativity. Last, Lawton (1991) provided a broad conceptual framework for QOL which includes four domains of importance; behavioral components, the objective environment, psychological well-being and perceived quality of life (cited in Logsdon, Gibbons, McCurry, & Teri, 2002).



Most QOL frameworks recognize environmental influences on a person's well being. This is something that is especially important to include when trying to understand the QOL of individuals living with dementia, considering how much the environment can affect them. For this study, two frameworks, that of Coons and Mace (1996) and that of Lawton (1991) were combined to provide a broader definition of QOL.

## **Models of Care**

### **Integrated versus Segregated**

There are a number of theories or models which relate to dementia care. One such model advocates for the segregation of persons who have a cognitive impairment from those that do not. Munson (1991) reported that:

[w]herever possible, people with progressive dementia ... should be housed on a separate unit dedicated specifically to meeting their needs.

This recommendation is based on a strong belief that such an arrangement is beneficial to all parties concerned: to individuals with progressive dementia, to the non-cognitive impaired residents of the setting and to the staff who provide care to both of these groups (cited in Ernst – Drosoloski & Karpan, 1995, p.28).

Hall, Kirschling and Todd (1986) reported that when residents who do not have a diagnosis of dementia are grouped together with those who do "... the lucid residents experience invasions of privacy, decreased socialization in order to avoid interaction with confused residents, interrupted sleep, and fear of physical harm from agitated residents" (cited in Ernst-Drosoloski & Karpan, 1995, p.25). Those in favour of segregation outline

the benefit in grouping these individuals for the purpose of individualizing their care.

They argue that the needs of cognitively impaired persons differ greatly from the needs of those who are mentally alert and that a single environment cannot be designed to accommodate persons with a wide range of needs and capacities (Ernst – Drosoloski & Karpan, 1995).

On the other hand, there are those who favor integration (Manitoba Health, 1999). They argue that having a few DCUs within a PCH would not accommodate the large number of residents who are living with dementia. The National Institute on Aging Collaborative Studies of Dementia Special Care Units (Teresi, Holmes, Ory, 2000) found that almost 90% of PCH residents in the United States were cognitively impaired, about half severely. Therefore those who are not living on a DCU would not receive specialized care. Recent studies in Manitoba indicate that over 50% of PCH residents have a diagnosis of dementia and only 12% of those personally reside on a segregated DCU (Manitoba Health, 1999). Those in favour of integration also indicate that there is inconsistent evidence that segregating these individuals is beneficial (Manitoba Health, 1999). These individuals propose changes to existing environments and approaches to care that would allow for dementia care to be integrated, allowing all residents diagnosed with dementia living in a PCH to receive specialized care (Manitoba Health, 1999).

Ultimately, one is confronted with a number of questions. What is the most beneficial way of providing care for individuals living with dementia who reside in a PCH? Should these residents be integrated or separated? This research attempted to determine if a segregated DCU within a PCH, had an effect on its residents' QOL, on

residents' reactive behaviours and family members level of satisfaction with the unit and care.

### The Medical Model

The medical model of care focuses on pathology and illness. "It is based on the Cartesian idea that the mind and the body are separate entities" (Ross, 1999, p.4). With regard to dementia care, focus would be placed on the treatment of the pathology and presenting behaviors would be interpreted according to disease stage attributions as opposed to environmental influences. This model according to Ross (1999),

[l]imits the therapeutic potential of care giving because it assumes that behaviour can be explained by the progression of stage specific symptoms which may or may not occur in the context of one's experience. It ignores the fact that there is great variation among people with dementia and therefore little conformity to any predetermined stage-like progression (p.5).

Management of these behaviours is usually focused on custodial care and the use of medication or chemical and physical restraints. Chemical restraints refer to "... psychotropic medications that are prescribed to subdue residents' activity" (Gruneir, Lapane, Miller, & Mor, 2008, p. 200). The most common types of chemical restraints used in PCHs are tranquilizers and hypnotics (Sloane, Mathew, Scarborough, Desai, Koch & Tangen, 1991). Physical restraints are defined as "... any device that prevents a resident's free movement ..." (Gruneir, et al., 2008, p. 200). The most common types of physical restraints used in PCHs are chairs with locking lap trays and seat belts (Sloane et

al., 1991). The goal of a medical model in managing these types of behaviours is to eliminate them, not understand why they occurred in order to assist the person and preserve their QOL.

This model also focuses on the physical aspects of care. In caring for people with dementia, emphasis is placed on meeting basic physical needs, such as dressing, toileting and eating. Care routines are usually rigid and focus on efficiency while ignoring residents' retained strengths and QOL. It is faster for the care provider to complete the care than to encourage the resident's independence, thus creating dependency. Few efforts are made in acknowledging a person's individual lifestyle and history and family members are not recognized as being part of the "care team."

The medical model can also be recognized by the physical environment. Maas, Swanson, Specht, and Buckwalter (1994) claimed that PCHs "... that operate according to the medical model of care often resemble hospitals more than homes. The care environment is usually sterile in appearance, has large numbers of residents who have limited personal space, and long continual hallways" (cited in Ernest-Drosdoski & Karpen, 1995, p.21). This environment can lead to increased confusion, agitation, and frustration for individuals living with dementia who are unable to identify with this type of environment (Maas et al., 1994 cited in Ernest-Drosdoski & Karpen, 1995). The focus of the care providers is on pathology and illness rather than on the resident's obtained strengths and QOL (Maas et al., 1994 cited in Ernest-Drosdoski & Karpen, 1995).

## Environment-Behaviour Models

### Ecological Perspective - Person-Environment Fit

Instead of focusing on illness and dependency, the ecological perspective focuses on the unity of a person with their environment. To understand a person's reactions one has to understand the relationship between the person and their environment which includes the physical, social and political (Heinonen & Spearman, 2001). According to this perspective, person and environment cannot be separated.

An important factor of the ecological perspective is the concept of "person-environment fit" or "goodness of fit" between the person and their environment. It emphasizes that optimal behaviour adaptation and affective outcomes occur when there is a good fit between the individual and their environment (Heinonen & Spearman, 2001). Problems occur when this is not accomplished. Furthermore, this relationship is circular in that the environment and the person affect each other (Heinonen & Spearman, 2001, p. 186). This concept in relation to dementia care, views the entire physical environment as a prosthetic device (Ernst-Drosdoski & Karpan, 1995). An environment as a prosthetic device is one that deliberately incorporates features that can serve to compensate for residents' physical and cognitive impairments as well as sensory losses (Ernst-Drosdoski & Karpan, 1995). "A prosthetic environment for people with Alzheimer Disease includes way-finding [signage], wandering paths and camouflaged doors" (Ernst-Drosdoski & Karpan, 1995, p. 26). This type of environment promotes maintaining an individual's independence. For instance, with way-finding signs individuals may no longer be dependent on staff to find their way around the unit. By camouflaging exit doors,

individuals can be prevented from leaving the facility and becoming lost, therefore maintaining their safety without staff having to intervene and redirect the individual.

This concept also recognizes that the "...meaning which individuals attach to situations and events in their lives are key factors in understanding how individuals interact and understand their physical and social environment" (Bond, 1991, p.565). It is therefore important to know the experiences of a person living with dementia for it may assist staff to understand their patterns of behaviour and the meaning that they attach to the situation. For example, a person who had a frightening experience with water may become defensive with staff when having a bath. By knowing this, staff can avoid this difficulty by examining bathing alternatives for the individual. To obtain this information the individual's significant others, such as family members, are seen as vital when it comes to care planning. They provide insight into the individual's past and are, therefore, seen as part of the care team.

Last, since this perspective recognizes that an individual not only reacts to the physical environment but also to the social environment, it therefore, sees that the approach used in caring for individuals will determine how they react in turn. An approach can either lead to successful care or confusion, resistance and/or aggression; it can also increase or decrease a person's anxiety. For instance when a person living with dementia is approached in a rushed manner and care is not explained prior to it being given, he or she may become annoyed and upset. The end result may be confusion as to what is occurring, resulting in lashing out because the person does not understand what is occurring.

The focus of care according to this perspective is different from that based on the medical model. "Instead of relying on medication and other interventions used in medical models of care, alternatives or non-medical models utilize specially designed environments and specially trained staff to provide care..." for individuals living with dementia (Ernst-Drosdoski & Karpan, 1995, p.22). By the mid 1970's DCUs were incorporating this perspective into their care practices (Ross, 1999). The focus was placed on modifying the physical and social environment to reduce the demands placed on the cognitive abilities of the person. Staff training on approach and understanding of the relationship between the person and the environment, were viewed as important components to quality of care.

#### Progressively Lowered Stress Threshold

From the notion of person-environment fit and the ecological perspective developed the concept known as progressively lowered stress (Hall, 1988 cited in Chafetz, 1991). "This concept postulates that dysfunctional (i.e., catastrophic) behaviours result from patients' inadequate stress threshold; and suggests that these behaviours are lessened by relieving the offending stressors" (Chafetz, 1991, p. 251). This concept describes individuals living with dementia as having progressively lowered stress thresholds which cause them to be increasingly vulnerable to disturbances from the environment.

[A]s people who have Alzheimer's disease become more impaired, they are less able to receive and process stimuli. It is a principle of this model that agitated behaviours can be a sign of an inappropriate level of activities

and stimuli, and that the level should be modified accordingly to reduce stress (Coons, 1991, p.12)

The solution according to this model is to control or manage environmental stimuli. This can be done by eliminating ringing telephones, public address systems, televisions, and radios. Some DCUs have applied this perspective in the development of the physical environment by creating a “low-stimulus” environment in an attempt to decrease aggressive behaviours and increase positive social behaviours among residents (Cleary, Clamon, Price & Shullaw, 1988; Coons, 1991). As did the ecological perspective and the person-environment fit concept, the progressive lower stress threshold perspective continues to place focus on the importance of the relationship between individuals and their environments. According to the following model this focus is important but incomplete in regards to offering care and understanding the person with dementia.

#### Person-Centered Model of Care

The person-centered model of care heralded by Tom Kitwood (1997) evolved from the concept of reminiscing, validation therapy by Naomi Feil (Lacey, 1999) and client-centered therapy by Carl Rogers (Froggatt, 1997) and incorporates the ecological perspective. The person-centered model of care recognizes the role of the environment. It acknowledges the circular reaction that the individual has with his or her physical and social environments. It views the person living with cognitive impairment as being more dependent on his/her immediate environment (physical and social) than most people, and less able than most to take steps unaided, to adjust, adapt, and control all aspects of it. The person-centered model of care incorporates the concept of “excess disability”



(Martichuski & Bell, 1993). The underlying notion is that a person with dementia may present with increased disability, not as a result of the progression of the disease, but as a result of incompatible components of the social and physical environments.

This model also takes into account that a person's state of being is affected by other factors than just the pathology in the brain tissue or the environment. These factors include personality, life history, physical health and social psychology (Loveday & Kitwood, 1998). It is concerned with the maintenance of an individual's rights, while validating his or her feelings and experiences (Morton, 2000). The focus of care is on optimizing individual strengths, developing relationships, encouraging independence and offering choices (Morton, 2000). Care is flexible and individualized to meet the person's needs and maintain his or her dignity. Family members or significant others are seen as an integral part of the "care team". It is also recognized that it is not only the individual who may require support but family members as well (Woods, 1997).

According to Loveday and Kitwood (1998), there are ten key principles in this model. The following is a brief description of each.

- 1) Attend to the whole person, emphasizes the need to incorporate a holistic approach to care (mental, physical, social, psychosocial and spiritual).  
Dealing with a person's physical needs or illness should not be the only focus. Caring for a person's emotional, spiritual and psychological needs is equally important.
- 2) See each individual as special and unique, emphasizes the need for individualized care plans to meet individuals' unique needs, a fact more important than knowing a person has dementia. This concept also views the

development of relationships between the individual and staff as vital, for it leads staff to see those they care for as persons, referring to them by name not by their disease.

- 3) Respect one's past, refers to the importance of knowing and acknowledging a person's history and experiences and incorporating this into the care offered. This is required to understand how a person views and interacts with her or his environment. It is also required in order to fully appreciate a person's qualities.
- 4) Focus on the positives, refers to shifting the focus away from what individuals with dementia are not able to do, to focusing on the skills they have retained. This means that care plans "... should have a positive and proactive emphasis, showing precisely what interventions are needed to enable a person to retain as much independence as possible" (p. 13). Value is placed on assisting individuals' independence.
- 5) Stay in communication, emphasizes the importance in adapting the means of communication to match each person's ability. Instead of focusing on the verbal, focus is given to body language or non-verbal communication (i.e., approaching an individual with a smile, holding a person's hand when they are anxious). Equally important to communicating is active listening. This involves "... giving careful attention not just to the words, but also to the tone of voice and all other non-verbal signals" (p. 15).
- 6) Nourish attachments, as a concept takes into consideration that "... the instinct-like need for attachments remains when a person has dementia"

(p.15). It therefore recognizes that “good care” encourages bonds and attachments and the need for these individuals to maintain them in order to prevent isolation. This includes supporting families to maintain their relationship with their relatives who are diagnosed with dementia. It also means that relationships developed between residents within a care facility and between residents and staff should be encouraged.

- 7) Create a community, refers to maintaining and developing a sense of belonging for individuals with dementia. Personalization of residents’ rooms within care facilities would assist with this and should, therefore, be encouraged. It is important for individuals with dementia, especially for those living in care facilities, to see a familiar environment in order to feel a sense of security.
- 8) Maximize freedom, minimize control, as a concept identifies the need to modify environments within care facilities in order to increase freedom for residents and minimize staff control. This would include a change in staff approach to care. It would include staff who offer flexible care, choices and minimize chemical and physical restraint use in managing “behaviours”.
- 9) Give, but receive as well. This concept acknowledges three facts; that individuals who have dementia may also want to contribute to their environment, the desire to be givers is built into our human nature as part of our social instinct, and that all true human encounters are reciprocal (p. 18). It therefore encourages staff to assist individuals living with dementia to find opportunities to contribute to their community or environment. This can be

done, for instance, by offering the opportunity to assist with the routine on the unit, such as folding laundry, washing dishes or setting tables.

10) Maintain a moral world. The moral world of dementia "... generally requires [staff] to slow down, to let things happen at the person's own pace" (p. 19).

This also means that deception should be avoided so individuals living with dementia know that the environment is trustworthy. The goal is to enable these individuals to feel secure, valued, included and personally known within their environment.

A person-centred model of care has led to a shift in the culture of care for those individuals with dementia. As indicated by Loveday and Kitwood (1998),

"[t]he old culture of care tended merely to see behaviour, without making a serious attempt to understand its significance. A person-centred approach makes the assumption that everything that is said and done has some meaning, even if that meaning is partial or fragmented" (p. 20).

What is referred to as "problem" behaviours are seen as actions or reactions. Instead of focusing on the medical aspects of the disease and the losses, this model focuses on the psychological needs (comfort, love, inclusion, occupation and identity) and the strengths that the person still maintains. The focus is on the "person" and his or her uniqueness.

## **Review of the Empirical Literature**

### **Research Findings**

The growing interest in dementia care has intensified research in this area.

Research on DCUs can be categorized into three areas of study:

- 1) The impact DCUs and/or care practices related to these units have on residents. This may include, QOL, functional and cognitive abilities, behaviour management, use of chemical and physical restraints (Bellelli, et al., 1998; Gruneir, et al., 2008; Leon & Ory, 1999; Morgan & Stewart, 1998; Phillips, Sloane, Hawes, Koch, Han, Spry, et al., 1997; Reimer, et al., 2004; Wilkes, Fleming, Wilkes, Cioffi & LeMiere, 2005)
- 2) The level of satisfaction and/or family members' perspectives of impact that DCUs have on their relatives who reside on these units (Donovan & Dupuis, 2000; Parker-Oliver, et al., 2005).
- 3) The impact DCUs have on staff specifically addressing issues such as satisfaction, burnout and turnover (Donovan & Dupuis, 2000; Grant, Kane, Potthoff & Ryden, 1996; Karner, Montgomery, Dobbs & Wittmaier, 1998; Middleton, Stewart & Richardson, 1999).

For the purpose of this review, the focus of the literature review on empirical findings will be on the impact that DCUs have on residents' and family members' level of satisfaction and/or perception of impact that the DCU has on their relative.

The findings in terms of effectiveness of DCUs on residents are inconclusive. There are a number of studies which show positive effects, studies which show no statistical significance of effects and studies that show mixed results. Most studies

examine the impact of DCUs on its residents by measuring residents' physical functioning, cognitive status, and behaviours usually associated with dementia (e.g. reactive, pacing, hallucinations, and irritability), incidence of falls, sleep patterns, social participation, use of chemical and physical restraints, and family visitation.

The effect that these units have on residents' QOL has started to gain attention. There are a growing number of studies that are assessing this effect. This is an important addition to empirical findings for it offers a psychological and emotional component to the effectiveness of these units on its residents. The same can be said of family members' perspectives on the DCUs' effect. Historically this was not usually included in past studies, but is being included in more recent studies. Family members' perspectives related to how the DCUs affect their relatives' lives provide additional information on what is found to be effective, or not, in regards to features of DCUs and care practices.

Nine studies on DCUs and their impact on their residents were reviewed. Two of these studies focused mainly on family members' perspectives on how the DCU has had an impact on their relative's life. Out of the nine reviewed studies, two studies indicated mostly positive outcomes; one study showed no statistically significant outcomes and four showed mixed outcomes. The following section will consist of a review of these studies.

Bellelli et al. (1998) compared eight special care units (SCUs) in Italy. They measured the effect that SCUs had on their residents who were diagnosed with moderate to severe dementia and presented with reactive behaviours. Measurements were taken on 55 consecutively admitted residents over an 11-month period. Variables that were measured included cognitive and physical functioning, somatic health (number of chronic

diseases), use of psychotropic medication and number of reactive episodes. This study was designed as a time series with a baseline at admission. Measurements were taken at 3 months and 6 months after admission. There was no control group. There were a number of standardized tools used such as the Mini-Mental State Examination (MMSE) to measure the residents' cognitive level, Barthel Index to measure level of functioning (ability to complete activities of daily living such as bathing, dressing and eating), Neuropsychiatric Inventory to measure episodes of reactive behaviours (such as hitting, kicking and swearing) and the Cumulative Illness Rating in order to track the number of chronic diseases that each resident was diagnosed with. The outcome showed mostly positive findings. The study showed that the reactive episodes presented by residents decreased after admission to one of these SCUs. The study also showed that there was a decrease in psychotropic use and application of physical restraints which had been used to control the reactive episodes prior to the residents' admission to these units.

In the following study the effect that multiple occupancy (shared bedrooms) versus private rooms has on residents living on DCUs was reviewed. In this study, Morgan and Stewart (1998) examined two new DCUs built with private rooms. The residents who transferred into these two new DCUs came from either different DCUs or traditional units that had multiple occupancy per room (two-persons and four-persons per bedroom) within the same home. The sample of residents included 23 men and 23 women who were 60 years old or older, diagnosed with dementia with moderate to severe cognitive decline, who were mobile (with or without the use of a mobility aid such as a walker or cane). This study incorporated quantitative and qualitative methods. It used a quasi-experiment with a pre and post-test design and a comparison group. The

researchers took measurements at baseline (prior to the move), at 6 months and again at 12 months. Variables measured included the effect of private occupancy on disruptive and non-disruptive behaviours and their effect on night-time sleep patterns. There were two standardized tools used, Global Deterioration Scale (to assess cognitive level) and the Environment Behavior Interaction Code (observational tool). The quantitative findings, calculated through an analysis of variance, indicated that the duration of time participants spent alone in their own bedrooms during the day and early evening was greater for those in single versus double occupancy. This meant less time spent socializing with other residents. However, participants were also found to sleep better at night and there was a decrease in agitation and conflict among residents when in single occupancy. The qualitative component of this study, which included interviews with family and staff members, incorporated grounded theory methodology of analysis. Overall the results of the interviews indicated a value in person–environment interaction model, which stresses that in order for individuals to achieve optimal outcomes, the environment must adapt to meet the individual’s needs (Morgan & Stewart, 1998).

The first two studies reviewed found a number of positive outcomes for residents living on DCUs. The following five studies showed either no significant differences or a mixed outcome regarding differences in the effects of DCUs and traditional units on residents with dementia. Regarding restraint use, the following studies showed that DCUs can assist to decrease one type of restraint (physical or chemical) but not both.

Phillips et al. (1997) included all individuals admitted to a PCH between 1993 and early 1994 in four American states. In total there were 77,337 individuals included in this study from 800 facilities. These individuals included those admitted to SCUs, to



traditional units within PCHs with SCUs, and residents admitted to traditional units within non-SCU facilities. The PCHs' staff members completed all assessments using the Minimum Data Set (MDS) computerized tool. Data were obtained at multiple points (six) over a one year period. This quantitative study used a multi-variant analysis with controls (length of stay in the PCH, resident's age and baseline cognitive level). Findings indicated no statistically significant difference observed in the speed of functional decline for residents living on DCUs in comparison to those living on traditional units over time.

Wilkes, et al. (2005) assessed the effects that an environmental approach had on reducing agitation when persons living with dementia were relocated from an "old" or traditional unit to a purpose-built SCU within the same PCH. The design was a simple interrupted time series, quasi-experimental, with no comparison group design. Measurements were taken weekly for a month prior to the resident's move to the SCU and weekly for a month at 3 months and 6 months post move. Sixteen residents (13 female and 3 male) were included in the study. All of these residents had resided on the "old" unit prior to being relocated to the SCU. They ranged in age from 63 to 94. They had varying degrees of physical disabilities and different levels of cognitive decline. Variables measured included cognitive functioning, which was measured using the Severe Mini-Mental State Examination (SMMSE), functional abilities which were measured using the Functional Dementia Scale (FDS) and reactive behaviours which were measured using the Cohen-Mansfield Agitation Inventory. The use of psychotropic medication was also monitored during the assessment period. Results indicated no significant differences observed in the usage of psychotropic medication throughout the study. There were no significant differences in residents' functioning abilities, or

reactive behaviours over time. Reactive behaviours did decrease between the pre-move to 3 months post move period, but did not continue onto 6 months post move. What was found to have had a significant difference was verbal agitation. This behaviour was reduced and sustained for 6 months following relocation. This study indicated that environmental designs can have a positive impact in the care of persons living with dementia, but it did not indicate or find what these environmental designs were.

Leon and Ory (1999) compared SCUs with traditional units in their effectiveness in reducing physically reactive behaviours presented by residents. The study involved residents with dementia who were newly admitted to select PCHs between December 1992 and June 1994. They compared 432 residents who resided on SCUs to 164 residents who resided on non-SCUs over a 6 month period. Variables measured included physical reactive behaviours (such as hitting, kicking, grabbing, pushing, and punching) and the use of chemical and physical restraints. Statistical analysis of the data indicated that when differences in age and baseline levels of reactive behaviours were controlled, residents in SCUs showed no difference in frequency of these behaviours. Furthermore, rather than SCU placement, "... it was the increased use of psychotropic medication and the reduction in the use of physical restraints that showed a relationship with lower levels of physical aggressive [reactive] behaviours" (Leon & Ory, 1999, p. 273 ).

While the above three studies assessed the effect that DCUs had on stabilizing residents' functional ability or on decreasing reactive behaviours, the following study assessed the effect DCUs have on residents' QOL. Reimer, et al. (2004) compared a specialized care facility with traditional environmental facilities and its effect on QOL for residents diagnosed with middle to late stage dementia. The special care facility in this

study was a 60-bed purpose-built facility with ten people living in six bungalows, which followed an ecological model of care. This longitudinal matched-group designed study was conducted over a one year period, with QOL assessments that were completed every 3 months. The residents were matched on diagnosis of dementia, Global Deterioration Scale score and age adjusted comorbidities. There were a total of 185 residents assessed. There were 62 (newly transferred) residents included from the special care facility and 123 residents included from traditional institutional facilities. The residents in the “traditional facilities” group were composed of two groups. The first group consisted of residents who were in multiple traditional institutional facilities (MTIF), awaiting transfer to another facility (that was not considered a special care facility). This was to mimic what would happen to individuals who were not admitted to the special care facility. The second group consisted of residents who resided in a single traditional institutional facility (STIF) that were not waiting for transfer. This group would mimic what would happen to individuals if they were not admitted to the special care facility but still housed within the same general managed organization. The average age of the participants was 81.8 ( $\pm$  7.5) and 73.5% were female residents. The QOL outcomes were measured using a number of assessment scales (six scales in total). Research assistants were responsible for data collection and completion of two scales. All other assessments were completed by asking staff or family members for their observations of the residents over the previous week. The results indicated that the special care facility group demonstrated more sustained interest in the environment and less negative affect than residents in the traditional facilities. There was a trend for the special care facility group to show more reactive behaviours from the third data collection period onwards. There was a

significant difference found with residents' function and self care abilities. The MTIF group showed the least decline. The pattern of psychotropic medication use did not vary between groups and there were no significant differences found between the groups in regard to cognitive decline (specifically in concentration, memory and orientation), depression or social withdrawal. This study suggested that a purposively designed (physical and social) environment can have a positive effect on the QOL of its residents.

The above studies looked at the environments and how they affected residents. The following cross-sectional designed study by Gruneir, et al. (2008), differs from those cited above in that it examined the differences between DCUs and traditional units with regard to care practices rather than environmental features. Residents in this study had a diagnosis of Alzheimer disease or dementia and were assessed as having moderate cognitive impairment (score  $\geq 3$  on the MDS embedded Cognitive Performance Scale). They had resided on the unit for at least 90 days (average length was  $< 2$  years for both groups of residents). The average age ranged from 85 to 94. The PCHs chosen for the study had to have at least one DCU within the facility. There were 69,131 residents included in this study (from 1,896 different PCHs), 28,730 residents of which were on a DCU. Data regarding the PCHs were collected through the Online Survey Certification and Reporting System. Information on residents was obtained from the Minimum Data Set (MDS). Both of these programs are government (federally) run and staff on the units input the information. The care processes that were assessed included physical restraint use, number of psychotropic medication, use of feeding tubes, toileting and incontinence programs. Results indicated that there were differences in care provisions between DCUs and traditional units. There were no differences in use of physical restraints; however

fewer DCU residents were reported to have had bed rails. Residents on the DCUs were more likely to be on a toileting plan and less likely to use pads or briefs in the absence of a toileting plan. These residents were also more likely than non-DCU residents to have received psychotropic medication. The authors concluded that even though the resident's experience cannot be directly measured, they postulated that "... the more infrequent use of distressing procedures positively affects the resident. Also alternatives to these care processes require additional staff time and attention, which may independently contribute to a more positive [PCH] experience for residents and family" (p. 203).

The last two studies to be reviewed focused mostly on family members' level of satisfaction with the DCU and their perceptions of how the unit impacted on their relative's life. Parker-Oliver, et al. (2005) examined family satisfaction with DCUs using a comparative case study design. Family members were asked to complete The Family Perceptions of Care Tool, which measured family satisfaction in four areas: (1) the residents' environment, (2) physical care, (3) relationship among residents, staff and family and (4) overall care of residents. Family members were also asked to participate in a follow-up interview. There were five DCUs that were included in the study. Three of these PCHs were involved in the Alzheimer's Demonstration Program which had these units incorporate a social model of care. The remaining two homes had already established DCUs which were not part of this project. There were 47 surveys completed and 8 family members participated in the interview process. Results indicated that there were no significant differences in the levels of satisfaction among family member groups. There were no significant differences in levels of family members' satisfaction related to participation in the Demonstration Project, except in the area of secure wandering.

Family members involved in the Project were satisfied with this addition of increased security. The new design and program features did not change family members' perception of the quality of care provided. Family members regardless of group felt more activities could be offered and did notice staffing concerns such as turnover and availability. Last, families did not identify design features, programming or social models as being central to their selection decision of PCH.

Donovan and Dupuis (2000) investigated the perceptions of family members regarding the characteristics of a SCU and how they contribute to positive outcomes for residents living with dementia. The SCU included in this study was a newly constructed, 24-resident unit within a 150-resident PCH, specifically designed to address the needs of residents with dementia. This qualitative study used in-depth semi-structured interviews with 17 family members of residents residing on this SCU. Family members included lived in close proximity to the facility and visited at least once a week. They included spouses, siblings and children. The interviews indicated that family members perceived the SCU had a positive impact on residents' lives and attributed three major reasons for this positive influence. The first included fostering residents' feelings of personal space, which meant residents, felt they had a physical area that specifically belonged to them, providing opportunity for personal expression and privacy. This was enforced by residents having private bedrooms and bathrooms, small group seating arrangements for socialization, an enclosed garden courtyard, a cozy kitchen and shadow boxes positioned outside each resident's room and used for arrangements of personally meaningful mementos. The second reason included residents' opportunity for expression of personhood. This was described as staffs' understanding of each resident's unique life

history and their response to each resident as an individual with unique needs and preferences. Most importantly it was noted that staff members were knowledgeable on the dementia process, this was a result of extensive in-service training. Personhood was also fostered by staff members' involvement in residents' activities. The last characteristic of the SCU considered influential in improving resident outcomes was the concept of flexible routine. This fostered residents' rights to establish personal preferences for scheduling daily activities such as bathing, eating and sleeping. According to the authors, these characteristics "... provide some practical strategies concerning special care unit design, care philosophy and staffing organization" (p. 33).

