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Family Caregiver Experiences of a Specialized Dementia Care Unit:

A Qualitative Study

by

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A THESIS

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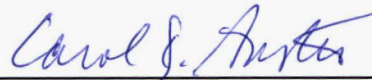
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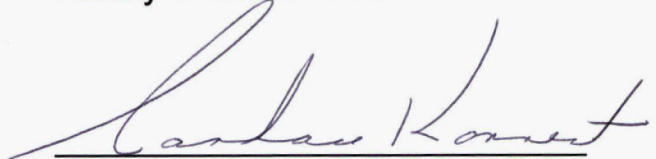
THE UNIVERSITY OF CALGARY

FACULTY OF GRADUATE STUDIES

The undersigned certify that they have read, and recommend to the Faculty of
Graduate Studies for acceptance, a thesis entitled "Family Caregiver Experiences
of a Specialized Dementia Care Unit: A Qualitative Study" submitted by Lana Marie
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Abstract

This qualitative study explores the experiences of family caregivers who have placed a relative with dementia on a special care unit in a long term care facility. Unit 300 at the Beverly Centre for Long Term Care in Calgary, Alberta was the research site selected. Six family caregivers consisting of adult children and spouses of Unit 300 residents, participated in individual interviews. A focus group of six staff members representing nursing and recreational therapy on Unit 300 was also conducted to obtain the staff members' perceptions of the family caregiver's experience following special care unit placement.

The findings show that caregivers experience various losses and adjustments when a family member with dementia is admitted to Unit 300. The themes of loss and adjustment tend to follow a turning point event or events in the lives of the caregiver and/or care recipient. Staff members also perceive the family caregivers' adjustment to various aspects of Unit 300 and the losses associated with dementia.

This qualitative study introduces several practical and research implications for social workers in this specialized field of gerontology.

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Finally, I want to thank my family, especially Mom and Dad, for giving me every opportunity to reach my goals. I love you.

Dedication

This thesis is dedicated to the incredible families of dementia sufferers, whom I have had the opportunity of working with through my experience as a social work student and social worker.

Table of Contents

List of Tables

List of Figures

x

List of Abbreviations

AD . . . . Alzheimer's Disease

ADL . . . . Activities of Daily Living

CBI . . . . Caregiver Burden Inventory

CBP . . . . Caregiver Burden Profile

CMI . . . . Case Mix Index

CSHA . . . . Canadian Study on Health and Aging

CT . . . . Computed Tomography

DSM-III-R/IV . . . . Diagnostic and Statistical Manual of Mental Disorders-
Third Edition, Revised/Forth Edition

FAST . . . . Functional Assessment Staging Tool

LPN . . . . Licensed Practical Nurse

LTC . . . . Long Term Care

MMSE . . . . Mini-Mental Status Examination

NA . . . . Nurse's Aide

NINCDS-ADRDA . . . . National Institute of Neurological
and Communicative Disorders and Strokes -
Alzheimer's Disease and Related Disorders Association

PCA . . . . Personal Care Aide

RN . . . . Registered Nurse

RPN . . . . Registered Psychiatric Nurse

RTA . . . . Recreational Therapy Aide

SCU . . . . Special Care Unit

Chapter One

Introduction

The prevalence of dementia in Canada's growing elderly population is significant. Preliminary findings of Canada's Study on Health and Aging (CSHA) reveal a 7.9% overall prevalence of dementia in Canada's 65+ age group (CSHA, 1993). Sixty-four percent of these dementia sufferers have Alzheimer's disease, 19% have vascular dementia and the remaining 18% suffer from other forms of dementia (CSHA, 1993). It is also interesting to note that 57% of the study's facility population evidence dementia as diagnosed by clinical assessment. Additionally, studies in the United States report a high percentage (60 to 70%) of elderly residents with dementia in long term care facilities (Holmes, Teresi, Weiner, Monaco, Ronch & Vickers, 1990; Levesque, Cossette & Potvin, 1993).

As the number of elderly persons with dementia in the population grows, so too will the number of family caregivers. A critical time for these caregivers is the period of transition and adjustment which occurs when the family member with dementia is institutionalized. For gerontological social workers in long-term care centres, the experience of the family caregiver following the placement of their relative in long-term care is identified as an important concept to be understood in order for practitioners to provide effective intervention.

Providing support and assistance to family caregivers is one of the main tasks of social workers who work in long term care special units (Rabins, Morrill,

Johnson, Smith & Low, 1990; Walker & Marchand, 1990). Recent studies which explore caregiver experiences are finding that even after institutionalization, families continue to experience various forms of caregiver-related stress, sometimes to a greater degree than when the family member was at home (Barber, 1993; Morgan & Zimmerman, 1990; Pratt, Schmall, Wright & Hare, 1987; Rosenthal & Dawson, 1991). Social workers and other health care providers in this field could benefit from more research in this area. Future directions for the necessary resources, effective programs and practice guidelines that would benefit caregivers are essential. This qualitative study explores the experiences of family caregivers who have a relative with dementia, on a special care unit in a long term care facility. The primary research questions are:

What are the experiences of primary family caregivers following the admission of their demented family member to a dementia special care unit in a long term care facility?

How do staff members working on a special care unit perceive the family's experience following admission?

These research questions are investigated utilizing two methods. Individual interviews with family caregivers explore their experiences in the placement of their cognitively impaired relatives on a special care unit and the impact of this unit on

the caregiver. In a focus group, staff members of the special care unit discuss their perceptions of the family caregiver's experience in placing a relative on the unit. Throughout this thesis, the researcher has utilized the term "caregiver" to identify the primary family member who has cared for the demented individual prior to and, in some manner, subsequent to long term care placement. The terms nursing home / long term care facility and continuing care facility are used interchangeably.

The following sections of this chapter review the major components of the area under study. These components are Dementia, Special Care Units, Caregivers and Burden.

Dementia

Definition

"Dementia" refers to the symptoms of progressive cognitive impairment which include impaired: memory, abstract thinking, reasoning, judgment and language (Health & Welfare Canada, 1991). "Dementia is not a disorder in its own right, it is rather a syndrome or a grouping of symptoms which can be manifested in a variable combination" (Arendt & Jones, 1992, p.9). In advanced stages of dementing illness, basic perception, coordination and regulation of physical activity are also affected (Health & Welfare Canada, 1991) as well as personality (McEwan, Maxwell & Gutman, 1992). The progressive nature of dementia cause the erosion of the "person's capacity to respond effectively to people, places and events in everyday life" (Health & Welfare Canada, 1991, p. 9). The Diagnostic

and Statistical Manual of Mental Disorders, Forth Edition (DSM-IV) outlines the

cognitive deficits characteristic of dementia as presented in Table 1.

Table 1 : Cognitive Disturbances Characteristic of Dementia

Cognitive Deficit	Consequence
Memory Impairment	- inability to learn new information or recall previously learned information
Aphasia	- language disturbance
Apraxia	- impaired ability to carry out motor activities despite intact motor function
Agnosia	- failure to recognize or identify objects despite intact sensory function
Disturbance in executive functioning	- impaired ability with planning, organizing, sequencing or abstracting

(American Psychiatric Association, 1994, p.142)

According to the findings of the Canadian Study on Health and Aging (1993), 60% of the cases of dementia are Alzheimer's Disease; 15% are a result of multi-infarct dementia; 5% account for dementia resulting from alcoholism; 5% is related to depression and the remaining 15% is a result of dementia associated with Parkinson's Disease, Acquired Immune Deficiency Syndrome, hypothyroidism and vitamin deficiency.

Alzheimer's Disease (AD) is defined as a specific form of dementia. Although an autopsy must be performed for a conclusive diagnosis of Alzheimer's, the disease is characterized by the "insidious progression of intellectual impairment, typically affecting memory early in the course of the disorder" (Coons, 1991, p. 252). Diagnosis of "probable" AD may be established by a number of methods. Administration of the Mini Mental State Exam (MMSE) or other similar assessment tools may be helpful in determining the level of cognitive impairment in the individual. Progressive deterioration may be found in the areas of language, memory, judgement, calculations or abstractions as well as deterioration in the performance of activities of daily living (ADL's) and evidence of cerebral atrophy on a computed tomography scan (CT scan) (Coons, 1991). As a result of its high incidence among those individuals with dementia, Alzheimer's disease continues to receive much attention in the literature (Dillehay & Sandys, 1990).

Multi-infarct dementia is the second most prevalent form of dementia in Canada (CSHA, 1993). Vascular dementia, as it is also referred to, may result following a cerebral vascular accident or stroke (Coons, 1991). The onset of multi-

infarct dementia is characteristically more abrupt than that of Alzheimer's disease.

Other dementias which are not as prevalent as Alzheimer's Disease and vascular dementia include dementia resulting from alcoholism, dementia associated with depression, Parkinson's disease, Acquired Immune Deficiency Syndrome, hypothyroidism and vitamin deficiency. Whatever the cause of dementia, a thorough assessment is necessary to rule out reversible dementias, such as those associated with depression, which may be treated with anti-depressant medication as well as various forms of psychotherapy. In addition, dementia resulting from hypothyroidism and vitamin deficiency may be treatable with medication (Coons, 1991).

The MMSE developed by Folstein, Folstein & McHugh (1975) may be used to determine the level of cognitive impairment of dementia victims. The MMSE assesses orientation, memory, attention, language and comprehension through a set of questions and problem-solving tasks (Coons, 1991). A score of 24 or less out of 30 indicates impairment. The MMSE is utilized on the SCU in this study to assess the resident's cognitive status. Other similar tools which assess mental status include the Short Portable Mental Status Questionnaire and the Cognitive Capacity Screening Examination (Coons, 1991).

It is also necessary to assess the functional status of the individual with dementia to determine which activities of daily living (i.e. bathing, toileting, continence, feeding, transferring and dressing) and instrumental activities of daily living (i.e. shopping, preparing meals, managing medication and finances) they are

able to perform (Coons, 1991). See the glossary in Appendix K for a more thorough definition of ADL and IADL. One tool which accomplishes this task is the Functional Assessment Staging of Alzheimer's Disease (FAST) developed by Reisberg (1988). This tool allows the evaluator to determine which abilities are intact. This tool is also utilized by the SCU selected for this study to assess the functional level of the residents. See Appendix I for a copy of the FAST. Coons (1991) identifies other assessment tools including the Functional Dementia Scale, the Clinical Dementia Rating Scale and the Functional Rating Scale for the Symptoms of Dementia. The following section reviews the prevalence of dementia in long term care.

Dementia in Long Term Care

McEwan et al. (1992) reviewed several studies to determine the prevalence of dementia among long term care residents. The findings vary greatly from study to study. For example, Alberta Health's (1988) study found a 30.0% prevalence rate in long term care facilities where as 54.4% of the population studied in Saskatchewan's long term care facilities were found to evidence dementia (Robertson, Rockwood & Stolee, 1981). Another study completed in Edmonton, Alberta found 68.8% of the long term care population to have dementia (Bland, Newman & Orn, 1988). This variation in prevalence may be contributed to a number of factors.

In McEwan et al.'s (1992) review of the studies there is variance in the

definitions of "dementia" for each study. Dementia and cognitive impairment are considered to mean the same thing in terms of the identifying disorder in the studies reviewed. The severity of cognitive impairment is also considered in one study (Bland, Newman & Orn, 1988). The methods of assessment also vary from study to study. Chart records, the Mini Mental Status Exam, a questionnaire developed by the researchers and the DSM-III-R and psychiatric assessment techniques were utilized in the various studies reviewed. Finally, the studies spanned the years 1981 to 1990, and this could attribute to the variance in prevalence rates.

More recently, the Canadian Study on Health and Aging (1993) has found that 57% of the residents in 1255 facilities sampled in ten provinces, evidenced dementia as diagnosed by clinical assessment including Diagnostic and Statistical Manual of Psychiatric Disorders (DSM-III-R) and National Institute of Neurological and Communicative Disorders and Strokes - Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) criteria. This is a significant finding considering that the elderly population is growing and the proportion of demented elderly will continue to grow with it. In Alberta in 1994, the percentage of persons in long term care facilities with a diagnosis of dementia (Alzheimer's disease included) was 48.2, an increase from 1993's 45.0 rate (Alberta Health, 1995).

The consequences of a dementing illness are devastating for the individuals who suffer from Alzheimer's disease or multi-infarct dementia. Several troublesome behaviours, in addition to deteriorating abilities may result over the course and

progression of the disease. Management of these behaviours accounts for a significant portion of the burden experienced by family caregivers and staff of long term care facilities. These behaviours are outlined in the next section.

Behaviours of Residents with Dementia

McEwan et al. (1992) identifies the behavioral features of institutionalized individuals with dementia. These behaviours present a challenge for effective management by staff members and may be upsetting to family members. Some of the most common maladaptive behaviours of cognitively impaired individuals include: wandering, suspiciousness, restlessness, impaired communication, nocturnal confusion, catastrophic reactions/agitation, eating difficulties, incontinence and memory loss (Johnson, 1989; Rabins et al., 1990). These are also the common behaviours which long-term care facilities strive to manage. Hostility, aggression, sleep disturbances, wandering, agitation and incontinence are problematic for the facility if found to be:

◆   disruptive to the social environment;

◆   dangerous or harmful to the patient or other residents;

◆   damaging to the physical environment and/or

◆   undermining or interfering with the provision of care

(McEwan et al., 1992, p.9).

Wandering presents a problem if residents are looking for a way out of the facility. Once the resident elopes, he/she is in unfamiliar territory and is at risk for a variety

of unpleasant consequences. Suspicious residents accuse others, even family, of stealing personal possessions or abandoning them. This occurs because the resident has usually forgotten where they have placed something or when they last saw their family member. Agitation, if not appropriately controlled, may erupt, resulting in aggressive behaviours. This places the resident and others around him/her at risk for injury. Catastrophic reactions result from confusion, information overload and overstimulation. The emotional responses of these residents can have a domino effect on other nearby residents, causing chaos in the unit.

From the studies McEwan et al. (1992) reviewed for the prevalence of dementia in long term care facilities, the presence of maladaptive behaviour is noted. For example, in the study by Alberta Health (1988), 84.6% of the residents with dementia exhibit at least one problem behaviour. Psychiatric features are also associated with dementia. Depression, delusions and hallucinations occurred in 30-40% of Alzheimer's patients in a study by Wragg and Jeste (1989).

Traditionally, many of the behavioral problems of residents with dementia have been managed with the use of medications or other physically confining measures, such as restraints (McEwan et al., 1992). Continuing Care centres are beginning to explore alternatives in caring for demented individuals. The "special care unit" or SCU, is receiving increasing attention.

Special Care Unit

Definition

A special care unit is a setting, usually in a long term care facility, which has been developed in response to the growing population of elderly persons with dementia (Coons, 1991). Special Care Units or SCU's are a relatively recent development in long term care so as of yet, there has not been a standardized description of what an SCU is or should be. Maas, Hall, Spect and Buckwalter (1992) state that for a unit to be designated as special, the following features must be present:

1. Physical environment

2. Admission and discharge criteria

3. Staff selection and training

4. Resident care and therapy programming

5. Family programming

Special care units vary in terms of their physical environment. Sloane and Mathew's (1991) study of 31 dementia units in five states note the wide variety with the size of the units, the number of rooms and how special units are separated from the rest of the facility. Locked doors, closed doors, space dividers and alarm systems have all been utilized to separate the residents of special care units from those of the regular part of the facility. In their study, Sloane and Mathew (1991) found 87% of the special units investigated, to be physically isolated from the rest of the facility. Of the remaining 13% of units which were not physically separated

from the facility, staff reported much time spent in looking for wandering residents (Sloane & Mathew, 1991). Maas et al. (1992) explain the necessity of meeting the needs of the target population with respect to controlled stimuli - noise reduction, decreased size of the unit, traffic reduction, adequate lighting and environmental cuing. Although physical environment is addressed by facilities providing dementia care, the degree with which modifications are made varies a great deal.

Admission and discharge criteria are also an important aspect of special care units. Comprehensive assessment ensures that a resident will be placed appropriately and specific discharge criteria provide indicators as to when the specialized care will no longer benefit the resident. Despite the establishment of set criteria for admission and discharge of residents to and from SCU's, the problems of severely long waiting lists and unavailable beds make flow-through a difficult task in facilities with a special care unit.

Staffing is identified as an important aspect of specialized dementia care. Mass, Swanson, Specht and Buckwalter (1994) contend that staff should be recruited "with the expectation that specialized, skilled care will be required" and be selected "for their commitment to the unique care demands of residents with AD" (p.180). Specialized, ongoing training is noted in these requirements for recruiting SCU staff.

Residents with dementia have special needs. Therefore, programming must meet the needs of these special individuals in a manner which is stimulating, yet not to the point of overstimulation or understimulation (Mass et al., 1994). Maas et

al. (1994) support an approach to care which is characterized by individualized, consistent and flexible programming ranging from assistance with ADL's to recreational activities such as dancing.

Although the literature is growing with respect to the aspects of SCU's which are most effective, very little empirical evidence exists to support the efficacy of SCU's. The following section summarizes the state of the literature on SCU's to date.

Overview of the Research on Special Care Units

Research on special care units is in its early stage at the time of this study. In general, the studies explore special care unit effectiveness as compared to traditional, integrated units in long term care facilities (Holmes, Teresi, Weiner, Monaco, Ronch & Vickers, 1990; Mathew, Sloan, Kilby & Flood, 1988). Literature on special care units predominantly offers subjective perspectives, based on anecdotal accounts of the authors' first-hand experiences with particular units (Ackermann, 1985; Hall, Kirschling & Todd, 1986; McCracken & Fitzwater, 1989; McCracken & Gilster, 1991; Rabins et al., 1990). Those who have questioned the efficacy of special care units advocate for the traditional, integrated settings where alert and cognitively impaired residents reside together (Brown Wilson, 1990; Getzlaf, 1987). More research is needed to explore the possible positive and negative effects of SCU's, particularly whether SCU's are effective in reducing disruptive or negative behaviours, or improving functional behaviours for the

cognitively impaired elderly (Maas et al., 1994). Suggested targets for future studies on the efficacy of SCU's include: the residents with dementia who reside on them, the alert residents in the facility, the families of the cognitively impaired residents, staff of the SCU's and health care administrators (Gold, Sloane, Mathew, Bledsoe & Konanc, 1991; Lipscomb, 1991; Mathew et al., 1988). The aim of this study is to specifically explore the family caregiver experience of admitting a demented family member to a special care unit, both from the family caregiver's and staff members' perspectives.

Caregiver Burden

Definition of Caregiver

One of the major criticisms of the caregiving literature is the lack of standardization of the definition for "caregiver" (Barer & Johnson, 1990). There is variance with regard to who the caregiver is and what style of caregiving is in place. Adult children, spouses, other family members or friends of the family may be defined as the caregiver. Barer and Johnson (1990) discuss how the style of caregiving refers to how often care is provided; routine, sporadic, back-up caregiving and combinations of these are noted among the variety of styles. Definitions also vary from very specific (adult daughter caring for her mother with dementia) to very broad (friend of the family) (Barer & Johnson, 1990).

Usually, only one key person in the family will be involved in the care of the individual with dementia. This person is referred to as the "primary caregiver"

(Duijnstee, 1992). In those cases where the individual is married, the spouse is designated as the primary caregiver. For those individuals who no longer have a spouse, or whose spouse is no longer well enough to provide care, one of the adult children will take over the caregiving role. In these cases, the adult child is more likely to be a daughter, as opposed to a son (Duijnstee, 1992). In this exploratory study, this researcher defined the caregiver as the family member, spouse or adult child, responsible for caring for the individual with dementia, who is now a resident of the SCU.

Providing care to a family member with dementia affects the caregiver in a variety of ways. The ways in which caregiving for a loved one with dementia impacts the caregiver is referred to collectively, as caregiver burden. This concept is introduced in the following section.

Definition of Burden

Different definitions of "burden" have also resulted in confusion in the literature, specifically in studies which measure caregiver burden. Dillehay and Sandys (1990) describe the concept of burden in terms of the psychological state resulting from "combinations of physical work, emotional pressure, social constraints, and financial demand accruing because of patient-care requirements" (p. 268). This multi-dimensional concept has been analyzed from numerous perspectives in the research literature, and has been applied in a variety of ways. However, it is noted that there has been little consensus as to which dimensions

of burden are relevant and which variables are related to burden. Over the past decade, research in this domain has explored the effects of various caregiver and care recipient characteristics on burden. Studies attempt to identify the factors which influence caregiver burden. Some explore various caregiver factors such as available supports, physical health, mental well-being or relationship to the care recipient. Other studies explore various factors related to the care recipient including degree or severity of dementia and other problematic behaviours. Yet others include a combination of the above factors and others such as the quality of the relationship prior to disease onset and its effects on caregiver burden.

A distinction is also made between objective and subjective perception of burden. Duijnstee (1992) reviews four different studies which examine this distinction and finds that the content between studies differs a great deal. The conceptualization of objective burden ranged from disturbing behaviours of the individual with dementia to adverse effects on family and household. Other examples of objective burden are the social costs including financial burden and role strain. Subjective burden is conceptualized as the extent to which the family feels burden, suffering and other negative emotions or feelings - embarrassment, depression, worry and resentment (Duijnstee, 1992). Duijnstee (1992) then defines objective burden as the characteristics of the patient with dementia, the characteristics of the caregiver and the characteristics of the surroundings. Subjective burden is framed as the experienced burden as a result of patient, caregiver and environmental characteristics as well as any other intervening factors.

Caregiver burden is a multidimensional concept which impacts caregivers in a multitude of ways. More research is necessary to fully understand the dimensions of caregiver burden and how caring for a demented relative in particular, impacts the caregiver. However burden is conceptualized, caregivers experience the devastating effects of the role. This discussion provides an overview of the various aspects of caregiver burden which will be described in greater detail in Chapter Two.

Summary

This chapter introduces the major, substantive concepts of this qualitative research study. Diseases which result in dementia dramatically alter the lives of the individual and his/her family. With the progression of dementing disease, numerous abilities will be lost and the caregiver is faced with managing the daily activities and problematic behaviours characteristic of dementia. The result is often great physical, emotional and social strain on the lives of the primary caregiver and other family members.

Long term care placement is a decision most caregivers would just as soon avoid. However, providing care for a demented elderly individual at home may no longer be feasible. A relatively recent innovation in the long term residential care of persons with a dementing illness is the special care unit. Current research is limited, however the knowledge base is growing. At this stage, it is important to learn more about the family caregiver's experience of placing a relative with

dementia on a special care unit. From a social work perspective, the information obtained from this study will have implications for education, practice and future research in this area.

Chapter Two

Literature Review

This literature review is organized into three sections. The first section describes special care units designed for long-term care residents with dementia. The next portion of the review discusses the concept of caregiver burden and which factors contribute to and influence burden. Finally, there will be a discussion of the caregiver's experience following the institutionalization of a demented family member leading up to the purpose of this study and the research questions which were asked.

The following section introduces which types of special care units exist, how they differ from one another and from traditional units in long-term care facilities. There is also a discussion of the arguments surrounding special care units. A review of the current research on special care units discusses the various questions, the findings, an overview of the methodological problems and implications for future research with SCU's. This will lead to the portion of the literature review devoted to caregiver burden.

Special Care Units

"Probably few developments in the health care arena have moved with the speed and unstructured abandon of the proliferation of new Alzheimer's or dementia care units..." (Coons, 1991, p.1). Special care units or SCU's refer to

those long-term care settings which are developed in response to the growing population of elderly persons with dementia in long-term care facilities (Coons, 1991). Individuals with a dementing illness such as Alzheimer's disease require care that differs "greatly from the needs of those who are mentally alert" (Coons, 1991, p.8). Hepburn, Severance, Gates and Christensen (1989) state more specifically that special care units emphasize a "modified environment in which stimuli are reduced, wandering is contained and the familiar is reinforced" along with specialized staff training that is required to work effectively with this special population (p. 19). Coons (1991) recognises that the increasing popularity of these units has led to the establishment of freestanding complexes designed especially for individuals with dementia, that operate apart from any larger facility.

It is necessary to note that not all SCU's are designed and not all SCU staff are trained to deal with difficult behaviours effectively. While some special care units may be identified by the above criteria, there are others which do not even come close to providing what might be described as "specialized care" for residents with advanced dementia. Ohta and Ohta (1988) and Gold et al. (1991) discovered that there are more differences than similarities between special care units.

Ohta and Ohta (1988) examined 19 special units using published and unpublished reports in the United States and discuss the heterogeneity of these units. They have found that in the SCU's considered, there are differences in terms of philosophy, environmental design and therapeutic approach (Ohta & Ohta,

1988). For example, a unit may be labelled "special" even if the only modifications include minimal drug therapy, which has been a regular feature of traditional units. Or, in terms of environmental design, a special unit may only have an alarm system installed to deal with residents who wander. In contrast, other units may utilize "highly textured, pastel-coloured, sound absorbent materials, and minimize high glare floors and noisy patterns on wall coverings" as well as placing the "name, photograph, and brief biography of each patient on the wall outside of the unit's rooms" (Ohta & Ohta, 1988, p. 805). As noted by Ohta and Ohta (1988), SCU's range from highly modified to minimally modified units. Research which attempts to evaluate the effectiveness of SCU's has therefore been very difficult, because standardization has not existed for SCU's.

Gold et al. (1991), however, surveyed 55 homes across five states and developed a typology of eight distinct types of settings designed to care for memory-impaired older adults. This typology includes the following: ideal, uncultivated, heart of gold, rotten at the core, institutional, limited, conventional and execrable (Gold et al., 1991). This study focused on those variables related to patient quality of life or how the quality of care has been affected. Such variables include: the appearance of the unit, patient behaviours, staff behaviours and administrative involvement. The "ideal" type of setting is associated with high ratings for cleanliness, no odours, staff with specialized training, high staff/patient interaction, caring staff attitudes towards patients, low staff stress level, a therapeutic administrative philosophy and a caring attitude by administration

towards patients. At the opposite end of the typology, the "execrable" setting is associated with low ratings for cleanliness, presence of odours, no staff with specialized training, low staff/patient interaction, apathetic staff attitudes toward patients, low staff stress level, a "maintenance" administrative philosophy and an apathetic attitude by administration towards patients (Gold et al., 1991). The other types of settings have a mixture of positive and negative ratings which place them at various points in the middle of the typology.

Figure 1 on the following page illustrates the proportions (in percent) of the types of units discovered by Gold et al. (1991) for the 28 SCU's and 27 traditional units sampled.

Figure 1: Typology of Units

Typology of Units

Special Care Units vs. Traditional Units
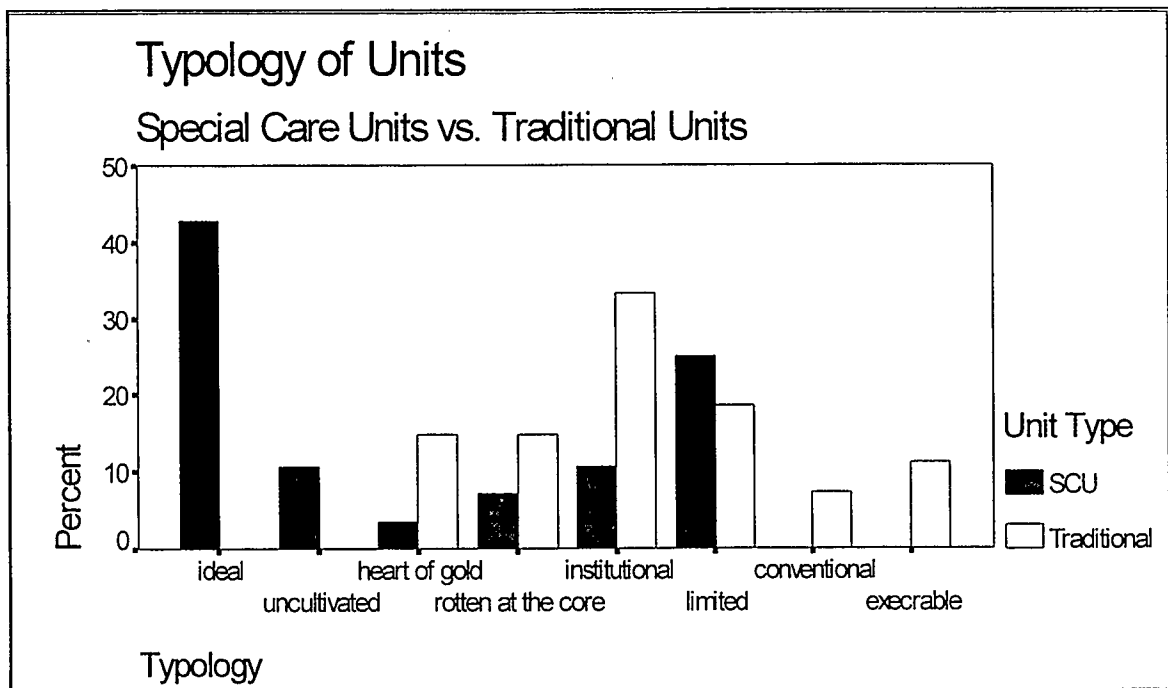
(Gold et al., 1991)

As illustrated by the graph, none of the SCU's sampled fall into the conventional and execrable categories. This typology has been developed using both SCU and traditional (control) care settings. Overall, SCU's are associated with higher-quality patient care than traditional care settings. The primary difference between SCU and traditional settings is the presence or absence of dementia specific care (Gold et al., 1991). While studies such as this one attempt to make the process of comparing units easier, this researcher must question the assignment of terms such as "ideal" or "limited" when there has not been sufficient empirical research to demonstrate what, in fact, is the "ideal" type of environment for residents with dementia.

Many of the studies conducted to date have contained serious methodological problems which limit the validity and generalizability of the findings. Holmes et al. (1990) compared patients with dementia in SCU's with those in traditional units over a six month period and have found little change among patients in the SCU's in terms of activities of daily living, mental status and various other related behaviours. Another comparative study by Mathew et al. (1988) explored possible differences between residents with dementia on an SCU and two traditional comparison units. The results of this study reveal that patients in the SCU "did not function at a higher level than their counterparts in traditional nursing home environments" (Mathew et al., 1988, p. 22). Limitations of these studies include small and unrepresentative sample size, lack of standardization among units and relatively brief periods of time to study the impacts of SCU's (Holmes et

al., 1990; Mathew et al., 1988).

A recent study by Sloane, Lindeman, Phillips, Moritz and Koch (1995) has found many other sources of bias to be evident in the research on SCU effectiveness. Because of the quasi-experimental nature of the studies on SCU's, there have been different sources of error discovered. For example, selection bias has been noted when subjects in the SCU's sampled have differed systematically from those individuals in control groups, namely those on traditional units. Studies which sample large numbers of SCU's have been limited with respect to the problem of differential facility characteristics such as the quality of care, unit size and refusal to participate in a comparative study. Because such variance exists among SCU's, generalizability is extremely limited. Resident characteristics are difficult to control in studies on SCU effectiveness. Possible confounding variables have included residents' comorbid conditions, length of stay and the type, staging and diagnosis of dementia which differs systematically from control residents (Sloane et al., 1995). Other sources of bias common to most comparative studies include various sources of measurement bias which affects the reliability, sensitivity and validity of the data as well as attrition of subjects due to death, refusal to participate or transfer from the study setting (Sloane et al., 1995).

A larger portion of subjective, descriptive data exists on the benefits of SCU's for residents, families and staff. These benefits are identified in Table 2.

Table 2 : Benefits of Special Care Units

Benefits for Demented Residents

-increased safety and security for wandering residents
-low-stimulus environment for decreased stress levels of residents in SCU's
(Hall et al., 1986)
-specially trained staff
-concentrated resources (Mathew et al., 1988)
-improvements in eating, sleeping, mood and social interactions
-decreased use of medication and physical restraints (McCracken and Gilster, 1991)
-residents enjoy a greater sense of autonomy because of the increased freedom of choice and flexibility in activities of daily living that SCU's may offer (Ackermann, 1985).

Benefits for Alert Residents

-decreased fear from harm to self, loss or damage of personal property
-increased socialization
-greater sense of privacy
-improvements in sleep patterns as a result of not having confused, wandering residents in the same setting (Hall et al., 1986)

Benefits for Staff

-opportunity to develop an expertise in caring for a special population (Dobbs & Rule, 1992)
-increased effectiveness of staff interventions with residents (Sloane & Mathew, 1991)

Benefits for Families

-increased support for families
-families are involved in the care planning process (Sloane & Mathew, 1991)
-decreased anxiety for family members (Mathew et al., 1988)

Many problems surface when residents with dementia share the same living space with lucid residents. The benefits of separating cognitively impaired residents from alert residents are noted in Table 2. One benefit highlighted in Table 2 is the increased security for wandering residents (Hall et al., 1986). One of the most common behaviours with persons who have dementia is wandering (Rabins et al., 1990). Sand, Yeaworth and McCabe (1992) found that 15% of the 203 long term care facilities without SCU's surveyed, reported daytime wandering problematic as it consumes much of the staff members' time, searching for these residents. Wandering is also problematic because of the possible risks to the resident's safety if he/she should elope. Proponents of SCU's argue that the security of locked exits decreases the possibility of elopement. Sand et al. (1992) have found significantly lower incidence of wandering in those facilities with a special care unit.

Another problematic behaviour of residents with dementia is the presence of aggressive or violent behaviours towards others. This presents a concern for alert residents who may suffer from or fear these acts of aggression. The special care unit provides a separate environment for aggressive residents and protects alert residents from possible harm (Hall et al., 1986).

Decreasing the stress for cognitively impaired residents by lowering stimuli in the environment is a common objective in the development of special care units. Overstimulation by noise, activity or large numbers of people have been known to agitate residents with dementia (Johnson, 1989; Hall et al., 1986). Maas et al. (1994) note that dedicated SCU's are developed "using the principles of controlled

stimuli, such as group size, for dining and activities and the elimination of overwhelming or conflicting stimuli that may be produced by mirrors, public address systems and televisions" (p. 179). A calm environment contributes to decreased stress, improved mood and more social interactions among residents with dementia (Hall et al., 1986). However, Maas et al. (1994) also caution against a lack of stimulation in SCU environments. Sensory deprivation has resulted in settings which are not stimulating enough for the residents with dementia. Various behavioral consequences of sensory deprivation include: tearing down drapes from windows, plugging toilets with clothing and other objects and rummaging and hoarding in other resident rooms (Maas et al., 1994). A balance of stimulating activities and quiet surroundings must be attended to in developing a special care unit that is beneficial for residents and the facility.

Another benefit of effective SCU's is specially trained staff to care for residents with dementia (Mathew et al., 1988). Staff members with the knowledge of the various care demands of these residents have the advantage of providing effective interventions in dealing with the difficult behaviours which occur on a daily basis (Maas et al., 1994).

McCracken and Gilster (1991) discovered a decrease in the use of medication and physical restraints in their study of a special care unit. Chemical and physical restraints are viewed negatively from a family member's point of view (Johnson, 1989) as well as a highly restrictive and degrading method of managing behaviour from a staff member perspective (Hall et al., 1986).

When cognitively impaired residents are admitted to facilities where they dwell with alert residents, many problems may arise for the alert resident as well. With SCU's being established for demented residents with problematic behaviours, Hall et al. (1986) note that the problems of "invasion of privacy, lost/damaged property, interrupted sleep, fear from physical harm and decreased socialization in attempts to avoid encounters with confused residents" are alleviated (p. 133).

From a staff member's perspective, one benefit of providing specialized care is the opportunity to develop an expertise in caring for a very special population. The is viewed as highly challenging and rewarding in this sense (Dobbs & Rule, 1992).

Finally, the family is recognized as having fewer anxieties when their relative is placed on a special care unit. When the resident is experiencing fewer frustrations due to a calm environment, families may be more satisfied (Mathew et al., 1988). Families also benefit in terms of receiving more support when they are part of the care planning process for their relative (Sloan & Mathew, 1991).

Some health care providers dispute the establishment of segregated settings for all residents with dementia. They caution proponents with regard to the efficacy of SCU's based on the fact that little empirical evidence supports the establishment of specialized units for dementia care. These proponents of integration or traditional nursing home settings, for residents with dementia, argue that segregation is not necessarily the answer for dealing with this special population. Some of the disadvantages of SCU's identified include: high costs of operation, the

labelling effect of the "special" unit, possible difficulties in recruiting staff, problems in determining admission criteria and dealing with family resistance (Mathew et al., 1988). Brown Wilson (1990) suggests that lowered expectations placed on residents of SCU's will result in an increased rate of decline. Dobbs and Rule (1992) add that families may find the SCU depressing to visit which could result in decreased visitation. In addition, staff may experience exhaustion and demoralization in dealing with a "difficult" population. Establishing the cost-effectiveness of SCU's is also a concern based on the lack of standardization criteria for special care units (Maas et al., 1994). These are the major arguments on which proponents of integration base their decisions to caution SCU development.

A few advantages are also mentioned to support the integration of cognitively impaired residents with alert residents. Brown Wilson (1990) suggests that cognitively impaired residents could benefit from having alert "role models" and may mimic positive behaviours. Also, cognitively impaired and alert residents have been observed forming mutually-helping relationships which are beneficial to both residents (Brown Wilson, 1990; Dobbs & Rule, 1992). Another advantage of traditional units is the lower operating expense (Getzlaf, 1987). And for those who view labelling as potentially damaging to residents, families and staff of SCU's, this is not an issue for the traditional, integrated units (Brown Wilson, 1990). It is interesting to notice, however, that even these proponents of integration recognize the advantages of SCU's for severely impaired residents with insoluble, disruptive

behaviours (Brown Wilson, 1990; Getzlaf, 1987).

The literature on SCU's raises several questions for future exploration. Since consensus has not yet been reached with regard to whether SCU's are effective, the question which must be investigated further is "Do special care units work?" (Mathew et al., 1988; Lipscomb, 1991). Specifically, do special care units improve the quality of life for residents with dementia? Other topics to explore include: How should SCU's be defined with respect to philosophy, environment and therapeutic approach? Are there certain residents with dementia who could benefit relatively more with SCU placement? Are there different types of units which are ideally suited to different types of residents? What are the effects of special care units on families, staff, administrators and alert residents? (Holmes et al., 1990; Lipscomb, 1991; Ohta & Ohta, 1988).

Methodological problems which require consideration in future studies include: the control of various sources of bias which affect the generalizability of results, the characteristics of appropriate control or comparison groups, the inclusion of relevant independent variables, the identification of appropriate and sensitive dependent variables, the utilization of qualitative as well as quantitative techniques and the attempt to obtain data directly from the resident as well as from the unit staff and the resident's family (Ohta & Ohta, 1988; Sloane et al., 1995).

Caregiver Burden

Caregiver burden has been studied from a variety of perspectives over the years. A large body of literature exists describing the characteristics of burden for caregivers of frail, disabled and cognitively impaired elderly. This researcher will focus only on caregiver burden with regard to caring for an elderly individual with a dementing illness, such as Alzheimer's Disease. This portion of the caregiving literature is growing at an alarming rate with the increased interest in the demands placed on the caregiver of an individual with dementia (Barber, 1993; Browning & Schwirian, 1994; Dillehay & Sandys, 1990; Collins, Given & Given, 1994; Cohen, Gold, Shulman, Wortley, McDonald & Wargon, 1993; Rosenthal & Dawson, 1991; Stevens, Walsh & Baldwin, 1993).

This section of the literature review will describe the various tasks and problems in caregiving for an individual with dementia. An overview of the research on caregiver burden and its relationship to several variables will be discussed. This will lead in to the final section which describes what has been explored with respect to the experiences of caregivers following the placement of a loved one with dementia in a long term care facility.

Problems of Caring for an Individual with Dementia

The effects of caring for a family member with dementia at home, in the community are well documented. Based on a review of the literature, Dhooper (1991) has organized the problems experienced by families into the following

clusters: family disruptions, psychological stress, physical fatigue, social isolation, financial problems and legal problems. These dimensions and their various categories and sub-categories are consistently observed in the literature (Browning & Schwirian, 1994; Dillehay & Sandys, 1990; Novak & Guest, 1989; Price & Levy, 1990).

Family disruptions include those instances where family members experience conflict as a result of role changes (Dhooper, 1991). The relationship changes quite drastically, often leaving the caregivers feeling some ambiguity about who they are and what they are, to the individual with dementia. The caregiver, in addition to being the spouse or adult child, for example, must now deal with those tasks involved in caring for someone with a dementing illness. Clark and Rackowski (1983) categorize the various tasks of caregiving under four headings: direct care of the patient, intra-personal tasks of the caregiver, interpersonal and family tasks and societal tasks. This tasks are summarized in Table 3.

Table 3 : Types of Caregiving Tasks

Direct care of the patient	- being available when needed, supervising treatments, evaluating significant changes, providing structure to daily activities, normalizing routines within the bounds of impairment, performing activities of daily living and coping with upsetting behaviours.
Intra-personal tasks of the caregiver	- compensating for emotional drain from constant responsibility, recovering personal time, gaining knowledge about the disease and the patient's condition, avoiding severe drain on physical health, resolving guilt over negative feelings toward patient and over one's performance and avoiding restrictions on future plans.
Interpersonal and family tasks	- balancing the giving of assistance with responsibilities to other family members and managing feelings towards those family members who do not regularly help.
Societal tasks	- interacting with medical, health and social service professionals.

(Dhooper, 1992, p. 24).

A second problem of caregiving for an elderly family member with dementia is the psychological stress "resulting from resentment, ambivalence, anger, guilt, watching a loved one deteriorate, competing demands for time and energy, and self blame" (Dhooper, 1991, p. 23). This stress can be extremely taxing on the caregiver who has been struggling with the acceptance of his/her loved one's disease, as well as other difficult decisions which need to be made regarding the individual's care. Kuhn (1990) has developed a model to describe the normative crises which caregivers experience when caring for a loved one with dementia. The major stressors identified are:

- the onset of troubling symptoms
- the diagnosis of an irreversible dementia
- the onset of behavioral problems
- seeking help outside of the family system
- the onset of incontinence for the individual with dementia
- hospitalization
- nursing home placement
- the onset of eating difficulties for the demented relative
- the death and subsequent grieving for the loved one .

(Kuhn, 1990)

Kuhn (1990) notes that the diagnosis, nursing home placement and death of the individual with dementia are the only "distinct events in the history of the illness; the exact time of the other crises is uncertain" (p. 453).

Another negative effect of caring for a person deteriorating from a dementing illness is physical fatigue. Mace and Rabins (1981) describe the "36

hour day" for caregivers of demented individuals. The demands of continuously supervising the demented individual's ADL's and IADL's (see Appendix K for definition) consume much of the caregiver's energy. In addition, there are the regular every day tasks of maintaining a home, raising children or being employed, for example. The physical strain of constant care-providing could place the caregiver's health in jeopardy.

A related problem to the physical fatigue is the resulting social isolation (Dhooper, 1991). Diminishing energy to engage in activities with friends, not to mention the lack of time for such activities may lead to the social isolation of the caregiver. Relationships with others tend to terminate since little time can be invested in such relationships when one is caregiving 24 hours a day. Argyle, Jestice and Brook (1985) have found in their study of caregivers of psychogeriatric unit patients that reduced social life is a problem with 74% of their sample of 62 primary caregivers (as cited in Price & Levy, 1990). Dhooper (1991) also notes that relationships with married friends diminish, particularly for spousal caregivers.

Finances soon become a concern for family caregivers as well (Dhooper, 1991). In the United States, fewer services are covered under Medicare and most private insurance plans. In Canada, Home Care, respite services and day programs are seriously lacking in the continuum of care. More and more private, for-profit agencies are beginning to provide care for families in need of respite, which presents a huge cost for the caregiver.

Finally, legal problems may be an issue for families with a demented

relative. Obtaining enduring power of attorney, guardianship and trusteeship are concerns of Canadian caregivers of individuals with Alzheimer's and other dementing illnesses. In one study by Nathan (1986) obtaining a divorce "as a method of maintaining financial solvency" has been a legal issue for wives of Alzheimer's patients (as cited in Dhooper, 1991, p. 23).