Overall, research on DCUs indicate mixed outcomes (refer to Table 1.1). The difference could be due to the fact that when comparing DCUs with non-DCUs, it is difficult to match individuals on the two different care units. There can never be a perfect match, therefore causing a difference from the beginning. This difference could also be related to the fact that DCUs are different in physical features, philosophy, and programming. It is these differences that make it difficult to conclude on the effectiveness that DCUs have on their residents. This is one reason why standard features are required for these units. Both residents and family members should be involved in the development of these standards. According to Parker-Oliver, et al.(2005), policy is too often "... made in isolation from the implementation and experiences of those it is meant to serve and as a result does not have the outcomes which were intended" (p. 123). At a minimum, residents and family members should continue to be included in future studies in order to provide their perceptions on the benefits of these specialized units.

**Table 1.1**  
Summary of Reviewed Studies

Name of Study	Investigator(s) and Year	Design	Number of Subjects	Variables Researched	Results
1. Special Care Units for Dementia Patients: A Multicenter Study	Bellelli et al., 1998	- Time series design with no comparison group. - 6 months	- 55 consecutively admitted residents - 8 DCUs	- Cognitive and physical functioning - Somatic health - Psychotropic use - Reactive behaviours	- Use of psychotropics and physical restraints decreased. - Reactive behaviors improved - No improvement with cognitive status and physical functioning.



**Table 1.1**  
Summary of Reviewed Studies

Name of Study	Investigator(s) and Year	Design	Number of Subjects	Variables Researched	Results
2. Multiple Occupancy versus Private Rooms on Dementia Care Units	Morgan and Stewart, 1998	- Part quasi-experiment with pre-post test with comparison group - Part qualitative -12 months	- 23 men and 23 women on two different DCUs	- Disruptive and non- disruptive behavior	- Time residents spent alone in own bedroom during the day and early evening was significantly greater for those in private rooms - Also found better sleep and decrease in agitation

**Table 1.1**  
Summary of Reviewed Studies

Name of Study	Investigator(s) and Year	Design	Number of Subjects	Variables Researched	Results
3. Effect of Residence in Alzheimer Disease SCUs on Functional Outcomes	Phillips et al. 1997	- Quasi-experimental design with a comparison group - 12 months	- Residents admitted to SCUs and traditional units in 4 US states - 77, 337 residents	- Physical functioning	- No significant differences in the speed of decline for residents in both groups.
4. Environmental Approach to Reducing Agitation in Older Persons with Dementia in a Nursing Home	Wilkes, Fleming, Wilkes, Cioffie and LeMiere, 2005	- Interrupted time series, design with no comparison group - 6 months	- 16 residents who moved from an "old" unit to a DCU in same PCH - 13 females, 3 males	- Reactive behaviours - Cognitive and physical function - Psychotropic medication use	- No difference in cognitive and physical function, psychotropic use and behaviours except verbal agitation

**Table 1.1**  
Summary of Reviewed Studies

Name of Study	Investigator(s) and Year	Design	Number of Subjects	Variables Researched	Results
5. Effectiveness of SCU Placements in Reducing Physically Aggressive Behaviours in Recently Admitted Dementia Nursing Home Residents	Leon and Ory, 1999	-Quasi-experimental design with comparison group - 6 months	- 596 residents admitted between 1992 to 1994 to DCUs or non-DCUs - 432 residents were in DCUs and 164 were in non-DCUs	- Physical aggression - Use of chemical and physical restraints	- No difference in behaviors - Increased use of chemical restraints for residents in the DCUs - Decreased use of physical restraints

**Table 1.1**  
Summary of Reviewed Studies

Name of Study	Investigator(s) and Year	Design	Number of Subjects	Variables Researched	Results
6. Special Care Facility Compared with Traditional Environments for Dementia Care: A Longitudinal Study of Quality of Life	Reimer, Slaughter, Donaldson, Currie and Eliasziw, 2004	- Longitudinal with comparison matched group - 4 follow-up assessments over 12 months.	- 185 residents, 62 living in a Special Care Facility (SCF), 123 living in traditional care facilities.	- Quality of Life Scores taken at Baseline, 3, 6, 9 and 12 months.	- SCF group showed less fear and anxiety, but more agitation. - No difference on memory, concentration, orientation, depression or psychotropic use

**Table 1.1**  
Summary of Reviewed Studies

Name of Study	Investigator(s) and Year	Design	Number of Subjects	Variables Researched	Results
7. Is Dementia Special Care Really Special? A New Look at an Old Question.	Gruneir, Lapane, Miller and Mor, 2008	- Cross sectional design with a comparison group	- 28, 730 residents in SCUs - 40, 401 residents in non-SCUs - Minimum of 3 month residency	- Physical restraint and psychotropic medication use - Incontinence care - Reactive Behaviours - Looked at care process not functional outcomes	- No difference in use of physical restraints - SCU group more likely to be on a toileting plan and less likely to use pad/briefs. More likely to use psychotropics and had increased behaviours.

**Table 1.1**  
Summary of Reviewed Studies

Name of Study	Investigator(s) and Year	Design	Number of Subjects	Variables Researched	Results
8. Dementia Special Care Units: A Policy and Family Perspective	Parker-Oliver, Aud, Bostick, Schwarz and Tofle, 2005	-Comparative Case design using a structured survey and personal interview	- 47 families with a relative living in a SCU, 8 families participated in a follow-up interview	- Family satisfaction with environment, physical care of relative and staff relationship	- Increased satisfaction only with increased secured unit
9. Specialized Care Unit: Family and Staff Perceptions of Significant Elements	Donovan and Dupuis, 2000	- Qualitative study	- 17 families with relatives living on a (SCU) and 8 staff members who worked on this unit	- Family and staff perceptions regarding features of a SCU and its impact on residents	Positive perception due to: personal space, expression of personhood, and flexible care

## Methodology

The majority of the reviewed studies incorporated a quantitative quasi-experimental design that included multi-variant analysis or they used a pre and post-test design with multiple measures. Some studies involved single units while others compared multiple DCUs. Other studies compared DCUs with non-DCUs. Only one study (Morgan & Stewart, 1998) combined quasi experimental and qualitative methodology design which included in-depth interviews with family members and staff. The length of studies varied, most used either a 6 month or 12 month measurement period. Most of the studies included standardized instruments to collect data, except for one (Donovan & Dupuis, 2000) which was a qualitative methods study that included in-depth semi-structured interviews. Some relied on unit staff to complete the measures (Gruneir, et al., 2008; Phillips, et al., 1997; Reimer, et al., 2004). Most relied on observation and data found in residents' charts or in MDS (Bellelli, et al., 1998; Gruneir, et al., 2008; Leon & Ory, 1999; Morgan & Stewart, 1998; Phillips et al., 1997; Reimer, et al., 2004; Wilkes, et al., 2005).

## Limitations

There were a number of limitations found in studies assessing the effects of DCUs which can possibly lead to biases affecting the results. This is especially true when random selection is not possible with controlled and experimental groups being compared. Sloane, Lindeman, Phillips, Moritz and Koch (1995) identified a number of sources of research biases. They defined biases as referring to "... misinterpretation taken on the effect of exposure on an outcome because of systematic differences in the way

subjects and controls have been selected or measured, or because a second explanatory variable confounded the estimate of the relationship between the exposure and outcome of interest” (p.105).

Sloane et al. (1995) identify the following types of systematic bias in quasi-experimental design studies of special care units.

1) Selection of subjects and controls

Bias occurs when study subjects in a research group differ systematically from those in the comparison group, leading to a distorted estimation of effect.

a) Facility level

Studies with comparison groups at times include a comparison group (traditional unit) from a different facility. At times these different facilities have DCUs and sometimes they do not. Facilities with DCUs can differ from those without. An example of this bias can be seen in the study by Leon and Ory (1999), in which they compared residents who were admitted to DCU facilities with those who were admitted to traditional units within non-DCU facilities. The differences between the facilities, such as their philosophy, staffing levels and type of staffing could have affected the outcomes instead of the differences between the two types of units (DCUs versus traditional units).

b) Resident Level

A second type of sampling bias can occur at the resident level. This problem of differential selection arises because DCU populations are likely to differ



systematically from those of the comparison units in terms of prevalence of comorbid conditions, length of stay, and type of dementia represented (Sloane et al., 1995, p. 106). The study by Gruneir, et al. (2008), found differences in the characteristics of residents in DCUs as compared to non-DCUs. The residents in DCUs were younger in age, require less physical care and receive more psychotropic medication possibly indicating increased reactive behaviour concerns than residents in non-DCUs. Such biases may make DCUs appear superior to the comparison setting.

This bias could have affected the outcome of some of the studies reviewed. For instance, the study by Reimer, et al. (2004) compared the QOL of residents of a dementia care facility with those either in multiple traditional institutional facilities (MTIF) or single traditional institutional facilities (STIF). Baseline measurements were taken on each group of residents however, these residents were in different locations at time of baseline. Some of those in the special care facilities or MTIF were in their own homes; others were on acute care facilities, traditional care facilities or assisted living facilities. Those in the STIF group were primarily on a psychogeriatric unit. The location of these individuals at the time of the baseline could have affected the baseline measurement. Those in acute care facilities could have had increased health concerns that could have affected the QOL measures indicating a lower score than those at home or in another facility. As well, those in psychogeriatric facilities could have been experiencing increased behavioural concerns which again would have caused an effect on baseline

scores and therefore showing a higher difference between baseline score and following scores. Furthermore, there was a second difference between the groups, the age of the residents, with those in the special care facility being younger. It is always difficult to match precisely the two groups and random selection is not always possible or ethical to minimize this effect. Another possible solution to minimize this effect is through statistical testing in which these variables could be controlled.

#### c) Treatment Diffusion Bias

When treatment and comparison subjects are drawn from the same facility, there is a risk of treatment diffusion bias. This may occur when staff from DCUs transfer to non-DCUs and treatment and techniques in the DCU becomes introduced elsewhere in the facility.

In the studies reviewed, only one identified that staff on the DCUs were consistent (Donovan & Dupuis, 2000). For the other studies, staff may have been able to rotate onto the DCU from other units. Therefore, training that these staff received while on the DCUs could have been transferred onto the traditional units and possibly influence the outcome of the study.

#### 2) Attrition of subjects

There are a number of sources of attrition that can occur in research, especially longitudinal studies. These include residents transferring off the unit, residents and/or family members refusing to continue in later phases of the study and a

resident dying during the study period. These occurrences could affect outcomes.

Another source of attrition which is unique and a critical threat to the validity of DCU studies is that of selective discharge bias. Dementia care units often have a policy which indicates that residents are discharged from the unit once they are unable to respond to and benefit from the DCU environment. Discharge criteria usually include increased behaviours such as physical aggression, decreased functioning, or complex medical conditions. Selective discharge bias can make a DCU's care appear to be superior to care offered on a traditional unit.

An example of attrition bias can be found in the study by Leon and Ory (1999), who conducted a longitudinal study. During the time of the study, there were residents who were discharged from the DCU and residents who passed away, therefore, measurements obtained from these residents were not included in the findings. The fact that residents were not included could have had an effect on the outcome of the study. The same can be said regarding the study completed by Reimer and associates (2004). In their longitudinal study there were residents who passed away and family members who withdrew permission for continued participation. Measurements obtained from these residents were also excluded from the results of the study and therefore could have affected the outcome of the study.

### 3) Measurements

#### a) Insensitive Measures Bias

This bias is concerned with the reliability and stability of dependent measures which may not be sensitive enough to detect meaningful change. There is particular concern in the use of measurement tools and the issue of subjectivity. This bias can be seen in some of the studies reviewed in the fact that the tools used were subjective, questioning the reliability of the measure. For instance, the study by Gruneir, et al. (2008) mentioned that even though staff receives training on Minimum Data Set (MDS) applications and even though MDS has undergone reliability and validity testing, there were still data quality concerns with how staff interpreted the questions. In some areas, MDS is subjective. This could mean that while one staff member interprets a resident's behaviour or concern and documents it one way, a different staff member may interpret the same behaviour or condition differently and input different information. Gruneir, et al. (2008) indicated that "... interfacility differences in data quality have been reported" with MDS (p. 204).

This bias could also have been a problem in the study by Wilkes, et al. (2005), who used two behavioural observational scales (FDS and CMAI) completed by unit nurses. Even though the staff who used these scales obtained training on their use, interpretation of the scales remained subjective. This therefore could mean that while one staff member would consider an incident as a behaviour episode and document it, another staff member may not and therefore not include it into the data.

b) Risk of Interviewer Bias.

Interviewers are not always blind to the control and experimental groups, possibly leading to interviewer biases. These interviewers may inadvertently show favorable results in the experimental group. This bias could have been a factor in the majority of the studies reviewed. For those studies that had comparison groups (Gruneir, et al., 2008; Leon & Ory, 1999; Morgan & Stewart, 1998; Phillips et al., 1997; Reimer, et al., 2004), none incorporated blind procedures of the control and experimental groups for the researchers. Second some of the studies used staff to obtain the data (Phillips, et al., 1997; Wilkes, et al., 2005). Staff members can be viewed as wanting to present their units in a positive light and, therefore, this affects the way measurements are taken or what is and is not included.

There were other difficulties associated with studies involving DCUs. For instance, none of the studies reviewed included residents' perspectives. Interviews were held with family and/or staff members instead (Donovan & Dupuis, 2000; Morgan & Stewart, 1998; Parker-Oliver, et al., 2005). If residents' perspectives had been included results may have been different. Another difficulty that was identified with the reviewed studies included the fact that units varied greatly in certain aspects such as in size (6-24 residents), philosophy, staff ratio, and resident characteristics. These differences can influence results, making it difficult to compare outcomes. Some of the studies reviewed

also included small sample sizes (Donovan & Dupuis, 2000; Morgan & Stewart, 1998; Wilkes, et al., 2005), which affects the level of significance in findings.

A second concern was related to the fact that in some studies, researchers relied heavily on unit staff and medical records (Gruneir, et al., 2008; Phillips, et al., 1997; Reimer, et al., 2004). There is risk of error in recording and at times some types of information are not included in the medical charts. A third concern is related to the fact that some studies used pre-and post-testing (Leon & Ory, 1999; Morgan & Stewart, 1998; Reimer, et al., 2004). The problem with this is that some studies involved short periods of time for their baselines, ranging from a few days to a month prior to admission to the units, which may not have allowed for measurements of trends. The individual's situation could have been improving or deteriorating prior to the admission, and therefore the outcome of the effect would not be due to the unit, but the individual's own changing condition. Even for those studies that have included a comparison group, this threat to internal validity due to interaction of selection with maturation can still occur. One way to minimize the threat and identify a trend could be done if the baseline is taken for a longer period. Another vulnerability in internal validity can occur between experimental and control groups due to interaction of selection with history. This would mean that extraneous events could coincide in time with the manipulation of the independent variable and therefore affect the outcome. This threat is difficult to control especially when random selection between the controlled and experimental groups does not occur. Last, there were some studies that did not include a comparison group (Bellelli et al., 1998; Wilkes, Fleming, Wilkes, Cioffi & LeMiere, 2005), which can make it difficult to

determine the outcome effectively. In these cases it is difficult to differentiate between unit effect and external effect.

### **Identification of Theoretical, Empirical, and Methodological Gaps**

The research conducted on DCUs usually tends to focus on physical, cognitive, and behavioural characteristics of care. There is a gap in the empirical literature regarding the effects of DCUs on the QOL of their residents. However, research in this area is growing. To measure the impact of DCUs, quality of life needs to be included. In the past, standardized measuring tools that effectively measured the QOL in persons with dementia did not exist. This has changed and there are now a number of standardized measurement tools that have been found to be reliable and valid in measuring QOL in persons with dementia. A second limitation is related to the fact that few studies include family members' perspectives on the benefits of DCUs related to their relatives. No studies were found that included the residents' perspectives compiled through interviews or satisfaction surveys. These are areas that need to be explored further.

## **CHAPTER THREE – RESEARCH DESIGN**

### **Research Site**

The research site selected for this study was Holy Family Home, a 276-resident PCH in the North end of Winnipeg. This residence is a not-for-profit PCH, established in 1957, with the purpose of providing health care services to the aged with special emphasis placed on creating an environment that supports the spiritual and cultural traditions of Ukrainian Catholics (Holy Family Home Brochure, undated). It is owned and operated by the Sisters' Servants of Mary Immaculate, a Ukrainian Catholic order of nuns. According to the statistics compiled by the Social Work department at Holy Family Home on September 15, 2006, most of the residents in this home are of Ukrainian (72%) and Polish (15%) ethnicity. As well, 50% of the total resident population identified themselves as Ukrainian Catholic followed by Roman Catholic (25%) and Ukrainian Orthodox (13%). Since this PCH is a Ukrainian Catholic facility, emphasis is placed on creating an environment that supports the Ukrainian Catholic culture. This is reflected through artifacts and icons found throughout the home. As well, a key aspect of this cultural group is their religious traditional beliefs. For this reason there is a Chapel in the facility that offers Ukrainian Catholic services. Furthermore, Ukrainian Catholic traditions and celebrations are maintained, such as Ukrainian Christmas, blessing of the baskets during Easter and the blessing of the fruit during Harvest season. Food is also a central part of the culture and therefore Ukrainian dishes are incorporated into daily meals. Last, the ability to communicate in one's own language is crucial. For many of the residents in this facility, English is not their primary language, and they are more comfortable speaking Ukrainian. Attempts are made to hire staff who are fluent in



Ukrainian or any other Slavic language. As well, programs offered at the home incorporate the language and traditions of the Ukrainian culture. For instance, dance folk groups perform at the home along with Ukrainian choirs and Ukrainian poetry and readings are shared with residents in weekly unit programs. Celebrations of birthdays or anniversaries incorporate the tradition of singing “Mnohaya Leeta,” a greeting song wishing long health and happiness. At Christmas hymns are sung in English and Ukrainian. Although the target population of this home is Ukrainian Catholics, the home does accept persons from other religious and ethnic backgrounds.

The home provides a range of services and programs, such as medical care, 24-hour nursing care (includes nurses and health care aides) and therapeutic services including physiotherapy, occupational therapy, social work, pastoral care, nutritional dietetics and therapeutic recreation. Other services include volunteers, housekeeping and laundry, dental, pharmaceutical and podiatry. Holy Family offers a number of community programs such as an Adult Day Program, Respite, Meals on Wheels, a 55+ seniors’ apartment (43 suites) and an information line. Currently this home has 374 employees, of whom 88% are female.

A Residents’ Bill of Rights is displayed on all the units and in the main hallway. It has four sections which include the following: every resident has the right to information and freedom of expression, to privacy, to respect and dignity, and to care. The home’s Mission is “To minister personal care and related health services to the elderly in a holistic approach with compassion and with the love of Christ” (Holy Family Home Brochure, undated). It also follows a philosophy of care for residents which

incorporates nine themes and is recognized on all the units (refer to Appendix A). This philosophy emphasizes and incorporates a person-centred model of care.

In 1999, Administration approved the development of two DCUs to offer specialized dementia care. This was in reaction to a review that was conducted in 1999, which showed that 80% of the residents in the home had a diagnosis of Alzheimer disease or a related dementia, and an estimated 23% were seen as benefiting from a specialized unit due to safety concerns related to pacing, restlessness and anxiety. Furthermore, Holy Family is the only Ukrainian Catholic PCH in Winnipeg. Therefore, prior to the development of these units, there were no alternative units available to offer specialized dementia care services that would meet the cultural and religious needs of this particular ethnic group in Winnipeg.

Planning for this project commenced in 2001 with a Steering Committee composed of the Director of Program Planning and Allied Health, a nurse (Unit Team Leader), three health care aides, a therapeutic recreation worker, the Coordinator of Recreational Services, a social worker, and a family member (whose mother was diagnosed with Alzheimer's Disease and was a resident of this home). This Committee also received input from the Alzheimer Society and from a private designer on physical environmental design options that would assist people living with dementia. The Committee was responsible for developing admission and discharge criteria (refer to Appendix B), the philosophy of the units (refer to Appendix C), and deciding on design options for the units. The admission and discharge criteria that were developed are similar to what is typically found as standard criteria in the literature (Day, Carreon & Stump, 2000; Mace, 1991; Mitchell-Pedersen, 2003). The admission criteria identifies

the target population for the DCUs. The discharge criteria addresses the type of issues that the units are not able to manage, specifically in regard to extremely reactive behaviours. The philosophy of the DCUs also incorporated a person-centered model of care, which takes into account that a person's state of being is affected by factors other than just the pathology. It focuses on the effect that the physical and the social environments have on individuals and it acknowledges their impact with excess disability. It acknowledges the circular reaction that the individual has with their environments and focuses on the importance of approach to care, personalization of space and homelike features. It acknowledges the importance of maintaining the individual's rights and validating their feelings and experiences. It acknowledges that each individual is unique with unique needs, even though they share a common diagnosis of dementia and, therefore, it stresses that the approach to care needs to be flexible and creative. It acknowledges that care should not focus on what is lost but on how to optimize the individual's strengths. Last it recognizes that family members are an important part of the care team and are included in care planning.

Two units were chosen to become DCUs. One unit, St. Francis is a 29 resident unit and has private and semi-private rooms (two people sharing a room). The second unit, St. Michael, is a 40 resident unit with private rooms, composed solely of male residents. A concern was noted by the Steering Committee related to the size of these two units and whether they could be successfully transformed into DCUs. The literature indicates that DCUs should be smaller, 5 to 15 residents in order to control for stimuli (Coons, 1991). However the Committee and Holy Family Administration decided to continue with the plan to retrofit these units into DCUs. This included physical changes

creating a “homelike” environment with distinguishable rooms, such as a kitchen and living room. The goal for the physical environment was to minimize the “institutional feel.” New furniture (upholstered chairs versus vinyl) was provided and greater open space was created. For instance, on St. Michael unit, the balcony was converted into an all season room opening into the dining room, and St. Francis unit has a small outdoor patio with a gazebo. All exits on these units are secured. There are trunks and rummage drawers placed strategically on the units to allow residents the opportunity to rummage. “Life Care Centers” have been added to the units and focus on a memory or significant topic related to the life experiences of the residents. For instance, on St. Michael unit there is a center with memorabilia and photos of The Canadian National Pacific Railway (CN), since most of the residents were employed by CN. Last, instead of meals being served on trays, St. Francis introduced buffet-style meals. This is a service in which staff members provide meal choices to residents and serve one item of the meal at a time, so as not to overwhelm the residents. The literature on meal services and dementia care indicates that institutional practice of meal delivery (cafeteria tray service) is more appropriate for young cognitively well functioning individuals (Young, Binns & Greenwood, 2001). This system fosters dependency and may overwhelm individuals by having all of the food items served together (difficult to decide what to eat first). This could cause increased confusion and frustration, leading to challenging behaviours (Altus, Engleman & Mathews, 2002). The plan with this new meal service at Holy Family was to eventually offer the service for all three meals on all units within the home. The plans for the transformation of these two units are ongoing and these units continue to evolve.

The process of retrofitting two traditional units into specialized DCUs began in December of 2003, and most of the renovations were completed by October of 2004. Residents continued to live on these units as the transformation progressed. As new residents were admitted to the units, they were admitted under the admission criteria for the DCUs (Appendix B). Those who were residing on the units prior to the decision to modify them and who did not meet the admission criteria had the option of remaining on the unit or being transferred to a different unit. Full and part-time staff members who work on these units are consistent, meaning that they do not work on other units. This is mostly true of all units in this home, which promotes consistency of care. Residents are familiar with the staff members and the staff members with the residents' care needs. As well family members become familiar with staff. The only time that regular staff would be replaced with casual (or non-regular) employees is on their days off or when they are on holidays. This consistency also allows for unit team building among staff members. These staff members tend to rely and count on each other for assistance. Last, the majority of the staff (approximately 90%) that work on these two units (all shifts and departments) have completed a one-year training course, which consisted of 15 modules related to dementia care. Facilitators of this education included two paid consultants and the Education Coordinator of the Alzheimer Society of Manitoba. Staff members received a certificate once all modules were completed (May 2004). The expectation is for staff to obtain ongoing education through in-services offered at the home and through conferences or seminars. Funding for these changes came from donations to the home, funds allocated from the budget and from fundraising activities.

Discussion regarding increased staff-resident ratios continues to date. At present staff-resident ratio (health care aides or primary care givers) on days is 1:8, during the evenings it is 1:10, and at night it is 1:19. There has also been discussion regarding increasing the availability of therapeutic recreation services from eight hours to twelve hours a day for 6 days per week. This has not yet been approved.

St. Francis, one of the two DCUs, was chosen to be part of this study. The reason for selecting this unit was due to the potential for identifying whether unit size (29 residents as opposed to 40 residents) could have an effect on the residents' QOL. A second unit, St. Joseph, considered to be a traditional unit (40 residents), was included as the comparison unit. There are a number of differences between these two units. These differences were documented and are part of the Results section of this study.

### **Research Question and Hypotheses**

The purpose of this research was to evaluate the effect that a DCU at Holy Family Home had on the residents who lived on this unit. This evaluation used both qualitative and quantitative methods to address the following questions:

- 1) How will the dementia care unit have an impact on residents' quality of life? This was measured by having residents on the two units answer a quality of life questionnaire, Quality of Life-Alzheimer Disease Scale. As well, staff members on these two units completed the same questionnaire on behalf of their resident (quantitative evaluation).

Hypotheses:

- 1.1 It is expected that the quality of life for residents who reside on the dementia care unit, will be higher as compared to those residents who have a diagnosis of dementia and reside on the traditional unit.

2) How effective will the dementia care unit be in managing reactive behaviours?

The behaviours of particular interest were physical aggression (hitting, kicking, slapping, biting, punching, and scratching) and verbal aggression (swearing and threats). This was measured by the number of occurrence reports related to aggressive reactions, completed by staff on the unit and through the number of chart entries made in the residents' medical charts, regarding aggressive occurrences (quantitative evaluation).

Hypotheses:

- 2.1 It is expected that residents who reside on the dementia care unit will present with fewer reactive behaviours as compared to those residents who have a diagnosis of dementia and reside on the traditional unit.

3) Does the dementia care unit meet family expectations related to the care of their relative? Are they satisfied with the care and the unit? In order to obtain an understanding of the family members' perspective of the unit benefit on their relatives and their level of satisfaction, a semi-structured interview was held with individual family members. During the interview family members were

encouraged to provide as much descriptive information as possible (qualitative evaluation).

#### Hypotheses:

- 3.1 It is expected that family members with relatives living on the dementia care unit will express greater satisfaction with care as compared to family members with relatives diagnosed with dementia who reside on the traditional unit.
- 3.2 It is expected that family members with relatives living on the dementia care unit will express greater satisfaction with the care environment (physical layout and programs) as compared to family members with relatives diagnosed with dementia living on the traditional unit.

Overall it was expected that this study would find that the dementia care unit would have a positive effect on the quality of life of its residents, and in turn, the family members of these residents would feel more comfortable with the care and unit.

#### **Research Design, Sample Definition and Recruitment**

The mixed design of this study included both quantitative and qualitative components. This was a quasi-experimental research with a comparison group. Quantitative data were collected using standardized measurement scales. The qualitative component included semi-structured interviews with family members. Both quantitative and qualitative methods were used for analysis of the information obtained. There have



been similar studies that have incorporated both quantitative and qualitative components into their design and analysis (Morgan & Stewart, 1998; Parker-Oliver, et al., 2005).

Both components are used to assist in creating a better understanding of the issues.

The residents considered for the study were those residing on St. Francis unit (the DCU, research group) and St. Joseph unit (the traditional unit, comparison group) who had resided on these units for at least three months, who had a diagnosis of dementia and presented with mild to moderate cognitive deficits (Folstein score between 9 and 21).

The inclusion criteria of family members for the interview were those related to residents who met the criteria for the study and who visited the resident on a regular basis (at least once a week). It was felt that if a family member who had regular visits with the resident would have a better understanding of what was occurring on the unit and how the unit and staff have an impact on the resident. A list of the family members who qualified for the interview was developed by the researcher. The list was randomly divided between the researcher and research assistant who then contacted the family members or significant others on the list to negotiate a time for the interview. The staff members participating in this study were full or part-time day shift primary caregivers (health care aides) for residents that met the inclusion criteria.

Prior to commencement of this study, informed consent was obtained for all residents, family and staff members. If a resident had been deemed incompetent to give consent, then their substitute decision maker was approached for consent (Health Proxy, a person with a court appointed Committeeship, or family member designated as a substitute decision maker by the PCH). A letter outlining the study was delivered by a third party (a research assistant) to each resident and/or their substitute decision maker,

family and staff members (refer to Appendices D, E and F). This letter identified the purpose of the study, the procedures and its measures, time length, and possible harm and benefits of the study. It also stated that there would be attempts to protect the identity of the participants. Since the researcher in this study was also an employee of the home (social worker) who worked on both the DCU and the traditional unit, there was a concern that consent would be influenced by this factor. Due to this the true identity of the researcher was withheld and instead my academic advisor Dr. Tuula Heinonen, was listed as the researcher in the consent letters to residents, family and staff members. Once the research was completed, the true identity of the researcher was identified to the staff members and an explanation as to the reason for the deception provided. A meeting to review the findings of this study with residents on both units and family members will be scheduled. At this meeting the explanation for the deception will be shared with all residents and family involved.

The consent letters specified that each resident, family and staff member would be assigned an identification number or pseudonyms to keep their identity confidential. Only the researcher and research assistant know their identity. No names were used in this study. The consent letters identified what parts of the resident's chart would be used for the purpose of the study. The letters also offered contact information for the University of Manitoba Human Ethics Secretariat. The resident and/or their substitute decision maker were asked for consent to obtain the information from the resident's chart (as per Personal Health Information Act requirements).

Residents or their substitute decision makers, family and staff members were informed that they had the right to leave the study at any point in time. A letter from the

Administrator of the home was also provided to each resident and/or substitute decision maker and family member reinforcing that care to the resident would not be compromised whether or not they decided to participate in the study (refer to Appendix G). This was an attempt to reassure residents and family members that if they did not want to participate they were not obligated. A letter was also given to each staff member (refer to Appendix H) emphasizing that there would be no repercussions had they chosen not to participate. If consent was given, then a consent form would be completed by the resident or substitute decision maker, family and staff member (refer to Appendices D, E and F). The size of the study depended on the number of residents that met the criteria and agreed to participate. The hope was to have at least twenty residents from each unit in the study and a family and staff member (health care aide) for each resident participant.

Since the researcher was also an employee of the home, to avoid possible measurement biases, the researcher randomly assigned half of the residents on each unit to the research assistant to gather data and complete the standardized measurement tools, and the other half to the researcher. Last, recruitment of residents, family and staff members for the study was made by the research assistant to avoid potential biases of undue influence for residents, family and staff members to participate.

## **Measurements**

In order to measure QOL and episodes of reactive behaviours (verbal and physical), the following methods of data collection were chosen and used:

## Quality of Life

### Quality of Life – Alzheimer’s Disease Scale (QOL-AD)

This scale, (refer to Appendix I) developed for individuals living with dementia has 13 items, which focus on QOL domains found to be important in cognitively impaired older adults (Logsdon, 1996). They cover “... the domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self, and life as a whole” (Thorgrimsen, Selwood, Spector, Royan, Lopez, Woods & Orrell, 2003, p.203). There were two steps to completing the scale. The first involved administering the scale in an interview with the individual whose QOL was being measured. There were instructions on how to ask each of the thirteen questions (refer to Appendix J). The second step was to offer the scale to a family member or caregiver (a person who knows the individual well and sees them on a regular basis) to complete (refer to Appendix K). To maintain consistency, the residents’ primary care givers (day shift) on the unit (health care aides) were the ones chosen to complete the questionnaire and not the family member. This decision was made since not all family members live in the city and some residents were under the care of the Public Trustee’s Office and had no regular contact with relatives or significant others.

The QOL scales were the same and they were tabulated in the same fashion. The measure consisted of 13 items rated on a four point scale, 1 being poor and 4 being excellent. Total scores range from 13 to 52. Scoring was the sum of all items. Resident and caregiver reports can be evaluated separately and/or combined into a single score if desired. The higher the score the higher the person’s QOL. When calculating the score on a scale with missing data, the mean item value is substituted for the missing data.

This is done when there are two or less values on the scale missing. If more than two values are missing the total score is entered as missing (R. Logsdon, personal communication, May 3, 2006).

Due to possible language barriers, interpreters were used to pose the questions when necessary. To ensure that the content of the tool was maintained with the interpretation, the tool was translated from English into Ukrainian and English into Polish. The tool was then translated back from Ukrainian to English and from Polish to English.

The QOL- AD Scale was found to have criterion concurrent validity, construct validity, convergent and divergent validity, internal consistency and was found to be a reliable measure of QOL. It was also found to be sensitive to change (Logsdon, R., Gibbons, L., McCurry, S., & Teri, L., 2002; Thorgrimsen, et al., 2003;). This scale, however, is limited to those with sufficient ability to communicate their moods, symptoms and satisfaction. It was found that persons with a Folstein score of 3 or higher were able to satisfactorily complete this scale (Thorgrimsen, et al., 2003).

This scale was chosen over others due to its ease of implementation, the fact that it was specific to Alzheimer Disease, that it was found to be both reliable and valid in measuring QOL in persons with cognitive impairment and that it was both a self-rating and proxy scale. Reviews of QOL scales have identified limitations with proxy only reports where caregivers or family members answer on behalf of the resident and with self rating only scales (Selai & Trimble, 1999). Permission to use this tool and to include a copy of the tool in the Appendix of this thesis was granted to the researcher by Dr. Rebecca Logsdon (personal communication, April 30, 2008).

## Reactive Behaviors (Verbal and Physical)

### Occurrence Reports

Occurrences of reactive behaviours (occurring between residents or resident towards staff) were tracked by keeping a record of the number of reports completed on these behaviours (hitting, biting, scratching, kicking, punching, swearing, threatening) on these two units during the research period. An occurrence report is mandatory, and it identifies occurrences of behaviours and clinical errors that occur on the units. These reports are submitted to the Resident Service Managers at Holy Family Home and the Winnipeg Regional Health Authority. The residents' medical charts were also reviewed to identify any missed reports related to aggressive reactions. The specific sections of the charts reviewed included, Interdisciplinary Progress Notes and History. The 24-hour report on each unit was also reviewed.

## Family Member's Level of Satisfaction with Care and the Unit

### Family Interview

Family members, significant others or health proxies were asked to participate in an interview with the researcher or research assistant. Prior to the interviews being held, the researcher met with the research assistant to review the questions for the interview and to respond to any questions the research assistant had of the interview and/or its process. A script on how to ask the questions was reviewed with the research assistant. Discussion occurred between the researcher and the research assistant after each interview to debrief and discuss any concerns during the interview. The goal of the interview was to obtain information from family members as to their level of satisfaction

with the care their relative received on the units and with the unit itself (refer to Appendix L). The interviews were recorded on audio tapes. Notes were kept regarding significant events or thoughts that occurred during the interviews. The data obtained from the interview were prepared in verbatim transcript form. Some of the recordings were difficult to comprehend due to the quality of the recording and/or accent of the individual participant. The recordings were reviewed multiple times until they were understood. All of the transcribing was managed by the researcher and the research assistant audited a few randomly selected transcripts for accuracy. This process took 6 months to complete.

### Cognitive Level

#### Folstein Mini Mental State Examination (MMSE)

This measurement tool was used to assist in measuring residents' baseline cognitive function. The MMSE is an effective screening instrument in separating persons with cognitive impairment from those without. The MMSE is an 11-item measure that tests five areas of cognitive function: (1) orientation, (2) registration, (3) attention and calculation, (4) recall and (5) language.

The total MMSE score can range from 0 to 30. The higher the person's score, the higher the perceived level of cognitive function. A score of 26 or higher indicates normal functioning (Sajatovic & Ramirez, 2001). A score of 13 or lower could indicate moderate to severe cognitive deficit depending on a person's culture, socio-demographic and level of education (Espino, Lechtenstein, Palmer & Hazuda, 2001). To minimize problems with testing due to language barriers, interpreters were used if there was a language barrier between the resident and the researcher. Translated copies of the

MMSE in Ukrainian and Polish were provided by Psychological Assessment Resources Inc., who own the copyright to the MMSE.

When calculating the score on a test with missing data (due to the resident having physical limitations such as visual impairment), the score was multiplied by 30 (the normal maximum score) and then divided by the actual maximum score for the test with missing data. This produced a proportional score out of 30 for a test with missing data. This procedure was completed in order to compare the scores of tests completed with missing data to those with scores of tests completed without missing data.

This instrument is widely used in research. A limitation of the MMSE is that it relies heavily on verbal responses and reading and writing skills. This may affect the ratings of people who have hearing and visual impairments or communication disorders. Past research has indicated that the testing of this instrument showed both validity and reliability of its measurements (Sajatovic & Ramirez, 2001). Permission to use this tool for this study was given to the researcher by Psychological Assessment Resources Inc. (personal communication, May 29, 2008).

## Environmental Changes

### The Therapeutic Environment Screening Scale (TESS)

This tool was used to compare the characteristics of the two units in this study and identify where they fell in the continuum of traditional and specialized care environments. The Therapeutic Environmental Screening Scale is an observational screening instrument which has 12 items used to evaluate the appropriateness of a PCH's unit for residents living with dementia. The therapeutic principles evaluated by the



instrument are: eliminating potential noxious stimuli, enhancing mood and self image, promoting safety, accommodating a range of private and social activities and providing access to the outdoors. The higher the rating the more appropriate the physical environment is for the care of those living with dementia. Although a score was obtained, in this study this tool was used for observation not to measure differences.

One limitation of this tool is the fact that it focuses heavily on one type of environment, the physical and excludes the social, psychological and cultural environments. This scale has been tested for reliability and validity, and the findings "... suggest that this instrument may provide useful quantitative data by which individual units can be compared" (Sloane & Mathew, 1990, p.25). However, because of the qualitative nature of the TESS, the potential for observer bias can threaten the validity of findings and obtaining reliable results depends on consistent application methods and common understanding of the unit's environmental features. Sloane and Mathew (1990) suggest the use of multiple raters as well as raters who are blinded as to which unit is the control or experimental unit, careful training of raters and standardization of data collection times as techniques to increase reliability. These techniques (with the exception of the raters being blind to the identity of the units) were applied to this study. Permission to use this tool in this study was given to the researcher by Dr. Philip D. Sloane (P. Sloane, personal communication, May 2, 2006).

#### Observation of the Daily Activities of the Unit.

The researcher spent one day, for one hour and a half (1100 hours to 1330 hours) on each unit observing in order to add to the results obtained from the TESS instrument,

to create a detailed description of the similarities and differences between the two units. The observation period on the two units occurred over a one week period. Observation focused on staff interactions with residents and staff to staff interactions, as well as resident to resident and residents with staff. It focused on the daily routine of residents, activities and noise level on each unit. This information was logged in a journal and included in the Results section of this study.

### **Sample Description**

#### **Residents**

There were 12 residents on the DCU and 12 residents on the traditional unit who participated. These residents were all female and their mean age was 86.00 (SD±6.65). The majority (75.00%) were of Ukrainian ethnicity and Ukrainian Catholic faith (58.30%). The mean length of time spent on the unit was 24.46 (SD ± 27.35) months.

#### **Family Members**

There were 18 family members who participated in the study. There were 10 family members associated with the DCU and 8 associated with the traditional unit. These family members consisted of daughters (8), sons (6), a son-in-law (1), a niece (1), and close friends (2).

#### **Staff Members**

There were 6 staff members who participated in this study, 3 on the DCU and 3 on the traditional unit. Staff members were all females. The ethnic background of the

staff members on the DCU who participated was Ukrainian (1) and Polish (2). On the traditional unit the ethnic background of the participating staff was Ukrainian (1), Croatian (1) and French Canadian (1). The mean length of employment as a health care aide was approximately 17 years. For the participating staff members on the DCU it was 16 years and for the participating staff members on the traditional unit it was 18 years.

### **Data Collection**

Data were collected by the researcher and the research assistant. A data sheet, consisting of two parts, was developed for each resident (refer to Appendix M). The first part consisted of demographic information and the second consisted of the QOL and MMSE scores and a record of reactive episodes. Information obtained from the residents' charts was obtained from the Interdisciplinary Progress Notes and the History sections. The data were collected as follows:

The MMSE measurements were taken:

- Once, prior to the start of any other measures, such as the QOL or family interview.

The MMSE was obtained by the first week of a two week period of data collection.

- Testing was done by the researcher or research assistant, through interviews with the resident.

The Quality of Life measurements were taken:

- Once within a two week data collection period.

- Interviews were completed by the researcher or research assistant with the resident and the resident's day time primary care giver (health care aide)

The Family Interview was held:

- Once within a two week data collection period.
- The interviews were conducted by the researcher or research assistant and transcribed verbatim by the researcher.

The numbers of episodes of reactive behaviors was tallied:

- From the number of occurrence reports completed by unit staff. The researcher obtained and compared them to documented information on the resident's health chart. Incidents of reactive behaviours were tracked over a two week period.

TESS observations were made:

- Once at the beginning of the two week data collection period.
- Observations were noted by researcher and the research assistant. The results were compared and documented.

Observation of the units

- One day on each unit for one and one half hours (1100 hours to 1330 hours).
- During a one week period
- Observations completed by the researcher.

## **Data Analysis**

### **Quantitative Data**

All of the statistical data obtained was entered into a statistical analysis software application (SPSS 14.0, student version). A number of statistical procedures were calculated with controls for residents' ages, length of stay on the unit, and baseline MMSE scores. Due to the limitation of the sample size and the fact that random assignment of residents to each unit could not be conducted, the researcher tried to eliminate influence of other variables on the results by controlling them through statistical procedures. A Kolmogorov-Smirnov test was calculated on all continuous independent variables to determine normal distribution curves. Normality was also assessed by viewing histograms on these variables. For those that were calculated as having non-normal curves, log transformations were calculated in an attempt to normalize their distribution curves. Multiple ordinary least square linear regression and multi-nominal logistic regression tests were used to calculate whether variations in the dependent variables related to differences between the two groups of residents, while controlling for a number of variables. All statistical testing was completed using an alpha level of  $<0.05$  to measure the level of significance in the findings. This indicates the level of probability at which the null hypothesis can be rejected with confidence. Having a 0.05 level of significance lowers the risk of a Type II error, accepting the null hypothesis when it should have been rejected (Levin & Fox, 2000). One-tailed tests were used when the main hypotheses were being tested. For all other calculations, two-tailed tests were used.

## Qualitative Data

The process used in this study to analyze the qualitative data obtained from the family interviews included methods associated with qualitative research analysis as outlined by Padgett (1998) in *Qualitative Methods in Social Work Research*. According to Padgett (1998) "... data analytic techniques in qualitative research are inductive – moving from specific to the general and systematic" (p. 73). One starts with the raw data obtained from the interview; the researcher then begins at the "... most basic level reading and reading every line of text in the search for meaning units" (p.76). These meaning units (statements) were coded and then grouped into categories. Analytic memos, which explain the decision making behind the categories, are generated at this stage. Relationships were then examined between the categories in order to form themes.

Once the interviews were transcribed the research assistant reviewed the transcriptions from three randomly chosen interviews to check for accuracy. The researcher then reviewed the transcripts repeatedly to gain a sense of the data obtained. Notes were made in the margins to further explain comments made by family members. The data was then read twice to derive "meaning units" (statements). This was done by first underlining exact words from the text that appeared to capture key thoughts and emotional reactions or opinions. This included single words, partial sentences or paragraphs. The researcher then sorted the "meaning units" (statements) into categories. The categories related to either the questions asked or a critical event that was identified in the interview. The categories were compared and contrasted to determine relationships. The goal at this point was to integrate the categories into themes and sub-themes (refer to Table 3.1 for examples). After a cluster of themes were organized, the

researcher compared them with the original description in the responses made by the family to validate their content. Once this was completed, the categories and themes were reviewed with the research assistant for validation. In preparation for reporting the findings, the researcher identified and included for each theme identified in the data, examples of statements made by the family members or significant others.

Table 3.1

Examples of Qualitative Analysis Method

Codes	Meaning Units (Interview excerpts)	Categories	Themes
Noisy unit	“A bit noisy at times. It sort of gets to me after 5 minutes. I can’t imagine it all day.”	Social environment effects	Description of the unit
Placement is a difficult decision	“I find it emotionally hard, but they reassure me.”	Why families need support	Family relations with unit staff
Increased QOL	“Her QOL is better than it was in the apartment. Here she socializes.”	How to increase QOL	Unit effect on the residents

Once the research was completed, the preliminary findings were shared with staff members at a presentation. Their interpretation of the findings along with the interpretation of the researcher is included in the Discussion chapter of this thesis.

## **CHAPTER FOUR – RESEARCH LIMITATIONS**

When completing a study one must consider possible threats to the validity of the findings. Methods to minimize these threats should be incorporated into the design and method of the study. The following is a review of the threats considered to affect the findings of this study and the steps that were taken to try and minimize them. This review will be divided into two sections. It includes a review of threats to the validity of findings associated with quantitative studies and those associated with qualitative studies.

### **Quantitative Analysis**

#### **Internal Validity**

Internal validity "... relates to questions about ascertaining whether the intervention caused the changes in the target problem" (Bloom, Fischer & Orme, 2003, p.351). There were seven threats which were considered when designing this evaluation. They were as follows:

##### **a) History**

This refers to any outside event, either public or private, that may affect the dependent variable and was not accounted for in the design. This is difficult to control. One way to address this concern was to incorporate a comparison group. If history effects occur then they would affect the outcomes of both groups. However, this may not assist with "local history" effect. These are events that could affect one unit but not the other. This could include the culture of the facility favoring one unit over another and therefore offering increased resources. Other examples could include a new staff member



starting on the unit or a concern with a resident's behaviour which may be causing other residents on that unit to be upset. All of these examples could lead to an effect of the outcome that is not related to the intervention. Local history effect is difficult to control and one must be aware of this possibility.

b) Maturation

This occurs when the progression of illness affects the results of individual residents rather than showing differences between the units. Through the use of a comparison group, changes that occur would be likely to occur in both groups. However, this may not always be the case. Since random assignment of residents to the two units was not ethically possible, there may still be a threat with selection by maturation. This means that the residents on one unit may be healthier or physiologically different than those on the other unit and therefore this difference could affect the outcome instead of the intervention. For this reason, one must be aware of the possibility of this threat.

c) Mortality

Due to the small sized sample of residents, one resident passing away or transferring out of the facility or unit may have a great effect on the outcome. One way to compensate would be to increase the size of the sample substantially, which was not possible in this study. Another way to try and compensate for this effect would be to use information about these residents to estimate what their scores would have been had they been included.

d) Diffusion of Treatment

In this case, the treatment would occur on the traditional unit if staff from the dementia care unit group is rotated to the traditional units acting as the control group. This was considered to be a minimal risk because permanent staff at Holy Family Home usually do not rotate to different units, but are assigned to only one unit. This includes the nurses, health care aides, recreation and housekeeping staff. There was however no way to prevent the replacement of regular staff on their days off or when on holidays. Staff is replaced with casual staff that rotates throughout the facility. Furthermore, there was no way to completely prevent staff from talking to each other on breaks or outside of the facility about the care that they provide. To minimize this effect the researcher met with the staff on the research unit (the DCU) to reinforce the importance of not discussing what was occurring on the unit during the 2 week research period.

e) Compensatory Rivalry

This effect occurs when the control group becomes motivated to compete with the research group. One way to minimize this is to try to minimize the identity of the unit which will be considered as the comparison group. Residents, family and staff members who participated in this study were aware; however, the research was not publicly announced in the facility. This was done in an attempt to minimize this effect on the findings.

f) Demoralization

This refers to the demoralization (feeling depressed or angry) among the comparison group for being compared to the research group. Again this was minimized in the same way as for compensatory rivalry, by not publicizing which unit was considered as the control group.

g) Differential Selection of Research Participants

This refers to the extent that the participants initially selected for the evaluation are different from one another. Ideally the best way to minimize this threat is by randomly selecting people into either the research group or the control group, which was not a possibility in this study. The second best option was to match the two groups as well as one can, which was also not possible. Instead a number of statistical procedures were used to control for this threat by placing controls on certain variables (residents' ages, length of stay in the facility and MMSE scores).

There was also a concern with the fact that the researcher was an employee of this home (social worker) and worked on both the DCU and traditional unit. To avoid possible biases some of the measurements were taken by a research assistant. The preliminary results were also shared with the staff on both units and their interpretations were included in the Discussion chapter of this thesis. This allowed for a second opinion on the interpretation of the findings instead of just relying on the researcher's interpretation.

## Construct Validity

This occurs when the procedures intended "... to represent a particular cause or effect construct can be interpreted as other constructs. So, intervention efforts that seem to produce changes in a target could be confounded with other variables" (Bloom, et al., 2003, p.352). Standard instruments were incorporated into the design of the evaluation in this study. These instruments had been used successfully in other studies and had been tested for validity and reliability.

In this study the main threat to construct validity was therefore related to confounding of the residents' cognitive functioning, specifically with QOL measures. In other words, this refers to their ability to verbalize and understand the questions asked when measuring QOL. To try and control for this threat the QOL scale that was chosen required a certain level of cognitive function (MMSE equal to or greater than 3) in order to understand and answer the questions (Thorgrimsen, et al., 2003). Due to this an inclusion criteria of residents with a MMSE between 9 and 21 was incorporated. This meant that a MMSE was completed with each resident to obtain a measure and determine their qualification in the study. Statistical control over the MMSE scores was also maintained while testing for unit differences.

## External Validity

The purpose of this study was to evaluate the impact that a DCU (St. Francis) had on the QOL of its residents and how it affected episodes of reactive behaviours (verbally and physically). To determine if there were any differences, a comparison group (St. Joseph) was incorporated into the study. Due to the limited size of the study and the fact

that residents were not randomly assigned onto the units, statistical procedures were applied with control of certain variables. This allowed for quantitative comparisons of the two units. Since the sample of residents studied may not represent the larger community, generalizations of the findings are difficult to make to the larger community. However the findings may be generalized to Holy Family Home.

### **Qualitative Analysis**

Regarding the qualitative data, to increase rigor in the research or trustworthiness, the researcher ensured the following as outlined by Tutty, Rothery and Grinnell (1996):

#### **a) Credibility**

Credibility refers to ensuring the information provided has “truth value” and is an accurate reflection of what was stated by those who were interviewed.

This was enhanced through peer debriefing completed after each interview.

When possible the interviews were also recorded on audio tape for accuracy (9 out of 18 interviews). When this was not possible detailed notes of the interview were kept. To ensure the information transcribed was accurate, a random audit of three transcripts was completed by the research assistant.

#### **b) Dependability of the Researcher’s Interpretation of the Data**

This was enhanced through an audit trail that was completed which recorded the decision-making process. The categories and themes that were developed were also reviewed with the research assistant for accuracy.

#### **c) Confirmability**

This was supported by having the coded transcripts reviewed by the research assistant and through the use of notes maintained by the researcher before and

throughout the analysis on her feelings and beliefs related to outcome. This was done in order to identify potential biases.

d) Transferability

This was enhanced through the detailed description of the participants, the setting, the methods and analysis techniques used. Due to this, transferability of this study could occur in other similar PCHs which incorporate a person-centered philosophy of care and have both dementia care and traditional units.

### **Summary**

When designing a study a number of possible risks to the validity of the study can occur. Steps need to be taken to ensure that these risks are minimized. In this study different procedures were taken to address possible risks to the validity of the findings. This included having a comparison group within the same facility, using statistical procedures, using standardized measurement instruments that have been tested for reliability and validity, having multiple forms of data collection, having the information collected and reviewed by a second person to determine accuracy of transcription, taking detailed notes and by obtaining feedback from participants (staff) on the results. While the information obtained from this study cannot be generalized to the general population, it may possibly be generalized to Holy Family Home. These findings can also contribute to the growing empirical knowledge related to DCUs and their impact on the QOL of their residents.

## **CHAPTER FIVE - RESULTS**

### **Overview**

The collected data for this study will be reviewed in three parts; 1) A description of the two units which was obtained through the use of the Therapeutic Environments Screening Scale (TESS), from observations made on the two units and discussion with staff, 2) An analysis of the quantitative findings and 3) Qualitative analysis of the family interviews. Due to the small sample size of this study, statistical testing was completed using an alpha value of 0.05 to measure the level of significance in the findings. This assisted in lowering the risk of Type II error.

### **Description of the Two Units**

The researcher and research assistant completed the Therapeutic Environments Screening Scale (TESS) on each unit. The score obtained on this scale for the dementia care unit (DCU) was 18. The score obtained on this scale for the traditional unit was 12. The higher the score obtained (maximum score is 24) the closer the unit is on a continuum of being an appropriate environment for individuals with dementia. The DCU was found to have furniture, décor and other features that gave it a “homelike” atmosphere. On the traditional unit, this was not found to be true. The DCU was found to be partially free of loud distracting noises (such as buzzers and residents calling out). The traditional unit was not found to be free or even partially free of these noises. On the DCU there was an outdoor courtyard that was directly accessible to residents. This did not exist on the traditional unit. On the DCU at least one private alcove suitable for family interactions was found. This was not the case on the traditional unit. The

television in the main public area was off, but on the traditional unit it was on. There were some residents sitting around the television, but none were watching it. Some were sleeping or looking elsewhere. The DCU was found to have overall better lighting than on the traditional unit. Both units were found to have overly shiny floors, and in some areas, there was a great deal of glare from the sunshine which made the floor appear wet. This can cause depth perception difficulties for those who already have visual deficits. Both units were odor free of cleaning solution and bodily excretions. Both were found to have personal items that belong to residents in their room (pictures and furniture) and both had kitchen areas available for resident use.

Based on the outcomes from the TESS scale, there appeared to be some differences between the two units. To determine further differences or similarities, the researcher spent one day for one and one half hour (1100 hours to 1330 hours) on each unit on two separate days to observe daily life for residents on the unit. The researcher took notes on the appearance of the unit, occurrences and interactions. The researcher also had discussions with staff members and with the administration of the home as to the differences between the two units. From this a number of further differences between these two units were noted (refer to Table 5.1). First, the DCU was smaller with 29 residents as opposed to the traditional unit with 40 residents. The DCU consisted of private and semi-private rooms, while the traditional unit consisted of only private rooms with private bathrooms. The colour scheme on the DCU was a soothing combination of greens and burgundies. On the traditional unit, the colours were dark blues, yellows and orange. The lighting was duller than on the DCU. The furniture in the common areas was aged. The chairs consisted of vinyl covers in all shades of colours.



**Table 5.1**  
Comparison of Unit Characteristics

Characteristics	Dementia Care Unit	Traditional Unit
Residents	<ul style="list-style-type: none"> <li>- Female</li> <li>- Living with dementia</li> <li>- Admission and discharge criteria</li> </ul>	<ul style="list-style-type: none"> <li>- Female</li> <li>- Some who are living with dementia and those who are not</li> </ul>
Physical Environment	<ul style="list-style-type: none"> <li>- Smaller (29 residents)</li> <li>- Private and semi-private rooms</li> <li>- Updated décor</li> <li>- New furniture, cloth covered</li> <li>- Soft colours, brighter lights</li> <li>- Secured entrance with on-off keypad access</li> <li>- Secured outdoor space with gazebo and garden</li> <li>- Alcoves for visiting</li> <li>- Therapeutic kitchen</li> <li>- Personalization of residents' rooms</li> <li>- Glare on floors</li> </ul>	<ul style="list-style-type: none"> <li>- Large unit (40 residents)</li> <li>- Private rooms and bathrooms</li> <li>- Dated décor</li> <li>- Dated furniture with vinyl covered chairs</li> <li>- Bright colours (yellows and oranges)</li> <li>- Dull lighting</li> <li>- Roam Alert system on elevator.</li> <li>- Therapeutic kitchen</li> <li>- Personalization of residents' rooms</li> <li>- Glare on floors</li> </ul>

**Table 5.1**  
Comparison of Unit Characteristics

Characteristics	Dementia Care Unit	Traditional Unit
Social Environment	<ul style="list-style-type: none"> <li>- Small group activities</li> <li>- Activities offered recognize individuals with cognitive impairment</li> <li>- Unit staff participate in programming</li> <li>- Meal delivery – buffet style</li> <li>- Noise level at times high</li> </ul>	<ul style="list-style-type: none"> <li>- Large group activities</li> <li>- Some activities recognize individuals with cognitive impairment</li> <li>- Meal delivery –tray style</li> <li>- Noise level most times high</li> </ul>
Staff	<ul style="list-style-type: none"> <li>- Resident-staff ratio similar on all units</li> <li>- Staff training in dementia care (90%)</li> <li>- Consistent staff–primary care</li> <li>- Ongoing training encouraged</li> </ul>	<ul style="list-style-type: none"> <li>- Resident-staff ration similar on all units</li> <li>- Staff training in dementia care (5%)</li> <li>- Consistent staff – primary care</li> <li>- Ongoing training encouraged</li> </ul>
Philosophy of Care	<ul style="list-style-type: none"> <li>- Holy Family Philosophy of Care followed</li> <li>- Philosophy of Dementia Care adopted</li> </ul>	<ul style="list-style-type: none"> <li>- Holy Family Philosophy of Care followed</li> </ul>

On the DCU, the furniture consisted of “homelike” furnishings: couches, fabric covered chairs, wing back chairs and coffee tables. The two units both had distinct kitchen areas. The DCU also had a living room area, dining room and space for visiting (an alcove), other than the residents’ rooms. There was a garden area with a gazebo directly outside of the DCU. The garden area was fenced for the resident’s safety. The traditional unit did not have areas of personal space other than the residents’ rooms (which were all private rooms). This unit also did not have an outdoor area directly outside the unit. It did have a balcony that, during the winter was used as a storage area, but in the summer, residents were able to access the area. The balcony was screened so residents were safe to go out for fresh air. The DCU had a secured entrance to the unit, a locked door with a key pad that controlled on-off access to the unit. On the traditional unit the elevators that lead to the unit had a Roam Alert key pad, so that if a resident who had a Roam Alert bracelet entered the elevator, a buzzer would be audible. This can be distressing for residents and staff, especially when the elevator door opens and a resident wants to enter to leave the unit and is not safe to do so. The buzzer would sound and the resident would become upset with staff who then tries to redirect them. The noise level on the unit increases due to this buzzer. This repeatedly occurred during the observation period.