Morycz (1985) classified the problems of caregiving into three contexts: 1) patient characteristics, 2) caregiver characteristics and 3) environmental characteristics. The interaction of patient, caregiver and environment characteristics produce the actual degree of family burden experienced by caregivers (Morycz, 1985). Patient characteristics include behaviours such as wandering, aggression and incontinence. Caregiver characteristics include physical illness, expectations and negative attitudes towards the patient. Environmental characteristics cover aspects such as the layout of the home, safety features and social factors including finances and family conflict (Morycz, 1985).

Despite the many different ways in which the dimensions of caregiver burden are classified, categorized or organized, similar themes emerge from the literature. Dillehay and Sandys (1990) group these aspects of caregiver burden and adjustment to caregiving in psychological, social and physical categories. Under these groupings, they have identified the studies over the past decade which have looked at the relationship between caregiver burden and psychological, social and physical factors believed to have an influence on burden.

Research on Caregiver Burden

The effects of various psychological, social and physical factors on burden have been examined by a number of researchers over the years. Studies have examined the potential correlations between caregiver burden and variables such as: age, sex, health status, income and educational level of the caregiver; the degree of cognitive impairment, memory and behaviour problems, functional abilities and duration of illness of the care recipient as well as the frequency of family visits, perceived social support and quality of premorbid relationship of the caregiver/care receiver dyad (Dillehay & Sandys, 1990). Dillehay and Sandys (1990) reviewed the literature on adjustment by family members to providing care to victims of Alzheimer's disease. They define the concept of burden as "the psychological state resulting from combinations of physical work, emotional pressure, social constraints and financial demand accruing because of patient-care requirements" (Dillehay & Sandys, 1990, p. 268). They also stress the importance of the distinction between the subjective experience of the caregiver's situation and the objective demands on the caregiver because it is the "psychological experience of the objective situation that determines caregiver response" (p. 268).

The studies reviewed by Dillehay and Sandys (1990) are quantitative in nature and report findings in terms of the statistical significance of the differences between study groups or the correlational relationships between burden and a variety of variables. Significant findings have been found with respect to the frequency of family visits (Zarit, Reever & Bach-Peterson, 1980) and the adequacy

of support received from the family (Scott, Roberto & Hutton, 1986) for caregivers of Alzheimer's disease and other dementia dependents. In the respective studies, lower burden scores were associated with more family visits and the perception of receiving "enough" (as opposed to too much or not enough) support from the family. Physical health of the caregiver has been shown to have a positive correlation to caregiver burden according to Morycz (1985) and Pratt, Schmall, Wright & Clelland (1985), but not according to Colerick and George (1986). Other caregiver characteristics such as income and educational level do not appear to be significantly related to burden (Pratt et al., 1985), while the findings regarding age and sex have been inconclusive due to significant and insignificant results among research examining these variables (Pratt et al., 1985; Fitting, Rabins, Lucas & Eastham, 1986; Zarit, Todd & Zarit, 1986). Price and Levy (1990) compared spousal and adult children caregivers of person's with Alzheimer's disease and found no significant differences between the experiences of burden for both groups. Harper and Lund (1990) however, did find significant differences between the influences of burden for wives as opposed to daughters as caregivers in their study. Even support group participation has not been conclusively linked with lower burden scores. Kahan, Kemp, Staples and Brummel-Smith (1985) did not find a relationship between membership in a support group and lower burden while Pratt et al. (1985) and Barnes, Raskind, Scott & Murphy (1981) did find a significant relationship. Price and Levy (1990) suggest that more research will be necessary "to validate the outcome of support group participation and burden" (p.

37).

Zarit et al. (1986) found a significant positive relationship between burden and the presence of troublesome and frequent memory and behaviour problems in the care recipient. This was in contrast to the findings of an earlier study by Zarit et al. (1980). Severity of illness has also been associated with higher burden in Fitting et al.'s (1986) study. Demand and dependency problems of cognitively impaired individuals are significantly related to burden according to Gilleard, Boyd & Watt (1982).

Residence of the caregiver with the victim of a dementing illness was found to create more burden in studies by Gilhooly (1984), Fitting et al. (1986) and George and Gwynther (1986) but not in the case of Pratt et al. (1985). Residence with the care recipient refers to the living arrangements of the caregiver and care recipient. A discrepancy is made between co-residence of the caregiver and care recipient and living apart from one another (Price & Levy, 1990). The quality of premorbid relationships between caregivers and care recipients has also been compared with the level of reported burden. The term "premorbid" refers to the time prior to disease onset or before dementia symptoms started (Price & Levy, 1991). Poorer quality of premorbid relationships was related to greater burden according to the researchers (George & Gwynther, 1986; Gilleard, Belford, Gilleard, Whittick & Gledhill, 1984; Gilleard, Gilleard, Gledhill & Whittick, 1984 and Zarit & Zarit, 1984).

Table 4 summarizes the findings of selected studies reviewed by Dillehay

and Sandys (1990). Caregiver burden was the dependent or measured variable in these studies. Findings are provided regarding the presence or absence of a significant statistical relationship between the variables listed and caregiver burden.

Table 4 : Studies of Caregiver Burden Relating to Dementia

LEGEND S = SIGNIFICANT NS =NOT SIGNIFICANT	Zarit et al. (1980)	Barnes et al. (1981)	Gilleard et al. (1982)	Gilhooly (1984)	Zarit & Zarit (1984)	Pratt et al. (1985)	Morycz (1985)	Kahan et al. (1985)	Colerick & George (1986)	Scott et al. (1986)	George & Gwynther (1986)	Fitting et al. (1986)	Zarit et al. (1986)
Degree of Cognitive Impairment	NS											S	
Memory/Behavior Problems	NS												S
Functional Abilities	NS												
Duration of Illness	NS												
Demand / Dependency Problems			S										
Perceived support from the family										S			
Sex						NS						S	S
Age						NS							
Income						NS							
Education Level						NS							
Membership in support groups		S				S		NS					
Physical health						S	S		NS				
Coping strategies						S							
Frequency of visits	S												
Social supports					NS	NS		NS					
Individual counselling					S								
Quality of premorbid relationship					S						S		
Residence together				S		NS					S	S	

Based on fingings compiled by Lillehay and Sandys (1990)

A quick glance at the preceding table reveals that for the findings of the various studies on caregiver burden for caregivers of demented individuals, there has been little agreement as to which factors have been related and which have not been associated with burden. Part of the inconsistency may be attributed to methodological limitations. One limitation is how burden is measured. Novak and Guest (1989) state that measures such as the Burden Interview by Zarit and Zarit (1983), are unidimensional and provide only an overall score for burden. These authors developed the multidimensional Caregiver Burden Inventory (CBI), a 24-item questionnaire which includes five subscales. This is a diagnostic tool for professionals. It does not rely on a single, summary score for burden. The dimensions of burden measured by the CBI include:

1) Time-dependence

2) Developmental burden

3) Physical burden

4) Social burden

5) Emotional burden

Application of the CBI results in an individualized Caregiver Burden Profile or CBP (Novak & Guest, 1989). To clarify, Novak and Guest (1989) include time-dependence, which refers to restrictions placed on the caregiver's time as a result of providing care to a family member with dementia. Another dimension which has not been commonly found in the burden literature is developmental burden. This refers to "the caregivers' feelings of being 'off-time' in their development with

respect to their peers," who are not caregivers and are enjoying their lives as expected, without missing out on anything (Novak & Guest, 1989, p. 800).

In this study, a sample of 107 caregivers of individuals with Alzheimer's disease, senile dementia or organic brain syndrome from Manitoba were administered the CBI. Several patterns emerged. In comparing two different caregiver burden profiles with the same total score, there are significant differences between each of the individual dimensions of the two profiles and subsequently, different patterns of burden for the caregivers. Another evaluation of the CBI by Novak and Guest (1989) reveals that: caregivers of individuals in institutions versus the community report less burden in four out of five dimensions; nonspouse caregivers versus spousal caregivers report less burden on all dimensions of the CBI; nonspouse caregivers with a care receiver in an institution describe the least burden on all dimensions and spousal caregivers with a care receiver in their own home report the highest burden on all but one dimension (Novak & Guest, 1989). The majority of the studies reviewed in the previous section, which address the caregiver burden issue, utilize the older "Burden Interview" assessment tool (Dillehay & Sandys, 1990; Price & Levy, 1990).

Price and Levy (1990) also observe that small sample size, diagnosis of Alzheimer's disease versus other dementing illnesses and discrepancies in the residence of the caregiver (with or without the care receiver) have made generalizations and the identification of the needs of caregivers difficult. Dillehay and Sandys (1990) identify the lack of a standard usage of the term "caregiver" as

a serious limitation of the existing research. Barer and Johnson's (1990) critique of the caregiving literature also recognizes this problem of multiple definitions of "caregiver" as well as sample bias in selecting groups of caregivers from self-help and support groups.

As with the research on special care units, the research on caregiver burden for caregivers of demented individuals must receive attention with regard to the methodological issues identified, in order to produce more valid, generalizable findings. The following section addresses the issue of long term care placement for individuals with Alzheimer's disease and other forms of dementia.

The Placement Decision

When does caregiving at home become too much for the caregiver? Often referred to as "the last resort," long term care placement can be perceived by family caregivers as admitting failure to manage things at home (Abraham, Onega, Chalifoux & Maes, 1994). An earlier study by Morycz (1985) concluded that high burden is an important factor in determining the desire to institutionalize. As well, the onset of disturbing behaviours by the care receiver is related to the caregiver's desire to institutionalize his/her relative with dementia (Chenoweth & Spencer, 1986).

More recently, Cohen, Gold, Shulman, Wortley, McDonald and Wargon (1993) conducted a longitudinal study of 196 caregiver/care receiver dyads to predict the variables which determine the decision to institutionalize dementing

individuals. They measured a range of variables including: care receiver age, MMSE score of the care recipient (an evaluation of cognitive functioning) and the presence or absence of troublesome behaviours (paranoia, aggression, wandering, incontinence) in the care recipient; the caregiver variables included: gender, age, duration of caregiving, the type and extent of assistance provided for ADL's, those aspects of caregiving that were enjoyed, the number and frequency of community services utilized, the number of additional caregivers involved, the type and frequency of current recreational activities caregivers were involved in, the general health, the subjective perception of patient memory and behaviour problems, burden (measured with The Burden Interview), the quality of prior relationship with care receiver and the satisfaction with and extent of social support (Cohen et al., 1993). Those caregivers who decided to institutionalize reported the following: using community services more frequently, less enjoyment of caregiving, higher levels of burden, worse overall health, appraising dependents as having more memory and behaviour problems and reacting more negatively to these problems and having dependents who had been given a psychiatric rating of more troublesome behaviours than those caregivers who wished to maintain the care receiver at home (Cohen et al., 1993). Other important findings included that non-spouses and those whose care recipients exhibited aggressive behaviours or incontinence were more likely to decide to institutionalize than spouses and those whose care recipient did not exhibit troublesome behaviours (Cohen et al., 1993). The researchers compared those caregivers who wished to maintain the care

receiver at home and those who wished to institutionalize. This comparison was based on several variables: use of services, enjoyment of caregiving, caregiver burden, health, caregiver rating of memory and behaviour problems, caregiver reaction to memory and behaviour problems and the presence of troublesome behaviours. Desire to institutionalize was associated with significantly higher use of services, perceived burden, care recipient behaviours and memory problems and caregivers' reactions to these problems and significantly lower enjoyment of caregiving and poorer health (Cohen et al., 1993). There was also a trend for female caregivers to actually place their dependent more often than male caregivers (Cohen et al., 1993).

Cohen et al.'s (1993) study also analyzed factors which were the actual predictors of placement compared to those which predicted only the decision to institutionalize. The predictors of actual placement were: high caregiver burden, poor caregiver health, more frequent use of community services, lower MMSE scores for the care receiver, more troublesome behaviours present and more negative reactions by the caregiver to the behavioral problems of the care receiver (Cohen et al., 1993).

As the research on caregiver burden relates, caring for a relative with dementia at home can have devastating effects on the caregiver's health, relationships and lifestyle. Sometimes, the burden becomes too much to endure and institutionalization becomes a necessary, but unpleasant option to consider. What happens to the caregiver after institutionalization occurs? Is the burden

alleviated for the caregiver once the dependent adult enters the nursing home? These questions are explored in the next section.

The Caregiver's Experience of Burden Following Institutionalization

"Nursing home placement may present the most difficult crisis of caregiving" (Kuhn, 1990, p. 456). Few studies have explored what happens when caregivers experience the institutionalization of their cognitively impaired relatives (Morgan & Zimmerman, 1990; Stevens, Walsh & Baldwin, 1993; Rosenthal & Dawson, 1991). As mentioned in the previous section, however, some studies are exploring the predictors of placing a relative with dementia in a long-term care facility (Cohen et al., 1993; Chenoweth & Spencer, 1986; Morycz, 1985).

Some of the research on the effects of institutionalization of relatives on family caregivers suggests that, even after placement occurs, caregivers experience a great deal of stress as they engage in "invisible caregiving" (Wilson, 1989, p. 94; Stevens, Kinney & Ogrocki, 1991). Although the daily responsibility for caregiving has been relinquished with placement, stressors of "financial concerns, guilt, ambivalence about the decision, feelings of loss of control and a lack of self-confidence in problem-solving abilities" still exist (Stevens, Walsh & Baldwin, 1993, p. 351). Zarit and Whitlatch (1992) explore the consequences of institutionalization for family caregivers of relatives with dementia. Their findings suggest that caregivers experienced relief in terms of the time devoted to the continuous "hands on" care provided before placement. However, the caregivers

do not report improved overall well-being following placement because of other continuing stressors of finding a facility and moving from facility to facility (Zarit & Whitlatch, 1992). The results of this study suggest that "the careers of caregivers do not stop at the institution's door, but continue in an altered and still stressful way" (p. 672).

In Matthieson's (1986) study, daughter caregivers experience guilt and grief related to a role change following institutionalization of their mothers. Another study found that daughters perceive themselves as being excluded from participation in their parent's care planning after admission as well as feeling ambivalence, lack of control and ethical dilemmas over some of their decisions (Johnson, 1990). Barber (1993), Pratt, Wright and Schmall (1987) and Stephens, Kinney and Ogrocki (1991) compared caregivers of dementia patients both in-home and in institutions and found that spousal caregivers of institutionalized partners experience negative impacts of caregiving similar to in-home caregivers. Rosenthal and Dawson (1991) conceptualized the period after institutionalization for spouses as "quasi-widowhood" - a life course transition when a spouse enters long-term care. Their study found many similarities of the spouse's experiences to those of actual widowhood: elevated levels of depression, decreases in perceived health, crisis, grief, loneliness, relief and ambivalence (Rosenthal & Dawson, 1991). Morgan and Zimmerman (1990) conducted a qualitative study of spouses of institutionalized AD men and women to look at needs of the caregivers at the time of placement. They found five factors which reduce the stress for the caregivers:

emotional support, control of the situation, acceptability of nursing home, acceptance of situation and permission/command (Morgan & Zimmerman, 1990).

In contrast to these negative effects experienced by families, Smith and Bengston (1979) found the positive themes of "renewed closeness and strengthening of family ties, continuation of closeness and discovery of new love and affection" (p. 438). In addition, Cohen, Gold, Shulman & Zucchero (1994) report that positive aspects such as the company of the care receiver, keeping the care receiver at home and a sense of duty and love were correlated with lower burden scores, better health and fewer negative reactions to care receiver problems. What about the experience of families with relatives who have a dementing illness? Are their experiences similar? From Chenoweth and Spencer's (1986) study there are reports that the majority of families are pleased with the care of their relative, but some expressed frustration with nursing home transition and the frequency of educating staff about Alzheimer's disease. Unfortunately, these comments about institutional care have been made only in addition to the measured variables and the authors do not report specific findings in this regard. George (1984) also suggests that family caregivers of institutionalized dementia patients often feel a strong sense of continued responsibility after placement. From their review, Stevens, Walsh and Baldwin (1993) suggest that turning over or relinquishing the active caregiver role "does not alleviate stress but rather it continues in relation to new concerns" (p. 353). Barber (1993) agrees noting that "stresses often continue and may in fact even be exacerbated after

institutionalization" (p. 29). This study examines the specific experience associated with SCU institutionalization and the experiences of family caregivers.

Purpose of the Study

Current research on SCU's suggests conducting more studies with the input of other stakeholders, such as family caregivers. Recent studies on the caregiver's experience of institutionalization are very limited in number and do not explore the impact of SCU's on the family caregiver. Therefore, this researcher decided to conduct a study which explores the experience of the family caregiver with respect to SCU placement.

For social workers and other health care providers in SCU settings it is important to understand the dynamics, processes and impacts of the SCU admission and post-placement phases for family caregivers in order to establish practice guidelines for providing support, information or assistance. This is one of the main components of the social worker's job description in special care unit settings and in long-term care settings in general (Patchner & Patchner, 1991; Rabins et al., 1990; Walker & Marchand, 1990). Information that this study and other similar studies provides will give direction to practitioners in how, what, when, where, why and to whom they give support.

This research will also add to current knowledge about how family caregivers perceive a particular SCU and what their experiences have been since the admission of their family member. Also, the qualitative nature of the study will

provide rich, detailed descriptions of family experiences which are otherwise difficult to obtain in large-scale quantitative research. Staff members' understanding of the family's experience will also be explored to gain an additional perspective of the family caregiver's experience. Exploratory studies, such as this one, can lay the foundation for future investigation into caregiver experiences and the effects of special care units on family caregivers.

Summary

This literature review revealed a limited number of studies in the area of special care units. The research that has been conducted focusses on the effectiveness of specialized dementia care versus traditional nursing home environments. Despite the growing support of anecdotal accounts of the benefits of SCU's, empirical research has not been able to show, consistently, that SCU's have necessarily been effective environments for individuals with dementia. The inconsistent findings of these studies may be attributed to the quasi-experimental nature of the research designs utilized. Perhaps researchers need to pay closer attention to other changes which have not been detected by quantitative measures. Perhaps a clinically significant standard needs to be established for this research, as opposed to a statistically significant standard for assessing effectiveness of special care units.

A massive body of literature is devoted to the understanding of caregiver

burden. In the past decade, more attention has been given to caregiver burden related to caring for an individual with a dementing illness such as Alzheimer's Disease. This has lead to an interest in the predictors of long term care placement and the subsequent experiences of family caregivers who have placed a relative with dementia in a continuing care facility. At this point, researchers conclude that stress is not necessarily alleviated for family caregivers who institutionalize their relatives. This researcher is interested in what the experiences are for caregivers of long term care residents with dementia, specifically, those residents who reside on a SCU. No studies, to date, have explored this specific area. The questions explored in this study are:

What are the experiences of primary family caregivers following the admission of their demented family member to a dementia special care unit in a long term care facility?

How do staff members working on a special care unit perceive the family's experience following admission?

The next chapter presents the methods utilized in this exploratory study.

Chapter Three

Methodology

This chapter provides a detailed description of the methods utilized in conducting this qualitative study of family caregivers of residents on Unit 300 at The Beverly Centre for Long Term Care. The topics covered include: rationale for selecting the qualitative approach; methodology; the researcher's point of view; selection of the research site; context of the study; selection of the sample; data collection; data analysis; trustworthiness of the data and ethical considerations.

Rationale for Selecting Qualitative Methodology

Marshall and Rossman (1989) state the importance for justifying the researcher's choice of the utilization of qualitative methods. Of particular relevance to this researcher's investigation are: 1) that qualitative studies should be undertaken when the research "delves in depth into complexities and processes" and, 2) when "relevant variables have yet to be identified" (Marshall & Rossman, 1989, p. 46). "Qualitative methods can be used to uncover the nature of people's actions and experiences and perspectives which are as yet little known in the world of research products" (Glaser, 1992, p. 12). Since very little research has examined the experiences of family caregivers after the institutionalization of a relative to a SCU, it is necessary to explore how caregivers "define the situation in which they find themselves" (Marshall & Rossman, 1989, p. 46).

<u>Methodology</u>

The methodology selected for this study is grounded theory methodology.

The following quote captures the essence of this method of research.

> "The grounded theory approach is a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon. The findings constitute a theoretical formulation of the reality under investigation..." (Strauss & Corbin, 1990, p. 24).

In this thesis, the researcher endeavoured to generate hypotheses which are grounded in the experiences of family caregivers of SCU residents. In grounded theory methodology, the researcher "begins with an area of study and what is relevant to that area is allowed to emerge" (Strauss & Corbin, 1990, p. 23). This is an appropriate choice of methodology since limited research exists with respect to what is relevant to the family caregiver's experience of placing a relative in a nursing home, not to mention placement on a SCU. Compared to other qualitative methodologies, the grounded theory method has the best "fit" for the research questions asked. Grounded theory possesses the properties of a general method that has not been "bound by either discipline or data collection" (Glaser, 1992, p. 18). With grounded theory, the researcher is able to account for a variety of different experiences of family caregivers with a few major categories. The constant comparing of incidents to one another, coding the incidents and generating categories to encompass the variety of incidents can be laborious. The result, however, is the opportunity to generate other relevant research questions for future exploration, which is meaningful and representative of the experiences

of those caregivers under study.

Grounded theory methodology refers to elaboration and modification of existing (grounded) theories that are appropriate to the area of investigation "as incoming data are meticulously played against them" (Strauss & Corbin, 1994, p.273). In this study, family caregivers were asked to describe their own experiences (emotions, reactions and behaviours) following the placement of their relative on a SCU. The interview questions are derived from the literature on related studies of caregiver experiences (physical, emotional, and social burden). These interviews were transcribed to enable the researcher to systematically analyze the data in depth. Through the coding of incidents in the data, the researcher identified various categories and themes which emerged from the data. The constant comparative method (Glaser, 1992) of coding the data, which is described in further detail under the section "Data Analysis," was utilized.