The two units had similar staff ratios. Each had a team leader (head nurse) who usually worked during the day. At times both units had a second support nurse. Each unit had one evening nurse and a part time night nurse (one nurse per three to four units). The ratio of health care aides (HCAs) to residents on both units was 1:8 on days, 1:9 on evenings and 1:19 on nights. The DCU had one housekeeper during the week. The traditional unit had two housekeepers during the week. On the weekend both units had a

part time housekeeper. Each unit had a full time recreation worker and a part time social worker (one social worker per three units). Both units had access to physiotherapy, occupational therapy, a dietitian, pastoral care, physician services and other services provided in the facility. Approximately 90% of the staff on the DCU had completed training and obtained certificates on dementia care. Only 5 % of the staff on the traditional unit completed the certificate program and 24% of the staff were at the time of the study enrolled in the program.

On the DCU activity programs included smaller group programs. Staff on the DCU also participated in spontaneous activities, such as dancing with residents, or putting puzzles together with them. There were also rummage drawers and a “life center” (sewing area) on the unit for the residents. These items did not exist on the traditional unit. Family members on both units were included in care planning and were seen as part of the care team. This is the philosophy of the home. Families on both units had access to support and educational groups on dementia care held at the home. The population on both units consisted of female residents only. There was an admission and discharge criterion for the DCU which did not exist on the traditional unit. The noise level on the DCU created by call bells, over head pages and residents who call out, was evident, but the noise level on the traditional unit was higher. This could possibly be due to the fact that the population on the unit is larger.

During the observation period on the units, the researcher noticed staff on the DCU calming and successfully redirecting residents. On one occasion during lunch a resident was getting up from the table without eating, a HCA approached this resident and hugged her and then redirected her back to the table. Once there, the HCA set up the

resident's meal and started the motions of feeding, which the resident mimicked and started to feed herself once the HCA stopped. On the DCU it was observed that staff frequently interacted with the residents. At times discussion between HCAs and residents occurred in Ukrainian or Polish. This personal interaction was not witnessed during the observation period on the traditional unit.

### Summary

The DCU appeared to have a number of features the literature indicated are common for a DCU (Mitchell-Pedersen, 2003). These included a segregated unit with modified physical and social environments with controlled on-off access, admission criteria, special staff training, activity programming designed for persons with dementia and the inclusion of family members in care planning. The main similarities in the two units were staffing ratio and the acknowledgement of the philosophy of the PCH regarding care and family members' involvement in their relatives' care planning. As well, staff on the traditional unit were also receiving increased training in dementia care.

## Quantitative Analysis

### Preliminary Analysis

There were 23 residents and/or family members on the DCU (St. Francis) and 22 on the traditional unit (St. Joseph) who were contacted to participate in this study. There were 12 residents who met the requirements of the study on the traditional unit and 10 residents who met them on the DCU. Although the sample size in this study was small it was similar to that of other studies. The study by Ross (1999), a retrospective pre and

post-test with no comparison unit, involved a limited number of residents (14). The study by Wilkes, et al. (2005) also included a limited number of residents (16).

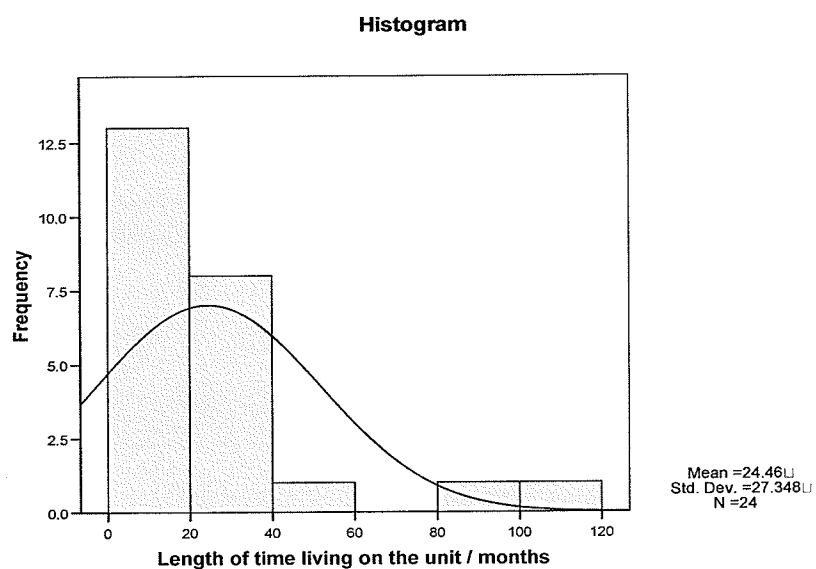
In an attempt to increase the sample size, the requirement of a minimum of 3 month residency on the unit was adjusted to 1 month. Although the adjustment period may have been shorter, it was felt to be sufficient time for the resident, to at least, become familiar with the physical unit, with the staff (especially since the staff are consistent and do not rotate off the unit), and with the unit's social activities. On the DCU, this adjustment allowed for a slight increase in the number of residents who qualified for the study (from 10 to 12). On the traditional unit, the number of residents who qualified for this study remained the same (12).

A second adjustment was required, which related to missing data (18 unanswered questions) found in the completed Quality of Life – Alzheimer's Disease Scale (QOL-AD) and the Mini Mental State Examinations (MMSE). Adjustments were required on five MMSE scores, one QOL-AD survey completed by a resident and eight QOL-AD surveys completed by staff. Four of the adjusted MMSE scores were from residents on the DCU. The other adjusted MMSE score was from a resident on the traditional unit. There was one QOL-AD survey completed by a resident on the DCU that was adjusted and four QOL-AD surveys completed by staff on the DCU that were adjusted. On the traditional unit, none of the QOL-AD surveys completed by the residents required adjustment, but there were four QOL-AD surveys completed by staff that were adjusted. The adjustments to the test scores were completed as directed by the scale instruction (refer to the Methods section of this study). All further calculations involving the MMSE and QOL-AD scores included the adjusted scores.

There were a number of independent variables in this study. A distribution curve was calculated for each (interval) variable (N=24). Positive skews were found for the variable age group (0.07), length of time living on the unit (2.38) and MMSE (0.07). To determine if the distribution curve on each of these variables were normal, histograms were created and reviewed and a Kolmogorov-Smirnov test was applied. Table 5.2 shows the Kolmogorov-Smirnov Z values for these variables and their significance. There was one variable, “length of time living on the unit”, that presented with a large positive skewed (2.38) distribution curve, (refer to the histogram in Graph 5.1). When a Kolmogorov-Smirnov test was calculated, the Z value for length of time living on the unit approached significance ( $Z = 1.31$ ,  $p_{\text{two-tailed}} = 0.07$ ), as seen in Table 5.2. A log base 10 transformation was calculated on this skewed variable, which assisted in normalizing the distribution curve (refer to Table 5.2 and Graph 5.2).

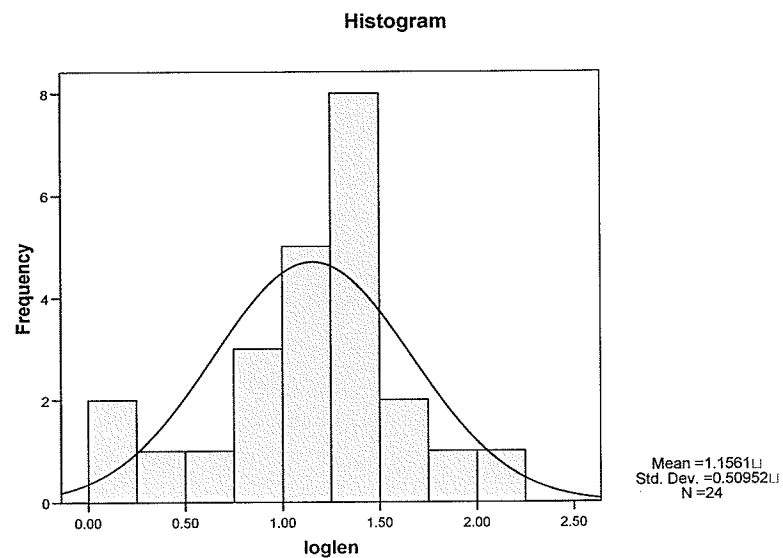
Table 5.2  
Normality Distribution of Independent Variables (N=24)

Variable	Kolmogorov-Smirnov Z score	$P_{\text{two-tailed}} < 0.05$
Age	0.63	0.83
Length of Time Living on the Unit	1.31	0.07
Length of Time Living on the Unit (Natural Log Transformation)	0.69	0.72
MMSE (with adjusted scores)	0.77	0.59



Graph 5.1 Histogram of the Length of Time Living on the Unit

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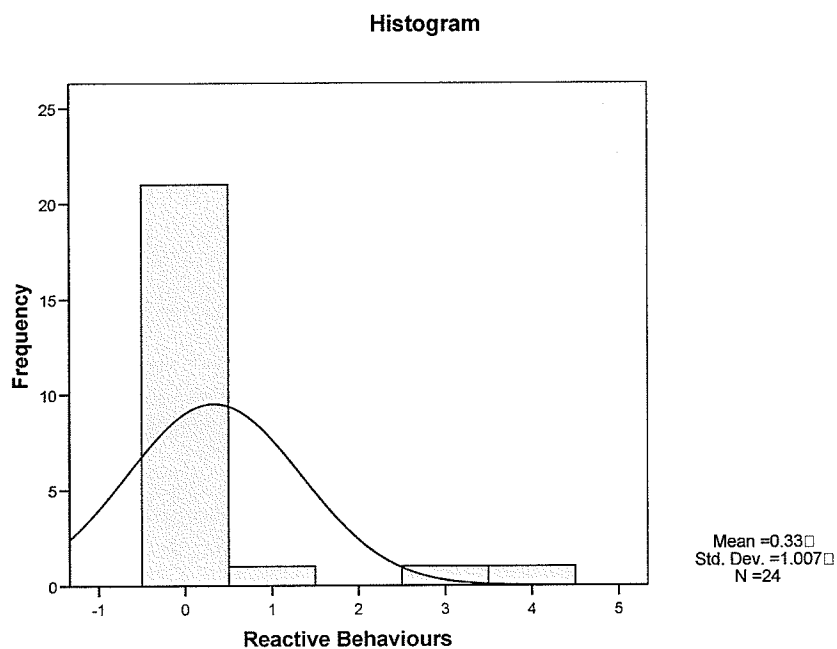


Graph 5.2 Histogram of the Log Base 10 Transformation of the variable Length of Time Living on the Unit

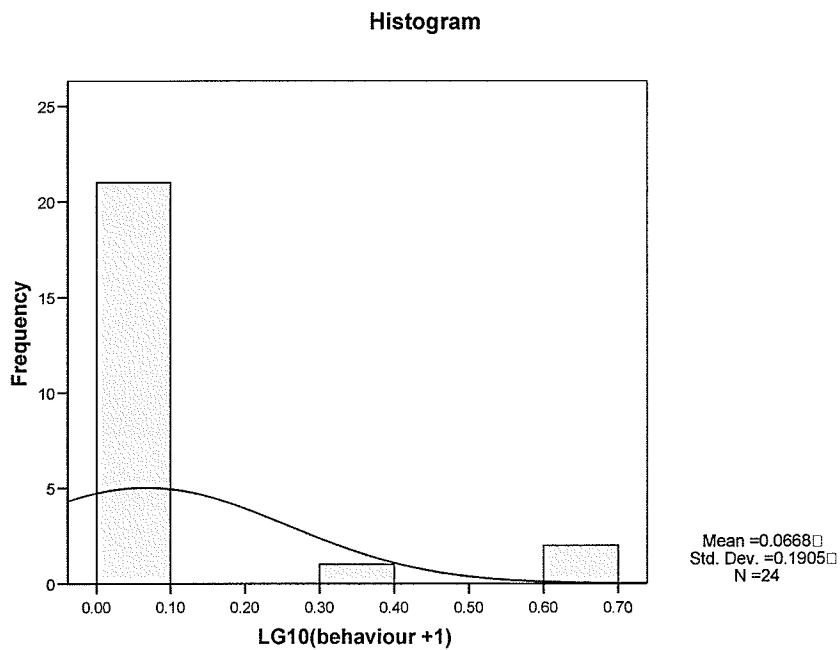
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There was a need to complete a transformation on another skewed variable. The dependent variable “reactive behaviour” also presented with a large positive skew (3.15), as seen in Graph 5.3. When a Kolmogorov-Smirnov test was calculated, it showed a significant value ( $Z = 2.47$ ,  $p_{\text{two-tailed}} = 0.00$ ). A log base 10 transformation was attempted but it did not assist in normalizing the distribution (skewness = 2.83), as seen in the histogram in Graph 5.4. An inverse transformation and a square root transformation were also attempted, but they did not assist in normalizing the distribution curve of this variable (as seen in the histogram in Graph 5.5 and Graph 5.6).

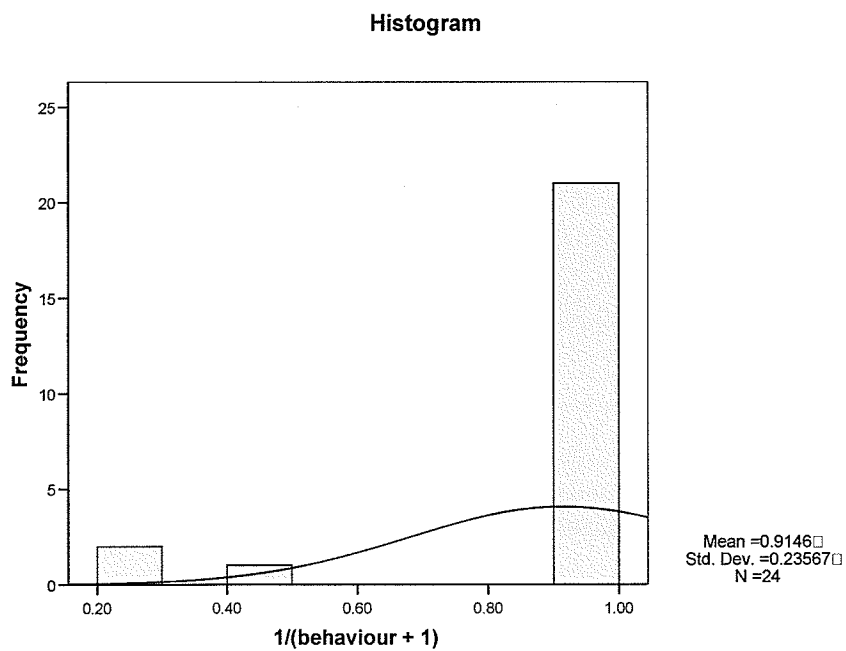


Graph 5.3 Histogram of the variable Reactive Behaviours



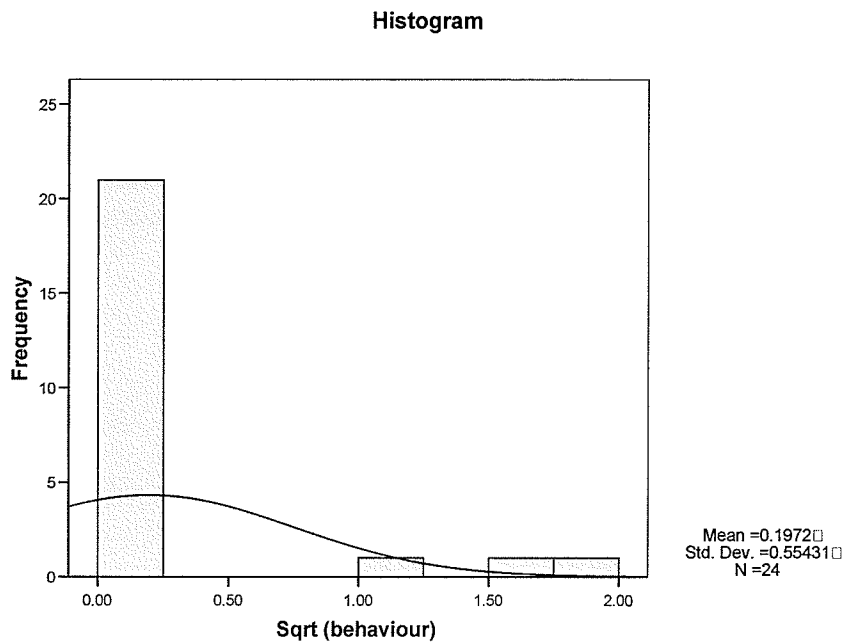
Graph 5.4 Histogram of Log Base 10 Transformation of variable Reactive Behaviours

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Graph 5.5 Histogram of the Inverse Transformation of variable Reactive Behaviours

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Graph 5.6 Histogram of the Square Root Transformation of variable Reactive Behaviours

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When a Kolmogorov-Smirnov test was calculated on each of the transformations, the results indicated significant values (refer to table 5.3). Since transformation attempts did not assist in normalizing the variable's distribution curve, a logistic regression model was used in the analysis of this variable. In preparation for this analysis, the number of reactive incidents were divided into a yes-no dichotomous variable.

Table 5.3

Kolmogorov-Smirnov values for the Transformations of the variable Reactive Behaviour (N=24)

Transformation	Kolmogorov-Smirnov Z Score	P <sub>two-tailed</sub> <0.05
Log base 10	2.51	0.00
Inverse	2.53	0.00
Square Root	2.52	0.00

### Descriptive Analysis

The residents in this study consisted of only females and their mean age was 86.00 (SD  $\pm$  6.65). Ages ranged from 75.00 to 98.00 (refer to Table 5.4). The mean age for the residents on the traditional unit was slightly older than on the DCU. The mean age on the traditional unit was 88.83 (SD  $\pm$  6.95), and ages ranged from 76.00 to 98.00. On the DCU the mean age was 84.08 (SD  $\pm$  5.65), and ages ranged from 75.00 to 92.00. The study completed by Reimer, et al. (2004) also had a younger age group living on the special care unit (mean = 80.2, SD  $\pm$  7.2) as compared to the non specialized care units found in a multiple traditional institutional facility (mean = 83.2, SD  $\pm$  7.2) and a single traditional institutional facility (mean = 81.7, SD  $\pm$  8.0). In the study by Leon and Ory (1999) the mean age of the residents on the specialized unit was also younger (mean age 80.43, SD = 6.89) than the non-SCU group (84.48, SD = 6.34). The fact that the mean age of the residents on the DCU at Holy Family Home was younger than the traditional unit group is comparable to similar studies. However, this difference in age between the two units would have to be tested for significance.

Table 5.4  
Description of Residents

Variable	Total Number of Residents (N=24)	Residents on Research Unit (N=12)	Residents on Comparison Unit (N=12)
Gender (% of female)	100%	100%	100%
Age (Mean, Standard Deviation)	86.00 (SD± 6.65)	84.08 (SD± 5.65)	88.83 (SD± 6.95)
Age (Range)	75.00-98.00	75.00-92.00	76.00-98.00
Cultural Status (% Ukrainian)	75.00%	66.70%	83.30%
Religion (% Ukrainian Catholic)	58.30%	50.00%	66.70%
Highest Level of Education (Median / Mode)	Grade 8.00 / Grade 12	Grade 9.00 / Grade post-secondary <sup>1</sup>	Grade 8.00 / Grade 12
Length of Time by Month (Mean, Standard Deviation)	24.46 (SD± 27.35)	11.75 (SD± 11.10)	37.17 (SD± 32.99)
Contact with Family (%)	87.50%	100.00%	75.00%
MMSE (Mean, Standard Deviation)	14.75 (SD± 4.00)	14.42 (SD± 4.36)	15.08 (SD± 3.78)

<sup>1</sup> Multiple modes exist. The largest value is shown.

The majority of the residents in this study were Ukrainian (75.00%) followed by Polish ethnicity (16.70%). The remaining residents were Danish (8.30%). The percentage of residents on the traditional unit who were Ukrainian was higher than on the DCU; 83.30% as compared to 66.70% (refer to Table 5.4). The majority of residents in this study were Ukrainian Catholic (58.30%) followed by Roman Catholic (25.00%), Ukrainian Orthodox (8.30%) and Lutheran (8.30%), refer to Table 5.4. There were a higher percentage of residents on the traditional unit who were Ukrainian Catholic

(66.70%) than on the DCU (50.00%). These percentages are similar to the total resident population at Holy Family Home (274 residents). According to the statistics completed by Holy Family's Social Work department on September 15, 2006, Ukrainian residents represented 72.00% of the total resident population followed by Polish residents (15.00%). According to the same statistics, Ukrainian Catholic (50.00%) is also the main religion for the total resident population at the home, followed by Roman Catholic (25.00%) and Ukrainian Orthodox (13.00%).

With regard to the level of education, 5 residents completed a grade 12 education (20.80%). There was only 1 resident (who resided on the traditional unit), who had no formal schooling and 3 residents (1 on the traditional unit and 2 on the DCU) who completed post-secondary education which included trade school or college. The median for the variable "highest level of education completed" was grade 8 and the mode was grade 12. The median for the variable "highest level of education completed" for the residents on the DCU was grade 9 and the mode was post-secondary education (multiple modes existed, the largest value was chosen). The median for the residents on the traditional unit was grade 8 and the mode was grade 12 (refer to Table 5.4).

As for the variable length of time living on the unit, there was a range from one to 115.00 months (refer to Table 5.4). The mean length of stay was 24.46 months ( $SD \pm 27.35$ ). The mean length of stay on the DCU was 11.75 months ( $SD \pm 11.10$ ) and for the traditional unit it was 37.17 months ( $SD \pm 32.99$ ). In the study by Gruneir, et al.(2008), the range in length of stay for residents on both the research and comparison units was between 3 months and approximately 48 months. The length of time living on the unit for the residents in the Holy Family study was slightly less than similar studies.

The majority of residents in the study at Holy Family Home had regular contact with their family members or significant others (87.5%). In this study there were 3 residents (12.5%) who did not have regular contact (minimum one visit or contact per week) with a family member or significant other. These 3 residents resided on the traditional unit. On this unit, 75.00% of residents had regular contact with family members or significant others. All of the residents who resided on the DCU (100.00%) had regular contact with a family member or significant other (refer to Table 5.4).

The last controlled variable to be reviewed was the MMSE scores. In this study the residents' MMSE scores (with adjusted scores) ranged from 9.00 to 21.00 (refer to Table 5.4) and the mean MMSE score was 14.75 ( $SD \pm 4.00$ ). The residents on the traditional unit had a slightly higher MMSE mean, 15.08 ( $SD \pm 3.78$ ) than did the residents on the DCU who scored 14.42 ( $SD \pm 4.36$ ). The mean MMSE score in this study for residents living on the DCU (14.75,  $SD \pm 4.00$ ) was higher than that found in the study by Bellelli et al. (1998). In that study the baseline mean MMSE score for those residents living on a specialized unit was 6.1 ( $SD \pm 5.0$ ) and the range was 0.00 to 14.00. This may indicate that, due to the higher level of education, residents' MMSE scores were higher than found in similar studies.

#### Differences Between Residents on the Two Units

There were a number of differences identified between the residents on the DCU and those on the traditional unit. A number of statistical procedures were calculated to determine significant differences between the two groups of residents. In this section these results will be reviewed.

There was a slight difference between the mean age on the traditional unit (88.83,  $SD \pm 6.95$ ) and the mean age on the DCU (84.08,  $SD \pm 5.65$ ). An independent sample t-test was calculated and the difference was found to only approach significance ( $t_{\text{equal variance}} = -1.84$ ,  $df = 22.00$ ,  $p_{\text{two-tailed}} = 0.08$ ). There was a difference in the percentage of residents who were Ukrainian on the DCU (66.70%) versus the traditional unit (83.30%). A Fisher's Exact test was calculated to analyze this unit difference between "Ukrainian" residents and those residents identified as being of an "other ethnic group". The results indicated no significant difference (Fisher's Exact test,  $p_{\text{two-tailed}} = 0.64$ ). A similar procedure was completed on the variables related to the residents' religious affiliation. There was a slight difference between the numbers of Ukrainian Catholic residents on the DCU (50.00%) versus those on the comparison unit (66.70%). This difference was not significant (Fisher's Exact,  $p_{\text{two-tailed}} = 0.68$ ). A Mann-Whitney U test was calculated to determine if there was a significant difference between the residents living on the two units with regard to the variable "highest level of education completed". The median for this variable on the DCU was grade 9.00 while on the traditional unit it was grade 8.00. No significant difference was found between the two units ( $U = 62.00$ ,  $Z = -0.58$ ,  $p_{\text{two-tailed}} = 0.56$ ).

The difference between the mean length of stay for residents on the DCU (11.75 months) and residents on the traditional unit (37.17 months) was found to be significant when an independent sample t-test was calculated ( $t_{\text{equal variance}} = -2.53$ ,  $df = 22.00$ ,  $p_{\text{two-tailed}} = 0.02$ ). When an independent sample t-test was calculated on the variable (transformed) length of stay, the findings indicated an even greater significant difference between the two units ( $t_{\text{equal variance}} = -3.54$ ,  $df = 22.00$ ,  $p_{\text{two-tailed}} = 0.00$ ). This variable



will need to be controlled when calculating further tests of significance related to the dependent variables (QOL and reactive behaviours). This is in order to control for the influence of its effect on the dependent variables.

Two other independent variables were tested for significance, regular contact with family and MMSE scores. There was a slight difference between the two units with regards to the variable regular contact with family. The percentage of residents that had regular contact with family members and/or significant others on the DCU was 100.00%. On the traditional unit it was 75.00%. When a Fisher's Exact test was calculated, the results indicated no significant difference (Fisher's Exact  $p_{\text{two-tailed}} = 0.22$ ). In the MMSE scores, there was a small difference between the mean MMSE score of the residents on the DCU (14.42) and the mean MMSE score of the residents on the traditional unit (15.08). An independent sample t-test was calculated on the residents' MMSE scores (with the adjusted scores), and the results indicated no significant difference ( $t_{\text{equal variance}} = -0.40$ ,  $df = 22.00$ ,  $p_{\text{two-tailed}} = 0.69$ ).

## Summary

The residents on the DCU were younger, had lower MMSE scores and had obtained a slightly higher level of education than those on the traditional unit. A greater percentage of residents on the DCU had regular contact with family or significant others than did the residents on the traditional unit. There were fewer Ukrainian and Ukrainian Catholic residents on the DCU than on the traditional unit. Final, the residents on the DCU lived on the unit for less time than the residents on the traditional unit. Although there were slight differences between the residents on these two units, there was only one

significant difference between the two groups of residents, and that was related to the length of time that they resided on the units. This variable was therefore identified as needing to be controlled when completing further tests of significance.

## Hypothesis Tests

### Quality of Life

It was hypothesized that the QOL for residents who resided on the DCU (St. Francis) would be higher compared to those who resided on the traditional unit (St. Joseph). In order to measure this, the QOL-AD survey was given to all residents who participated in the study. As well, each of the residents' primary staff members (on days) were asked to complete the same survey on behalf of their resident. The higher the score on the QOL-AD survey (maximum score is 52), the higher the perceived level of QOL.

The mean score for the QOL-AD surveys completed by residents was 33.04 (SD  $\pm$  5.47) and 33.83 (SD  $\pm$  4.79) for those completed by staff on behalf of their residents. The range in scores was 18.00 for the residents and 19.00 for the staff members. To determine if the QOL-AD scores were normally distributed, Kolmogorov-Smirnov tests were calculated. The results indicated normal distributions (refer to Table 5.5).

Table 5.5  
Normality Distribution for Dependent Variables (N=24)

Variable	Kolmogorov-Smirnov Z score	P <sub>two-tailed</sub> <0.05
Residents' QOL-AD scores	0.80	0.54
Staffs' QOL-AD scores	0.55	0.92
Reactive Behaviour	2.47	0.00

The mean QOL-AD score for residents on the DCU was 34.83 ( $SD \pm 4.59$ ) and for staff it was 34.95 ( $SD \pm 5.23$ ). The mean QOL-AD score for residents on the traditional unit was 31.25 ( $SD \pm 5.86$ ) and for staff it was 32.71 ( $SD \pm 4.22$ ). The largest difference between what each resident scored and what their respective staff member scored was 11 points. The mean difference between the residents' scores and the staffs' scores for the two units was 0.79 ( $SD \pm 1.08$ ). There was a slightly greater mean difference in scores on the traditional unit ( $1.46 SD \pm 6.02$ ) than on the DCU ( $0.13, SD \pm 4.69$ ). A Kolmogorov-Smirnov test was calculated on the difference between scores and they were found to be normally distributed (Kolmogorov-Smirnov  $Z = 0.78$ ,  $p_{\text{two-tailed}} = 0.58$ ). Significance tests were calculated to determine whether there was a mean difference between the residents' and staffs' QOL-AD scores. One such test was a paired sample t-test. The mean difference between the residents' and staffs' QOL-AD scores did not reach significance ( $t_{\text{equal variance}} = -0.729$ ,  $df = 23.00$ ,  $p_{\text{two-tailed}} = 0.47$ ).

An independent sample t-test was calculated on the difference between residents' QOL-AD scores and staffs' scores between units. The difference did not reach significance ( $t_{\text{equal variance}} = -0.61$ ,  $df = 22.00$ ,  $p_{\text{two-tailed}} = 0.55$ ). A Pearson correlation was calculated to determine if there was a significant relationship between the QOL-AD scores completed by residents and those completed by staff. There appeared to be a moderate positive correlation ( $r = 0.47$ ,  $N = 24$ ,  $p_{\text{two-tailed}} = 0.02$ ). As the residents' scores increased, so did the scores completed by staff.

A number of linear regression tests were then calculated on the QOL-AD scores (residents' and staffs') to determine if there were unit differences. The first regression test was calculated on residents' QOL-AD to determine if there was a difference between

the units. The results indicated that the unit slope approached significance ( $B = 3.58$ , std. error = 2.15,  $t = 1.67$ ,  $p_{\text{one-tailed}} = 0.06$ ). The same test was repeated while controlling for the variable (transformed) length of time living on the unit. There was no significant difference found between the units ( $B = 2.42$ , std. error = 2.73,  $t = 0.89$ ,  $p_{\text{one-tailed}} = 0.19$ ), refer to Table 5.6. A regression test was then calculated on staff's QOL-AD scores to determine if there were any differences between units. The results indicated no significant differences ( $B = 2.25$ , std. error = 1.94,  $t = 1.16$ ,  $p_{\text{one-tailed}} = 0.13$ ). When a regression test was calculated on the staff's QOL-AD scores to determine if there were any differences between the units while controlling for (transformed) length of time living on the unit, the results also indicated no significant differences ( $B = 0.40$ , std error = 2.40,  $t = 0.17$ ,  $p_{\text{one-tailed}} = 0.43$ ), as seen in Table 5.6.

Regression tests were also calculated with a number of different controlled variables in an attempt to limit the effect of irrelevant variation. To determine the level of unit effect on the QOL-AD scores completed by residents, a regression test was completed while controlling for the variables highest level of education completed and (transformed) length of time living on the unit. The results approached significance ( $B = 3.75$ , std. error = 2.32,  $t = 1.62$ ,  $p_{\text{one-tailed}} = 0.06$ ). The estimated adjusted mean for the resident's QOL-AD scores was 30.87 (std error = 1.48) on the traditional unit and 34.77 (std. error = 1.53) on the DCU. The marginal mean difference between the units was 3.90. A regression test was then calculated on staff's QOL-AD scores to assess unit differences while controlling for the variables highest level of education completed and (transformed) length of time living on the unit. There was no significant difference found ( $B = 1.23$ , std. error = 2.31,  $t = 0.53$ ,  $p_{\text{one-tailed}} = 0.30$ ).

Table 5.6 Linear Regression – Testing for Unit Differences (N=24)					
Dependent Variable	Control Variables	Beta (B)	Standard Error	t-test for units	Significance (p <sub>one-tailed</sub> <0.05)
Residents' QOL-AD	Length of time living on the unit <sup>1</sup>	2.42	2.73	t = 0.89	0.19
Staffs' QOL-AD	Length of time living on the unit <sup>1</sup>	0.40	2.40	t = 0.17	0.43
Residents' QOL-AD	Length of time <sup>1</sup> and level of education <sup>2</sup>	3.75	2.32	t = 1.62	0.06
Staffs' QOL-AD	Length of time <sup>1</sup> and level of education <sup>2</sup>	1.23	2.31	t = 0.53	0.30
Residents' QOL-AD	Length of time <sup>1</sup> and age	2.59	2.94	t = 0.88	0.19
Staffs' QOL-AD	Length of time <sup>1</sup> and age	0.71	2.58	t = 0.28	0.39
Residents' QOL-AD	Length of time <sup>1</sup> and MMSE	1.76	2.78	t = 0.63	0.27
Staffs' QOL-AD	Length of time <sup>1</sup> and MMSE	0.37	2.52	t = 0.15	0.44
Residents' QOL-AD	Length of time <sup>1</sup> and Ethnic Background <sup>3</sup>	2.33	2.77	t = 0.84	0.21
Staffs' QOL-AD	Length of time <sup>1</sup> and Ethnic Background <sup>3</sup>	0.42	2.46	t = 0.17	0.43
Residents' QOL-AD	Length of time <sup>1</sup> and Religious belief <sup>4</sup>	2.21	2.80	t = 0.79	0.22
Staffs' QOL-AD	Length of time <sup>1</sup> and Religious belief <sup>4</sup>	0.64	2.45	t = 0.26	0.40
Residents' QOL-AD	Length of time <sup>1</sup> and Family Contact <sup>5</sup>	0.96	2.72	t = 0.35	0.36
Staffs' QOL-AD	Length of time <sup>1</sup> and Family Contact <sup>5</sup>	-0.99	2.36	t = -0.42	0.34

<sup>1</sup> Variable "Length of Time Living on the Unit" = (Transformed) Length of Time Living on the Unit

<sup>2</sup> Variable Level of education was divided into two variables, (1) actual value, grade 1-12 and (2) dummy variable, post secondary, 0 = no, 1 = yes

<sup>3</sup> Variable "Ethnic Background" was entered as a dummy variable, 0 = Ukrainian and 1 = Other

<sup>4</sup> Variable "Religious Belief" was entered as a dummy variable, 0 = Ukrainian Catholic and 1 = Other

<sup>5</sup> Variable "Family Contact" was entered as a dummy variable, 0 = No contact and 1 = Contact

Further regression tests were calculated on the residents' as well as the staff members' QOL-AD scores to assess unit differences while controlling for the following variables: (1) age (of the resident) and (transformed) length of time living on the unit, (2) MMSE scores and (transformed) length of time living on the unit, (3) ethnic background (Ukrainian or other) and (transformed) length of time living on the unit, (4) religious beliefs and (transformed) length of time living on the unit and (5) regular contact with family and (transformed) length of time living on the unit. No significant differences were found between the units for either residents' or staffs' scores (refer to Table 5.6).

### Summary

The differences between residents' and staffs' QOL-AD scores were found to be small, especially for those on the DCU. Although no significant differences were found, the mean difference between the residents' QOL-AD scores and those of staffs' on the DCU ( $0.13$ ,  $SD \pm 4.69$ ) was smaller than on the traditional unit ( $1.46$ ,  $SD \pm 6.02$ ). A moderate correlation was also found between residents' and staffs' scores, indicating that when residents' scores increase so did the staffs'. Could this indicate a positive relationship between residents and staff members (primary care givers)?

The residents' QOL-AD scores on the DCU were also higher than the residents' QOL-AD scores on the traditional unit, as were the staffs' QOL-AD scores. When a regression test was calculated (with no controls), the difference between units only approached a significant difference ( $B=3.58$ ,  $std. error = 2.15$ ,  $t= 1.67$ ,  $p_{one-tailed} = 0.06$ ). There was also no significant unit difference found with staffs' QOL-AD scores completed on behalf of their residents. When a number of regression tests with

controlled variables were calculated to determine unit differences related to residents' QOL-AD, no significant unit differences were found (refer to table 5.6). Unit differences with regards to residents' QOL-AD scores only approached significance when the variables highest level of education completed and (transformed) length of time living on the unit were controlled for. Given the small sample size, this could be seen as, at least tentative evidence of unit difference. As for the results of the regression tests (with controlled variables) calculated on staffs' QOL-AD scores, no significant unit differences were found (refer to table 5.6).

#### Reactive Behaviours

The second hypothesis stated that the residents who resided on the DCU would present with fewer reactive behaviours as compared to those who resided on the traditional unit. There were eight reactive incidents that occurred on the DCU and no incidents on the traditional unit. These eight reported incidents involved 3 out of the 12 residents (25.00%) on the DCU that participated in this study. When a Kolmogorov-Smirnov test was calculated, it indicated that the distribution was not normal ( $Z = 2.47$ ,  $p_{\text{two-tailed}} = 0.00$ ). Due to this significant difference, the variable "reactive behaviour" underwent a number of transformations to assist in normalizing the distribution curve. The transformations (log base 10, inverse, and square root) did not assist in normalizing the distribution curve, as seen by the histograms in graphs 5.4, 5.5 and 5.6.

Due to the small sample size and the inability to transform this variable successfully a multi-nominal logistic regression model was used to calculate significance in relation to unit effect. The variable was converted to a binary indicator, 0 for no

incidents, and 1 for any number of incidents. The first multi-nominal logistic regression test compared a full model, controlling unit and transformed length of time living on the unit, with a reduced model (unit effect removed), and found a significant effect ( $2LL = 16.70$ ,  $\text{chi-square} = 6.40$ ,  $df = 1$ ,  $p_{\text{two-tailed}} = 0.01$ ). This indicated that the higher percentage of residents' reactive incidents that were reported on the DCU as compared to the traditional unit was significant. It however showed the opposite of what was hypothesized.

A second multi-nominal logistic regression test was then calculated, in which a full model, controlling (transformed) length of time living on the unit, MMSE and unit, was compared to a reduced model (unit removed). Controlling for MMSE and (transformed) length of time living on the unit increased the significance ( $2LL = 17.50$ ,  $\text{chi-square} = 8.69$ ,  $df = 1$ ,  $p_{\text{two-tailed}} = 0.00$ ). This indicated that the variables MMSE scores and (transformed) length of time living on the unit do not explain the unit difference since controlling these variables did not eliminate the significant difference.

Last, a multi-nominal logistic regression test was also calculated in which a full model, controlling (transformed) length of time living on the unit, regular contact with family and unit, was compared with a reduced model (unit removed). The results showed no difference in the level of significance ( $2LL = 15.81$ ,  $\text{chi-square} = 5.51$ ,  $df = 1$ ,  $p_{\text{two-tailed}} = 0.02$ ). This indicated that regular contact with family members or significant others and (transformed) length of time living on the unit did not explain the unit difference since controlling these variables did not eliminate the significant difference.



## Summary

Findings related to reactive behaviours showed that a significantly higher percentage of residents on the DCU presented with reactive behaviours compared to those on the traditional unit. Although a number of multi-nominal logistic regression tests were completed with various controlled independent variables to explain the unit difference, this explanation was not found. A further study would be beneficial to determine if the unit effect could decrease reactive behaviours over time on the DCU.

## Additional Findings

There were additional tests that were calculated with various independent variables to determine their effect on the overall level of variance in the QOL-AD scores (regardless of unit). One independent variable tested for effect was regular contact with family. An independent sample t-test was calculated to determine mean differences between residents' QOL-AD scores for those residents with regular contact with family versus those without. The results showed that the difference reached significance ( $t$  equal variance = -2.37,  $df = 22.00$ ,  $p_{\text{two-tailed}} = 0.03$ ). The mean QOL-AD score for residents with regular contact with family members or significant others was 33.95 ( $\pm 4.82$ ), while the mean QOL-AD score for residents with no regular contact was 26.67 ( $\pm 6.43$ ). The mean difference was 7.28 ( $\pm 1.61$ ). An independent t-test was also calculated to determine mean differences between the staffs' QOL-AD scores for those residents with regular contact with family versus those without regular contact. The results also indicated a significant difference ( $t$  equal variance = -2.32,  $df = 22.00$ ,  $p_{\text{two-tailed}} = 0.03$ ). The mean QOL score for staff completed on behalf of residents with no regular contact

with family members or significant others was 28.33 ( $SD \pm 3.06$ ), while the mean staff's QOL-AD score for residents with regular contact was 34.62 ( $SD \pm 4.50$ ). The mean difference was 6.29 ( $SD \pm 1.44$ ). This indicated that the variable "regular contact with family" had an effect on the resident's QOL (regardless of which unit the resident resided on).

A number of regression tests were then calculated to identify if there were independent variables that could explain the variance in the QOL-AD scores completed by both the residents and their staff. There were two independent variables that showed a significant result, regular contact with family or significant others and highest level of education completed (refer to Table 5.7). The percentage of variance in the QOL-AD scores (completed by residents) explained by regular contact with family or significant others was 20.60% ( $R^2 = 0.20$ ,  $F = 5.60$ ,  $p_{\text{two-tailed}} = 0.03$ ). The percentage of variance in staff's QOL-AD scores explained by regular contact with family or significant others was also 20.00% ( $R^2 = 0.20$ ,  $F = 5.38$ ,  $p_{\text{two-tailed}} = 0.03$ ).

Prior to completing a regression test to identify the effect that (residents') level of education had on the variance in the residents' QOL-AD scores, this variable was subdivided. An interval variable was used for grades 1 to 12 and a dummy variable for post-secondary education (0=no, 1= yes). Results indicated that the residents' level of education accounted for 31.00% of the variance in the residents' QOL-AD scores ( $R^2 = 0.31$ ,  $F = 4.81$ ,  $p_{\text{two-tailed}} = 0.02$ ). The calculated slope showed a positive direction for the education level of grade 1 to 12 ( $B = 0.52$ , std. error = 0.28,  $t = 1.84$ ,  $p_{\text{two-tailed}} = 0.08$ ). This was not found to be significant. However, the results indicated a slope with a negative direction for post-secondary level of education ( $B = -9.62$ , std. error = 3.19,  $t = -$

3.02,  $p_{\text{two-tailed}} = 0.01$ ). This was a significant finding. When the same tests were completed on staffs' QOL scores, level of (residents') education accounted for 19.08 % of variance in the scores and this effect was not found to be significant ( $R^2 = 0.19$ ,  $F = 2.46$ ,  $p_{\text{two-tailed}} = 0.11$ ). A slope with a positive direction was found for staff members' QOL-AD scores when the (residents') education level of grade 1 to 12 was tested ( $B = 0.38$ , std. error = 0.27,  $t = 1.41$ ,  $p_{\text{two-tailed}} = 0.17$ ). This was not a significant finding. The results indicated a slope with a negative direction for post secondary level of education ( $B = -6.46$ , std. error = 3.04,  $t = -2.13$ ,  $p_{\text{two-tailed}} = 0.04$ ). This was a significant finding. This indicated that the higher the level of education a resident received, the lower the QOL-AD scores were for both the residents and the staff members. Further research would be beneficial to determine the cause of this direction.

Last, a regression test was completed to determine if including both regular contact with family and level of education would lead to a similar level of variance as found when these variables were controlled individually. The percentage of variance explained by these two variables for residents' QOL-AD scores was 53.00%. This was found to be significant ( $R^2 = 0.53$ ,  $F = 7.41$ ,  $p_{\text{two-tailed}} = 0.00$ ). The percentage of variance explained by these two variables for staff's QOL-AD scores was 39%. This was also found to be a significant result ( $R^2 = 0.39$ ,  $F = 4.28$ ,  $p_{\text{two-tailed}} = 0.02$ ). With both residents' and staffs' QOL-AD scores, the level of variance was found to be higher when the variables contact with family and highest level of education completed were tested together than when these variables were tested individually.

Table 5.7  
Linear Regression – Effects Upon Quality of Life

Dependent Variable	Independent Variable	R <sup>2</sup>	F	p two-tailed <0.05
Residents' QOL-AD scores	Regular Family Contact	0.20	5.60	0.03
Residents' QOL-AD scores	Age (of residents)	0.01	0.15	0.70
Residents' QOL-AD scores	MMSE Scores	0.04	0.98	0.33
Residents' QOL-AD scores	(Transformed) length of time living on unit	0.10	2.45	0.13
Residents' QOL-AD scores	Ethnic Background	0.05	1.03	0.32
Residents' QOL-AD scores	Religion	0.03	0.63	0.44
Residents' QOL-AD scores	Highest Level of Education	0.31	4.81	0.02
Residents' QOL-AD scores	Regular Family Contact and Highest Level of Education	0.53	7.41	0.00
Staffs' QOL-AD scores	Regular Family Contact	0.20	5.38	0.03
Staffs' QOL-AD scores	Age (of resident)	0.00	0.00	1.08
Staffs' QOL-AD scores	MMSE Scores	0.00	0.02	0.89
Staffs' QO-AD scores	(Transformed) Length of time living on unit	0.13	3.13	0.09
Staffs' QOL-AD scores	Ethnic Background	0.00	0.08	0.78
Staffs' QOL-AD scores	Religion	0.01	0.25	0.63
Staffs' QOL-AD scores	Highest Level of Education	0.19	2.46	0.11
Staffs' QOL-AD scores	Regular Family Contact and Highest Level of Education	0.39	4.28	0.02

## Summary

These results indicated that the variance in QOL-AD scores could have been affected by variables unrelated to unit effect, such as regular contact with family members and highest level of education completed. Although significant results were found, the sample size of this study was small. This could have had an effect on the findings by possibly increasing the chances of Type II error, even though precautions were taken. Further research, specifically longitudinal research, is recommended to determine unit effect on QOL for residents living on a DCU over a prolonged length of time. Although outside the scope of this study, it would be beneficial for future research to further examine regular family contact and/or level of education and their effect on the QOL of those living with dementia in a PCH setting.

## **Qualitative Analysis – Family Interview**

### Overview

The qualitative component of this study intended to identify any differences in the level of satisfaction with the care and the physical and social environments of the unit, as reported by family members whose relatives resided on a DCU compared to family members with relatives living with dementia who resided on a traditional unit within the same home. This was completed through a semi-structured interview held with family members of those residents who participated in this study.

In total there were 24 residents who participated in the study, 12 on the DCU and 12 on the traditional unit. Nineteen family members of these residents agreed to participate in the interview. There were 10 family members associated with the DCU and

8 with the traditional unit who participated in the interview. One family member of a resident on the DCU agreed to the interview, but could not be reached during the study period. Those who were interviewed consisted of daughters (8), sons (6), a son-in-law (1), a niece (1) and close friends (2). The researcher interviewed 10 families (5 associated with the DCU and 5 with the traditional unit) and the research assistant interviewed 8 families (5 associated with the DCU and 3 with the traditional unit). Each interview took 60 to 90 minutes. Family members were asked if the interview could be recorded with an audio cassette recorder. There were 9 families who did not feel comfortable with having the interview recorded (4 associated with the DCU and 5 with the traditional unit). Detailed notes were taken during these interviews.

There were six themes and eight sub themes that were derived from the participants' responses to the interview questions. Themes included the following: family members' descriptions of the units, family members' satisfaction with level of care and unit staff, social life on the unit, meal program, family relations with unit staff and unit effect on the residents.

#### Family Members' Description of the Units

The changes incorporated on the DCU at Holy Family Home were completed with the goal of providing residents with a more suitable living environment that accommodated their ability and met their needs. It was felt that this in turn would provide residents with a higher quality of care, their family members with increased support and increased opportunity for residents to socialize with each other. It was expected that family members associated with the DCU who participated in this research

would find that the environment had an impact on their relative's wellbeing? The following is what both groups of family members had to say about their associated unit. Since there was a distinction between physical and social components of the units, this section is divided into two parts; physical factors and social factors.

### Physical Factors

#### Dementia Care Unit

The majority of the family members with relatives or significant others on the DCU offered positive feedback on the unit's physical environment. These family members used words such as homelike, safe, secure, bright and clean to describe the physical unit. Most identified that they felt "good" about their decision to place their relative on the unit. One family member said, "[o]f course I feel badly that my mother is in a setting, but I realize that it is where she has to be, you know. I feel she is very safe in that environment and that makes me feel good." This was echoed by another family who stated "this place makes her [feel] like home, and therefore happy."

There were three physical features that families consistently identified as being important changes that have had an impact on their relative's wellbeing; (1) the security that the unit now offered, which prevented residents from "roaming" out of the facility, due to the secured doors to the entrance of the unit, (2) the gazebo and (3) the outside vegetable garden. Families explained that the vegetable garden was important due to the fact that it allowed residents to reminisce about their homes and their own gardens. One family member indicated "[h]er view of the window, like she always grew tomatoes off her balcony and now she sees tomatoes there and you know that is something to see."

Another family member stated that the vegetable garden was important in triggering memories for a lot of people. This family member stated “[i]t was their home environment. It brought back memories for me too. You know the scent, the smell, the tactile, being outside.” As for the outdoor patio and gazebo, families indicated that it was appreciated. It is “nice especially in the summer time to get out in the garden. It is always a big thing for a lot of people.” Another family member stated, “I think that it is a wonderful setting for those ladies just to be able to go out in the fresh air.”

There were a couple of families that could not offer an opinion of the unit since they had nothing with which to compare the unit. There were also a few families who provided recommendations on areas on which the unit could improve. One family member made the observation that the unit was large in size (number of residents residing on the unit), as compared to other DCUs. This family member thought this DCU should be smaller. Another family member felt that the unit should have more private areas for family members to visit with their relatives. This family member’s relative was sharing a semi-private room, and therefore, he felt that the family did not have a private area where they could visit. Last, one family member identified problems with the location of the nursing desk and the fact that there are couches and chairs for residents to sit around the desk. This family member felt that residents sitting by the desk are privileged to private conversations that the unit staff have regarding the condition of other residents. She was also concerned over the fact that the residents may hear staff discussing issues about themselves, possibly causing feelings of anxiety and needless concern for the resident who may wonder “why are they talking about me?” This family member stated, “I think that if staff need to discuss things that perhaps it should be away from the area.”



It appeared to several families that, although the physical unit appeared “nice, warm or homelike”, the features that were most important and which they felt had the most impact on their relative’s wellbeing, were related to the social environment. Included were the care given by staff, programming and the opportunity for socialization. One family member indicated that the physical environment is “nice”,

[b]ut I don’t think it is important to daily life. Increasing the amount of social change [opportunities for socialization], that would make more of a difference than the physical environment. Social well being has a huge impact on the well being of residents.

Another family member indicated that the physical surroundings of the unit were nice, but he felt that this was not an important factor since the residents on the unit did not notice the difference due to physical and cognitive decline. Therefore, this family member felt that the changes were more tailor-made for the families so that they felt comfortable visiting.

#### Traditional Unit

At the time of this study, the traditional unit had not had a décor update since the 1970s. Regardless of the institutional appearance of the unit, most of the families with relatives on this unit also gave a positive description of the physical environment. This was a surprise to the researcher who thought there would be more negative comments. These family members used words such as pleasant, nice and clean to describe the physical appearance of the unit. The focus shifted to the social environment and the staff when family members described the unit in general. There was minimal focus on the

physical environment. When family members were specifically asked about the physical environment, some commented that it was a nice environment, as one family member said, "I think it is a nice place. Some of them are pretty depressing, or you know dingy, so I think it is nice." Other families indicated that it was a regular unit, nothing special and made no impact on the resident's wellbeing.

There were two family members who described the physical appearance of the unit as dull. One family member stated, "[i]t needs more pictures and colour. Something to cheer up the unit." Another family member explained "I take her [the resident] out of here as much as possible to stretch her legs and get her mind off of the closeness of the environment because it is institutional." The family members who felt that the unit was "dull looking" did welcome physical modifications or décor updates to the unit. The need for private areas for family visits was not an issue on the traditional unit and this was probably due to the fact that the residents' rooms on this unit were all private.

Although there was some discussion on the physical environment, the main focus continued to be on the social environment and the staff. As one family member indicated, the décor was average and the unit was not bright, but this was not important and did not bother her. Ensuring that the residents were well looked after and not lonely was more important for this family member.

### Summary

Overall, the family members interviewed offered positive descriptions of the physical environment on both units. The families associated with the DCU appreciated some of the physical changes such as the security features, the gazebo and vegetable

garden and used the term “homelike” to describe the unit. They also used the words opportunity for reminiscing and happy, to describe their relative’s reaction to these changes. Even though this was a locked unit, it was not described as being enclosed or restrictive. Instead family members used the term safe. Families associated with the traditional unit welcomed upgrades or décor changes to the unit and used the term “institutional” or dull to describe the unit. One family member even felt the need to take the resident off the unit due to the “institutional” feel of the environment. Although both groups of families indicated that the physical environment was not important in the residents’ lives, some of their descriptions or comments indicated that they placed some value on the physical environment and that the physical environment did have some impact on their relative’s wellbeing.

### Social Factors

#### Dementia Care Unit

When describing the unit, the family members’ associated with the DCU placed more emphasis on the social features (programs, opportunity for socializing and quality of care) as compared to the physical features. Most of these families offered positive descriptions of the unit’s social environment. Words such as friendly, warm, well managed and good care provided were used to describe the DCU. Some families indicated a comfort level with the unit because it was a DCU and, therefore, to them this meant that their relative would receive specialized care. As one family member explained, “I was happy to hear that it was a specialized area and that there was ongoing

research and even work into trying to, I guess provide better living for people particularly with dementia.”

There were two social features of the DCU that some family members identified as problematic. The first was the fact that staff appeared to have busy or “demanding” care routines. This was apparent to these families for they could see staff attempting to ensure that the residents were safe and well cared for by their constant supervision or redirection of residents. These families alluded to the need for increased staffing on the unit. The second issue was related to the increased noise level occurring at times on the unit that resulted from residents “calling out”. Families expressed concern that this affected the well being of the residents who lived on the unit. As one family member indicated, “[t]he constant yelling that goes on [by one resident] is a concern. I have sat with mom in her room while she has been napping and she would be in a deep sleep snoring and would wake up to this yelling and like she would get scared.” Some families indicated that this problem could be due to the fact that there were residents living on the same unit who were at different levels of dementia and therefore maybe the residents on the unit should be closer or similar in care needs.

#### Traditional Unit

The family members associated with the traditional unit, offered both positive and negative descriptions of the social environment. These families stated that residents were well looked after and that the unit was warm and friendly but also noisy at times. This was related to other residents who call out and to staff slamming doors. One family stated, “[i]t is bothersome with those who call out. Difficult for her [the resident]. She

closes the door. That bothers her.” Another family stated, “[i]t sort of gets to me after five minutes, you know I can’t imagine what it is like all day.” Families with relatives on the traditional unit identified a solution that resembled the one offered by family members with relatives on the DCU. It was to group residents together by similar levels of dementia or cognitive abilities as opposed to having a mixed unit of residents at different levels of care needs or abilities. This was also a solution for dealing with the issue of residents who roam into other residents’ rooms and invade privacy or take items from others believing that it is theirs. This seemed to be quite bothersome to one resident and therefore to the resident’s family member. This family member stated “...they [other residents] enter her room and even while she is sitting in her room watching TV, someone has wandered in and started going through her drawers helping themselves to her treats.” This was described as causing distress for the resident.

Although some families felt that there were a variety of programs or activities offered on the unit, they still felt that there could be more done to increase the opportunity for socializing among residents. One family member indicated that she was bothered over the fact that she sometimes sees residents sitting by the elevator, looking lonely or bored. This family member stated, “I hate to say this but it is a sad place. The ladies look so sad. Those that sit by the elevator, they look lonely.” This family member felt that there could be more opportunity for socialization and activity for the residents on the unit. Two solutions were provided for this problem, either increasing the number of programs offered on the unit or grouping residents of similar cognitive levels together on the same unit.

## Summary

Overall, both groups of families were content with the unit in which their relative resided. This had more to do with the quality of care and programs offered than with the physical appearance of the unit. Families on both units used words such as warm, friendly, good care and noisy to describe the social environment of the unit. Families with relatives on the DCU indicated a need to increase staffing levels and decrease the noise level on the unit. Families with relatives on the traditional unit felt a need to increase the number of programs in order to decrease the level of residents' loneliness or boredom. They also indicated a need to decrease noise levels. Both groups indicated that the social environment had a greater impact on their relative's wellbeing than did the physical environment.

### Family Members' Satisfaction with Level of Care and Unit Staff

#### Dementia Care Unit

The family members who had relatives on the DCU had positive descriptions of the unit staff. Staff members were described as nice, friendly, accommodating, compassionate and caring. Two families used the term excellent to describe the care that staff provided to their relatives. One family member identified staff as being the key to the success of the unit and to the quality of care a resident received. This family member stated, "[t]he whole thing that makes the unit is staff." In general, families indicated that the staff demonstrated genuine concern for the residents. They also indicated a high level of trust in the staff related to being contacted and informed when there were concerns.