Researcher's Point of View

The issue of personal bias and objectivity in qualitative research is frequently mentioned in the literature (Berg, 1989; Marshall & Rossman, 1989; Patton, 1990). This researcher had been employed with The Beverly Centre for Long Term Care for approximately three months prior to the beginning of the data collection process. As an employee of the Beverly Centre, the experiences of Unit 300 family caregivers are extremely important to understanding the role of the social worker in this environment. While this may have presented a threat to the

neutrality of the situation, the researcher did find herself in rather special circumstances which helped to prevent any preconceived notions or expectations from the study. As a relatively new employee of the Beverly Centre, this researcher had not yet developed close relationships with family caregivers of Unit 300 residents. A benefit of being in this position was that it enabled the researcher to have time to learn about the programs and identify staff members who would be considered "gatekeepers." Gatekeepers are those individuals who provide the researcher with assistance in gaining entry to study the phenomena of the caregiver experience on the Unit 300. Therefore, this researcher might have been considered to be both an insider and an outsider at the same time. A benefit of being an outsider is that it precluded the researcher from having extensive knowledge regarding what the family caregivers of Unit 300 residents actually experience.

Patton (1990) recognized the difficulties of attaining neutrality in qualitative studies. It is required that researchers "carefully reflect on, deal with and report potential sources of bias and error" (Patton, 1990, p. 56). This researcher's commitment to the facility as an employee may be viewed as one potential source of bias as it was necessary to change "hats" (researcher versus social worker) at various times during the study. During the process of the interviewing, this researcher needed to be aware of the caregivers' reactions and how they managed the stress they were experiencing, if any. From the "social worker's" point of view, it was necessary to follow up with anything that was viewed as

difficult to cope with for the caregiver.

While neutrality is an extremely important aspect of research, one should not lean towards detachment. Quality and credibility of the data may also be enhanced by the personal qualities of the researcher. Strauss and Corbin (1990) and Glaser (1992) have referred to this as "theoretical sensitivity." One source of theoretical sensitivity for this researcher was professional experience. In this instance, the researcher possessed the experience of working on a one to one basis with cognitively impaired residents and their families as a personal care aide in a long term care facility. Prior to this study, the researcher also had eight months of experience working with families of residents with dementia as a social work practicum student. These experiences increased this researcher's sensitivity to the issues presented by study participants. At the same time, there needed to be awareness of selective perception and personal bias. Periodic distancing from the data collection and analysis process was helpful in increasing this researcher's awareness of such bias.

Selection of the Research Site

The opportunity to work on a part-time basis in a long term care facility happened while this researcher was preparing for the data collection phase of the study. The Beverly Centre was eventually chosen as the research site based on the fact that the facility housed a recently established special care unit and have staff and administration personnel who were supportive to this researcher's

proposal. The staff of the Beverly Centre viewed this study as being valuable to future programming for the SCU and the facility as a whole. The findings would also be beneficial from a social work perspective. As the social worker for the facility, working with the residents, families and staff of Unit 300 is a significant portion of this worker's caseload. Conducting the study in this environment allowed this worker to gain some insight into the family caregiver's experience of having a relative on a special care unit. This insight is advantageous to a social worker who will continue to work in the same environment and assist staff to develop programs which are beneficial to family caregivers.

In September 1994, consent was obtained from the Executive Director of the Beverly Centre for Long Term Care, to proceed with interviewing family caregivers of Unit 300 (Special Care Unit) residents. Unit 300 is a 36-bed, secured environment developed especially for residents with a cognitive impairment, who display various behaviours which make them appropriate residents for a secured, specialized environment.

Context of the Study

Development of Unit 300

Unit 300 was established in December 1993 following the increasing numbers of residents admitted to the Beverly Centre with a diagnosis of dementia. Approximately 80% of the Beverly Centre's residents have varying degrees of dementia (Cornick, 1993). The resultant problems of wandering, inappropriate

elimination, aggressive behaviour, hoarding, rummaging and elopement began to increase with the growing population. Prior to the establishment of Unit 300, residents with these behavioral problems presented a management concern in the overall nursing home setting. Therefore, Unit 300 was established to meet the needs of these residents, the needs of other residents in the Beverly Centre and the needs of staff of the facility.

In December 1993, residents were admitted to Unit 300 if they met one or more of the following criteria:

1) A diagnosis of dementia.

2) Presence of predictable behaviour - i.e. wandering, agitation, combative with lack of response to behaviour management.

3) Inability to maintain social norms - i.e. inappropriate elimination habits, inability to respond to normal social stimuli.

4) Ability to benefit from the program.

5) Ambulatory, self or in wheelchair.

6) Pre-admission visit by unit personnel.

(Cornick, 1993)

Once admitted to the unit, residents are assessed in the following ways: administration of the MMSE to assess language, motor skills, orientation and memory; medication review; administration of the FAST to identify the functional losses characteristic of a dementia of the Alzheimer's type. A copy of the FAST can be found in Appendix I.

While the resident is oriented to the unit, nursing staff develop a care plan which outlines the resident's abilities in terms of activities of daily living and coping behaviours. Recreational staff complete a history and use the trial and error method in devising an activity schedule which is appropriate for the resident. The physiotherapist conducts an assessment and is periodically consulted to attend to concerns of ambulation and posture. A social work assessment is conducted on all new residents. The family caregivers are invited to meet with the social worker in order to share information for the resident's social history, receive support/education/assistance and determine the need for future social work intervention.

A monthly family support group exists for family members of Unit 300 residents. The support group is co-facilitated by the Administrator, Director of Care and Social Worker, to provide education and support for families who wish to attend.

Eventually, as their disease progresses, residents will no longer benefit from the specialized care provided on the unit. The following criteria have been developed to assist staff with the evaluation of when to discharge a resident from the program.

1) Residents who are physically too ill to remain on the unit.

2) Behaviours are too disruptive to be managed on the unit.

3) The resident is non-ambulatory.

4) The resident no longer benefits from the program.

(Cornick, 1993)

Admission and discharge criteria are regularly evaluated to determine the appropriateness of the criteria for the unit. The next section describes the philosophy, environment, staffing and programs of Unit 300 as they existed at the time of this study.

Description of Unit 300

Philosophy

The underlying philosophy of Unit 300 is the belief that "cognitively impaired residents should be treated as normal functioning adults [with] dignity and respect" (Cornick, 1993, p. 2). Stated in this philosophy are the expectations that aggressive, agitated and resistive behaviours will be encountered in the day to day living of residents on the unit and are forms of communication for the resident. As well, various forms of physical contact, including touching, holding and hugging between residents and staff, family and friends and repetitive behaviours such as wandering will be acceptable provided they do not cause harm to those involved (Cornick, 1993).

A multidisciplinary team of staff members developed the goals and objectives of Unit 300. This team consisted of: the Administrator, Director of Care, staff nurses, licensed practical nurses, personal care aides, Physiotherapist,

Recreation Therapists, Registered Dietician, Occupational Therapist and the Inservice Education Coordinator. As Unit 300 undergoes evaluation and modification, the goals and objectives may need to be modified with the changing needs of the residents on the unit. Table 5 outlines the Goals and Objectives established for Unit 300 at the time of this study.

Table 5 : Unit 300 Objectives and Program Goals

PROGRAM OBJECTIVES	PROGRAM GOALS
1. Provide a better quality of life within the institutional setting.	1. Care will be individualized, utilizing strengths to build upon quality of life and compensate for deficiencies.
2. Create an environment where staff, families and friends can aid the resident in maintaining a meaningful dignified lifestyle.	2. To prevent excess disability due to other health problems or medication.
3. Provide a secure area where residents have the freedom to wander indoors and out without danger to themselves or others.	3. To use as few psychotropic medications as possible and use few if any physical restraints (i.e. geri-chair).
4. Provide a calm, peaceful, comfortable living area: -No overhead pages -No call bells ringing -Reduced phone volume -Enhanced, comfortable furniture	4. To enhance remaining function rather than to restore function lost through the disease process.
5. Provide an environment that recognizes residents remaining strengths and capabilities and promotes the use of same.	5. To reduce long hours of idleness. 6. To use activities and a caregiving style that enhance resident comprehension of appropriate roles as friend, parent and volunteer and that reinforce a sense of person and dignity.
6. Provide a supportive environment responsive to human needs: -Conducive to interacting with resident on 1:1 basis or in small groups -Recognition of contributions made to residents by families, friends and community -Prevent harassment by cognitively well residents caused by inappropriate behaviour	7. To create a home-like environment in which residents are able to continue with desired lifestyles and routine. 8. To use a mixture of flexibility, creativity and both structured and non-structured approaches of activities.
7. Create a personal milieu that encourages autonomy and promotes individuality, dignity and self esteem.	9. To emphasize the importance of respect for residents and to individualize approaches. 10. To recognize the importance of a non-stressful, supportive environment. Provide a manageable level of sensory stimulation. 11. To support the family in a continuing relationship with the resident.
(Cornick, 1993)	12. To act as a role model and educator for other facilities.

Environment

Unit 300 is a 36-bed, secured setting with six private and 15 semi-private resident rooms. A door security system allows all persons, except unit residents, to enter and exit the unit freely (Cornick, 1993). "There is a wandering pathway indoors and out which allows residents to walk at will" (p.3). See Appendix H for a diagram of Unit 300.

There is a dining area with adjoining kitchen to be utilized by residents during meals and various other activities. A lounge area with piano and television is situated beside the dining area for residents to relax and enjoy music. This lounge has a skylight to give a bright freshness to the room. Additionally there is a double room which stands as a second lounge area for small groups of residents. This is located in the middle of the central corridor as opposed to the end of the hall. Carpeting and reduced background noises from people, machines, audiovisuals and overhead paging systems are implemented to provide a "calm, peaceful living space [to] minimize stress" (Cornick, 1993, p. 3). Comfortable chairs and small tables are situated at various points along the corridor pathway to cue residents to sit and rest if they wish. The decor is calming and provides an atmosphere of serenity. Resident rooms are designated by name plates for each resident. Bathrooms on the units have the special feature of dark coloured flooring so that residents can differentiate the white toilets and sinks. The temperature on the unit is slightly warmer than other areas of the facility as residents with dementia often feel cold. Integral to the environment of Unit 300 are the staff

members who care for residents on the unit.

Staff

Staffing for Unit 300 is based on the Case Mix Index (CMI), which refers to the number of hours of nursing care calculated per resident, per day. Classification is the process by which each resident is given a rating as to what level of nursing care is required in the areas of activities of daily living (ADL's), behaviours of daily living (BDL's) and continuing care level (CCL). See Appendix K for definitions of ADL, BDL and CCL. The resultant level is calculated based on all three areas of care. Levels of care range from A to G; A represents the lowest nursing care required and G represents the highest level of care required. In 1994, Unit 300 residents were found to range from level C to level G: 3 level C, 4 level D, 17 level E, 8 level F and 4 level G. The levels of residents on Unit 300 were combined with those of other units in the facility to calculate the CMI for the Beverly Centre. This process of classification occurs on an annual basis. At the time of this study, nursing staff at the Beverly Centre participated in the training which would enable them to conduct the classification of the residents. In the future, classification will be conducted by facility staff, as opposed to Alberta Health, who has been responsible for classification in the past.

Unit 300 currently staffs one Registered Psychiatric Nurse (RPN) or Registered Nurse (RN) for each day and evening shift. On the night shift the RN is shared with one other unit in the facility. One Licensed Practical Nurse (LPN)

works on each day, evening and night shift. Three Personal Care Aides (PCA) work on the day and evening shifts and one PCA works at night. In a 24 hour rotation, there are 2.5 RPN/RN's, three LPN's and seven PCA's on Unit 300 (Cornick, 1993).

One recreation staff member works on the unit per day and evening shift as well as for a period of time on the weekends. Physiotherapy and social work are available on a consulting basis at present. The optimal ratio of staff to residents has not yet been established for Unit 300. Volunteers and companions augment the ratio during a variety of program hours.

In recruiting staff, the Beverly Centre has paid special attention to the qualities that are believed to be beneficial for the SCU and it's residents. Of primary importance is an interest in working with the cognitively impaired resident. Other characteristics which are desirable in Unit 300 staff include: commitment to the philosophy of care; flexibility and resilience; patience, understanding and compassion; motivation; common sense, ability to learn and willingness to expand personal value system; people oriented versus task oriented approach; effective communication skills; sense of confidence; sense of humour; ability to derive satisfaction and reward from small achievements; willingness to continue to learn and experiment; a sense of comfort with one's own aging process; ability to draw upon innate skills of observation and report nuances of change and authoritarianism (Cornick, 1993).

An educational component and ongoing support for staff is provided to

facilitate the unit's success. The educational program consists of a ten part series of inservices covering topics such as: the philosophies of the unit, program description, staging of behaviours, behavioral mapping, team work and the roles of each department. This is mandatory for all staff working on the unit, from casual relief to full-time staff including nursing, recreation, food services and housekeeping personnel. Volunteers are also encouraged to participate in the inservices.

Programming

"Programming" refers to all activities which occur on Unit 300, 24 hours each day, 7 days a week (Cornick, 1993). Reflecting the philosophy of Unit 300, programming for the residents must be consistent so as not to produce undue stress. Every single activity including dressing, bathing, eating and exercise is considered in the daily programming. A flexible, monitored, daily care plan is designed for each resident to assist the individual in achieving full potential with respect to : 1) Activities of daily living, 2) Physical exercise and 3) Cognitive stimulation.

Activities of daily living (ADL's) include: bathing, dressing, mobility and transferring, toileting and eating (see Appendix K). While each of these activities is a program in itself, specialized programs to highlight these skills include "Powder Puff" which is a manicure and make-up program for ladies and "Walk 'N Talk" which is an outing where residents have coffee at a restaurant nearby. Physical Exercise activities give residents an opportunity to engage in stretching and

movement. These are offered in small groups twice per week. One to one activities include dancing, going for walks, shovelling snow and raking leaves. Cognitive stimulation programs involve residents in reminiscing, current events, singing and games of knowledge testing. "Teacher's Quiz, Fact File and Music Appreciation" are examples of programs which are cognitively stimulating to residents. In all aspects of daily programming for the residents of Unit 300, "normalization" is something which staff strive to achieve. A list of the other types of programming and the daily schedules, based on nursing routines with Unit 300 residents can be found in Appendix J.

Selection of the Sample

Purposive sampling was utilized to select caregivers to participate in the study. The logic behind this method of sampling "lies in selecting information-rich cases for study in depth" in order to learn about "issues of central importance to the purpose of the research" (Patton, 1990, p. 169). This researcher selected family caregiver participants based on whether they were a spouse of the resident or an adult child. For simplicity, other relatives, such as nieces and nephews or friends of the family were not considered in the selection of study participants. This form of sampling is referred to as combination or mixed purposeful sampling (Patton, 1990). This researcher was interested in learning about the experiences of both spouses and adult children and sampling both populations allowed for a variety in the sample and a variety of experiences to draw from.

Family caregivers who attended the Family Support Group for Unit 300 residents were identified as possible participants in the study. Subsequent consultation with a Unit 300 staff member assisted the researcher to identify prospective subjects who would be willing to participate. Since only family members who attended the support group were invited to participate, this presented a source of bias in that other family caregivers were not considered. However, the reasoning behind this method of sampling is to select participants who will be comfortable with discussing their experiences. Family caregivers who attended the group demonstrated a degree of comfort in discussing their experiences. These caregivers also had the opportunity to meet this researcher, as a social worker, for the first time, and hear about her role at the Beverly Centre. In this way prospective participants would be able to recall meeting this researcher when they were invited to participate in the study.

No other qualities of the participants were considered in the selection process. Telephone contacts were made with seven family caregivers. Consent to participate in an interview was obtained from three spousal caregivers and three adult child family caregivers.

Process of Obtaining Consent

Family caregivers were identified at the Family Support Group, a group co-facilitated by the Administrator, the Director of Care and the Social Worker. The purpose of the group was to give family members of Unit 300 residents an

opportunity to meet together to discuss issues of concern. Prior to this writer's employment, group discussions focussed on Unit programming, staff, and time was allowed for families to share difficult experiences related to their family member with dementia. There had been no prior professional (social worker-client) relationships with any of the family caregivers before the study. Consultation with a Unit 300 Registered Nurse aided this researcher in the selection of family members who might be willing to participate in the study.

The caregivers were initially contacted by telephone. After a brief explanation of the purpose of the study and the methods of data collection was given, this researcher invited the prospective participant to an interview. Of the seven family members invited, six agreed to participate in a one to one and a half hour individual interview.

At the time of the interview, participants were asked to read over the consent letter and ask any questions to clarify their understanding. Participants were then asked to sign the consent form. All participants that came for interviews gave their consent to continue with the interview. A copy of the consent letter and form for the caregiver participant's is found in Appendix A.

Study Sample: Caregivers

As the literature on caregivers reveals (See Chapter Two), the experiences of caring for a family member with dementia have been associated with characteristics of the care receiver or in this case, the Unit 300 resident. This

description of the study sample of caregivers includes information about the respective Unit 300 resident which may be associated with caregiver burden.

Six family caregivers participated in this exploratory study. Three participants are spouses (wives) and the other three are adult children (two daughters and one son) of Unit 300 residents. Two of the spousal caregivers are age 81 and one is age 80; two of these caregivers are in fair physical health while one spouse is coping with a serious ailment. These spouses have cared for their husbands for a length of time ranging from four to fifteen years since the onset of dementia.

The adult children range in age from 37 to 56 years and are all married with children. The time spent in the caregiving role for these participants ranges from four to nine years.

Visitation schedules vary from caregiver to caregiver and range from visiting on a daily basis to once every three months. Table 6 describes the caregiver resident dyads and is presented to assist in the understanding of each caregiver's experience.

Table 6 : Caregiver/Resident Dyads

	Caregiver	Resident
#1	- Adult child - Age 37 - 4 years in caregiver role - employed part-time - short visits with resident approximately 2 times per week	- Age 65 - lived in apartment before initial admission to facility - 8 months on Unit 300 - diagnosis of probable AD - symptoms occurring over last 8 years - Stage 6b
#2	- Adult child - Age 48 - 9 years in caregiving role - does some volunteer work - short visits with resident 2-3 times per week	- Age 82 - lived in seniors apartment prior to initial admission to facility - 11 months on Unit 300 - diagnosis of probable AD - Stage 7a
#3	- Spouse - Age 81 - 4 years in caregiving role - some health problems - visits 2 times per week	- Age 81 - admitted to facility from another SCU - 11 months on Unit 300 - diagnoses of multi-infarct dementia - Stage 6c
#4	- Spouse - Age 80 - 15 years in caregiving role - visits 2-3 times per week for 2-3 hours/visit	- Age 84 - admitted to Unit 300 from an SCU in another facility - 5 months on Unit 300 - diagnoses of probable AD - Stage 6e
#5	- Adult child - Age 56 - 4 years in caregiving role - employed full-time - visits once every 2-3 months	- Age 84 - lived with caregiver prior to admission to facility - 11 months on Unit 300 - diagnosis of probable AD - Stage 6e
#6	- Spouse - Age 81 - poor health - visits daily (short visits)	- Age 83 - lived at home prior to initial admission to facility - 10 months on Unit 300 - diagnosis of probable AD - Stage 6b

The Pilot Interview

A pilot interview was conducted initially to assess the interview schedule and allow for modifications before the other interviews took place. The purpose of this interview was explained and consent was obtained from the pilot participant in the same manner as for other participants in the actual study. Following the pilot interview, feedback was elicited from the participant. The participant expressed a level of comfort with the questions and flow of the interview. During the interview, this researcher felt somewhat uncomfortable with the apparent redundancy of the some of the questions and probing. However, a review of the transcribed interview, revealed that, despite the researcher's feelings about the questioning, the participant was describing different aspects of the same topic. This alerted the researcher that perhaps this line of questioning was beneficial to allow participants to think of other ways of viewing their own circumstances. The discussion with the participant following the pilot interview lead this researcher to assess the interview schedule as effective. Because no modifications were deemed necessary, the pilot interviewee was asked if he/she would give consent to actually participate in the study. Consent was obtained.

Semi-Structured Caregiver Interviews

Subsequent to the first/pilot interview, five family caregivers were interviewed utilizing the original schedule. Each interview seemed to follow a slightly different path. That is, the questioning of each participant was dependent

on the direction the participant chose to follow with each question. In each instance, however, all of the question topics were covered. Questions asked during the interview (see Appendix B) were derived based on a review of the literature on caregiver burden. Topics which emerged from the literature included perceived physical health, emotional well-being, lifestyle disruptions, relationship strains, practical problems, ethical tensions and positive experiences. Another helpful guideline in preparing the interview schedule was a table developed by Carl Bretscher, MSW, which describes the experience of the family as their family member progresses with dementia. This table is a representation of the experiences of family members based on Mr. Bretscher's professional experience in working with families of dementia patients in the United States. A copy of this table is in Appendix E.

Following each interview, the researcher briefly summarized the information obtained with the participants, to ensure that the main points of the discussion were obtained correctly. This was done in an attempt to increase the credibility of the data. This check following the interview was a "period of guaranteeing the quality of the data" (Patton, 1990, p.352).

Interviews were audio-taped, with the participant's permission, to enable the researcher to allow for more attention to be paid to the caregiver during the interview and increase the accuracy of data collection (Patton, 1990). Following the interviews, the tapes were reviewed to ensure that the entire interview had been recorded correctly. Notes were made as the researcher reviewed each interview,

to highlight certain points which required attention during the analysis of the information.

Following the analysis of the data collected in the interviews, the findings were drafted and distributed to each participant in order to perform a validity check of the data. Participants were asked to fill out a form (see Appendix F) which stated whether they agreed with the presentation and interpretation of the findings.

The purpose of the individual caregiver interviews is to provide rich, detailed information about the caregivers' experiences of burden since the admission of their family member to Unit 300. In essence, the information obtained from the interviews allowed the researcher to gain insight and provide possible explanations for answers to the research question. A semi-structured format was utilized to provide the researcher with a guideline in which certain, predetermined topic areas could be covered. However, there was also allowance for digression and probing into the various topics as necessary, with each interviewee (Berg, 1989).

Staff Focus Group

An additional method of data collection occurred in the form of a Unit 300 staff member focus group. A focus group is "an interview with a small group of people on a specific topic {...} where people can consider their own views in the context of the views of others" (Patton, 1990, p. 335). The purpose of conducting a "staff" as opposed to a "family caregiver" focus group was to obtain an alternate perception of the family's experience in an efficient manner. A focus group as

opposed to individual staff interviews was chosen as the option because it was the most cost-effective method of obtaining a number of different staff perceptions in a limited amount of time. This was also one form of increasing the strength of the study through triangulation, "the combination of methodologies in the study of the same phenomena" (Patton, 1991, p. 187). The focus group was also audio-taped and transcribed for analysis purposes.

It was difficult to schedule the staff focus group for a number of reasons. Most staff members were not willing to volunteer their time outside of working hours, which meant finding a time during the shift to conduct the interview. The day shift routine was too busy to take time and staff members away for the interview. Since this researcher wanted at least one hour to conduct the interview, a shift with a natural "break" in the routine was desirable. The night shift was ruled out due to the small numbers and variety of staff available. After discussing this concern with a Unit 300 staff member, a decision was made to hold the group discussion during an evening on Unit 300. This presented a source of bias in that only a select group of staff were available to participate, even though staff from the day shift were also invited. It was decided that the benefits of doing the staff member focus group outweighed the bias concerns. The alternative was to omit the focus group altogether because of time constraints. This would not have been desirable, from a research point of view, as it would have eliminated triangulation in terms of the data collected.

A maximum of sixty minutes was allowed during which the group interview

was conducted. Of seven staff members invited to participate, six agreed and gave their consent. A copy of the staff letter and consent form can be found in Appendix C. Table 7 describes the group composition and the members' experience in long term care.

Table 7 : Unit 300 Staff Member Focus Group - Participant Work Experience

Position Title	Experience in LTC	Experience on SCU
Registered Nurse (part-time)	4.5 years	1 year, 2 months
Licensed Practical Nurse (full-time)	1 year	6 months
Personal Care Aide (full-time)	6 years, 5 months	1 year, 2 months
Personal Care Aide (full-time)	3 years, 4 months	1 year, 2 months
Personal Care Aide (full-time)	2 years, 4 months	1 year, 2 months
Recreation Therapy Aide (full-time)	1 year, 2 months	8 months

Four questions were prepared to be discussed during the focus group. Approximately fifteen minutes was allotted per question so that all questions could be covered in one hour. Each participant was encouraged to discuss each question. An interview schedule for the focus group can be found in Appendix D.

Data Analysis

"Qualitative analysis means any kind of analysis that produces findings or concepts and hypothesis, as in grounded theory, that are not arrived at by statistical methods" (Glaser, 1992, p. 11). The data collected in this study was in the form of transcribed interviews. Once data collection was complete, an enormous amount of information was available for analysis. In order to prevent this researcher from becoming overwhelmed by such a vast amount of data, it was necessary to learn and develop some very critical skills.

According to Glaser (1992), one of the founders of grounded theory methodology, the required skills for doing this method "are to absorb the data as data, to be able to step back or distance oneself from it, and then to abstractly conceptualize the data" (p. 11). Data analysis began with the review and transcription of the audio taped interviews. This initial step allowed the researcher to become familiar with her data. A second review of the transcriptions was necessary to double check for accuracy during the transcription process and make notes along the margins of the transcriptions about points of interest and highlights in the interviews. Once this process was complete and the researcher felt a degree

of comfort with the data, the actual "coding" of the data began.

Constant Comparative Coding Method

The constant comparative method of analysis involves a number of phases. Open coding is the initial stage (Glaser, 1992). The interview data are broken down into incidents, given a code name and compared for similarities and differences to other incidents in the interviews. Categories are developed based on the properties (of categories) indicated by each incident (Glaser, 1992). This process of open coding is finished when no new patterns or properties of categories are evident in the data. This point where no new concepts emerge is referred to as "saturation" of the data (Glaser, 1992).

In this study, saturation occurred fairly early in the analysis process. Several varieties of experiences were discovered from the initial caregiver interviews. The underlying meaning or properties of the incidents soon became clear and it was discovered that although the specifics of the individual experiences differed between caregivers, the effects of the incidents were similar for each caregiver. That is, the meaning for each caregiver was emerging as a similar theme. By the third interview, no new themes or categories of incidents were emerging in terms of caregiver experiences.

The staff member focus group was conducted following the six caregiver interviews. By scheduling the focus group after the caregiver interviews, time was allowed for this researcher to reflect on and distance herself from the caregiver

data before facilitating the staff group. Although there are no rules as to when and how interviews should be scheduled, it was important for this researcher to have a period of time to reflect and consider the questions for the staff focus group. This group was audiotaped, transcribed and analyzed in the same manner as the individual interviews. The focus group provided an alternate method of gathering data (group process) as well as an alternate perception from which to view the research question (staff member perception). This was done to achieve "triangulation" and increase the credibility of the data.

With the data collection complete, this researcher was able to begin the analysis of caregiver experiences and integrate the incidents discovered into categories and themes which emerged from the data. The constant comparative method of incident coding was a challenging process. Throughout this process the researcher needed to step back and distance herself from the data. Glaser (1992) recommends asking the following questions, which assisted this researcher with the analysis and helped to prevent any forcing of the data:

What is this data a study of?

What category or property of what category does this incident indicate?

What is actually happening in the data?

(p. 51).

It was necessary to utilize this neutral questioning in order to get at the relevance and fit of the incidents (Glaser, 1992). Regular distancing from the data was also achieved by discussing the process of analysis with this researcher's advisor.

Repeated questioning and comparing soon lead to the development of categories to describe the experiences of the family caregivers in this study. These themes are described in greater detail in the subsequent chapter on findings. The next section of this chapter discusses the issue of addressing trustworthiness in qualitative research.

Trustworthiness of the Data

Krefting (1990) has noted that too often "qualitative research is evaluated against criteria appropriate to quantitative research and is found to be lacking" (p. 214). Lincoln and Guba (1985) state that the criteria of internal validity, external validity, reliability and objectivity, which are appropriate for evaluating the trustworthiness of quantitative research, are not appropriate means for qualitative data. The purposes of quantitative and qualitative research differ in many ways and therefore it can not be expected that the criteria for assessing the reliability or validity of the research methods can be the same. Therefore, ensuring rigor in qualitative research such as this study means addressing several criteria which are relevant to qualitative research.

Lincoln and Guba (1985) emphasize the criteria against which the trustworthiness of the qualitative research can be evaluated. These criteria which help to establish the truth value, applicability, consistency and neutrality of the qualitative findings in the study include: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). The following paragraphs describe how each

of the criteria was dealt with in this exploratory study.

Credibility

With respect to credibility, the researcher is required "demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described" (Marshall & Rossman, 1989, p. 145). The logical method of assessing the data's credibility in this study was to go back to the data's source. At the end of each caregiver interview and the staff focus group, this researcher recounted the major topics discussed by the participants to ensure that, basically, what the researcher heard was interpreted correctly. In addition to this, copies of the findings were distributed to the study participants for their review. They were asked to read the findings and complete a brief questionnaire which asked if the findings, as presented and interpreted by the researcher, were correct. A copy of this questionnaire can be found in Appendices F and G. These forms of ensuring credibility of the findings are referred to as a validity check which confirms that the presentation of the data is truthful, as opposed to the researcher's perspective of the truth (Patton, 1990).

Another technique which enhanced the credibility of the research was triangulation. Triangulation refers to the "act of bringing more than one source of data to bear on a single point" (Marshall & Rossman, 1989, p. 146). This researcher incorporated triangulation with the use of more than one source of data (caregivers and staff members) and more than one data collection technique

(individual interviews and focus group interview). Consistency was also assessed with respect to what the participants said verbally compared to what was revealed nonverbally. Especially with respect to the theme of loss, caregiver verbal and nonverbal communication was observed to be consistent. During the interviews, credibility was further enhanced by reframing the questions in slightly different ways to ensure that the participants are being consistent throughout the interview and the researcher is interpreting the verbalizations consistently (Krefting, 1991).

Transferability

A second criteria which is addressed in this study is the transferability of the findings. In qualitative research, the nature of the study often makes it almost impossible to generalize the findings to the greater population. For example, there were only six family caregivers and six staff members interviewed in this study. Their descriptions and perceptions are only generalizable to themselves. What is possible in qualitative research, however, is the "extrapolation" of the findings to other similar applications (Patton, 1990). Through detailed descriptions of the theoretical and methodological parameters of this study (provided in Chapter 2 and Chapter 3), other interested researchers who wish to study the phenomenon of caregiver experiences in a similar setting will have sufficient information with which to duplicate the study.

Dependability

Dependability refers to the researcher's "attempt to account for changing conditions in the phenomenon" under study (Marshall & Rossman. 1989, p.146). Three strategies outlined by Krefting (1990) are utilized in this study to increase the consistency of the findings: triangulation (described above), dense description of the data collection, analysis and interpretation of the findings and keeping a reflexive/field journal. Triangulation and dense description were addressed earlier so this researcher will present the importance of keeping a field journal. The field journal was a helpful way for this researcher to organize the steps to be taken throughout the process of the research. In earlier phases of this study, the journal was used to keep notes of methodological decisions such as sample selection, development of the interview questions and the steps taken in the interpretation of the data. In addition, the journal was used to keep track of important resources such as contact persons in various agencies and valuable literature sources. Finally, the journal was used to keep notes on this researcher's personal reflections and reactions to various aspects of the study. This was especially helpful to increase this researcher's awareness of bias during data collection.

Another more in depth technique to ensure dependability is described by Lincoln and Guba (1985) as a dependability audit. Records of data collection and analysis processes were documented by this researcher in a journal. However, the dependability audit would have required that an external auditor evaluate the process and findings of the research (Lincoln & Guba, 1985). This audit would

require more time than could be afforded by this researcher and therefore was not included as a strategy to increase the dependability of the findings.

Confirmability

Finally, confirmability addresses the objectivity of the researcher. in the study. Total objectivity in any research is virtually impossible but steps can be taken to control for various forms of bias in the interpretation of the data. Triangulation, described above, was one method of enhancing confirmability of the interpretation of the family caregivers' experiences. Another was searching for negative cases. This referred to the researcher's search in the data for incidents which deviated from the patterns which were emerging. This was accomplished through frequent distancing from the data and asking questions about the data: "What is this data a study of?" and "What category does this incident belong to?"

The final section of this chapter discusses the ethical issues which were considered in this study. .

Ethical Considerations

The nature of the information to be collected in this study can be viewed as highly sensitive in regard to the family's experience. For this reason, informed consent and confidentiality had to be considered very carefully.

With reference to the consent form (Appendix A), participation in the study was voluntary, giving caregivers and staff the right to withdraw at any time

throughout the process. All participants were provided with a copy of the research findings when the data analysis was complete.

Since staff members discussed only their perceptions of the families' experience of burden, the information was not sensitive to themselves. However, the issue of confidentiality was addressed by having staff sign a form which stated that they would keep confidential, any information that was discussed in the focus group and respect the anonymity of residents and family members discussed. Staff member anonymity was achieved by not associating comments made by staff members with their job titles.

Family members, however, may be viewed as taking a risk in sharing information about their personal experiences of burden. Confidentiality was addressed with family members in the following ways: participant's names were not used in the presentation of the research; identifying information was presented in such a manner as to protect the anonymity of the participants and their family member. That is, family caregivers were not identified by their names or the names of their family members. Audio tapes of the interviews were stored in a safe, secure manner and were destroyed following the completion of the research and persons, other than the researcher, who had access to the data, were identified.

In the event that family members shared information which could not be addressed by this writer during the research interview (i.e. issues not related to the study or issues which evoked an uncomfortable emotional response for the caregiver, that required social work or other staff member intervention), these

concerns were revisited following the research interview and an appointment was scheduled during this social worker's regular hours. Participants were also given permission, both verbally and in the letter, to consult this researcher should any questions or concerns arise that required clarification at any time.

Summary

This chapter describes the methodology utilized to collect and analyze the data on caregiver experiences and staff perceptions of the family caregivers' experiences following admission of relatives to a special care unit. Grounded theory methodology was selected as the most appropriate method with which to guide this study. Individual caregiver interviews and a staff member focus group were the methods of data collection utilized to obtain information about the phenomenon of the family caregiver's experience, a topic which has not received much attention in the research literature to date. Comparative coding methods of analysis allowed this researcher to determine common themes and patterns in the data. These patterns emerged quite quickly, revealing that the point of saturation (no new patterns were forming) had been reached. Finally, the issues of credibility, dependability, transferability and confirmability were addressed by this researcher along with the ethical issues which arose in this study. The following chapter discusses the findings of this study.

Chapter Four

Findings

This study explored the following research questions:

What are the experiences of family caregivers who have placed a relative on a SCU in a long term care facility?

How do staff members of a SCU perceive the family caregivers' experiences of placing a relative on a special care unit?

The findings are organized around the major themes which emerged in the analysis of the audio-taped interviews. Under each theme, excerpts from incidents in the transcripts are presented to illustrate how these themes were identified.

<u>Emerging Themes</u>

This researcher found it extremely helpful to organize the data collected from the caregiver interviews in terms of the phases of their relatives residential experience - home, nursing home and special care unit. Through the organization of the family experiences over time, an underlying, core theme of "change" for the family caregivers as they passed through the phases of caring for their loved one at home, at the nursing home and at the special care unit emerged. The change

of residence for the care recipient was the most obvious incident that tied the family caregivers' experiences together. Other themes which brought the theme of change to the forefront are those of turning point, loss and adjustment. "Turning point " refers to the incident or incidents described by the caregivers as being instrumental in the subsequent decline and placement of their relative with dementia in long term care. "Loss" is a second theme which appeared throughout the data in reference to the effects of dementia on the individual and the consequences of the deterioration. "Adjustment" describes the experience of family caregivers following the SCU placement of their relatives. With regard to adjustment to the SCU, caregivers discussed their impressions of various aspects of Unit 300. These aspects emerged as subthemes of the adjustment process for the caregiver. The subthemes include the impact of the Unit 300 environment, staff, other residents, programming and caregiver role. This chapter describes how caregivers experience the changes associated with having a relative with dementia on Unit 300.

The staff member focus group findings were compared and contrasted to those of the family caregivers. The theme of adjustment emerged from the data collected in the staff member focus group. Staff members of Unit 300 described the reactions of family members based on what they observed or heard. Some staff members also speculated about the process experienced by family caregivers after the admission of a relative. The similarities and differences among the caregivers themselves and between the caregivers and staff members are

discussed throughout the chapter.

Turning Point

One of the initial patterns which emerged from the data collected on family caregivers was an incident or series of incidents which lead to a decline in the demented individual's cognitive abilities and subsequent admission to long term care. Several different combinations of caregiver and care recipient characteristics were identified during this "turning point" for the family caregiver/resident dyads. In every case, the turning points were experienced as losses by the caregiver.

In each individual caregiver interview, the caregiver was asked to describe the circumstances which brought their relative to the special care unit. This often involved recalling the resident's living arrangements prior to nursing home placement in general and then recounting the events which led to the SCU placement. At this point in the time span (preceding SCU admission), the caregivers recalled incidents which resulted in a deterioration for the resident or decreased capability for the caregiver to carry on in the same caregiving role. This was determined to be the turning point for that individual with dementia and his/her caregiver. For two caregivers, it was a sudden decline in the health status of their loved one:

> **Caregiver #3**."But he must have had a few little strokes that I wasn't aware of prior to entering the hospital but when he did go he also had diverticulitis and, he had an acute case of diverticulitis and was bleeding very heavily from the bowel. And the thing at that point was whether to operate or not ..."

Caregiver #2 "...she developed shingles, and when you know anything about Alzheimer's you know every time something happens, they are dropped another level."

Others reported an increase in wandering behaviours or an accident which placed

the relative's safety at risk.

Caregiver #5 "He wandered away far enough that he went into the school and asked to go home, he had the wherewithal to do that. And it got me worried, it was winter, it was cold. He could forget where he was going and he looks well dressed and he looks a lot better than he really is and he could walk......he could have been out on the street all night, scary."

Caregiver #2 "Well one day, I guess she decided on her own to have a bath and their water was extremely hot. She slipped and fell into the tub and really burnt herself. She burnt her arms and her buttocks."

The three spousal caregivers discussed declines in their own health status which

indicated a decreased capacity for them to care for the individual at home.

Subsequently, long term care placement occurred.

Caregiver #6 "So that's when they moved him and I of course have cancer in my back and bones. So I wasn't too well."

Caregiver #3 "I deteriorated before that. I was not able to breathe. I still can't breathe properly. And I just...it's not altogether due to nerves. It's my bronchial condition too but, I was just not a happy person and much as I tried to be, you know, put on a good front."

Caregiver #4 "I can't look after him any more. I did for about ten, eleven years and I think the toll is just beginning to take charge now, it doesn't happen right away....I would never have believed it but I'm going to be 81 this month and I find that my feet don't go as quickly and the roads are longer and every thing is more difficult. More arthritis, pains..."

Adjustment to long term care placement, in general, and then subsequent

transition to the special care unit was an experience for all of the caregivers

because their relatives with dementia spent anywhere from at least one week to

two or three years on regular nursing home units before making the transition to the special care unit at the Beverly Centre. This will be described later under the theme of "adjustment." The transition to the SCU served as a second turning point for the caregivers as they prepared themselves for the resident's transition to Unit 300. In some instances, the second turning point was somewhat unexpected. For other family caregivers, it was understood that their relative would be making the transition to Unit 300 as soon as it was established. This was especially the case for those residents who wandered. The Beverly Centre utilized a security system for wandering residents, prior to the establishment of Unit 300. Residents who were wanderers wore a bracelet which activated the door locks of certain exits when they approached an exit which lead to unsupervised territory. This system was not effective in preventing residents from wandering outside via the fire doors. However, when a resident exited through the fire doors, an alarm was activated which alerted staff that someone had eloped. Two of the residents related to family caregivers in this study wore the bracelets. These caregivers were made aware of the fact that their family members would be on the special care unit prior to its establishment. They also understood the need for a secured, safe area for the residents to wander.

> **Caregiver #2** "I think that once they changed their security so that there was only security in the SCU, she had to be in that unit. Otherwise she would have been out the door. Even with the alarm system before the renovations, she got out the door a couple of times, even with her security bracelet on."

> **Caregiver #5** "and they had to have a way where people couldn't wander away, get out of the place, what not, so at that time they had the bracelets and so on...So I really was relieved when they actually segregated them

and got them into their own environment, got their bracelets off them and got them where they can do what they want to do, roam around."

One caregiver, whose wandering resident had resided at the Beverly Centre for one year prior to admission to the special care unit, did not understand why the secured unit was necessarily a better situation for his/her loved one:

> **Caregiver #3** "And I don't know, they tell me that it's better for them to be amongst people of their own...but I know he couldn't find his room when he was out in the rest...you know, building as a whole, but neither can he find it now, so where's the difference?"

In another situation the newly admitted resident had experienced a quick deterioration and was placed on a medication which caused a negative reaction. The subsequent deterioration lead to this resident's admission to the SCU as the traditional unit was no longer an appropriate environment.

> **Caregiver #1** "But shortly after she was admitted she had several falls and she went to the hospital and they put her on an anti-seizure medication. They put her on Dilantin and she immediately started going really downhill..."

The turning points were experienced at different times and varied in severity from caregiver to caregiver. This researcher observed that the turning point(s) for caregivers and their relatives with dementia culminated with the initial admission to the nursing home or to the later admission to the special care unit. Following the crisis period of the turning point, the family caregivers noted a "levelling off" period, where there was less change in the resident. While some residents levelled off following general nursing home placement as in the case of Caregivers #2, 3 and 5, others levelled off following SCU placement (Caregivers #1, 4 and 6). Because this time span (deterioration-nursing home placement-SCU admission) ranged from

several weeks to two years, there were a variety of experiences, as highlighted above. Factors attributed to the turning point varied from characteristics of the resident with dementia (deterioration of cognitive or physical ability, problematic behaviours) to those characteristics of the caregivers (health decline, burnout) or combinations of both. This researcher discovered that the turning points indicated some of the earlier losses experienced by the family caregivers. Loss was a salient theme throughout the individual caregiver interviews. As the resident progressed from home, nursing home and special care unit, each move symbolized another loss or losses for the resident and/or the family caregiver.

Loss

Loss was another theme which emerged fairly early in the caregivers' descriptions of their experiences with the SCU and their family member with dementia in general. In examining the change process for each caregiver, various losses were noted at the different phases of home, nursing home and special care unit placement. "Loss" not only emerged in what they said, but also in how the caregivers expressed themselves and how this researcher felt during those descriptions of loss. Some caregivers became tearful at times when they recalled who the person (family member with dementing illness) was, before dementia took over and destroyed many of the special qualities of that individual. Loss was expressed in terms of the grief or sadness experienced over a number of incidents including the loss of the resident's ability in cognitive functioning, due to the

disease process and the felt loss of the relationship shared between caregiver and care recipient.

Caregivers experienced loss with regard to how their family member with dementia had lost the ability to relate to the family caregiver or deteriorated over time, following placement on the SCU, although they did not necessarily contribute the deterioration to the SCU placement.

> **Caregiver #6** "Well for instance bridge, we used to play quite a lot but he can't even tell the cards now so it's little things like that. He doesn't read anything anymore. He doesn't read the newspaper. He doesn't know what's going on."

> **Caregiver #1** "...some days she knows me and some days she doesn't. She always is happy to see me, but I'm not always her daughter. Lots of days I'm just a nice person that she's happy to see and at first it was hard to accept that but it...like I think now I can accept that she's always happy to see and it really doesn't matter if she calls me by name...Sometimes, like I see other women my mom's age that are still working or I see grandparents out doing things and it hurts. It's not fair. But basically, you kind of do, you do sort of go through a grieving process because basically the mom I always had is no longer there. "

> **Caregiver #2** " I don't think she has any idea that I'm her daughter. I guess I feel that I don't have a mother anymore. My mother has gone and this lady that I visit, that she's not anything like what my mother was like. If you look at those charts that we have she's probably at about maybe an eighteen month level. If you compare ages. So I mean obviously she doesn't know relationships and her children and her grand children. I find that very sad. I don't particularly want to get like that. It scares me that I will."

> **Caregiver #5** "he's getting worse, but that's to be expected. I was...I would get into states of depression, myself, when I'd come in and visit him, then I'd leave. He wanted to come with me and that really affected me at the time."