Family members linked quality of care or consistency in care with “regular” staff and with the level of staff knowledge. Most felt that the nurses and health care aides (HCAs) understood how to relate to or approach each resident, even though they may be at different stages of the disease process (dementia). As one family indicated, “[t]hey [staff] seem to know how to care for her [the resident] better, much better than I would. The way they talk to her like when I see them dealing with whether it is my mother or someone else they seem to know how to calm her down.” Another family stated “I notice that staff are more knowledgeable than in the Respite [unit] she [the resident] was in. It comes through.” Some families felt that staff who choose to work on a DCU, should be knowledgeable in the area of dementia care and be committed to receiving ongoing education. Families also indicated a preference for the “primary care” concept (pairing a resident to the same HCA on each shift instead of a resident being paired with different HCAs each day on each shift). As one family member explained, “[primary care] is an important thing because they [staff] get to know them [residents] on a regular basis.”

Although most families felt staff were knowledgeable and offered good care, one family member was disappointed with the lack of communication among staff members (between different shifts) and also with the lack of experience that a few staff demonstrated in their approach to residents. This family member stated, that unfortunately staff members “... don’t share their knowledge of tid bits of information about the residents to other shifts.” She added that “[s]ome of the staff on the unit are more gifted, compassionate than others and know the right approach with residents. You have to be special people to do this every day.” There were two families who were not comfortable discussing their opinion of staff’s knowledge level and declined to comment.

### Traditional Unit

On the traditional unit, staff members were also described as being patient and providing good care. One family member stated,

I know that some staff are able to deal with her [the resident] very well on a personal level not just on a professional level but on a personal level, someone she trusts, someone who gives her extra time. They know how to approach her, they know her moods and tempers and her ups and downs. They almost read it but not label it, its something that comes from a person's own background or whatever, not just what they learned about certain physical or mental elements. It's something that the person brings to their job.

Families with relatives on the traditional unit indicated that residents appear to be well cared. They also acknowledged, as they did on the DCU, that this type of work is not easy. The families associated with the traditional unit, just like those associated with the DCU, indicated that regular staff were seen as critical in order for consistency and quality care to be offered.

There were 5 families who felt that they could not comment on staff knowledge base related to dementia care. There were also a few families that indicated some difficulties with staff. One family indicated that although they felt things were good, there could still be improvements. They made reference to the "little" things that mattered so much to the resident, such as ensuring eyeglasses were cleaned so the resident could see. The same family indicated that they had to continuously remind staff to do these "little" things for their relative. This was echoed by another respondent who



felt that they had to remind staff to encourage their relative to participate in activities or else she would remain sitting alone in her room. There was one family member who questioned the level of knowledge of some staff. This person felt that some staff lacked an understanding of the person and focused solely on the disease or care routine. This family member took exception to staff using the diagnosis of dementia as a “label” or an excuse for a resident being agitated, calling out or aggressive. This family member stated that, staff should try to understand why the person was agitated or irritated, indicating that staff members do not realize that there could be many reasons for the behaviour which were not necessarily linked to the diagnosis of dementia. For instance, this family member stated, there could be a phobia, the resident could have pain or the reaction could be a result of how staff approached the resident. This family member felt staff members “... could use little bit more knowledge regarding dementia care.”

### Summary

Both groups of families appeared to have had somewhat similar experiences with the unit staff. Most commented that care was good, some even described it as excellent (the DCU). Both groups of respondents placed value on regular staff and the concept of “primary care”. Both also indicated that some staff had the right personality for working with and understanding people with dementia and others did not. Families with relatives on the DCU focused on the need for staff to have the opportunity for ongoing dementia care education, while a few families associated with the traditional unit felt that some staff required education related to dementia care. They indicated that some of the staff members on that unit need to focus on how to approach and understand the person

holistically and not just focus on the diagnosis. Although the respondents associated with the traditional unit indicated that staff provide good care, there were a few families who indicated frustration over the fact that staff had to be reminded of simple care needs. This was not voiced as a concern from family members with relatives on the DCU.

## Social Life on the Unit

### Activity Programs

#### Dementia Care Unit

The families interviewed who were associated with the DCU acknowledged the importance of socializing and programming and felt that these were features that were as important to a resident's wellbeing as was quality care and committed staff. Most of the families interviewed regarding the DCU felt that the programs or activities offered on the unit were appropriate. Six of those families indicated that their relative attended most of the programs. Reference was specifically made to certain programs such as music, crafts, baking and cooking. Families acknowledged the beneficial effect that cooking and baking programs had on their relative. They indicated that the aroma that filled the air connected residents to memories of cooking for the family or baking for special occasions. A family member indicated that offering programs which provide positive memories is important for her relative. She stated, "she [the resident] loves music, I know that she did when she was growing up and you can see that there is a part of her personality that comes out, it makes her happy, she likes to become involved." This family member also felt that the recreation worker understood the residents' interests and involved them appropriately, focusing on their strengths, not deficits. She stated,

The recreation worker realized that she [the resident] has the ability to read and read well so she would in a group setting allow her to do the reading. She [the resident] took pride in this ... that is a positive thing. Anything else that they [staff] can provide or find out and I think that the recreation worker does try to obviously do some research to see what it is that she can provide for the individuals on her unit.

Families acknowledged that involvement in the activities or “life” on the unit can assist residents to have confidence in themselves and feel good about what they have accomplished, increasing their self esteem. One family member made reference to the art program and felt that her mother had pride in the work she did and the fact that she was able to display her work on the unit. This also made the family member feel good. Respondents commented that involvement in programs assisted in keeping residents less irritable or bored. Most of these families, who were associated with the DCU, indicated that they at times participated in these activities with their relative.

Although the majority of these family members offered positive feedback on the programs available on the DCU, a few reported a need to further adapt programs to address the needs of residents at different levels of cognitive abilities and/or who require increased physical assistance. Families stated that programs offered on a DCU should reflect the abilities of all residents. There were two families who stated that there were not enough opportunities for their relatives to participate in the activities offered due to their differing interests and abilities. One family member indicated that since their mother’s medical and cognitive condition had changed, staff’s involvement with her

related to programming had declined. According to another family member, there were not enough things for residents to do throughout the day. This family member stated,

[i]t does bother me that I come in and those women are sitting there [by the desk] all day long. I don't know what else they do. But they are sitting there. I mean I think it is wonderful that they can collect there, but I walk out of there thinking, I hope they are not sitting there all day long".

There were also a few family members who indicated that they would appreciate increased feedback from the unit staff regarding program participation of their relatives.

#### Traditional Unit

Comments made by the families with relatives on the traditional unit were similar to those made by families associated with the DCU. Most families indicated that their relatives participated in programs or activities. These families also indicated that their relatives enjoyed the activities offered, especially outings and parties. One family member felt that it was great how, in the summer time, the recreation workers take residents on outings with the Holy Family bus. Some families stated that it was important to offer residents the opportunity to participate in activities outside of the facility due to the fact that the unit had an institutional feel, and therefore this would be a break from the unit. Most families were happy with the recreation worker and felt she tried to meet individual needs and made time for each resident and encouraged them to get involved. One family member stated,

It isn't easy to get my mother out to do things that are going on. The recreation worker will get her going to certain things, like I have come and

she has been bowling and the other day, I came in and the recreation worker was giving her a manicure which I thought was sweet. I think there is enough variety.

A few indicated that their relative's involvement in programming was either minimal or non-existent. These family members were quick to point out that this was not due to the worker or the programs offered, but it was due to the individual's personality or medical and/or cognitive changes. Some families indicated, as did the family members associated with the DCU, that the programs offered were not appropriate for residents at all levels of cognitive ability and that this needed to be changed.

Although the majority of families whose relatives were on the traditional unit were happy with the program choices, some felt that there was still an opportunity to improve on the variety of programs offered. A few families recommended changes to programs, such as including less bingo and more exercise programs. However, one family member stated that it is not reasonable to expect that programs be adjusted to meet everyone's needs because "... there are 40 residents on the unit and it would be impossible to address everyone's interests with only one recreation worker."

### Opportunity for Socializing

#### Dementia Care Unit

The discussion on activity programming lead most family members into a discussion related to socialization. Some families associated with the DCU explained that the opportunity for socialization among residents was minimal due to the fact that the residents were at different functional and cognitive levels. Interaction occurred more

between staff and residents. One family member indicated that when her relative socialized with other residents, the focus was usually comparing themselves to others on the unit. This family questioned if this comparison was “a good thing” or could it cause increased anxiety? Again, the discussion focused on having residents of the same level of ability on the unit. The same family member stated, “[the resident] wants to talk to people but when she starts they don’t understand each other because they are all sick.” Another family member stated “[i]ncreasing the amount of social change, that would make more of a difference than the physical environment. I see my mother with blocks instead of socializing.” This family member was referring to staff placing objects in front of the resident for her to use instead of socializing with her or encouraging a co-resident to sit and socialize with her.

#### Traditional Unit

All respondents associated with the traditional unit focused on the importance of residents being able to socialize with each other. A number of family members indicated that being on the traditional unit had provided an increased opportunity for their relative to socialize. One family member stated, “[h]ere she socializes. At home in her apartment she did not.” This was shared by another family member who stated “she [the resident] doesn’t like to be by herself; here she has other people around her.” In another situation, the family member explained that she felt her mother’s opportunity for socializing had decreased since her admission to the unit because at home she had more visitors than now. There were also a couple of families who felt that since there were residents at

various stages of ability on the unit, socialization is difficult. As one family member stated,

[i]t seems to me that there aren't that many people on that floor, that are really able to just converse. Have a conversation about anything. Go off on a tangent about something. I think it would improve her [the resident] spirits, her mood [if there were more people she could socialize with].

Several recommendations were offered by some families on how to increase the opportunity for socialization on the traditional unit. They included changing the client population on the unit to include residents with similar levels of abilities and rearranging the furniture in areas to encourage spontaneous socialization between residents (not having the chairs all in a row).

### Summary

In general, most of the families interviewed on both units felt that the programs were appropriate and there was an effort from the recreation worker to offer a variety of programs. There appeared to be more of an expectation on the DCU for feedback from the recreation worker to family members on the resident's involvement. Feedback was something that the families with relatives on the traditional unit did not discuss. The researcher was not sure if this was due to the fact that families felt that they did receive feedback or because they just never thought to discuss it. Most of the families interviewed indicated that their family members attended programs. Some of the programs of interest that were mentioned included music, cooking and baking, art, reading programs, parties and outings. In both groups of families some indicated a need to further increase the

variety of programs offered. These families indicated that not every resident enjoyed playing bingo and that some residents were not able to participate in most programs due to their limited abilities. Some families felt that programs should be adjusted to meet the abilities of all residents.

There were some families in both groups that indicated that they did notice residents who just sat and “did nothing”. They questioned if this meant that there was not enough for people to do. Families also commented that there were limited opportunities for residents to socialize with each other and questioned if this would change if the unit consisted of residents who were at similar levels of ability. Regardless of the unit the families indicated that they were happy with the recreation worker and for the most part, the programs that were offered.

## Meal Program

### Dementia Care Unit

Meal time for those with cognitive impairment can be at times a difficult period. Cognitive impairment may complicate the task of eating, compromising the individual's ability to attain and maintain adequate nutrition and hydration (Young, Binns & Greenwood, 2001). Recognizing this and in an attempt to simplify meal time, a new meal service for residents was introduced on the DCU (buffet style instead of tray service).

The interview found that most families with relatives on the DCU were not aware of the new system because they visited outside of meal times and therefore stated that they were not able to comment on preference of systems. Once the new meal service was



explained to them, most of these families indicated that it was a good concept. One family member stated that although she was not familiar with the new system of serving meals she felt that "... any effort in trying to make something feel like it's more of a home atmosphere is worth an effort." This family member felt that the concept should be expanded to other meal times. A few of the families commented that for their relatives, it did not matter how the food was served as long as the quality of the food was good.

There were 4 families who were aware of the meal services on the DCU, and all of these family members offered positive comments. One family member stated that compared to supper, "[l]unch is better. There is too much at once the other way, they [residents] get confused ... Lunchtime way – fresher, hotter easier on patients." Another family indicated that there was consistency with the quality and temperature of the food. One family indicated that this system was an improvement, but felt that things still needed to be worked out to ensure that all residents were served the meal in the right order. This family member stated that with more than one server, some meal items can be missed and the residents may not receive their full meal. This happened to her mother who, on one occasion, did not receive her main course.

#### Traditional Unit

On the traditional unit none of the families associated with the unit were familiar with the new delivery system. These families indicated that since their relatives did not complain about the tray service delivery, they assumed that it was fine. There were, however, some families that felt that the new system may be an improvement and therefore something worth trying. There were other families who felt that the new

system might not be beneficial. One family member indicated that using the tray system, it may be easier to accommodate diet restrictions. Another family member indicated that the new system would not make a difference to residents' well being. This person stated "[the resident] still knows what she wants and what she eats ... Doesn't matter if one item or all items on a tray ..." One family member stated that what would assist in improving meal time for residents was extra staffing during this period to assist in feeding residents. The family member stated "there are a number of ladies that require help and if they don't get it, then they aren't eating."

### Summary

The comments made by the families with relatives on the DCU and those with relatives on the traditional unit were similar. Those families who were familiar with the new meal program and some of the families that had the service explained to them felt that this new concept was good. However, a few families indicated that the quality of the food was most important, not how it was delivered. Most of the families with relatives on the traditional unit did not feel that there would be any benefit to the residents in introducing this delivery system. This was a surprise to the researcher, who thought that once the concept was explained to the families interviewed, that they would all indicate a preference for the new system.

### Family Relations with Unit Staff

Through the interview process, the researcher wanted to explore what the relationship was like between family and staff on these two units. Was there a difference

in the experience between family members involved on the DCU and those on the traditional unit? The following is what the families had to say.

### Level of Involvement with Care Related Decisions

#### Dementia Care Unit

All of the family members associated with the DCU, but one, indicated that they felt involved in care planning and decision making related to medical and day to day care of their relatives. They also indicated that staff informed them and kept them up to date on what was occurring with their relatives. One family member explained how difficult it was for them to accept the decline of their relative's physical and cognitive functioning. This family member explained how staff provided her with information related to her relative's condition and together they tried to work out concerns. She stated that at times there were misunderstandings regarding the information that was shared with family. These misunderstandings were usually resolved by meeting with the staff.

One family member associated with the DCU indicated that she did not feel that staff involved her, nor did she feel that her comments or concerns made a difference to staff. She stated "[w]ith regards to involvement in the care planning, I am not approached. I have been made to feel that feedback would not help. I do mention to staff the little things that I think may be more effective with mom, but I don't know if that information is useful or not." This family member indicated that her relationship with some of the staff was not always comfortable or trusting.

### Traditional Unit

Regarding the traditional unit, all of the family members indicated that they felt that staff involved them in decision making and in care planning for their relatives. There were no hesitations when these family members responded. They stated that they were kept informed even though they were not there on a daily basis, because staff would call them with updates when something occurred. One family member stated that, although staff members were good at involving family in the care decisions of their relatives, she felt that it was still the family member's responsibility to ensure that they were involved and not just waiting for the staff to call them.

### Summary

It is important for families to feel involved and trust the staff caring for their relative. The majority of the families associated with the DCU and all of the families associated with the traditional unit stated that staff listened to them when they had a concern and that they were involved and did have a trusting relationship with staff. Most of the families with relatives on the DCU stated that they recognized staff's efforts in keeping them informed and appreciated the calls from staff when a change or incident occurred relating to their relative. If something was to occur, these family members indicated that they knew they would be called by staff. The same was stated by all of the families with relatives on the traditional unit.

## Level of Support Offered to Family Members

### Dementia Care Unit

During the interview with family members, discussion was held as to whether or not families received support from staff. For those families interviewed, support to them meant staff providing them with information on their relative's condition, informing them of any changes, answering their questions, providing them with education related to dementia care and ensuring that their relative was safe and comforted when necessary. One family member associated with the DCU explained that watching the staff comforting her relative by placing an arm around her when she was upset was a form of support to this family member because it reassured her that she made the right decision to place her relative at Holy Family Home.

Most of the family members interviewed about the DCU stated that they received support from staff. Some families expressed feelings of guilt due to accepting placement for their relative, but knew that it was what was best for them. One family member stated "... it's taxing for me. I find it emotionally hard, but they [staff] are there and they reassure me and the social worker you know reassures me." Another family stated that "I feel she [the resident] is safe in that environment and that makes me feel good." Most indicated that they did not have to worry and felt supported because they were informed if something happened to their relative. The focus was on trusting that staff members were caring towards their relative and that if something happened that the staff would notify the family. One respondent indicated that support came from not just the nurses, but the primary care givers (HCAs), as well. She stated, "If there is anything wrong I know that, like the day nurse will mention it to me or the evening nurse will, or the health

care aide or whoever. I can talk to any of them.” Another family member pointed out that things were not easy for her at first with the staff, but with time a comfort level developed between them. She stated “...any time I had any kind of concern, there was always somebody there willing to listen and at first you know, it was tough..” The same family member pointed to the dementia care education in-services which were held once a month in the home and were offered to family members, staff and the community as also being a good form of support for families. Another way that families indicated that they felt support was when staff addressed their issues immediately. Families also pointed to the importance of consistency in staffing, and therefore the “primary care” concept to ensure that they were kept up-to-date on information. Another family member expressed her level of comfort with the unit and staff by stating, “[i]t makes me feel like I am coming home, not a visitor visiting [when she is on the unit].”

Those family members who stated that they did not feel support, indicated the reason was due to staff always running around and not able to take a few minutes to answer questions. A few indicated that some staff members were more approachable than others for support. One family member indicated that she was always the ones that had to approach staff and ask about her relative, staff did not approach her. Most of these family members did not feel comfortable commenting any further.

#### Traditional Unit

All but one respondent with a relative on the traditional unit indicated that they felt supported by staff. This support meant different things to each family member, but overall, it meant that they were informed or updated on the resident’s condition. One

person expressed that he received support from staff, because staff would always answer his questions and concerns. Another family member stated “Yes they always tell me everything. They always tell me what is going on and that is great support to me, to know that I will be informed of what is happening with my mom.” One family member indicated that not all staff were approachable; “[s]ome of the staff on the unit I would say yes, others no.” This comment was in reference to casual staff. Families stated that the concepts of regular staff and “primary care” were important to them and to the consistency of care and support for their relative.

### Summary

Regardless of the unit, most families interviewed stated that they felt supported by staff, which was due to staff updating them on changes to their relative’s relatives’ condition. Regardless of the unit, there were a few families who indicated that, even though they felt support, it was not given by all staff, as some staff were perceived as approachable and others who were not (usually casual staff). For those families who felt supported by staff, they stated that the support was given not just by the nurse on days, but by multiple staff members, from different disciplines, such as the nurse on evenings, the primary care givers (HCAs) and the social worker. This reflected a team approach in supporting residents and their families.

### Unit Effect on the Residents

At Holy Family Home the goal in developing the St. Francis unit into a DCU was to improve the care offered to residents (flexible, individualized care routines) and

increase their QOL. The researcher expected that the respondents associated with the DCU would indicate that the unit and therefore the modifications had a positive impact on their relative, and therefore, their quality of life. The following is what family members expressed.

### Unit Benefit

#### Dementia Care Unit

As previously noted, there were some families with relatives on the DCU that had indicated a few areas that required improvements on the unit. These improvements were related to the noise level, limited opportunity for residents to socialize and the need for private areas for families to visit with residents. Regardless of how these families felt about such issues, all of them indicated that the unit had been beneficial to their family member. One respondent asserted "... I don't think I would want her [the resident] anywhere else right now." There were a number of reasons why families felt this way, mainly due to increased care and the sense of security. As one family member stated,

I think it has [been beneficial to be on the unit] because she's been cared for on many levels. Her personal care, her emotional well being, she's got her three meals. This is a marked improvement to what she had at home.

Another family member expressed that she did not have to worry about her relative anymore. "I don't worry about her, she is safe ... [h]er needs are taken care of, her medical care, food and clothes are all taken care of." Other families focused on the fact that the unit had been beneficial because it had offered increased opportunities for socialization. One family member stated that the unit



has had a positive effect on her mother's well being because she is actively participating in programs. She stated "I think it's a wonderful floor, you know when she came here she wouldn't even think of playing bingo, I mean, now she participates."

Two family members specifically stated that, although they found the unit to be beneficial, they had some concerns regarding certain aspects of the unit. One family member expressed concern with the level of noise on the unit (related to other residents calling out) and how it affected her mother, possibly leading to increased reactive behaviours. The other family member expressed concern related to the management of her mother's medication, specifically the psychotropic medication used to calm her. She stated, "I believe she is still yelling a lot so they give her something because she is now dopey." This family member was not happy with this intervention, "[n]o absolutely, I am not happy. I can talk to her quite clearly but sometimes she just looks in one spot."

Some families were happy that their relatives, were on a DCU or specialized unit. For others the fact that they were on a safe or secure unit was just as important. As one family member stated, "[o]f course I feel badly that my mother is in this setting but I realize that this is where she has to be, you know. I am happy that she is safe. I feel she is very safe in that environment and that makes me feel good."

#### Traditional Unit

The families with relatives on the traditional unit also indicated that the unit had been beneficial to their relatives even though it was not a DCU. The main reason indicated was related to the increased security and quality of care by staff. One family

member explained, “[s]he [the resident] is now eating properly, bathing, and changes clothes, before she did not. She has even gained more weight. It has helped her being here.” Another family member stated, “... well for the most part, personally, I know that it is better. I am less concerned about her, she is getting really good care 24/7.” Even though there were some problems reported regarding the unit, specifically with the physical environment and with the noise level families still thought that their relatives benefited from being on this unit. One family member said that his mother was nervous about moving, particularly about communal living. When she moved into the unit, the family member indicated that her response was very positive. He stated “...coming here was like stepping into heaven, you know, a real change for her. It is a 100% of what we ever hoped as far as this point in her life.” Another person expressed that the benefit was not only due to care provided or security but also the opportunity to socialize.

It has been beneficial. When she was on her own, she wasn't eating anymore, you know. I was worried about whether she was going to burn her apartment down. She was lonely I was basically only five minutes away from her, but I did not see her like every day. But I think it is nice to have people around and three meals a day and whenever, you know, whenever she wants company she can always find it.

Overall families felt that the unit had been beneficial because of the staff, specifically the regular staff. As one family member stated, “[t]he unit has been beneficial for my mother. When staff is regular we don't have to come three to four times a day because we know she is okay. Regular staff is important.”

## Summary

Regardless of the unit, the family members interviewed felt that the units had been beneficial for their relatives, specifically because they offered security, opportunity for increased socialization and regular consistent good care. Regarding both units, the families stated that the main reason that the unit was a success was related to the staff. Families supported the idea of primary care (HCAs) and were more comfortable when regular staff were looking after their relatives because they knew them better and they had developed a relationship with them. Although there were some concerns expressed with the units related to noise level (both units) and use of medication (DCU), both groups of families continued to feel that, overall the units had been beneficial for their relative.

## Unit Effect on the Residents' Quality of Life

### Dementia Care Unit

Quality of life (QOL) can mean different things to different people. Regardless of its interpretation it is something that is important for a person's well being and self esteem. Regarding the DCU, most of the family members indicated that the QOL of their relative improved due to being on the unit and due to the fact that there was increased opportunity for socialization and involvement in activities. One family member stated,

[there has been a] big difference in her QOL, because when she lived at home she wouldn't have Home Care. She would unlock the door and away she went. This way I know she is here. If she walks around, people will always find her and I am not worried. And she is involved. There is

a lot of people here; she is surrounded. Like I've said, she is communicating. That's amazing. She didn't communicate at home. She would come to my place, she would want to go home. It is a relief to know she is being looked after.

Another family member stated,

I think she [the resident] has a better QOL now than she had at home... More things to do and more chances to have visitors. It was a very positive move. It was very positive in comparison to the kind of life she had at home, because I feel that the most important thing was her QOL and she wasn't adding to her potential at home.

Other families felt that the unit has had a calming effect on their relatives and therefore a positive effect on their QOL.

Some families compared the unit to past facilities that the resident had stayed in prior to coming to this unit. "In hospital [s]he was just like, all day in bed. I felt so sorry for her." This family member stated that the resident experienced depression in hospital and would not want to socialize or get out of bed to go for a walk. Since her move to this DCU, this has changed. This resident, according to the family member became involved in activities and "[s]he is happy here."

A number of families indicated that although the unit has had some positive effect on their relatives' QOL they felt that more could be done for their relatives to enhance QOL. One family expressed the following, "[h]er needs are taken care of. Her QOL improved. She receives more care than what was previously provided for her...

Emotionally I would like to see more for her.” This family member wanted socialization and activity opportunities to be further increased for her relative.

Two family members reported that they did not feel that the unit has had an effect on the QOL of their relative. One stated, “Well, she went down very dramatically. Completely different than when she was at home, just like that.” This family member indicated that due to the dramatic decrease in the resident’s status they were not sure if the unit had any effect on her QOL . Another family member said that although the family was happy with the care provided on the unit she did not feel that it has had any effect on the resident’s QOL.

#### Traditional Unit

Among the families with relatives on the traditional unit the responses were similar to those with family members on the DCU. Some families felt that the unit had a positive effect and others felt that there had been no effect on the residents’ QOL. One family member said that the reason her relative’s QOL improved was due to the fact that she was now receiving regular care. “She never ate well, washed well before she came here. She was locked in her house before. Never had anything clean. This is now different here.” Another family member indicated that the resident’s QOL improved due to increased opportunity for socialization. “Her QOL is better than it was in the apartment. Here she socializes. In the apartment there was no opportunity. It is very good here.”

Two family members did not feel that the unit had an effect on the resident’s QOL. “No [effect on QOL]. She was well cared for before [being admitted onto the

unit] and after, it is the same. No complaints however, from anyone.” Another family member indicated that the residents’ QOL could improve with increased socialization if there were more residents at similar levels of functioning and ability on the unit.

### Summary

Regardless of the unit, most families felt that their relatives’ QOL had improved. Reasons given related to increased opportunity for socialization and involvement in recreational activities and the fact that their relatives received regular care and were now in a safe environment. For both groups of families these reasons were the main focus or themes throughout the interview as being the critical factors that influenced their relatives’ wellbeing.

## **CHAPTER SIX - DISCUSSION**

### **Overview**

The Person-Centred Model of Care heralded by Tom Kitwood (1997) suggests that the practice of care offered to persons diagnosed with dementia living in long term care facilities should not be seen primarily as a matter of attending to physical needs. It should acknowledge the “whole person” (physical, social, psychological and spiritual). An “ethic of respect for persons requires it” (Kitwood, 1997, p. 88). In an attempt to improve quality of care and incorporate care practices, a number of specialized or DCUs have been developed. Although the development of these units continues, there has been no clear sense of their benefit, and therefore, impact on the QOL (Grunier, et al., 2008; Leon & Ory, 1999). This could be due to the lack of clear theoretical guidelines, policies or environmental standards for DCU implementation (Grunier, et al., 2008; Teresi, et al., 2000). Continuing to build on the research related to DCUs, this study, which focused on a person-centered model of care, evaluated the effect of a DCU in three areas: unit effect on QOL, decreased reactive behaviours and family members’ level of satisfaction, in an attempt to identify benefits of living on a DCU, for those diagnosed with dementia.

### **Unit Effect on Quality of Life for Residents**

The findings in this study indicated that there were no significant differences between the QOL of residents residing on the DCU and those residing on the traditional unit. The residents’ QOL-AD scores were higher ( $34.83 \text{ SD} \pm 4.59$ ) for those living on the DCU as compared to those living on the traditional unit ( $31.25 \text{ SD} \pm 5.86$ ). The difference between the scores of the two groups of residents was found to only approach

significance when a regression test was calculated. Support for the first hypothesis in this study was therefore not apparent (it is expected that the QOL for residents who resided on the DCU would be higher as compared to those residents who have a diagnosis of dementia and resided on the traditional unit). This is possibly due to the fact that the sample size of this study was small. A larger effect may have been detected with a larger sample size. Furthermore, a longitudinal study at Holy Family Home would be recommended to determine if, over a longer period of time (1 year), QOL would increase for residents on the DCU as compared to those on a traditional unit. In a study by Reimer, et al.(2004), the QOL of residents in a special care facility was compared to the QOL of residents in traditional institutional facilities over a one year period. The results suggested that the QOL for the residents in the special care unit were the same or better than the traditional institutional environments.

The QOL-AD scores obtained from staff on behalf of residents living on the DCU were also higher than those obtained from staff on behalf of residents living on the traditional unit. But this difference was not found to be significant. When the QOL-AD scores obtained from staff on behalf of residents' were compared to those obtained from the residents themselves, they were found to be similar. Although this was true on both units, the scores on the DCU were closer than those on the traditional unit. This difference however was not found to be significant when an independent t-test was calculated. What was found to be significant was a correlation between residents' and staffs' scores. A Pearson correlation was calculated and it indicated that as residents' scores increased so did the scores completed by the staff (regardless of unit). Although the differences between scores were not significant, the closeness of the scores does lead



one to question why. Since both units practice primary care (of HCAs and nurses) does this assist in developing positive, comfortable and trusting relationships between staff (especially the HCAs) and residents in which staff therefore have a better understanding of residents' needs?