Grief and loss were prominent features of the caregivers' experiences in this study. To describe the change process of family caregivers of dementia residents as a

grieving process, seemed to fit with the caregivers in this study. As the resident progressed from home to nursing home to special care unit, the caregivers were faced with the resultant adjustment to this change as well as changes in the resident. The pattern of loss/change followed by adjustment occurred throughout the caregiver interview data. References to sadness, guilt, depression and unfairness were frequently cited. Moments of tearfulness and recollections of the "person he/she used to be" illustrated this grieving experience. One caregiver mentioned the anticipation of his/her relative's further decline, which would result in discharge from the unit:

> **Caregiver #2** "I think it will bother me even more when she is moved out of the 300 unit, than moving into it. Because, I knew where she was but eventually, as soon as she is not mobile, I mean once she is in a wheelchair and doesn't wander around at all, they will move her out of the 300 unit. And to me that will be sadder than moving in. That will be down to the last level and as long as she's here and she's walking and there's activity, but once she has to move out of that unit, she won't be capable of the walking or any activities. So it will be far more difficult to move out than it was to move in."

Individually, the family caregiver circumstances in this study were different. However, the common thread of "change" was shared by all. It could be said that every one experiences some sort of change in life, but the caregivers of residents with dementia in this study were observed as experiencing change in their lives associated with great loss, prolonged grieving and subsequent adjustment to the loss and changes in their relative with dementia.

Following SCU admission, caregivers revealed a number of experiences based on the questions asked about various aspects of the SCU and how they

impacted the caregiver. The theme which emerged from this portion of the data was "adjustment" following the placement of the relative with dementia on the SCU. This theme has been explored in terms of adjustment to: 1) the environment, 2) the staff, 3) other residents, 4) the programs and 5) the caregiver role.

Adjustment

A major goal of this study was to understand the experiences of family caregivers following the SCU admission of their relative with dementia. The experiences described were related to various ways that caregivers adjust to different aspects of the special care unit. What was striking to this researcher in the interviews was that each caregiver had a somewhat different initial impression of the SCU. Another noteworthy observation was that there was almost complete consensus (five out of six caregivers) on their impressions of the staff on the unit and the staff member's role in assisting with the caregivers' adjustment to having their relative on Unit 300.

The following excerpts from the caregiver interviews highlight the initial impact of the SCU on the caregivers.

> **Caregiver #1** "her room upstairs of course was really large and it seemed more like a private room and all the sudden to have two beds side by side ... is this going to be the right thing?...I think it would be nice if they were all private rooms like rather than having to share another room. I doesn't bother mom to have a roommate, it's probably me more than her."

> **Caregiver #2** "I was disappointed at first because she was so used to walking the whole building that I felt gee isn't it too bad that they couldn't make the special care unit one quarter further so she could have walked, because she was so used to walking a circle and I really felt kind of

disappointed that this...you never really, you walked and you met a door and I thought this would really bother her."

Caregiver #3 "Well, I'll tell you, when I first came and saw those big doors, those completely closed in...my heart just went down to my boots and I could have cried buckets but I didn't because I had to go in and see him and I didn't want to be crying and I still to this day have bad feelings about going into that locked unit."

Caregiver #4 "I was amazed at the lavishness and the beauty of it because it certainly isn't like most nursing homes. I don't know any other that's like this and after coming from the _____, I was so pleased that [he] was going to have surroundings like this and that there was an activity program and that there were wonderful people that would help him so I was very happy to have him come here."

Caregiver #5 "There seemed to be a calmness. Before it was always, when they had the mixture of residents, there was always noise, something going on, somebody's yelling, somebody's crying. There was always, it was busy. Right now you go down to the 300 unit and it just seems like everything's nice and calm. Nobody's pressuring anybody. "

Caregiver #6 "No I really can't [describe my initial impression] because I wasn't well at that time. That's when my back was so bad. I thought it was a very nice place for them...."

Based on these initial impressions, there did not appear to be reports that differentiated spousal caregivers from adult child caregivers. For two caregivers (#1 and #2) the initial impressions about the resident rooms, decor and layout of the unit became less significant over time whereas the initial impacts of the Unit for the other family caregivers were longstanding and consistent with how they viewed the unit at the time of the study. Caregiver #3 described the initial experience as "very traumatic" and guilt-evoking. Much emphasis was placed on the negative impact of the locked doors by Caregiver #3. Caregivers #4 and #5 were very positive in their discussions of the unit. Both of these caregivers felt that the move to Unit 300

from the previous setting was "a step up" or an improvement for their family member and consequently, they were pleased as well. In Caregiver #6's case, severe illness prevented him/her from any awareness of what was going on for the relative with dementia after SCU admission. Following these initial descriptions of the impact of the SCU on the caregiver, there were discussions of the various aspects of the unit, and how the caregivers adjusted to them. These are described in the following sections.

Environment

The environmental aspects of the special care unit were some of the early impressions noted by the caregivers in the interviews. Physical aspects were identified by the caregivers as factors which seemed particularly noticeable. There were a variety of reactions to environmental factors. Two caregivers commented on decor:

> **Caregiver #2** "I felt some parts of this place are so pretty and the 300 Unit doesn't look pretty. It still doesn't. Just because these residents can't voice their opinions, I felt they got kind of cheated on a lot of things. And I still think they've been cheated a bit in decor. But that's for me not for her."

> **Caregiver #3** "Kinda thought the rooms would be a little nicer too than they are. You know when they were putting that much renovation on in a lot of the...Like they said they were going to have a special Alzheimer's Unit, very very nice and lovely. Well they actually didn't do that much to it. And I was a little disappointed when I walked in there. I think it's maybe more important for them to have all the nice surroundings in some ways. "

These descriptions of Unit 300 were in contrast to Caregiver #4's comment about the "lavishness and beauty of the unit." Size of the unit was also discussed by two

caregivers. It was noticed that the smallness of the unit and a feeling of confinement for the caregiver was difficult to become accustomed to as illustrated by Caregiver #2's initial reaction above and the following comment by this participant:

> **Caregiver #3** "Well one thing...it bothered me....well, he was able to walk around wherever he was but not having the locked door. It didn't bother me so much, as much. But now it bothers me more...I don't know that it makes a great deal of difference to him whether he's in the locked unit or out here but it does make a difference to me. I just feel that they're like in a jail. Even if the door was open half way you know. I could see it better...and certainly none of them could get out but having it all the way locked up all by themselves in that corner to me it's...it does something to me."

The presence of "locked doors" was noted as a major concern for only one of the caregivers. This was a surprising finding from the researcher's point of view. Because the secured doors were the first thing one encountered on the SCU, there was the expectation that more families would have had something to say about the locked doors. However, this caregiver also later noted that if there was one positive aspect of the entire experience of SCU placement it was that his/her loved one would not be able to wander away and get lost. This suggested a feeling of ambivalence for this caregiver, which was evident among the other caregivers with respect to the special care unit. Other caregivers made a reference to the locked doors but it was not necessarily a negative experience for these caregivers. Ambivalence, however, was experienced by other caregivers (#1 and #6) with respect to the move of their relative to special care unit.

The presence of safe access to the outdoor courtyard was a positive aspect of the unit noted by caregivers.

Caregiver #4 "I was thrilled to see the patio, the little verandas, you know the patios where [he] and I could go and sit because all summer I would come at 6:30 and I would take him outside and we would sit outside and he just loved that."

Caregiver #1 "I like the way that it's in a square, that they can actually go outside and continue around. You know some of them walk miles in a day and yet they can go outside without getting lost or without wandering out..."

It was interesting to find that Caregiver #5 was the only participant who commented on the calmness of the unit and noise reduction. The other caregivers discussions emphasized reactions to the physical aspects of the environment and things which could be visualized.

Staff

In five of the caregiver interviews, there was a discussion of the impact of the staff on the caregiver. For these caregivers who discussed their impressions of the staff of Unit 300, the comments were very positive. The following verbatim passages illustrated this.

Caregiver #1 "I was actually really impressed with it especially the staff. I found the staff really easy to talk to. Certainly if I had a question at all, it was really easy to approach any of the staff. I found it to be very caring, very in tune with the residents.

Caregiver #2 "but it didn't take long to realize that umm the development of all other things they were doing and how hand picked the staff was....I was impressed with the staff they chose because I felt that they took extra care to make sure that the staff that worked in that 300 unit wanted to be there and they were very caring. And I think all the staff is caring, but some people do better with dementia than others and I think they put a lot of time into making sure that the nurses they chose and the aides etc. were wanting to be there. They're very good with them."

Caregiver #4 "...the wonderful caring people they have around here to look

after them. I think that helped me through more than anything knowing that these caregivers were, I really think at the highest calibre. I'm writing a journal for my own self because I think it's good for me, and in it I say I really think all these young men and women were hand picked by God himself because they are just above... there is no fault of any kind to find."

Caregiver #5 "they're doing more than I expected. I'll back them up and I'll support them...if they got any problems"

The staff component of SCU adjustment for caregivers was definitely a highlight of the interviews. It appeared that the caregivers made an effort to commend the staff, even though they were not asked about whether or not they were *satisfied* with Unit 300 staff. For one family caregiver, a comparison was made in terms of staff reactions on the regular unit versus the special care unit. While the resident was on the traditional unit, the caregiver expressed feelings of guilt because staff members would say things that made the caregiver feel responsible for the resident's inappropriate behaviour. On the special care unit, however, the staff was described as more accepting of behaviours common to dementia residents. The following section discusses the impact of other Unit 300 residents on the family caregivers.

<u>Other Residents</u>

Three family caregivers made comments which revealed that they were sensitive to the other residents on the unit. The comments pertained to various behaviours of other residents which were bothersome to the caregivers. Incidents which were described as difficult to adjust to in terms of other residents included the following:

Caregiver #4 "I don't think women, like this one women who walks around all day...poor thing, she can't help it but she goes,"da da da da da" and she doesn't speak she just pushes you aside. I don't think she should be here, the women like that, umm it's very depressing, very depressing for families."

Caregiver #3 "where his room is right now, I objected strenuously to that room because being that it's at the end of the corridor where they come to get out of those doors. They can't get out, his door's on this side at the end. Automatically they all walk in. They've gone to the bathroom on the floor in his room and done all sorts of things."

Caregiver #1 "...it was really hard for mom that everybody takes everything of each...and she does the same, but at first it was hard for me...That was really upsetting for me, but, like I said mom, it's not the staff, they all do it...."

Two caregivers who were bothered by the behaviours of other residents initially, reported that the same things still bothered them. It was also noticed that of all the aspects of the SCU, other residents' behaviours would be the most difficult, if not impossible to change. The next section highlights the reactions of caregivers to the specialized programming of Unit 300.

Programming

Caregivers also commented on the modified programming of Unit 300. Programming on Unit 300, from a staff perspective, included every activity that was done with a particular resident, 24 hours per day. This included the staff approach and interventions in activities of daily living as well as recreation. The caregivers' reactions to the term "programming" revealed that they understood programming to refer to recreational activities. Comments included the following:

Caregiver #1 "I think those have been really good for my mom I think that was partly, she certainly needed more direction. When she was upstairs it

was up to them to make their own decisions and if you want to go play bingo, if you want to go do this, they expected the residents to make those decisions on their own and mom really wasn't able to say "yes now I'll go do this" and so it's better having her on the unit.

Caregiver #2 "...the programs they are developing and allowing them to wash some dishes because that's something they remember and folding laundry and doing these... now my mother is so advanced that she doesn't necessarily get very much out of a lot of these programs. But they will include her any time they can and but, they don't force her to do any thing that.. cause she can't do very much."

Caregiver #3 "They weren't really ready with any...I thought by the time they got into that unit, that they would have had, all the things set up, the programs for them, which they didn't have. I don't even know whether it's completed yet, you know the full program. And, I was hoping there's maybe be more activity but I don't know how many of them would partake of it."

Caregiver #4 "I love the musical entertainment, I think that's a necessity. I think music is something that soothes the savage beast you know, it really does."

Caregiver #5 "...they have a professional come in for music appreciation or something like that and they phoned me and says can we try it with him and I said 'sure go ahead.' 'It's going to cost you money.' I said 'I don't care, go ahead!' It's his money...if it's going to help him, if he'll get some pleasure out of it, fine, go right ahead, do it. And that's what I consider part...they're doing something that's not really required of them, here at the Beverly....Progressive thinkers and people that really care."

Caregiver #6 "Mind you one thing, he's taking up dancing. Dancing with all the girls there."

Generally, the caregivers were positive about the various aspects of the special care unit. Only one of the caregivers interviewed described continuing difficulties with accepting the SCU as an effective environment for his/her loved one. Those caregivers who had some initial negative concerns about the environment, explained that they became more accepting of it over time, as they observed how their family member and other residents on the unit, settled in.

Another pattern which emerged from the data under the category of adjustment to the SCU was the caregivers' experience of the caregiver role following SCU placement.

Caregiver Role

Balancing the multiple roles which caregivers take on when a family member has dementia has also been a common experience among the caregivers in this study. A difference between the adult children and the spouses in the study was noted with respect to continuing on in the caregiver role following admission to the SCU. While adult children felt that they could get on with their lives following the placement of their family member, the spouses still felt very much involved in the care of their loved one. The following quotations illustrate the adult children's experiences of being able to return to their former role as son or daughter, with much of the stress of caregiving alleviated, with SCU placement.

Caregiver #1 "...there was still a lot of little concerns that still were hard for me to deal with where as once she came downstairs, then I could sort of get on with my life and realize that yes she was being looked after and it wasn't all up to me anymore, now that she's on Unit 300, and I find that I can come here and visit and it's just a short visit and then I can go away feeling that she's happy, she's settled and I don't have to worry."

Caregiver #5 "Hey relief! I don't worry about him. I don't worry about him. I worry about him less now than I ever did. Like when I was going and taking trips after his wife died, I started to really worry about him but now I worry even less."

Caregiver #2 "All those worries that I had before, are now taken care of and if I have two or three days that I can't get over, I know that I can telephone and say how is mother today? And nobody is upset that I call. So a lot of the worry of taking care of her are now on someone else and I just come

in and enjoy whatever there is I can enjoy with her."

The spousal caregivers in this study described more involvement on a physical and/or emotional level after SCU placement.

> **Caregiver #3** "But it's just when I come here, 'Why am I here? what am I doing here, there's nothing wrong with me.' So I go through the whole performance...'you had heart surgery, bowel surgery,'...'I did?'...Well he doesn't remember any of these things. So it makes it that much more difficult and when I leave, you can see his face change, it gets black almost, but, frustration or rage at the fact that I'm leaving...they've got a name for it, oxymoron....referring to the fact that we were more or less of a nonentity. We're neither fish nor fowl...you know we're married and we're not married. We have a husband, we don't have a husband."

> **Caregiver #4** "I work very hard when I visit him and I never stay less than two hours sometimes three, and I spend a great deal of time with him because I'm firmly convinced that reminiscing, talking about the past, showing him how much I love him and that I really will do just about anything, umm, has really kept him at this stage that he's at, you know..."

> **Caregiver #6** "he likes to...be where I am. But to get him to go back now is what the problem is. I get very upset trying to tell him that he has to go when it's 5 o'clock and so on. There's really not much I can do except...him get mad at me. Cause he forgets all about it...that he was mad, the next day. Where as I still worry about it."

Adjustment to the special care unit was a process distinguished by a variety of experiences for the caregivers in this study. At one end of the continuum, the relative's admission to the SCU was a welcome change for the caregiver. At the other end, it was the most difficult experience for the caregiver to endure. The only noticeable difference between adult child caregivers and spousal caregivers' reactions was the experience of more change (adult children) or less change (spouses) in the caregiver role. The following section describes the staff members' perceptions of family caregivers' experiences following SCU placement.

Staff Member Focus Group

A Unit 300 staff member focus group was facilitated by this researcher in order to obtain an alternate perception of the family caregiver's experience after admission of their relative to Unit 300. The group consisted of six Unit 300 staff members: a Registered Nurse, a Licensed Practical Nurse, three Personal Care Aides and a Recreation Therapy Aide. The theme of "adjustment" to Unit 300 emerged from the staff members' perceptions of family caregivers. The focus group revealed both similarities and differences with respect to family caregivers' experiences following SCU placement. In general, the staff perceived very positive reactions from the family caregivers with respect to the unit's modified environment and the staff members themselves.

Staff perceptions of the family caregivers' adjustment to the SCU followed a similar pattern to that which emerged from the interviews with the family caregivers. Staff members perceived that some family members were more involved and concerned about their family member's well-being immediately following admission to Unit 300 as compared to later on after the resident had settled on the unit. Some of the initial reactions noted by staff are illustrated by the following comments.

> **Staff Member #2** "Well, lots of family attention, right at the beginning. There's a you know, on a daily or every 2 day basis, concern that they're settling in. I don't know, I think that may happen anywhere that they take them. A lot of, right at the beginning concern until their own fears are maybe alleviated that their family member is settling...They want to know about everything that we do. They're very interested, concerned that their family member's needs are going to be met, that ..they phone, check on them."

Staff Member #3 "Some say that, they're happy that their mom was here because they say their mom was looking after good...they're very much concerned about care given to their mother...that's what I heard one of the families"

Staff Member #4 "They come, they come any time they want to see what their mother's doing. If we engage them in some activity."

Other staff members witnessed the family's sense of relief with having their relative on Unit 300:

Staff Member #3 "she's not worried because her mom was in good hands and in a good place. That's what I mean."

Staff Member #6 "One of the ladies, even today was saying what a relief it was that their father was here and that before at home it was quite a concern to look after him and so now they're quite relieved that they are here."

Another staff member reported that his/her perception of initial family reactions was that of uncertainty, especially when residents are admitted from another part of the nursing home versus being admitted from home.

Staff Member #1 "I've heard them say 'My husband doesn't belong on a demented unit. He's not the same level as the rest of the residents...if he goes with people who are more demented, then he will became more demented and he will not retain the abilities he now has'...When they're coming from another unit they feel intimidated that this is a dementia unit and they don't know for sure if they want to leave the freedom of normal life and go to a place where everyone is demented."

This general comment about family caregivers alludes to the ambivalence or denial that family caregivers may experience during this transition to the SCU environment. More general staff comments included the impressions that family members were quite pleased with the unit and happy that their relative was being cared for. The following comments illustrate the appreciation felt by staff members

who work on Unit 300.

> **Staff Member #5** "Some are happy too because we do their hair and nails. Like they said they're quite happy because their mom cannot be going to the parlour. Or they're comfortable here after a bath."

> **Staff Member #1** "When you attend an admission conference.... It always makes the relative very, very appreciative and that's when I feel that a lot of the bouquets are passed out and they say "I am so pleased that my family is able to come to a place like the Beverly Centre and I just appreciate the staff so much. And when I walked in I know this was the place I wanted my family to be. I felt something in the staff, a caring in the staff that I just knew that this was the right place and all of these things sound very good."

This lead to a discussion of what staff members perceptions were concerning what the family caregivers reacted to on the special care unit as their relative was initially admitted. Staff have observed both positive and negative reactions to the various aspects of the special care unit. Some of the negative reactions were to other residents, noise, lack of privacy and invasion of personal space.

> **Staff Member #2** "The other residents. they react to them immediately and they're wary of them especially the more demented ones. Like __ for example, if she happens to be one of your first encounters, it's a little intimidating. They're afraid some might be aggressive to the resident."

> **Staff Member #3** "Like residents who keep on hoarding things from different rooms. I think that's one they don't like."

<center>***</center>

> **Staff Member #4** "I think they are concerned about the noise too. When it's noisy, they observe what's happening."

<center>***</center>

> **Staff Member #6** "I think personal space too. Like I think they're concerned too that their family member needs some time of quiet too and not just constant busyness. Or people coming in the room constantly and sleeping on their bed when it's not their bed."

> **Staff Member #2** " Yeah, people will,...One resident just wandered into the room as they all do, all the time, and as I was talking to the family and to the other patient, the son-in-law said, 'does she have to go somewhere?' It make me aware that someone had invaded the space and made them uncomfortable and that I should have taken the resident out of there and leave them with some private space. But it must have bothered them to a degree."

Some staff reported that families had positive reactions to the SCU with respect to security, staff and programming.

> **Staff Member #3** "Oh I think, one that they're happy about is it's a locked one, since their family keep on eloping and going out."

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> **Staff Member #4** "I think that they feel that the staff are giving special or more attention to the residents...that's what concerns them most. One of the family members approached me and said 'Oh, I really admire the staff here because you are all patient.' That's what she said to me. So I think they feel that what we're doing here is really for the resident."

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> **Staff Member #6** "...a few of them come during exercises. They actually take part and they enjoy it too. We're trying....generally they like that."

> **Staff Member #2** "Positive responses to the programming, to the fact that there are actual activities and attention, specific kinds of attention given."

The comments pertaining to the staff are in agreement with the caregiver experiences. Staff explained that their impressions of the family members' perceptions of them, were very positive. Other discussions of the problematic behaviours of other residents (wandering, hoarding) are also consistent with caregivers' comments about their difficulties adjusting to those aspects of the special care unit. It is interesting to note that staff perceived aggression or possible aggression to residents by other residents, to be a concern of families. Two staff

members commented on how families must have a sense of fear that their relatives may be hurt or at risk of being hurt. This was not a concern expressed by those family caregivers interviewed for this study.

One of the expectations for this researcher was that staff would perceive the family's discomfort with the locked doors on the unit. Staff did not recall any negative impressions from family members regarding any environmental aspects.

When asked if staff could detect any differences between spousal caregivers and adult child caregivers in their reactions to the special care unit, the responses were mixed. One staff member suggested that it was difficult to generalize because everyone was different. Two staff members began to hypothesize that it was easier for the adult child to adjust as opposed to the spouse, but later commented on instances where the reverse was true. A variety of factors may account for the changes in experience. Staff were unable to agree on a clear pattern in this instance.

Summary

This chapter has described the findings of this study in terms of what caregivers of demented SCU residents experience from two perspectives. The theme of change was present in nearly every experience described by family caregivers and staff members of Unit 300. Pivotal points in the phases of the family caregivers' experience produced coping with and grieving various losses. Three major themes were identified in the experiences of family caregivers. These

themes were turning point, loss and adjustment. Adjustment was further categorized into subthemes of the impacts of environment, staff, other residents, programming and caregiver role.

The turning point(s) for the family caregiver consisted of an event or events which lead to the eminent nursing home placement and eventual special care unit admission. These varied among the caregivers and were found to be a result of the following: health decline in the resident and/or family caregiver, increased risk for safety of the resident, decreased capacity for the caregiver to continue in the caregiver role or combinations of these factors. For the majority of the caregivers, the turning point occurred before nursing home admission. Two caregivers, however, described events which were evidence of a turning point which occurred following nursing home placement, but preceding SCU placement.

A second theme of the caregivers' experience was loss. Loss emerged in several instances: loss of the resident's cognitive ability and progressive deterioration as a result of the dementing illness; loss of a meaningful relationship between caregiver and resident (mother, father, husband, wife) as well as anticipatory grief for losses to come - inability to walk or talk, eventual discharge from Unit 300 and death. Loss was salient throughout the caregiver interviews, emerging under references to home, nursing home, special care unit and beyond.

The third theme which emerged in the caregivers experiences was adjustment to the special care unit. Family caregivers discussed the impacts of environment, staff, programs, other residents and their caregiver role. Agreement

between caregivers was noted under factors such as decor, staff members, recreational programming and troublesome behaviours of other residents on the unit. A definite pattern was noted in terms of the spousal versus adult child experience of the caregiving role. While adult child caregivers experienced a sense of relief and ability to go on with their lives, spousal caregivers still invested much time emotionally and/or physically with their loved ones.

The findings in the staff member focus group also revealed that staff observed and speculated about the family members' experience of adjustment following the placement of their relative on the special care unit. There was agreement between staff perceptions and caregiver experiences with respect to reactions to other residents on Unit 300 and impressions of staff on Unit 300. Although some family members expressed disappointment with the decor or layout of Unit 300, the staff did not perceive any negative reactions from family caregivers with respect to environmental modifications. The difference detected between spouses and adult children with regard to the caregiver role was alluded to in the staff focus group. Staff members could not reach a consensus with regard to a definite difference between spouses and adult children in their experiences. Staff members reported that it was difficult to generalize because of the variety of variables which intervene in the reactions of both spousal caregivers and adult child caregivers. These findings and those summarized above will be discussed in greater depth in the next chapter.

Chapter Five

Discussion

The purpose of this study was to explore the experiences of family caregivers, following the placement of a relative with dementia on a SCU in a long term care facility. To accomplish this, six individual caregiver interviews and a staff member focus group were conducted. A semi-structured schedule was utilized for both the individual and group interviews. The caregiver interviews collectively reveal the broad themes of turning point, loss and adjustment, as well as several interesting individual findings. The staff member focus group findings support the theme of adjustment for the caregivers.

This study is one of the first to explore a "new" area, namely family caregiver experiences of a SCU. Research in this area is in the early stages. Special care units have only begun to be evaluated in the past decade and are receiving more attention with respect to studies comparing SCU's to traditional nursing home units. The research on family caregivers' experiences is massive, especially with respect to the burden of those caregivers who have a relative with dementia in the community. Researchers are beginning to study the experiences of the family caregiver following the institutionalization of their relatives with dementia. This qualitative study brings these two emerging areas together in an attempt to study the family caregiver's experience following the placement of a relative with dementia on a SCU. This joining sets the stage for future research to

take place in this specific area. This chapter discusses the findings of this exploratory study and presents the implications for social work practice and research.

The Change Process

The stories shared by the family caregivers in this study reveal how various aspects of their lives and the lives of the resident have evolved over time. The focus of this study was the time following SCU placement. The process following SCU placement for family caregivers, specifically, had not been explored in previous research. Initially, it seemed that this researcher collected data on six caregivers with nothing in common, but a relative on an SCU. However, three major themes soon emerged out of the variety of caregiver experiences. These included: turning point, loss and adjustment. These themes overlapped and interconnected in a multitude of ways. At a very basic level, the caregivers experienced significant "change" at various points over time. "Turning point" categorizes those changes which involve various crises or sudden deteriorations for the caregiver/resident teams. "Loss" describes those incidents of negative change or decline in the relative with dementia. "Adjustment" pertains to those experiences in which caregivers described the changes within themselves, in reaction to various losses or changes for the resident, such as SCU placement. For this researcher, it has been a learning experience to analyze the data qualitatively and allow categories or themes which were meaningful to the study

participants, to emerge. It was this search for the underlying meaning in the variety of incidents described which helped this researcher to see the themes of turning point, loss and adjustment emerge.

During the initial analysis of data collected in caregiver interviews, the major phases of residential experience, for the relative with dementia, were noted. The following phases of residential change for the relative with dementia have been identified.

- ► Home

- ► Nursing Home

- ► Special Care Unit

Hospitalization was a significant experience for half of the caregivers in this study. Hospitalization of the relative with dementia occurred throughout the three major phases, depending on the resident's physical health status, which may or may not have been affected by the presence of cognitive impairment. For five out of the six of the caregivers in this study, nursing home placement, which occurred between home and SCU admission, was possibly the most stressful point in the process. When SCU admission occurred, things settled somewhat. This finding indicates that because nursing home transition was difficult for these residents, they may have benefitted from SCU care much earlier. It was simply a matter of the SCU not having been developed at the time. This was the case for four caregivers whose relatives had been "traditional" nursing home residents for several months before the SCU was established. More nursing homes might benefit from having an SCU

or at least SCU qualities to better manage residents with dementia.

As the population of dementia residents in long term care centres continues to grow, SCU's will likely continue to be established. Currently, SCU's are being developed in many long term care centres with a significant population of residents with dementia. This is occurring despite the lack of empirical evidence to support SCU establishment. The findings of this study highlight the issues for a group of family caregivers. The following sections identify and discuss the findings.

Turning Point

In each caregiver case, an event or series of events were described that emerged as a turning point in the lives of the family caregiver and resident. This event was classified as the turning point by this researcher because of certain properties. In the turning points of these family caregivers there was (1) an isolated incident or incidents which posed a serious threat or risk to the safety of the resident and/or caregiver, followed by (2) a change in the status of the relative with dementia or the caregiver which (3) resulted in nursing home placement and eventually special care unit placement for the relative with dementia. The turning points, for those Unit 300 residents with adult child caregivers, were attributed in all cases, to a change in status of the relative with dementia. For those Unit 300 residents with spousal caregivers, it was discovered that there was a change in health status for the caregiver in addition to a change in health and/or mental status for the care recipient. It was difficult to determine if spousal caregivers

waited too long before considering long term care placement. Because the spouses' health was also in jeopardy when the turning point occurred, this may have increased the risk for a crisis. There was no clear basis on which to compare spousal to adult child caregivers regarding the length of time that elapsed before the relative was placed. This was because of the variance in duration of caregiving for both groups. For the majority of the caregivers, placement occurred after a crisis or turning point in the physical health or mental health status of the resident. Could these crises have been prevented? If these families had been identified as "at risk," while the person with dementia resided in the community, could the crisis have been prevented? Hospitalization occurred for two of the residents before placement, and by this time, the situation was urgent. Waiting lists for long term care placement continue to grow. The time when a person can benefit from specialized services may not be the time when care is available to that person and her/his family. This is a concern for families in need of respite, adult day care or long term care placement/SCU services.

Two caregivers reported incidents which signalled a major turning point following nursing home placement. This concept of turning point was similar to Kuhn's (1990) model of the normative crises of families facing dementia. Kuhn's model identified hospitalization and nursing home placement as major stressors following the crises of behavioral problems and possible health decline. Three of the caregivers in this study witnessed their relative's hospitalization prior to or during nursing home placement. Illness and subsequent decline were identified as

turning points by this researcher. As suggested by Kuhn (1990), this is "a major setback" for the relative with dementia (p. 456) and consequently, the family caregiver.

The caregivers in this study reacted to nursing home placement in a variety of ways including: guilt, anger, grief, apprehension, ambivalence, concern, worry and relief. These findings are consistent with other studies that explored the period following institutionalization (Kuhn, 1990; Matthieson, 1989; McGannon, 1993; Rosenthal & Dawson, 1991 and Steven, Walsh & Baldwin, 1993). No clear patterns were noted with regard to these reactions. That is, not every caregiver experienced each reaction nor did any particular order of reactions emerge. However, all of the caregivers either remarked that the experience was stressful or they alluded to the stress experienced during the recollection of the time of nursing home placement and/or subsequent SCU admission. Because of the variety of experiences discovered in this small sample of caregivers, this researcher questions the use of previously published "adjustment processes" which tend to categorize individuals in one particular stage of development. For example, Austrom and Hendrie (1991) and Dhooper (1991) discuss one such process of adjustment, based on the famous Kubler-Ross stages of accepting death:

1) Denial

2) Overinvolvement

3) Anger

4) Guilt

5) Acceptance

(Austrom & Hendrie, 1991; Dhooper, 1991)

Dhooper (1991) cautions and this researcher agrees that "because of its unique and peculiar situation, every family may not pass through these stages in this order" (p. 22).

This researcher discovered fairly early during the caregiver interviews that it would have been extremely difficult to focus solely on the caregivers' experience following SCU placement. Gathering information about the circumstances prior to SCU admission was necessary to establish the turning point pattern in the caregivers' experience. Knowledge of the circumstances prior to SCU placement also shed some light on the individual caregivers' experiences following SCU admission. The second major theme is loss.

Loss

Loss was experienced by all family caregivers throughout the process of change in the residence of their relative with dementia. Once again, having the knowledge of the caregivers' pre-placement (nursing home and SCU) experiences was critical to understanding the losses experienced during the post-placement phases. The caregivers in this study reported a multitude of losses: the resident's and/or caregiver's loss of home; the resident's loss of independence, ability to comprehend, function in daily living and ability to relate to others; loss of the parent-child or husband-wife relationship; the loss of the caregiver/care receiver

relationship that was in existence prior to long term care placement and the loss of the person that used to be.

As a result of the dementia process, many of the residents' losses increased after placement. Therefore the caregivers' experience of loss continued to intensify throughout this process. An important distinction must be made at this point. While most caregivers reported an alleviation of stress following the SCU placement of their relative, the loss experience continued. For these family caregivers, losses were cumulative. Whether the losses were gradual or sudden, the grief experienced was difficult for all caregivers.

While the caregivers may not have described the resident's deterioration or other negative changes as "loss," a number of factors signalled that, in fact, these experiences could be categorized as losses. During analysis of the taped interviews some of the caregivers became tearful or upset as they communicated an incident which was difficult for them to deal with. These incidents were coded as negative changes or losses. Grieving was a common experience to all caregivers in this study. Rosenthal and Dawson's (1991) concept of quasi-widowhood seemed to fit for the spouses in this study. What about the adult children of SCU residents? More research is needed to assist health care professionals in the conceptualization and understanding of this experience.

Adjustment

The third major theme was adjustment. For every loss or change described

by the family caregivers, there was an initial reaction to the loss or change, followed by a period of confronting or dealing with the change. The term "adjustment" captured this period for the family caregivers. The caregivers coped with numerous changes and losses as they witnessed their family member's transition from home to nursing home to special care unit. This adjustment was a very individual experience. Each family caregiver experienced adjustment in a different way. As one family member states, "it's all stressful" indicating that there was not necessarily one particular time which had been more stressful than another. However, another caregiver could recall very specific incidents during her/his adjustment to the SCU which had been particularly stressful.

Family caregivers' reactions to the various aspects of the SCU ranged from very positive to very negative. To hear the family caregivers speak so positively about the staff was significant. Possible bias in the responses of the caregivers could account for the overwhelming positive nature of the comments. However, the fact that five out of six caregivers made this comment may suggest that they were truly affected by staff in a positive way. It appeared that caregivers were very reassured by the presence of dedicated and caring staff with the expertise to deal with the residents effectively. This finding supports the vital need for staff who work on SCU's, to have specialized training and a sincere desire to work with residents with dementia. It may be helpful to discover other sources of support that families appreciate following SCU admission.

A variety of reactions to the physical aspects of the SCU were observed. In

some cases, these impressions changed over time (i.e. from negative to more positive or from negative to neutral). Other caregivers' impressions were consistent over time (positive then and positive now or negative then and negative now). Previous studies which have evaluated the effectiveness of SCU's have not examined the specific reactions and feelings that family members have about various aspects of special care units. The closest that previous research has come to determining the reactions of family members/caregivers has been in the form of satisfaction surveys (Mathew et al., 1988). This type of data reveals very little about what the family caregiver was or was not satisfied with in terms of the special care unit. Moreover, the emotional impact of other factors associated with SCU placement is not clear. The findings of this exploratory study revealed specific reactions to specific aspects of Unit 300. Overall, the family caregivers in this study reacted positively to staff and programs. Fifty percent of the participants found other residents to be a negative factor, especially those residents whose dementia was quite advanced. Mixed reactions to environment, programs and other residents may indicate the following factors: (a) that families possibly need more education about the so-called negative aspects of SCU's, especially with regard to why certain environmental modifications are necessary, (b) that because SCU's are a relatively new phenomenon, there will be a developmental process which will improve the provision of care. Families must be part of this developmental process to ensure that their needs are being considered.

Staff members, surprisingly, recalled receiving only positive comments about

the environmental aspects of the unit, if they heard any at all. It was especially surprising to this researcher that no other family caregivers were perceived by the staff as being uncomfortable with the locked doors and considerably smaller size of the unit. A possible explanation may be that staff become accustomed to this aspect of the unit so quickly that it does not become a concern for them. Another explanation may be that staff are not regularly near the doors when family caregivers arrive (the nursing station is situated in the middle of the unit, away from the doors) so they do not see how family caregivers react to the secured doors. Staff members felt that family caregivers had the most difficulty coping with the deterioration of the resident and possibly fear of other residents' aggressive behaviours.

Another observation related to the family caregiver's adjustment to the SCU concerned the caregiver role. The findings uncovered a pattern which distinguished the role of the adult child caregiver from that of the spousal caregiver following SCU placement. The adult children described being able to turn over the caregiving role much easier following SCU placement, where as spousal caregivers were more involved physically and/or emotionally after SCU placement of their relatives. A study reviewed by Morgan and Zimmerman (1990) found that:

> "the reactions and adaptive strategies of spouses and adult children tend to differ: children were more likely to distance themselves from parent, whereas spouses found themselves progressively "enmeshed" in the relationship" (p. 4).

This finding seems to fit closely with the patterns observed in this study. The staff focus group did not reach a consensus regarding this pattern noted in the

caregiver data. Staff members could recall instances of spouses who distanced themselves after SCU placement and adult children who became intensely involved after SCU placement, as well as the pattern noted above. This is where variables such as the premorbid relationship or the stage of dementia for the resident may come into play. It may be more difficult for spouses to relinquish the caregiving role completely because of the long history of their relationship, often over fifty or sixty years. Adult children however, are not connected to their parents in the same way. Perhaps this makes it easier for children of individuals with dementia to place their parents in a SCU.

The caregiver burden research discussed in Chapter Two did not produce consistent findings regarding which variables influence caregiver burden. The findings of this study have lead this researcher to consider a number of variables which may influence the adjustment experience of family caregivers following SCU placement. It is possible that the relationship between caregiver and care recipient had some influence on caregiver role following SCU placement. That is, spouses tended to be more involved than adult children. The staff focus group findings, however, alluded to the possibility that perhaps it is the quality of the relationship and not the relationship itself, which determines caregiver involvement after SCU placement. The stage of dementia that the resident copes with may also contribute to the family caregiver's involvement or willingness to continue to be involved in caregiving. In this study, the spouses were more involved on a weekly basis than the adult children. Comparing the stages of dementia for the residents of spousal

and adult children caregivers, no clear pattern was discovered. The degree of dementia was not necessarily associated with high or low involvement.

The special care unit transition presented a noticeable change in the lives of the family caregivers. It was difficult to distinguish adjustment to the SCU from the constant adjustment and coping with the losses of the relative with dementia. Premorbid relationships, the type of relationship, health status and degree of dementia may influence the experience of family caregivers. Caregivers seemed to place more emphasis on recollections of various losses, such as the day that their relative no longer recognized them. Various physical aspects of the SCU, such as the size of the residents' rooms or the decor on the unit, were more of an annoyance than a difficult adjustment for some caregivers. This suggests that caregivers must continue to be supported and educated with respect to the disease process of dementing illness.

The following section outlines the strengths and weaknesses of this study, followed by the implications of these findings for social work in long term care.

<div align="center">

Strengths and Limitations of this Study

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Strengths

Some of the circumstances surrounding this study facilitated both its initiation and completion. This researcher was fortunate to experience a social work field practicum that provided an opportunity to learn about a special care unit setting in a long term care facility. This provided the motivation to conceptualize

a study to explore the experiences of family caregivers following SCU placement. Even more advantageous was this researcher's recent employment as a social worker for the Beverly Centre for Long Term Care, a facility which houses a 36-bed SCU for residents with dementia. The timing of this new employment was a strength for the research because the researcher was stepping into this new situation with a degree of objectivity. In addition, as a permanent employee of the facility, the researcher was able to develop relationships with staff and family caregivers which would carry on following the study.

The selection of grounded theory methodology was also a strength of this exploratory study as it was the most appropriate method for the research questions asked. Previous research in the area of family caregivers' experiences following institutionalization was limited. Research on SCU's has not examined the impacts of SCU admission on the family. These factors indicated a need for qualitative methods, namely grounded theory methodology, to discover the meaning behind the family caregiver's experience. This method allowed the researcher to generate researchable questions which are grounded in the actual experiences of family caregivers of SCU residents.

The steps taken to ensure the credibility of the data was a strength of this study. Data were triangulated, including information collected from two different groups of caregivers: adult children and spouses, as well as staff. This triangulation of data collection methods and study participants increased the credibility of the findings. The validity of the findings was also increased by having the study

participants review the data to insure accuracy in its presentation and interpretation by the researcher. This way of ensuring the truth value of the study's findings is referred to as a validity check. Family caregivers and staff participants indicated that they were satisfied with the presentation and interpretation of the findings.

Limitations

One of the limitations of this study is the limited past research in the area. The potential for bias was introduced in various areas of methodology: selection of the study sample, data collection and analysis of the data. This could be attributed to insufficient guidance from the research conducted to date on family caregivers. One of the desirable traits in selecting a prospective caregiver participant was the degree of comfort in discussing his/her experiences. Therefore, this researcher identified potential subjects from a group of family members who participated in a support group for Unit 300 family caregivers. Because only those family caregivers who participated in the group were considered, bias was introduced. The possibility that support group family members would be more willing to participate than other family members presented a limitation in the study. Those family members who were not considered may have reported an alternative experience of SCU's, not detected in the data from support group members. Another potential for bias occurred in the selection of staff members for the focus group. Because it would be easier to interview the staff during a shift, it was necessary to only consider evening staff because of the natural break in their

routine during the shift. The perceptions of other staff who worked during the earlier portion of the day were therefore excluded in this research, limiting the representativeness of the focus group findings. Evening staff could not report their perceptions of family caregivers who visit during the day.

In terms of data collection, this researcher's previous experience with SCU's and present employment and connection with Unit 300 may have presented a bias as to how the interviews had been conducted. However, a semi-structured interview schedule was utilized for both the individual caregiver interviews and the staff member focus group. This structure helped to keep the researcher on track, asking questions which were general enough to be subject to the caregiver's and/or staff member's interpretation. Frequent distancing and reflection, where the researcher was able to physically step back and view the interview process from different perspectives, was also helpful to keep the presence of such personal bias in check; the possibility still exists that this researcher's presence in the interviews may have altered the responses of the participants.

The credibility of the findings in this study was also dependent on the participants ability to recall events or incidents in the past. For some of the caregivers, this meant retrieving information from four or five years earlier. Therefore, a limitation may also be present with regard to the reliability of the participants' memory and ability to relay events which occurred several years earlier.

In the interview situation, family caregivers may have been influenced by the

presence of this researcher as an employee of the facility. Where an outside observer may be able to obtain more objective responses about various aspects of the SCU, this researcher's presence may have motivated participants to respond more positively with regard to their impressions of Unit 300.

During the analysis of the data, another limitation was present. This researcher's own thoughts and ideas about how the family caregivers may react to the SCU placement of their relatives introduced a bias, despite the precautions taken to reduce this subjectivity. Frequent distancing during analysis was also necessary to allow only those themes which were meaningful to the family caregiver and staff participants, to emerge. As an exploratory study, however, the goal was to identify potential sources of bias, not necessarily to control them.

Implications for Social Work

A multi-disciplinary approach to the care of long term residents of continuing care facilities is more commonly the rule as opposed to the exception. The social model of care is a concept which is beginning to shift the traditional medical model paradigm in health care across the nation. Specialized care units for individuals with dementia are examples of how the social model has been embraced by those who are interested in providing care which is believed to be ideal for sufferers of dementia. As members of multi-disciplinary health care teams, social workers have served a vital role for staff, residents and their families. Part of maintaining effective working relationships with family members of SCU residents involves

gaining an understanding of their experience and being empathetic to their individual circumstances. Sharing this perspective with the multidisciplinary team provides an alternate view or understanding of the family's situation.

The findings of this study have several implications for this social worker and others who work with families of SCU residents. Engaging families to work through their grief and loss issues will require a degree of skill and understanding of the family's experience. A variety of responses and reactions to SCU admission were noted by this researcher. For social workers who deal with family caregivers on a one to one basis, perhaps the simple acknowledgement and normalization of various reactions is all that is necessary for the caregiver to feel validated.

Taking histories from family caregivers to better understand the family and resident, has been a common social work practice in long term care facilities. In this study, the researcher obtained a brief history from the caregiver as to the circumstances which lead to Unit 300 admission. This researcher was left with a greater understanding of each caregiver's experience by being aware of what happened prior to the SCU placement. Lynch-Sauer (1990) conducted a phenomenological study of caring for a family member with Alzheimer's disease. Her results confirmed the necessity of taking personal histories to better understand the caregiving relationship.