In an attempt to limit the effect of irrelevant variation between units, a number of statistical tests were calculated. This included regression tests calculated on the QOL-AD scores (residents' and staffs') for both units, with a number of different controlled variables, such as "length of time living on the unit" (due to the significant differences found between the units). The level of unit effect on residents' and staffs' QOL-AD scores alone was not found to be significant. Unit effect only approached significance with the residents' scores when the variables "highest level of education completed" along with (transformed) "length of time living on the unit" were controlled. This indicated that the resident's level of education could have an impact on their QOL.

To identify if residents having regular contact with family had an affect on their QOL, an independent sample t-test was calculated to determine the mean difference between residents' QOL-AD scores for those residents with regular contact with family versus those without (regardless of unit). The results showed that the difference reached significance. The same results were found when staffs' scores were calculated. This indicated that regular contact with family can have an impact on residents' QOL, regardless of unit. This finding is supported in the literature related to dementia care. It has been found that "... human relationships and social contact especially with family is crucial in determining quality of life" for residents of long term care facilities (Iwasiw et al., 2003, p. 46). Families should be viewed by staff as an extension of services to the

resident and therefore be encouraged to visit and become involved in the care decisions. This is especially important when their relative is no longer able to make decisions on their own due to cognitive impairment.

Further regression tests were calculated to identify if there were independent variables that could explain the variance in both groups of QOL-AD scores (residents' and staffs'), regardless of unit. There were only two independent variables that showed significant results, "regular contact with family" and "highest level of education completed". The percentage of variance in the residents' QOL-AD scores explained by regular contact with family was 20.60%. The percentage of variance in the staffs' scores explained by the same variable was 20.00%. With regards to the variable "highest level of education completed", the results indicated that it accounted for 31.00% of the variance in the residents' QOL-AD scores. When the level of education was divided between completing grade 1 to grade 12 and attending post-secondary, the results showed a positive slope for the education level of grade 1 to grade 12 ( $B = 0.52$ , std. error = 0.28,  $t = 1.84$ ,  $p_{\text{two-tailed}} = 0.08$ ). However, there was a negative slope found for post-secondary level of education ( $B = -9.62$ , std. error = 3.19,  $t = -3.02$ ,  $p_{\text{two-tailed}} = 0.01$ ). This was significant and this negative slope indicated that the higher the level of education a resident received, the lower the QOL-AD score. As for the staffs' scores, the variable "highest level of education" (residents') accounted for 19.08% of the variance in scores. When the level of education was divided results showed a slope with a positive direction for education level of grade 1 to grade 12 ( $B = 0.38$ , std. error = 0.27,  $t = 1.41$ ,  $p_{\text{two-tailed}} = 0.17$ ). The results also showed a negative slope for post-secondary level of education ( $B = -6.46$ , std. error = 3.04,  $t = -2.13$ ,  $p_{\text{two-tailed}} = 0.04$ ). This was significant and this

negative slope indicated that the higher the level of education a resident received, the lower the staff' QOL-AD score. The same pattern found with residents' QOL-AD scores.

An additional regression test was calculated that controlled for both variables "regular contact with family" and "highest level of education completed" to determine the percentage of difference in the scores of QOL-AD for both the residents and staff. The results showed that the percentage of variance explained by these two variables for residents' QOL-AD scores was 53.00%, a significant finding. The percentage of variance explained by these variables for staffs' QOL-AD scores was 39.00%, which was also a significant finding. The level of variance was found to be higher for both residents' and staffs' QOL-AD scores when the variables "regular contact with family" and "highest level of education completed" were tested together compared to when these variables were tested independently.

Although steps were taken to control certain variables from affecting the results, the above findings suggest that a number of factors could have had an impact on residents' QOL. The small sample size of this study could be one factor. If the sample size was larger, there could have been a greater difference found between the QOL-AD scores. Since primary care is practiced on both units, this could have had an impact on the QOL of residents and on how staff completed the QOL-AD scale on behalf of residents. What the residents' and staffs' QOL-AD scores indicated was that staff had a good understanding of their resident's needs. This was true of both units, but especially on the DCU (closer scores).

The results in this study also showed that family connection benefited residents (increased QOL). A goal for PCHs would be to increase family members' comfort level in visiting. It is important to have family members' feedback on their views of the unit and its impact on their relatives regardless of type of unit.

During the family interview, both groups of families were asked if the unit had been beneficial for their relative and if the unit had affected their QOL. Although the family members associated with the DCU did indicate some negative aspects of the unit (at times increased noise level, need for increased opportunity for socialization and disagreement in the management of medication), they all indicated that the unit had been beneficial for their relatives. The families associated with the traditional unit offered similar responses in spite of their acknowledgement of difficulties with the unit (institutional looking, high noise level, need for increased opportunity for socialization, need for increased staff education). Both groups of family members identified unit programs, increased opportunity for socialization, primary care and the quality of care their relative received as reasons for why the unit was seen as beneficial for their relative. On the DCU, some family members also indicated that they were content with the fact that it was a specialized unit and felt this had been beneficial for their relatives, more so than if their relatives had been on a regular unit. This was mostly due to the level of staff knowledge related to dementia care and unit security (secured entrance to unit). This does show that families value certain aspects of specialized units. However, regardless, if families felt that the unit was beneficial, not all felt that it had an effect on their relative's QOL. There were 2 family members on the DCU and 2 family members on the traditional unit who indicated that the unit had no effect on their relatives' QOL. One

family member on the traditional unit felt that his relative's QOL could improve if she had increased opportunity for socialization which would be accomplished if there were an increased number of residents on the unit who were at a similar level of ability. A similar response was given by a family member associated with the DCU, who stated that more could be done to increase opportunity for socialization, and therefore, the emotional well being of her relative. This family member felt that increasing the opportunity for socializing was required for residents at all levels of abilities. Although the recreation worker on the DCU modified unit programs to meet the needs of all residents on the unit, some families associated with this unit still felt a need for an increase in programming and further modifications to accommodate all residents' abilities. The unit impact on QOL for the residents on the DCU and those on the traditional unit was therefore similar according to these family member's responses.

These results were reviewed with the staff on both units. The staff members expected that the QOL-AD scores for residents on the DCU would have been significantly higher. Both groups of staff indicated that this limited difference could be due to "primary care" and the fact that a relationship and trust is developed between them and residents which could therefore impact on the residents' QOL regardless of the unit. Both groups of staff supported the "primary care" concept and neither group was surprised with the findings that their scores on the QOL scale were close to the residents' own scores. One staff member on the DCU indicated, "We work closely with them. The residents get used to you. It is our job to know them. Primary care is important." A staff member on the traditional unit added, "[w]e get to know them; we talk to them. That is why we know about their lives. I am not surprised our scores were close to the residents'

scores.” The importance of nurturing attachments and relationship building between residents and staff is also supported by a person-centered model of care. It recognizes that this relationship improves quality of care, and therefore, residents’ QOL.

With regard to residents’ level of education influencing QOL, staff offered that this could be due to residents’ understanding of what is happening to them and therefore presenting with difficulty in accepting these changes. When the findings related to the impact of family involvement on residents’ QOL were reviewed with staff, the staff on the traditional unit stated, “[w]e can see that family contact is important. We can see it when family visit. It keeps them [residents] connected to family and the community.” On the DCU, staff had similar responses. One stated, “[t]hey are happy when family involve them. We see these residents who are flat or sad. Family arrives and they are happy.”

When the findings of the family interview related to unit benefit were shared with staff, both groups indicated that the reason families were content on both units was due to primary care. A staff member on the DCU also felt that sometimes families are happy with what they see and do not realize that it could be better. This meant that if families associated with the traditional unit saw what occurred on the DCU, they would probably change their mind. The DCU staff also indicated that if there was an increase in staffing the difference in residents’ QOL-AD scores between the two units would have been larger, for they would have more time to spend with residents. To determine if this would be true, further research is required.

### **Unit Effect on Reactive Behaviours Presented by Residents**

The second question this study endeavored to answer was related to episodes of reactive behaviours. Would residents who reside on a DCU, present with fewer reactive incidents as compared to those residents who live on a traditional unit within the same PCH? There were a higher number of reactive incidents (8 separate incidences involving 3 residents) reported on the DCU as compared to the traditional unit (none). A Kolmogorov-Smirnov test was calculated to determine if the number of incidents between units had a normal distribution. This distribution departed significantly from normal. When a multi-nominal logistic regression test was calculated (comparing a full model to a reduced model), the difference was also found to be significant. This indicated that there was a significantly higher portion of residents reported to have reactive incidents on the DCU compared to the traditional unit. Further multi-nominal logistic regression tests were calculated controlling for certain independent variables (MMSE, family contact). The results indicated no difference in the level of significance and therefore did not explain the unit difference. These findings did not support this study's second hypothesis, which expected that residents who resided on the DCU would have presented with fewer reactive behaviours as compared to those residents who had a diagnosis of dementia and resided on a traditional unit.

When these findings were reviewed with staff, those on the DCU were not sure why this difference occurred, but felt that maybe it was because the residents who were chosen to be admitted on that unit had more "difficulties." The staff on the traditional unit indicated that, the difference could also be a result of not reporting incidents of reactive behaviours. They stated, "[w]e are so use to the behaviours that it could go

unreported.” If no record of the occurrence is found, these incidents were therefore not included in the data of this study.

A number of responses reflected this finding. Residents with greater tendency for reactive behaviours could have been placed on the DCU instead of the traditional unit since it is “specialized.” This could be the reason why there was a significantly higher percentage of reactive episodes found on the DCU. Research in this area has been inconclusive. While in some studies it has shown that presenting with “problematic behaviours” does not increase the likelihood of placement (Riter, Brand & Fries, 1992), in other cases, studies have shown that Special Care Units admit a higher number of residents who present with reactive behaviours (Holmes, Teresi, Weiner, Monaco, Ronch & Vickers, 1990; Leon & Ory, 1999). If there were a higher number of residents with reactive behaviours admitted to the DCU, could this unit be able to decrease these reactive episodes over time? A longitudinal study would be required to answer this question. The difference could also be related to length of experience of staff or staff on the traditional unit not reporting reactive incidents. Future studies would have to take this into consideration.

### **Unit Effect on Family Members’ Perception**

The last two questions that this study attempted to answer were related to family satisfaction. Are family members with relatives on a DCU more satisfied with (1) the care their relatives receive and (2) the unit in general, as compared to the family members with relatives on a traditional unit? Family interviews indicated that the majority of families in both groups were satisfied with the care and the unit. The responses identified



that in some areas there was a difference in the level of satisfaction, as discussed in the following sections.

#### Care Provided to the Residents

There were slight differences between the responses of both groups of family members regarding their level of satisfaction with care. The majority of families (except for one) associated with the DCU indicated that staff were knowledgeable and knew how to approach residents in regard to offering care and comfort, as well as decreasing anxiety. This approach incorporated flexibility and empathy. Family members also identified that staff acknowledged residents' unique needs when care was provided. These two characteristics, flexible approach and incorporating individualized care plans to meet residents' unique needs, are supported by a person-centered model of care. This model encourages approaches that maximize freedom while minimizing control and that see each individual as special and unique. Although families associated with the DCU found staff to be knowledgeable, the expectation of these families was for staff to commit to ongoing education. Family members with relatives on the traditional unit felt that staff required more education, especially on approach techniques and understanding the person with dementia. One of these respondents felt that staff on this unit tended to label residents instead of trying to understand them and their needs.

Family members' responses indicated that they saw a difference in staff knowledge between the two groups, related to dementia care and approach to care. They also indicated that knowledgeable staff was something that families valued. Although family members recognized a difference in the knowledge base of staff on the two units,

family members from both groups still acknowledged that they were satisfied with the care offered to their relative. Family members linked quality of care to regular staff and the primary care concept.

Both groups of families indicated a need for increased staffing (health care aides) on the unit. Both groups felt that staff involved them in the decision making process and in care planning for their relatives except for one family associated with the DCU. Family members also stated that staff kept them informed or updated on their relatives' conditions. This offered reassurance and support to families, which increased the trusting relationship between family and staff. Recent studies have also shown that families value being informed or updated as to their relative's condition and routine on the unit (Iwasiw et. al., 2003; Reuss, Dupuis & Whitefield, 2005). Support to family members meant different things, but generally it meant keeping them informed, staff being approachable and feeling that staff members listen to them. Dementia care education in-services for staff and family were also seen as a form of support for families. Support was something that families associated with the DCU described as being provided by multiple staff members or different disciplines. This indicated a "team approach" in supporting the resident and families on this unit.

The importance of family involvement is recognized in the values and philosophy statements of Holy Family Home, "To help foster the spirit of the family unit, relatives and friends are encouraged to participate in the delivery of the total care plan for the residents" (Holy Family Home Pamphlet, undated). Staff members on both units understand the need to involve and support family members, which were further emphasized with the staff on the DCU through staff training and through the adoption of

the Philosophy of Dementia Care (refer to Appendix C). Since acceptance of family involvement is an expectation of all staff, this may have been the reason why both groups of families felt staff involved them in their relative's care. Both groups of families stated that primary care was key in ensuring they were informed of changes to their relatives' conditions. If primary care does have an impact on family satisfaction and quality of care received by residents, this therefore, could be a reason why there was only a slight difference between the two units relating to family satisfaction with care.

When the findings were shared with both groups of staff, workers on the DCU indicated that they agreed with the need for ongoing education and felt that this was important to ensure "you don't fall into a rut." One staff member on the DCU stated "[w]e do our best. We try different approaches. We do things with them, games, play music, and dance. Residents come together when we play music, it is like a family." The staff on the traditional unit indicated that they would welcome increased education. They added that motivational speakers would also help staff by giving them a boost of energy to continue offering quality of care for those residents that are challenging. Both groups of staff also indicated that they recognized the importance of involving family, supporting them and updating them on their relatives' conditions. Both indicated they do their best and feel that primary care helps this. It is obvious from both family and staff members' responses that the primary care concept is a benefit for residents, family members and staff.

## Physical and Social Environments

With regard to satisfaction with the physical and social environments, both groups of families, were content with the unit their relative resided on and offered positive descriptions. There were some families from both groups that also offered negative descriptions of the units. Both groups placed more value on opportunity for socializing and quality of care than the physical environment. The study by Morgan and Stewart (1997) identified similar findings. In their study, families indicated that "... the physical environment cannot compensate for the deficiencies in the social environment" (p.747). Although families stated that the physical environment was not important when asked, their more detailed responses indicated that they did find value in the physical environment and acknowledged its benefit to their relative's QOL. For instance, families used the word "homelike" to describe the DCU and the families related to the traditional unit used the term "institutional".

Most families associated with the DCU acknowledged the physical changes to the unit and offered positive comments on certain additions, such as the gazebo, vegetable garden and patio. Families indicated how important these items were for residents in connecting them to past pleasant memories (i.e., taking care of a garden), and therefore, increasing QOL. Most also commented on the sense of security the unit offered due to the secured door to the unit, which also allowed freedom of movement for the residents while on the unit. One family member felt that the unit may be too large for a specialized unit and felt it would be beneficial to decrease the size (number of residents). Although some of the rooms on the DCU were shared, this did not seem to be a problem for families. Privacy was an important issue for families associated with the traditional unit

and they were content with the fact that on that unit all rooms were private. Families associated with the traditional unit described the unit as needing renovations to “cheer-up” the unit. Furthermore, one family member indicated that he takes his relative off the unit when they visit to get her away from the “closeness” of the unit. These comments indicated that the physical environment was important and that families associated with the DCU indicated a higher satisfaction with the physical appearance of the unit.

As for the social environment, both groups of families also shared similar views regarding opportunity for socializing and participation in activity programs. Both indicated that this was an important aspect for their relatives’ well being. This view is supported in the literature on dementia care, which indicates that the opportunity for socialization and development of relationships assists in decreasing boredom, restlessness and loneliness, and is an important factor in enhancing a person’s self worth, and therefore, quality of life (Morgan & Stewart, 1997).

Both groups also indicated that the noise level on the unit was high. This was viewed by both groups as being disturbing, indicating that noise level could affect level of satisfaction. Although both groups of families were content with the recreation worker, they also felt that there was a need to increase the variety of programs and pointed to the fact that there was limited opportunity for socializing for some residents. There were more families associated with the DCU who indicated that since their relative’s physical status decreased, opportunity for participation in the programs offered also decreased. Other families associated with the DCU acknowledged the staffs’ attempts at incorporating residents’ past history into daily life or programming and staff members’ efforts with spontaneous involvement in programming with the residents (i.e.,

dancing to music). This is something that the person-centered model of care acknowledges as important, “taking life history into account – bringing each person’s past into the care setting (Loveday & Kitwood, p. 13). This perspective was also supported in the study by Morgan and Stewart (1997), which identified that “[e]very person had a different history, personality and set of preferences. Despite the person’s dementia, these factors were still important. ... The more staff knew about an individual resident, the better they could tailor their care giving approaches to meet that person’s needs” (p. 756).

Some of the family members with relatives on the DCU also indicated a need for feedback from the recreation worker. This was not something that families associated with the traditional unit indicated as a problem. Some of the families in both groups found that since there were residents at different levels of ability on the unit that there was a need to have programs tailored for all residents and all levels of ability. Other families (in both groups) indicated that the limited opportunity for socializing was due to the unit having residents who were at different levels of abilities and felt this should change. This raised the question, would it be beneficial to leave residents in place as their condition deteriorated to remain with the staff they are used to or should they be moved to a different unit? A person-centered model of care would say nurturing of relationships between staff and residents is important and should be maintained, not disrupted. Loveday and Kitwood (1998) stated that

[i]t has been found that people with dementia form new attachments, especially when they are in residential care. Some of these may be with ... members of staff. These attachments may become the person’s lifeline

during the last phase of their life, and there is likely to be renewed anxiety and grief if any of them are broken (p.16).

Another social aspect of the unit discussed was the meal program offered on the DCU. Although most of the families from both groups were not familiar with the program, all of the families with relatives on the DCU who were familiar with the program indicated that it was beneficial. Some felt that there were “kinks” with the program that still needed to be changed. The feeling from families involved on the traditional unit was mixed. Some felt that the new meal program was not a good idea and others saw the benefit and felt it should be incorporated on the unit. Both groups of families felt that the most important aspect regarding meals was the quality of the food. It would be beneficial to follow-up with families on the DCU after they have become used to the meal program to ask the question again.

When the results of the family interviews regarding satisfaction with the unit were reviewed with staff on the two units, they were surprised that the families placed minimal value on the physical environment. Staff on the DCU indicated that their unit was physically pleasant and homelike, but agreed that care and how it is offered is also important. They indicated that when families visited, they were comfortable on the unit, which could be due to the fact that the physical environment is pleasant. As one staff member stated, “[t]he changes to the unit make families feel more comfortable in visiting. They enjoy going out to the gazebo. It is nice there. We think the unit is great, pretty, smaller and better lighting.” The staff on the DCU also stated that the secured door on the unit was beneficial because they did not have to worry about residents

leaving and they did not have to chase after the residents who resist being redirected.

Allowing freedom of movement also allowed residents to feel increased control. This is a concept which a person-centered model of care also supports, the idea of maximizing freedom for residents and "... enabling the greatest possible degree of independence that is compatible with safety" (Loveday & Kitwood, 1998, p.17). Staff on the traditional unit were not surprised that families described their unit as "institutional". They themselves described the unit as limited and institutional. As for the suggestion to have residents of similar levels placed on the same unit, staff from both groups indicated that "this would be difficult to manage." One staff member on the traditional unit indicated, "it is good to mix to learn from each other and live together. That would mean a lot of transfers."

With regard to the new meal program offered on the DCU, both groups of staff were not surprised that most families were unaware of this program since it was new.

## Summary

The findings of this study cannot be generalized due to the limited sample size and uncertainty of how typical these units and resident populations are compared to other units and facilities. However, the findings can be added to the growing knowledge on the effects of DCUs on residents' QOL, episodes of reactive occurrences and family members' level of satisfaction. This study did not find significant differences between the two units. This could be due to both units having similar staffing levels, similar care practices (primary care and support for family involvement) and a small sample size. There was no significant difference between the residents QOL-AD scores on the DCU compared to those on a traditional unit. The same was true of the staffs' scores. Level of



education and regular family contact affected the residents' QOL-AD scores. This study also found that staff on both units had a good understanding of the needs of the residents, since the staffs' QOL-AD scores (completed on behalf of residents) were close and related to the residents' own scores. In regards to level of reactive incidents, this study showed that there were increased reactive episodes on the DCU. This could be due to the characteristics of the residents admitted to the unit as compared to the traditional unit.

From the family interviews, this study did find that families associated with the DCU found some physical aspects of the environment to be important in connecting residents with pleasant memories. Although the social environment was identified by both groups of families as being most important, along with quality of care and staff, they also indicated that the physical environment was valued. Family members associated with the DCU presented with a higher satisfaction with the unit's physical environment than did the families associated with the traditional unit. The DCU was seen as homelike and the traditional unit as institutional and in need of renovations. The important physical features of the DCU included close proximity to outside space, a secured unit, and presence of a gazebo and vegetable garden. Some of the families associated with the DCU commented on the size of the unit and how it should have fewer residents. Families in both groups valued programming and opportunity for residents to socialize. A need for increased activities was seen as important and not a "frill". The need for programs to match the abilities of all residents was also seen as important to prevent boredom and to preserve a sense of purpose. Some families on both units felt that the resident population of the unit should be similar in level of ability. Staff education was valued by both groups of families and was seen as improving quality of care. Families on the DCU

found staff to be knowledgeable but expected that they would receive ongoing education.

Both groups of families indicated a need for increased staffing (HCAs). Families placed great value on primary care. There was also recognition of the importance of a “team” approach in care for residents and support to family members. This was acknowledged by the families associated with the DCU. There was great value expressed by both groups of families in keeping family involved in care decisions related to the resident. Family members, therefore, valued two key practices of this home, primary care and involvement of family in care decisions.

This study found, through the acknowledgement of staff and family, that key concepts in a person-centered model of care were practiced on the DCU. These concepts include the importance of seeing each individual as special and unique, that it is important to respect residents’ past and incorporate this into residents’ daily life, to nourish attachments and to maximize freedom and minimize control when offering care (Loveday & Kitwood, 1998). These were all concepts that were valued by staff and family members.

## **Implications**

### **Implications for Future Research**

This study explored the effects of living on a DCU, specifically relating to QOL, decreasing reactive behaviours and family members’ satisfaction with care offered and with the unit environment. It found that residents’ level of education and regular contact with family had an impact on residents’ QOL regardless of which unit the resident resided. It found that there was a higher number of residents exhibiting reactive episodes

on the DCU compared to a “traditional” unit. It identified the importance of the physical and social environments, staff knowledge, regular staff and involvement of family members in care planning related to their relative, as influencing family satisfaction with care, as well as possibly affecting residents’ QOL. What this study also found was a need for further research in this area.

A number of questions developed from this study. Ultimately, it would be beneficial for future studies to incorporate a larger sample size and to examine if “primary care” (nurses and health care aides) can affect residents’ QOL. Future studies should compare DCUs that follow the primary care concept with traditional units that do not. Future studies could also look at the effect that smaller DCUs (<29 residents) and increased staffing levels (lower than 1 staff member to 8 residents) can have on residents’ QOL and ability to decrease residents’ reactive behaviours. A longitudinal study could identify if the number of residents’ reactive behaviours decreased the longer they resided on a DCU, as compared to a “traditional” unit. Family involvement was also seen as an important variable in affecting the QOL of the residents in this study. It is, therefore, important for future studies to not only incorporate families members’ but also (when possible) residents’ perspectives related to their experience on the unit and what they value or see as important aspects of the unit and care practices.

Continued research related to DCUs is required to further understand what aspects of the DCU make a difference in the lives of individuals diagnosed with dementia. Improvements to the QOL of these individuals are required. This can be achieved through the knowledge created from research and from the dedication of family members and those who care for individuals living with dementia.

## Implications for Social Work Practice

Social workers who work in personal care homes (PCHs) play an important role in ensuring that the voices of those who reside in these homes are heard and that their needs and rights are not ignored. This is especially true of individuals who have cognitive impairment and may not be able to verbally express their needs. Social workers in PCHs also need to work with families to ensure that concerns are addressed and support is offered. Along with a team of professionals, social workers advocate for the focus of care to include the whole person, specifically ensuring that the psychosocial needs are not left behind and that a person's social history is recognized, respected and integrated into care practices, essentially advocating for a person-centred approach to care.

This study is significant to social work practice and policy because it identified certain factors that could improve the quality of care and QOL of individuals living in a PCH. It showed that regular family contact was important in increasing the residents' QOL. It also showed that families valued being involved in care planning and/or decision making related to their relatives. From this, social workers within PCHs could facilitate opportunities for increased family involvement in care planning and decision-making regarding their relative. For families that live out of town, social workers could facilitate opportunities for other forms of regular contact, such as mailings that include pictures, tape recordings of messages from the family member to the resident or phone calls. This study indicated that family members valued support from staff and education related to dementia. Social workers within PCHs could develop support groups for families with an educational component. This would allow families a safe venue to

express their views or frustration and receive support. Families in this study indicated that aspects of the physical environment, such as a vegetable garden, provide the opportunity for residents to reminisce, and therefore, had a positive effect on their QOL. Social workers can assist with the development of programs that incorporate past history of residents into daily life. Families also stated that they valued knowledgeable staff and found that this assisted them in understanding residents' needs and how to approach them. Social workers can become leaders in providing education to staff members on understanding the person behind the disease, valuing his or her history in order to incorporate that into his or her daily life and respecting his or her needs. This can assist staff in coming to understand the reason behind residents' actions or reactions as opposed to just labeling them "aggressive" or becoming frustrated. Essentially, this would mean a change in philosophy. As the literature suggests, '... developing a therapeutic milieu for persons with dementia requires a change in the philosophy, from managing behaviours to understanding and meeting needs' (Taft, Delaney, Seman & Stansell, 1993 cited in Morgan & Stewart, 1999).

Social workers need to continue to develop and expand knowledge related to improving quality of care and QOL for individuals diagnosed with dementia who reside in PCHs. Further research of the physical and social environments of DCUs and their impact on QOL of residents is required, and social workers should be involved. On a micro level, social workers can incorporate satisfaction surveys within their own facility to obtain feedback from residents and families. They can incorporate QOL surveys with residents to identify needs and areas for improvement. On a macro level they can continue to design and complete studies in this area, ensuring that the knowledge is

shared while advocating for establishment of standards related to dementia care. Social workers can ensure that the focus on the person and his or her psychosocial needs are highlighted, and that the development of new theory, practices and policy incorporate a person-centred approach.

#### Implications for Personal Care Homes

Findings from this study lead to a number of recommendations for Holy Family Home, but they could also be considered by other PCHS or DCUs as possibly being beneficial for their site to incorporate. Results from the family interview in this study suggested that homelike environments, which incorporate objects that provide residents with pleasant memories and easy access to the outdoors, were found to be important. It is recommended that Holy Family Home continue with renovations to other units creating a homelike atmosphere (i.e., updated décor, colours and appropriate furniture). This would include incorporating items into the environment that provide residents with opportunities for reminiscing, such as vegetable gardens and sewing centers and allowing for secured space for residents to pace and explore.

It is important to understand the past history of these residents. In order to be able to effectively accomplish this, families could be asked for their input and asked to bring in items to help personalize residents' rooms. The social environment was viewed by families as being important in increasing residents' QOL. Holy Family Home could explore ways to expand activities throughout the day and evening, ensuring that there are programs that are appropriate for all levels of ability. Further reviewing activity

programs on a regular basis to determine what is beneficial and what should be adjusted would be helpful.

The families associated with the DCU found that 29 residents on a DCU was too large, leading to increased noise and therefore increased restlessness and anxiety for the residents. It is recommended for Holy Family to review ways to decrease this size, however, it would probably be difficult due to the structure of the facility. If remodeling is not possible then there are two factors Holy Family Home could consider: the first is to decrease the noise level on the unit by eliminating extraneous noises. This would include overhead pages, buzzers and call bells. A new communication strategy should be considered on the unit, such as individual pagers instead of overhead pages. Second, it would be beneficial for Holy Family Home to consider increasing staffing ratios (HCA) especially on the DCU, but it would be important to review this for all units. The ratio of 1 staff for every 8 residents was seen by families as not being sufficient in meeting residents' needs at times, especially on a DCU. To accomplish this, the administration of this home would need to lobby Government, since funding for staffing falls within the responsibility of the Manitoba Government's Department of Health.

It is recommended that Holy Family Home continue with the "primary care" concept and to ensure that regular relief workers are assigned to units. The QOL-AD scores indicated that staff members were able to understand the residents' needs. Family and staff attributed this to primary care and identified high value in this concept. It would also be important to provide staff (which incorporates the interdisciplinary team) with ongoing education on dementia care. In this study, knowledgeable staff members were seen as understanding how to approach and comfort residents as well as recognize

the importance of flexibility in care and incorporating residents' history into their daily life. This was not only found by families to increase quality of care, but it also offered them reassurance that their relative was receiving good care. Increased training of all staff on dementia care would be an important aspect for Holy Family to continue and expand on.

It would be recommended for Holy Family Home to continue with their philosophy and practice of involving family members in care planning related to their relatives, which was found to be reassuring and supportive to families. Holy Family could consider support groups and/or continue with educational in-services for families. It is important for families to have a venue to voice concerns, and for residents to have the same opportunity.

Recognizing that the medical model of care is not an effective way of providing care to persons with dementia, Holy Family Home (as have many other homes) developed two DCUs, which incorporated a person-centred model of care. From this study a number of recommendations for Holy Family Home were developed and listed above. It is beneficial for Holy Family Home to continue with their efforts in improving QOL for their residents.

## **Conclusion**

Dementia affects many lives, those with the illness, family members and friends. The need for effective programming and care for persons with dementia is growing since the incidence of dementia continues to rise. It is estimated that by 2011, there will be 111,600 new cases of dementia nation wide. By 2031, over 750,000 Canadians are predicted to have Alzheimer Disease or a related dementia (Alzheimer Society of



Canada, 2003). Today, approximately 50% of people diagnosed with dementia in Manitoba reside in an institution (Mitchell-Pedersen , 2002). This number will only continue to grow. The need to find methods to improve the QOL and care of these individuals within PCHs is crucial. To respond to this need, PCHs have developed DCUs to offer placement to individuals living with mild to moderate dementia. Research continues to show inconsistencies in the benefits of these units.

This study identified certain factors that can affect the QOL of residents within a PCH, regardless of unit. These factors included residents' level of education and regular contact with family. It also showed that there were a higher number of reactive behaviours on the DCU than the "traditional" unit, possibly related to the admission criteria of the DCU. From the family interviews, this study showed that families do value the physical environment and find that aspects of the environment that connect residents to positive memories can increase their QOL. They also indicated that environments that allowed freedom with continued sense of security was also valuable (secured entrance). Families believed that residents would be more comfortable in an environment, which was "homelike" as opposed to "institutional". They felt that the social environment and opportunity for socialization also had an impact on residents' QOL. Families valued knowledgeable staff, ongoing support and opportunity to be included in decision making and care planning related to their relative. Families also welcomed program trials that attempt to provide opportunities for increased QOL for their relatives (i.e. meal program).

Significant differences between the two groups of residents related to QOL were not found. Although findings from this study cannot be generalized, this study was still able to provide knowledge in two areas. What were some of the factors that affected the

QOL of the residents who participated in this study and what aspects of the environment and care were viewed as being important to family members. This study has also identified recommendations for future research, social work practice, Holy Family Home and possibly other PCHs.

Research has recognized that the physical and social environments can have an effect on residents diagnosed with dementia and living in a PCH, as can the way care is offered. The medical model, which emphasizes illness and dependency, is no longer viewed as being appropriate for those living with dementia. Instead, a person-centered model of care, which encourages flexibility in care and recognizes the uniqueness of the person, is viewed as being more appropriate for dementia care. This requires a culture change in the organization from a focus on routine, illness and managing behaviours to flexibility, meeting needs and an understanding of individual histories. In an attempt to increase quality of care and QOL for individuals diagnosed with dementia living in PCHs, one option has been DCUs which attempt to incorporate changes to the physical and social environments and incorporate a person-centred approach to care. However, research on the benefit of DCUs on the QOL of its residents needs to continue. By first understanding which aspects of the DCU have a positive effect on QOL, standards and policies can be developed. In this study what was found was a need to provide residents with knowledgeable staff who provide person-centred care in a comfortable “homelike” environment. This was important regardless of whether the unit was specifically for dementia care or if it was traditional. This, therefore, leads to the question, are DCUs the answer to increased QOL for people diagnosed with dementia living in PCHs? Additional research would assist in shedding light on this question.

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## APPENDIX A

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### Philosophy of Care at Holy Family Home<sup>1</sup>

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#### Themes

- 1) A philosophy of care rooted in the Christian ideals of dignity, uniqueness and intrinsic value of each individual.
- 2) Respect of the resident's preferences and care provided in a manner that is sensitive and responsive to those things that are personally meaningful.
- 3) Spiritual and cultural traditions supported with special emphasis on Ukrainian beliefs
- 4) Families and residents seen as part of the health care team and encouraged to participate in the decision-making and care planning process.
- 5) In recognition of those with diminished capacity, staff members identify and respond to "excess disability" to support the resident's remaining intellectual function and to compensate for lost abilities.
- 6) In recognition that those with reduced mental capacity have diminished control of their behaviour or environment, caregivers are encouraged to develop dementia care skills and supports to respond to behaviours of concern in a positive and creative manner
- 7) Programs and experiences must be positive and meaningful for the resident and are personalized to adapt to his or her diverse and changing needs. The resident's history of what gave him or her pleasure and purpose is included in care planning and programming
- 8) Staff members required to investigate and incorporate best practices in dementia care program planning and services. Ongoing training and education of staff is valued.
- 9) Recognition that end of life is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends

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<sup>1</sup> Holy Family Home, July 2006.

## APPENDIX B

### Holy Family Home Dementia Care Units Admission and Discharge Criteria

#### Admission Criteria

1. Diagnosis of an **irreversible Dementia** (moderate to severe range)
2. Presents with obvious **uncompensated increased deficits** in;
  - a. Memory
  - b. Judgment
  - c. Orientation
  - d. Competence
  - e. Thought process
3. Presents with the **ability to follow direction** with prompting and demonstration.
4. Evidence of the following, which are **not easily altered** through current management strategies;
  - a. Wandering
  - b. Repetitive Behaviour
  - c. Agitation/Restlessness
  - d. Increased difficulties attaching meaning to sensory perception (agnosia)
5. Presents with increased disability due to **progressively lowered stimulus threshold**

#### Discharge Criteria

1. Violent, uncontrolled behaviour towards self or others
2. Sexual aggression not easily altered through current management strategies
3. Request for transfer by family
4. Major psychiatric symptomology

## **APPENDIX C**

### **Holy Family Home – Philosophy of Dementia Care**

1. Persons with dementia who are experiencing memory loss, impairment of functional abilities and other cognitive skills have unique needs.
2. Individuals with dementia struggle to maintain self-respect and there is a framework which can influence the care and programs. These individuals can flourish if they are given an environment that offers a sense of well being and makes the most of their potential to develop.
3. Care providers must recognize that their reality is not the only reality and residents with dementia may perceive sights, sounds and behavior in a manner that impacts on their sense of safety and comfort.
4. The loss of cognitive abilities threatens the interpersonal relationships and can involve threats of personal safety of self and others. Such individuals have diminished resources to control or direct their behavior. Care providers must accept increased responsibility to be sensitive to the individual's needs and to respond with compassionate life-enriching programs and environment.
5. It is recognized that individuals with dementia have a diminished threshold for stimulation. The care providers are responsible for identifying and responding to excess disability, supporting the resident's remaining intellectual function and compensating for lost abilities.
6. There is no single approach to meeting the needs of individuals who have dementia. The approaches to care are best determined by the needs of the individual; there is flexibility to accommodate individual differences. The therapeutic nature of the environment is supportive and compensates for the individual's cognitive deficits.
7. Care providers understand the disease process and provide sensitive care over the full progressive course of the illness. The staff are supported and encouraged to reach out with dementia care skills, creativity and respect for each unique individual and their family. Ongoing education of staff and acknowledging their ideas and creative spirit are paramount.
8. All care and medical interventions integrate the best practices established to meet the individual's changing needs. Respect for the individual's ethno cultural and spiritual makeup supports optimal functioning.
9. Family are integral and vital members of the team. The importance of family and care providers working together towards the same end is recognized.
10. The environments are homelike and support personalized living space. It is a safe environment where the individual with dementia can sense pleasure, comfort and security.

Holy Family Home, July 2006.



UNIVERSITY  
OF MANITOBA

Faculty of Social Work

## APPENDIX D

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Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7050  
Fax (204) 474-7594  
Social\_Work@UManitoba.CA

### Consent Form

Title of Project: Evaluation of a Dementia Care Unit

Researcher: Dr. Tuula Heinonen

Dear Resident,

A study is going to be conducted at Holy Family Home, through the University of Manitoba and Dr. Tuula Heinonen (Associate Professor with the Faculty of Social Work). This study will evaluate the effectiveness of a dementia care unit, (St. Francis unit) by comparing it to a “traditional unit” (St. Joseph’s unit). This letter is to inform you of the evaluation and to ask for your informed consent to participate in this study.

The purpose of this study is to determine the effect that a dementia care unit has on its residents in regards to their quality of life and effect on aggressive behaviours. To obtain this information your medical chart will be reviewed, specifically the “Interdisciplinary Progress Notes” and “History” sections of your chart over a two-week data collection period. Information will also be obtained through the use of scales or questionnaires. To evaluate quality of life, you and your primary caregiver (health care aid) will be asked to complete a questionnaire called – “Quality of Life–Alzheimer Disease”. This questionnaire is normally completed on the individual and their caregiver. Your response will be compared with your caregiver’s perspective (response) related to your quality of life. This questionnaire has 13- points that address such areas as your physical health, energy, mood, your living situation, memory, family, marriage, friends, everyday jobs, fun, money, and life in general. You will also be asked to complete a test that will measure your memory. This short test is called the Mini-Mental State Examination. To measure aggression within the two-week data collection period, your chart and Occurrence Reports (completed by staff whenever an aggressive behavioural incident occurs) will be reviewed. Last, to measure your family’s satisfaction with care, an interview (12 question survey) will be completed with one of your family members. A research assistant or the researcher will spend approximately one hour with your family member to answer these questions and another hour with you to complete the scales.

The purpose of this evaluation is to generate information that will be useful to the Home in providing care and services to its residents. There should be minimal risk to you as a result of participating in this study. Possible risks may include agitation or anxiety related to questioning. If this should occur, all questioning is to stop immediately. The benefits of the evaluation are the ability to expand the services throughout the Home that

are found to be beneficial and to modify those aspects that have been found to be less useful. This evaluation will also contribute to the existing knowledge base on dementia care and quality of life.

This evaluation is planned to start by October 31st, 2005 with completion of the questions and information gathering by November 14<sup>th</sup>, 2005. A presentation will be held at the Home to review the results with staff, family and residents. You will be informed of this date.

Your identity will be kept confidential through the use of fictional names and identification numbers. If occurrences of abuse are discovered during this study, it will be reported to the Director of Program Planning and Allied Health at Holy Family and to the Protection of Persons in Care Office of Manitoba as required by law. The findings of this study will be shared with Administration and staff from Holy Family, family members and residents. It may also be shared with other organizations or individuals interested in this topic. A summary of this study can be made available to you if you should wish. Please indicate below if you wish to obtain a summary of this study. All of the data collected for the purpose of this study will be destroyed once the study has been published. It is hoped that this will occur by June of 2008.

Should you choose to not participate in this study, you may do so without penalty. Participating in this evaluation is voluntary. If you should chose to withdraw from the study after it has started or chose to refuse to answer any questions, you can do so without penalty. If you should choose to participate or not, this will have no bearing on the care that you receive in this Home. By now you should have received a letter from the Executive Director of Holy Family Home emphasizing this. If you have not received this letter, please contact the Front Desk at Holy Family at 589-7381 to request a copy.

If you should choose to participate, prior to starting the study, your written consent to participate is required. Please complete the consent form below and return it to the Front Office at Holy Family in the envelope provided, addressed to Dr. Tuula Heinonen.

The Psychology/Sociology Research Ethics Board at the University of Manitoba has approved this research. If you have any concerns or complaints about this project you may contact the Human Ethics Secretariat at the University of Manitoba, Margaret Bowman at 474-7122 or email her at [margaret\\_bowman@umanitoba.ca](mailto:margaret_bowman@umanitoba.ca).

-----  
Consent Form

I, \_\_\_\_\_, consent to participate in the Evaluation of a  
Name

Dementia Care Unit at Holy Family Home.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

I would like a copy of the results of this study.

☐ Yes

☐ No

Method of  
delivery:

\_\_\_\_\_  
Home Address, Fax, E-mail Address



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Social\_Work@UManitoba.CA

## APPENDIX E

### Consent Form

Title of Project: Evaluation of a Dementia Care Unit

Researcher: Dr. Tuula Heinonen

Dear family member / substitute decision maker,

A study is going to be conducted at Holy Family Nursing Home through the University of Manitoba and Dr. Tuula Heinonen (Associate Professor with the faculty of Social Work). This study will evaluate the effectiveness of a dementia care unit, (St. Francis unit) by comparing it to a "traditional unit" (St. Joseph's unit). This letter is to inform you of the evaluation and to ask for your informed consent to participate in this study and/or allow your relative to participate.

The purpose of this study is to evaluate the impact that a dementia care unit has on its residents in regards to their quality of life and effect on episodes of aggressive behaviours. Obtaining required information will involve searching through the resident's medical chart. Information will be retrieved from the "Interdisciplinary Progress Notes" and "History" sections of the resident's medical chart over a two-week data collection period. Information will also be obtained through the use of scales and questionnaires. To assess quality of life, a scale will be used called the "Quality of Life - Alzheimer Disease", on each resident and their primary care giver (health care aid). This scale is normally completed on the individual and their caregiver. The resident's response will be compared to the caregiver's perspective (response) on the quality of life of the resident. This scale has 13- points that address such areas as physical health, energy, mood, resident's living situation, memory, family, marriage, friends, everyday jobs, fun, money, and life in general. In order to determine the cognitive status of the resident the Mini-Mental Status Exam will be completed on each resident. This is a short simple test of the resident's orientation, attention, calculation, recall and language skills. To track the number of incidences of aggressive behaviours within the two-week data collection period, the resident's chart will be reviewed as well as the Occurrence Reports (completed by staff when an aggressive behavioural incident occurs). Last, to measure family satisfaction with care, the researcher or a research assistant will be completing an interview (12 question survey) with a family member of each resident on these two units. A research assistant will be contacting the family members who consent to the interview to set up an interview time. Approximately one hour will be spent with each resident to answer these questions and another hour with each family member.



The purpose of this evaluation is to generate information that will be useful to the Home in providing care and services to its residents. There should be minimal risk to you or your family member as a result of participating in this evaluation. Possible risks may include agitation or anxiety related to questioning. If this should occur, all questioning is to stop immediately. The benefits of the evaluation are the ability to expand the services through out the Home that are found to be beneficial and to modify those aspects that have been found to be less useful. This evaluation will also contribute to the existing knowledge base on dementia care and quality of life.

This evaluation is planned to start by October 31<sup>st</sup>, 2005 with completion of the questions and information gathering by November 14<sup>th</sup>, 2005. A presentation at the Home will be held to review the results with staff, family and residents. You will be informed of this date.

Your family member's identity and yours will be kept confidential through the use of pseudonyms or fictional names and identification numbers. If occurrences of abuse are discovered during this study, it will be reported to the Director of Program Planning and Allied Health at Holy Family and to the Protection of Persons in Care Office of Manitoba, as required by law. The findings of this study will be shared with the Administration and staff from Holy Family, family members and residents. It will also be shared with other organizations or individuals interested in this topic. A summary of this study can also be made available to you if you should wish. Please indicate below if you wish to obtain a summary of this study. All of the data collected for the purpose of this study will be destroyed once the study has been published. It is hoped that this will occur by June of 2008.

Should you choose to not participate or to not have your family member participate in this study, you may do so without penalty. Participating in this evaluation is voluntary. If you or your relative should chose to withdraw from the study after it has started or chose to refuse to answer any questions, you can do so without penalty. If you should choose to participate or not, this will have no bearing on the care that your relative receives at this Home. By now you should have received a letter from the Executive Director of Holy Family Home emphasizing this. If you have not received this letter, please contact the Front Desk at Holy Family at 589-7381 to request a copy.

If you should choose to participate, prior to commencing this evaluation, your written consent to have you and / or your relative participate in the evaluation is required. Please complete the consent form below and return it to the Front Office at Holy Family in the envelope provided, addressed to Dr. Tuula Heinonen.

The Psychology/Sociology Research Ethics Board with the University of Manitoba has approved this research. If you have any concerns or complaints about this project you may contact the Human Ethics Secretariat at the University of Manitoba, Margaret Bowman at 474-7122 or email her at [margaret\\_bowman@umanitoba.ca](mailto:margaret_bowman@umanitoba.ca).

-----  
Consent Form

I, \_\_\_\_\_  
Name

▪ Consent to the involvement of \_\_\_\_\_ ☐ Yes ☐ No  
Name of Resident

▪ Consent to participate myself ☐ Yes ☐ No  
in the Evaluation of a Dementia Care Unit study at Holy Family Home.

\_\_\_\_\_  
Date Signature Relation to Resident

I would like a copy of the results of this study. ☐ Yes ☐ No

Method of delivery:

\_\_\_\_\_  
Home Address, Fax, E-mail Address



UNIVERSITY  
OF MANITOBA

Faculty of Social Work

521 Tier Building  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7050  
Fax (204) 474-7594  
Social\_Work@UManitoba.CA

## APPENDIX F

### Consent Form

Title of Project: Evaluation of a Dementia Care Unit

Researcher: Dr. Tuula Heinonen

Dear staff member,

A study is going to be conducted at Holy Family Home through the University of Manitoba and Dr. Tuula Heinonen (Associate Professor with the faculty of Social Work). This study will evaluate the effectiveness of a dementia care unit, (St. Francis unit) by comparing it to a "traditional unit" (St. Joseph's unit). This letter is to inform you of the evaluation and to ask for your informed consent to participate in this study.

The purpose of this study is to evaluate the impact that a dementia care unit has on its residents in regards to their quality of life and effect on episodes of aggressive behaviours. Obtaining required information will involve searching through the resident's medical chart. Information will also be obtained through the use of scales and questionnaires. To assess the quality of life of each resident, a scale will be used called the "Quality of Life - Alzheimer Disease", on each resident and their primary care giver (health care aid). You will be asked to complete this scale in order to compare your perception of the resident's quality of life with that of the resident's. This scale is normally completed on the individual (resident) and their caregiver. This scale has 13-points that address such areas as physical health, energy, mood, resident's living situation, memory, family, marriage, friends, everyday jobs, fun, money, and life in general. It would take no more than an hour to answer this questionnaire.

The purpose of this evaluation is to generate information that will be useful to the Home in providing care and services to its residents. There should be minimal risk to you as a result of participating in this evaluation. Possible risks may include agitation or anxiety related to questioning. If this should occur all questioning is to stop immediately. The benefits of the evaluation are the ability to expand the services throughout the Home that are found to be beneficial and to modify those aspects that have been found to be less useful. This evaluation will also contribute to the existing knowledge base on dementia care and quality of life.

This evaluation is planned to start by October 31<sup>st</sup>, 2005 with completion of the questions and information gathering by November 14<sup>th</sup>, 2005. A presentation will be held at the

Home to review the results with staff, family and residents. You will be informed of this date.

Your identity will be kept confidential through the use of pseudonyms or fictional names and identification numbers. If occurrences of abuse are discovered during this study, then it will be reported it to the Director of Program Planning and Allied Health at Holy Family and to the Protection of Persons in Care Office of Manitoba, as required by law. The findings of this study will be shared with the Administration, staff from Holy Family, family members and residents. It may also be shared with other organizations or individuals interested in this topic. A summary of this study can be made available to you if you should wish. Please indicate below if you wish to obtain a summary of this study. All of the data collected for the purpose of this study will be destroyed once the study has been published. It is hoped that this will occur by June of 2008.

Should you choose to not participate in this study, you may do so without penalty. Participating in this evaluation is voluntary. If you should chose to withdraw from the study after it has started or chose to refuse to answer any questions, you can do so without penalty. If you should choose to participate or not, this will have no bearing on your employment status at Holy Family. By now you should have received a letter from the Executive Director of Holy Family Home emphasizing this. If you have not received this letter, please contact the Front Desk at Holy Family at 589-7381 to request a copy.

If you should choose to participate, prior to commencing this evaluation, your written consent to participate in the evaluation is required. Please complete the consent form below and return it to the Front Office at Holy Family in the envelope provided, addressed to Dr. Tuula Heinonen.

The Psychology/Sociology Research Ethics Board at the University of Manitoba has approved this research. If you have any concerns or complaints about this project you may contact the Human Ethics Secretariat at the University of Manitoba, Margaret Bowman at 474-7122 or email her at, [margaret\\_bowman@umanitoba.ca](mailto:margaret_bowman@umanitoba.ca).

-----

Consent Form

I, \_\_\_\_\_, consent to participate in the Evaluation of a  
Name

Dementia Care Unit at Holy Family Home.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

I would like a copy of the results of this  
study.

☐ Yes

☐ No

Method of  
delivery:

\_\_\_\_\_  
Home Address, Fax, E-mail Address



# Holy Family Home

Holy Family Home, Inc.  
165 Aberdeen Avenue  
Winnipeg, Manitoba  
R2W 1T9

204 589.7381  
204 589.8605

## APPENDIX G

Dear resident / family member / substitute decision maker,

My name is Jean R. Piché and I am the Executive Director of Holy Family Home. Currently at Holy Family there is a study being conducted through the University of Manitoba regarding the effectiveness of one of our dementia care units. The findings of this study will assist Holy Family in its ongoing development and commitment to excellence in dementia care. This evaluation is also contributing to the existing knowledge base on dementia care.

Shortly, you will be receiving a letter asking for consent to participate in this study. This letter outlines in some detail the plans of the study. Participation in the study is completely voluntary and no one should feel obligated to participate. If you choose to join the study or have a family member participate, I can assure you that you and/or your family member's identity will be protected. There will be minimal risk to you and/or your relative as a result of participating in this evaluation. Possible risk may include anxiety related to questioning. If this should occur, all questioning is to stop immediately. I can also assure you that there will be no negative repercussions should you and/or your relative choose not to participate. If you and/or your relative do participate, you are free to discontinue your participation in the study at any time.

If you should have further questions please do not hesitate to contact me 589-7381.

Sincerely,

Jean R. Piché  
Executive Director



# Holy Family Home

Holy Family Home, Inc.  
165 Aberdeen Avenue  
Winnipeg, Manitoba  
R2W 1T9

☎ 204 589.7381  
☎ 204 589.8605

## APPENDIX H

Dear staff member,

Currently at Holy Family there is a study being conducted through the University of Manitoba regarding the effectiveness of one of our dementia care units. The findings of this study will assist Holy Family in its ongoing development and commitment to excellence in dementia care. This evaluation is also contributing to the existing knowledge base on dementia care.

Shortly, you will be receiving a letter asking for consent to participate in this study. This letter outlines in some detail the plans of the study. Participation in the study is completely voluntary and no one should feel obligated to participate. If you choose to join the study, I can assure you that your identity will be protected. There will be minimal risk to you as a result of participating in this evaluation. Possible risk may include anxiety related to questioning. If this should occur, all questioning is to stop immediately. I can also assure you that there will be no negative repercussions should you choose not to participate. If you do participate, you are free to discontinue your participation in the study at any time.

If you should have further questions please do not hesitate to contact me 589-7381.

Sincerely,

Jean R. Piché  
Executive Director

## APPENDIX I

<b>Quality of Life: AD</b> (Interview Version for the person with dementia)				
Interviewer administer according to standard instructions. Circle responses.				
1. Physical health.	Poor	Fair	Good	Excellent
2. Energy.	Poor	Fair	Good	Excellent
3. Mood.	Poor	Fair	Good	Excellent
4. Living situation.	Poor	Fair	Good	Excellent
5. Memory.	Poor	Fair	Good	Excellent
6. Family.	Poor	Fair	Good	Excellent
7. Marriage.	Poor	Fair	Good	Excellent
8. Friends.	Poor	Fair	Good	Excellent
9. Self as a whole.	Poor	Fair	Good	Excellent
10. Ability to do chores around the house.	Poor	Fair	Good	Excellent
11. Ability to do things for fun.	Poor	Fair	Good	Excellent
12. Money.	Poor	Fair	Good	Excellent
13. Life as a whole.	Poor	Fair	Good	Excellent

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



## APPENDIX J

### Quality of Life-AD Instructions for Interviewers

The QOL-AD is administered in interview format to individuals with dementia, following the instructions below. Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type):

**I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.**

Point to each word (poor, fair, good, and excellent) on the form as you say it.

**When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area.**

**If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.**

It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. Each of the four possible responses should be presented, and the participant should pick one of the four.

If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments.

As you read the items listed below, ask the participant to circle her/his response. If the participant has difficulty circling the word, you may ask her/him to point to the word or say the word, and you may circle it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

- 1. First of all, how do you feel about your physical health? Would you say it's poor, fair, good, or excellent? Circle whichever word you think best describes your physical health right now.**
- 2. How do you feel about your energy level? Do you think it is poor, fair, good, or excellent?** If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.

3. **How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?**
4. **How about your living situation? How do you feel about the place you live now? Would you say it's poor, fair, good, or excellent?**
5. **How about your memory? Would you say it is poor, fair, good, or excellent?**
6. **How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent?** If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.
7. **How do you feel about your marriage? How is your relationship with (spouse's name). Do you feel it's poor, fair, good, or excellent?** Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it's a family member or friend. If there is a family caregiver, ask about their relationship with this person. If there is no one appropriate, or the participant is unsure, score the item as missing. If the participant's rating is of their relationship with someone other than their spouse, note this and record the relationship in the comments section.
8. **How would you describe your current relationship with your friends? Would you say it's poor, fair, good, or excellent?** If the respondent answers that they have no friends, or all their friends have died, probe further. **Do you have anyone you enjoy being with besides your family? Would you call that person a friend?** If the respondent still says they have no friends, ask **how do you feel about having no friends—poor, fair, good, or excellent?**
9. **How do you feel about yourself—when you think of your whole self, and all the different things about you, would you say it's poor, fair, good, or excellent?**
10. **How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it's poor, fair, good, or excellent?**
11. **How about your ability to do things for fun, that you enjoy? Would you say it's poor, fair, good, or excellent?**
12. **How do you feel about your current situation with money, your financial situation? Do you feel it's poor, fair, good, or excellent?** If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.
13. **How would you describe your life as a whole. When you think about your life as a whole, everything together, how do you feel about your life? Would you say it's poor, fair, good, or excellent?**

***SCORING INSTRUCTIONS FOR THE QOL:***

Points are assigned to each item as follows: poor=1, fair=2, good=3, excellent=4.

**The total score is the sum of all 13 items.**

## APPENDIX K

### Quality of Life: AD

(Questionnaire Version for the Family Member or Caregiver)

*The following questions are about your relative's quality of life.*

When you think about your relative's life, there are different aspects, some of which are listed below. Please think about each item, and rate your relative's current quality of life in each area using one of four words: **poor, fair, good, or excellent**. Please rate these items based on your relative's life **at the present time** (e.g. within the past few weeks). If you have questions about any item, please ask the person who gave you this form for assistance.

*Circle your responses.*

1. Physical health.	Poor	Fair	Good	Excellent
2. Energy.	Poor	Fair	Good	Excellent
3. Mood.	Poor	Fair	Good	Excellent
4. Living situation.	Poor	Fair	Good	Excellent
5. Memory.	Poor	Fair	Good	Excellent
6. Family.	Poor	Fair	Good	Excellent
7. Marriage.	Poor	Fair	Good	Excellent
8. Friends.	Poor	Fair	Good	Excellent
9. Self as a whole.	Poor	Fair	Good	Excellent
10. Ability to do chores around the house.	Poor	Fair	Good	Excellent
11. Ability to do things for fun.	Poor	Fair	Good	Excellent
12. Money.	Poor	Fair	Good	Excellent
13. Life as a whole.	Poor	Fair	Good	Excellent

Comments: \_\_\_\_\_

## APPENDIX L

### Family Interview

1. How would you characterize / describe St. Francis unit / St. Joseph's unit?
2. Do you notice any environmental (physical and/or social) differences on the unit? If yes, would you say that these changes are important to the resident's daily life? How?
3. Has the environment had any effect on your family member's well being?
4. How would you describe the care offered to your family member?
5. How would you describe staff's knowledge of dementia?
6. Do you think the programs offered on the unit are appropriate? Does your family member attend them?
7. Do you feel the way we serve our meals makes a difference with your family member?
8. Do you feel included in the care planning of your family member?
9. Do you feel supported by staff? If yes how would you describe the support? If no explain?
10. How would you describe your family member's mood? Does it fluctuate? What affects it?
11. Has this unit been beneficial for your family member?
12. Has this unit affected in any way the quality of life of you family member? If yes, how?

## APPENDIX M

### Data Sheet

Assigned Number		Date of Birth	
Name			
Date of Admission to HFNH			
Date of Admission to DCU (if applicable)			
Sex			
Diagnosis			

### BACKGROUND INFORMATION

Education Level		Language	
Ethnicity		Religion	
Birth Place		Marital Status	
Number of Children			

Support Network	
-----------------	--

Assigned Number and Name				
	Score	Date Administered	Adjusted Score	Administered by
MMSE				
QOL Resident				
QOL Staff				
Family Interview				

Number of Reactive Occurrences and details	