Each caregiver dealt with grief as a result of loss in his/her own way. This finding suggests that social workers and other health care workers in this field need to validate and accept the grief reactions of family caregivers, in whichever

manner they are presented. The family caregivers in this study had different coping mechanisms for managing their grief. A common thread of the caregivers in this study was their participation in a family support group. The group was an important outlet for these caregivers. One of the concerns for this social worker is how to engage those families who do not attend the support groups. Is there a stigma associated with support groups? Or are the daily schedules of working families too hectic to include group attendance? Social workers need to explore other avenues to support family caregivers whose experiences are similar.

This study's findings in the staff focus group component also shed some light on an area which requires attention. As mediators between family members and staff members of long term care facilities, social workers can share information about the experiences of family members. Staff members may benefit from education .regarding the variety of coping mechanisms that family caregivers employ as they experience the devastation of a family member with dementia. Past experiences with long term care staff have given this researcher the impression that some staff have difficulty understanding the families that do not involve themselves in the resident's life. This is based on negative points of view expressed by staff. Families who prefer to distance themselves from the relative with dementia also need to be supported in this decision just as much as the caregiver who visits daily. Communication is necessary to ensure that both staff and families have an understanding of each other and their purpose as members of the same caregiving team.

Social workers can be part of educating the community family caregivers of individuals with dementia who are awaiting long term care or SCU placement. Knowledge of the purpose of SCU's prior to admission may ease an otherwise difficult transition for family members and prospective residents. Two family caregivers in this study commented on how reassured they were with the information that was shared regarding the establishment of Unit 300. The transition was made easier for these family members because of this education.

This study suggests that social workers who wish to or are specializing in this area of practice must understand the complexity of the situation. An understanding of the various grieving processes related to having a living family member with dementia is necessary. More research is needed to build the knowledge base of understanding, assessing and providing effective treatment interventions for this population.

Directions for Future Research

The purpose of this research was to discover the experiences of a small group of family caregivers whose relative had been placed on a special care unit. Following this, a second purpose was to generate hypotheses grounded in these experiences. This study was practical in nature. From a social work perspective, research needs to continue to explore how families are best supported through the difficult experiences of watching their loved ones with dementia deteriorate. The following research questions have been derived from the findings:

- ◆ Do adult child caregivers of demented SCU residents experience the post-placement phase differently from spousal caregivers?

- ◆ What types of loss are most difficult for family caregivers to cope with?

- ◆ Does support group attendance enhance the family caregivers' coping abilities?

- ◆ What aspects of SCU's are difficult for family caregivers to adapt to?

- ◆ What aspects of SCU's enhance family caregivers adaptation to them?

- ◆ What positive changes do family caregivers notice in their family members following SCU placement? Negative changes?

Although this study did not evaluate the effectiveness of Unit 300 as a specialized care environment, the state of the research which has begun to develop in this area clearly indicates that more empirical evidence is needed to support the establishment of SCU for residents with a dementing illness. Despite this lack of definitive evidence, SCU's are being established in many facilities as an alternative to managing the difficult behaviours of demented residents. At the grass roots level, individual SCU's need to continue to establish measurable goals and objectives from which they can evaluate any changes over time. Dissemination of this information in the field of health care will educate other researchers about what appears to be effective and what does not appear to be effective in

specialized care. These studies must contain detailed descriptions of the methodologies utilized in order for other settings to replicate program evaluations. A problem with the research on SCU's at the present time is the considerable variation among the units being compared. Until standardization can be established among special care units for dementia residents, large scale comparative studies will continue to pour out inconsistent findings confounded by many sources of bias.

The research on family caregivers is starting to branch out into new directions. Specifically, the experiences following long term care placement are receiving some attention in the literature. As no other studies have explored the family caregiver's experience following SCU placement of a relative with dementia, more studies are needed to understand the impact of the SCU on family caregivers. In particular, research could be enhanced by asking more specific questions about the loss and adjustment aspects of the caregiver's experience, as well as their perceptions of the physical aspects of SCU's..Focus groups with staff members and other facility stakeholders would add to the knowledge in this area.

With limited resources in health care, studies which are practical in nature and have some value to the agency or facility will be the most useful to social workers in long term care. For example, evaluations of educational, support and therapeutic programs for family caregivers of SCU residents are necessary to give direction for areas of focus in clinical practice. Dissemination of this information through publication, educational inservices and conferences will also be helpful to social workers in other facilities who provide assistance to family members caring

for a loved one in a SCU in a long term care facility. From practical research applications such as this exploratory study, future research can then delve into more specific questions. Which forms of educational or support group programs are most helpful in assisting family caregivers with their experiences of loss and adjustment to having a relative on a SCU? Does early detection of caregiver/care recipient dyads who are at risk for a crisis or devastating turning point, impede nursing home placement? What kinds of support do family caregivers' find most helpful at different phases of community (home), nursing home and SCU placement? How can SCU's be further adapted to increase the comfort level of family caregivers?

Conclusion

To conclude, this study opened a new area of research with family caregivers of demented elderly individuals. The SCU is a concept which family members of a relative with dementia may encounter as the individual progresses to reside in a long term care facility. Three major points capture the significance of this research. First, family caregivers who have a relative in a SCU continue to experience loss and grief long after they have relinquished the "hands-on" caregiving role. Adjustment may vary from caregiver to caregiver. It is crucial for social workers and other health care professionals to understand this experience and not "pigeon-hole" families into various stages of a grief process we do not yet fully understand. Second, social workers must continue to evaluate the ways in

which assistance is provided to these families and search for innovative and creative ways to help family caregivers through their loss and adjustment, if they want to be helped. Finally, more research is required to assess the effectiveness of SCU's and their impact on residents, staff and family members. Improvements in the methodology of such studies must be strived for in order to produce meaningful findings.

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Appendix A

September 23, 1994

Dear Family Caregiver,

My name is Lana Harder and I am a graduate social work student in the process of completing my thesis at the University of Calgary. My research involves an exploratory study of family caregivers of residents with dementia on a special care unit. I hope to gain an understanding of the family member's experiences after admission takes place. My employment with the Beverly Centre as a part-time social worker has allowed me to become familiar with the Unit 300 special care unit for residents with dementia. I hope to conduct interviews with six family caregivers of Unit 300 residents. In addition to individual caregiver interviews, I will also be conducting a staff focus group to obtain their perceptions of the family member's experience following admission.

The interview will take place at the Beverly Centre and will be approximately 1 1/2 to 2 hours long. The interviews will also be audio-taped to ensure the information gathered is accurate.

Your responses during the interview will be kept completely confidential and your name and the name of your family member will not be mentioned with the information presented in the thesis. Any other identifying information will be presented in such a way as to protect the anonymity of yourself and your family member. The tapes and transcriptions of the interview will be kept in a secure place with the researcher and will be destroyed at the completion of the research.

You have the right to withdraw from the study at any time. Your decision to participate in the research or not, will not affect your relationship with Unit 300 staff or have any affect on the care received by your family member. This study is not an evaluation of Unit 300. The purpose of the research is to learn about what the family caregiver experiences following the placement of his or her family member on the unit.

If you are willing to participate, please read and sign the consent form attached to this letter and leave it with the case manager on Unit 300. If you agree to participate, I will contact you by telephone to set up a time for the interview to take place. Any questions about the study can be directed to me through the Beverly Centre Social Work Department at 253-8806.

Thank you for your assistance. Your help in this research will be greatly appreciated.

Sincerely,

Lana Harder
MSW Student

Appendix A - continued

CONSENT FORM

I agree to participate in the study of family caregivers of Unit 300 residents to be conducted by Lana Harder, Social Worker, at the Beverly Centre for Long Term Care.

I understand that I will be participating in an interview which will be audio-taped. All information will be kept <u>completely confidential</u> and any identifying information will be presented in such a way as to protect the anonymity of myself and my family member. The audio-tapes and transcriptions will be kept in a secure place with the researcher and will be destroyed at the completion of the study. Further, I understand that I may withdraw from the research at any time, without affecting my relationship with the Unit 300 staff, the Beverly Centre or the care received by my family member.

Signature _____

Phone Number _____

Date _____

Appendix B

CAREGIVER INTERVIEW

1) Would you share with me the circumstances which led to the admission of your family member to Unit 300? [Where was the resident living? Who was the primary caregiver(s)? What was the reason for placement on Unit 300?]

2) Would you describe the admission process?

3) Describe how you felt during the admission process. [Physical health? Emotional well-being?]

4) Was anything particularly stressful during this time?

5) What made you feel particularly _____ during this time?

6) What were your initial impressions of Unit 300? [Environment? Staff? Programs? Other residents?]

7) Please describe any lifestyle changes that occurred at the time of admission. [Family relationships? Legal issues? Finances?]

8) What are your impressions of Unit 300 today? [Environment? Staff? Programs? Residents?]

9) How have things changed/not changed for you since the admission of your relative to Unit 300? [Physically? Emotional well-being? Lifestyle? -family relationships, practical issues? Ethical concerns?]

10) Please describe how your caregiving role has changed or altered since the admission of your relative to Unit 300? [How are things better, worse, unchanged? What is most stressful now?]

11) As you adjust to your relative being on Unit 300, what is the most negative aspect about the process? The most positive?

Background Information
RESIDENT
Resident's Age:_____   Resident's Gender:_____
Date of Admission:_____
Date of Admission to Unit 300:_____
Marital Status:_____
Admitted from:_____

Appendix B - continued

Diagnoses:_____
Stage:_____

CAREGIVER
Caregiver's relationship to the Resident:_____
Years in caregiver role:_____
Caregiver's Age:_____ Occupation:_____
Frequency of visits:_____
Other family members/friends involved (Support
Network):_____

Appendix C

Staff Consent Letter and Form

November 1, 1994

Dear Unit 300 Staff Member,

My name is Lana Harder and I am a graduate social work student in the process of completing my thesis at the University of Calgary. My research involves an exploratory study of family caregivers of residents with dementia on a special care unit. I hope to gain an understanding of the family member's experiences after admission takes place. My employment as social worker at the Beverly Centre has allowed me to become somewhat familiar with Unit 300. I hope to conduct a staff member focus group to discuss your perceptions of family caregivers' experiences following the admission of their family member.

The focus group will take place at the Beverly Centre and will be approximately 1 1/2 to 2 hours long. Every attempt will be made to schedule the focus group at a time that is convenient for all participants. The discussion will also be audio-taped to ensure the information gathered is accurate.

Your responses during the interview will be kept completely confidential and your name or job title will not be mentioned with the information presented in the thesis. The tape and transcription of the interview will be kept in a secure place with the researcher, and will be destroyed at the completion of the research.

You have the right to withdraw from the study at any time. Your decision to participate in the focus group is voluntary. This study is **not** an evaluation of Unit 300. The purpose of the research is to learn about what family caregivers experience following the placement of their family members on the unit.

If you are willing to participate, please read and sign the consent form on the reverse side of this letter and leave it with me at the Social Work office. If you agree to participate, I will contact you by telephone to set up a time for the focus group to take place. Any questions about the study can be directed to me at 252-7565 (residence) or at the Beverly Centre on Mondays or Fridays.

Thank you for your assistance. Your help in this research will be greatly appreciated.

Sincerely,

Lana Harder
MSW Student

Appendix C - continued

CONSENT FORM

I agree to participate in the study of family caregivers of Unit 300 residents to be conducted by Lana Harder, Social Worker, at the Beverly Centre.

I understand that I will be participating in a focus group interview which will be audio-taped. All information will be kept <u>completely confidential</u> and any identifying information will be presented in such a way as to protect the anonymity of myself and my job title at the Beverly Centre. The audio-tapes and transcriptions will be kept in a secure place with the researcher and will be destroyed at the completion of the research. Further, I understand that I may withdraw from the research at any time.

Signature _____

Phone Number _____

Date _____

Appendix D

FOCUS GROUP INTERVIEW SCHEDULE

I)   Generally, how do family members react when a relative is admitted to Unit 300?

2)   What do family members react to with respect to Unit 300;
Staff?
Environment?
Programs?
Other residents?

3)   Please describe any differences in reactions to aspects of Unit 300 among family members--spouses versus adult children?

4)   Please describe any changes in the families/ reactions to Unit 300 over time?

ALZ**EIMER'S**
ASSOCIATION
Someone to Stand by You

STRESSFUL DIMENSIONS OF THE FAMILY EXPERIENCE	PHASES OF THE FAMILY EXPERIENCE				
	(1) FIRST SUSPICIONS TO FORMAL DIAGNOSIS	(2) MINIMAL ASSISTANCE TO TOTAL CARE	(3) HOME TO NURSING HOME	(4) POST-PLACEMENT IN NURSING HOME (NH)	(5) PATIENT'S DEATH AND BEYOND
(A) PHYSICAL DEMANDS	Minimal, e.g. patient takes longer with ADLs	Demands increase to overwhelming proportions by end of this phase.	Continuous excessive demands, precipitating nursing home decision. Physical exhaustion.	Overall demands diminish, though new ones surface. e.g. routine of visiting the patient in the NH	Considerable relief of physical demands.
(B) LIFE STYLE DISRUPTIONS	Minimal, but are of growing concern. Less spontaneity Less enjoyment	Disruption increases in proportion to increased practical and physical responsibilities. Need for respite.	Total disruption: severe curtailment of leisure/freedom. Exhaustion from physical and emotional demands.	Disruption diminishes, but NH visits cause new issues.	General return to normalization after adjustments are made.
(C) PSYCHOLOGICAL/ EMOTIONAL IMPACT	FEARS: start early eg. fear of the unknown; fear of the future	Grow and proliferate	New fears re: NH affordability, acceptability, transition	Some diminishing	Genetic fears may linger.
	ANGER: Starts here, builds fast		Often intense here	Usually continues	Lingering effects, e.g. wasted years, feelings of martyrdom, lost opportunities, and resentment.
	GUILT: May start here	Builds here	Very severe Ambivalence re: continued life.	Often most severe, e.g. second guessing decisions	Not yet resolved.
	ANTICIPATORY GRIEF	GRIEF: Builds fast Loss of relationship.	Very poignant Caregiving transfer.	May run its course before end of Phase 4	May periodically resurface with memories.
	HOPELESSNESS: May start here with recognition of prognosis	Already intense Need for formal support may begin here.	Severely intense	General reduction in hopelessness as family is resigned to or relieved by NH decision having been made	Some lingering.
		LONELINESS: Starts and intensifies fast	Often overwhelming throughout Phase 3	Usually continues until social reintegration takes place.	
(D) RELATIONSHIP STRAINS	Usually limited to pre-illness conflicts, but may include dealing with patient's forgetfulness, depression and personality changes.	New conflicts occur and old ones frequently intensify because of paranoia, emotional outbursts and frustration.	Often severe straining of familial and other relationships. e.g. conflicting opinions/ideas of patient care.	Some diminishing, but still may have continued tensions.	Diminished, however, unresolved feelings may remain.
(E) PRACTICAL PROBLEMS	Minimal at first but rapidly increasing.	Increasing problems, e.g. finances, legal issues, needing community resources, etc.	More of same with increasing complexity, cost, frustration.	Frequent severe depletion of financial resources	Often minimal resources with which to rebuild.
(F) ETHICAL TENSIONS	For many, ethical tension insignificant; for others, ethical concerns are burdensome depending upon individual, religious and moral values. Other issues re: being forced to limit independence of a loved one, facing mortality, making end of life wishes clear, "broken promises", realistically evaluating abilities, facing the future.				

Adapted from chart by Carl Bretscher, MSW.
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Appendix F

Validity Check

April 7, 1995

Dear Family Caregiver,

It has been approximately five months since we met to conduct the interview where you described your experiences of having a relative on Unit 300. Since that time, I have completed the transcribing and analysis of the interviews and I am now ready to share the findings with you. I hope to have your feedback with regard to the accuracy and interpretation of these findings. This process is referred to as a validity check. The check helps to increase the credibility of the data if it is found to "fit" with your experiences as you see it.

I have included a copy of the findings chapter for your perusal. You have been identified as caregiver #__. Please read the chapter and complete the "Validity Check" form included. To save time, I will be telephoning within one week to receive your feedback. If you wish, you may drop off the chapter and form at my office in the Beverly Centre.

Thank you once again for agreeing to participate in this study. I look forward to receiving your feedback. Please call me at 253-8806 if you have any questions.

Sincerely,

Lana Harder

Appendix F - continued

Validity Check

Please indicate whether or not you agree with the following statements by checking "yes" or "no".

1) The researcher's presentation of the findings is accurate with respect to the information discussed in the interview.

_____ Yes   _____ No

If no, please state what is inaccurate:

2) The researcher's interpretation of the findings "fit's" with my experience as a family caregiver.

_____ Yes   _____ No

If no, please state what does not fit:

3) I am satisfied with the information presented in the findings of this study.

_____ Yes

Appendix G

Validity Check

April 7, 1995

Dear Unit 300 Staff Member,

It has been approximately five months since we met to conduct the focus group interview where you described your perceptions of family caregivers' experiences of having a relative on Unit 300. Since that time, I have completed the transcribing and analysis of the interviews and I am now ready to share the findings with you. I hope to have your feedback with regard to the accuracy and interpretation of these findings. This process is referred to as a validity check. The check helps to increase the credibility of the data if it is found to "fit" with your experiences as you see it.

I have included a copy of the findings chapter for your perusal. You have been identified as staff member #___. Please read the chapter and complete the "Validity Check" form included. I will be visiting the unit within one week to receive your feedback. If you wish, you may drop off the chapter and form at my office in the Beverly Centre.

Thank you once again for agreeing to participate in this study. I look forward to receiving your feedback. Please call me at 253-8806 if you have any questions.

Sincerely,

Lana Harder

Appendix G - continued

Validity Check

Please indicate whether or not you agree with the following statements by checking "yes" or "no".

1) The researcher's presentation of the findings is accurate with respect to the information discussed in the focus group interview.

_____ Yes   _____ No

If no, please state what is inaccurate:

2) The researcher's interpretation of the findings "fit's" with my perception as a staff member.
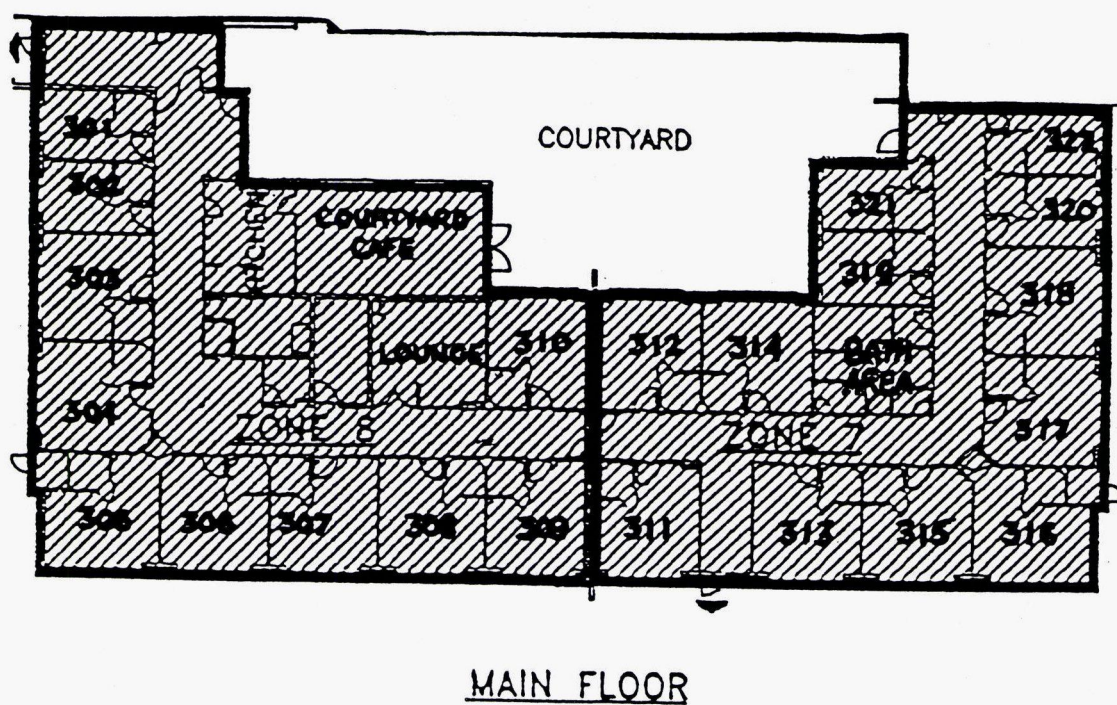
_____ Yes   _____ No

If no, please state what does not fit:

3) I am satisfied with the information presented in the findings of this study.

_____ Yes

Appendix H

Diagram of Unit 300

MAIN FLOOR

Resident Name:_____ _____

FUNCTIONAL ASSESSMENT STAGING (FAST)

ID Number:_____

GDS Stage	Functional Characteristics	Estimated Duration	ASSESSMENT											
			DATE / /			DATE / /			DATE / /			DATE / /		
			NO	YES	MO.*	NO	YES	MO.*	NO	YES	MO.*	NO	YES	MO.*
1	No difficulties, either subjectively or objectively.													
2	Complains of forgetting location of objects; subjective work difficulties.													
3	Decreased job functioning evident to co-workers; difficulty in traveling to new locations.	7 yrs												
4	Decreased ability to perform complex tasks (eg; planning dinner for guests; handling finances; marketing.)	2 yrs												
5	Requires assistance in choosing proper clothing.	18 mo												
6a	Requires assistance to dress.	5 mo												
6b	Requires assistance to bathe.	5 mo												
6c	Requires assistance with toileting (ie; forgets to flush; doesn't wipe properly.)	5 mo												
6d	Urinary incontinence.	4 mo												
6e	Fecal incontinence.	10 mo												
7a	Ability to speak limited (1 to 5 words a day).	12 mo												
7b	All intelligible vocabulary lost. (single word)	18 mo												
7c	Nonambulatory.	12 mo												
7d	Unable to sit up independently.	12 mo												
7e	Unable to smile.	18 mo												
7f	Unable to hold head up.	12 mo												

NOTE: Functional staging score = Highest GDS Stage checked

* Number of months deficit has been noted.

Check "yes" if characteristic is present. If due to other causes apart from dementia (ie; arthritis, paralysis), please check "no" and note these other causes next to the characteristic.

Appendix J

Programming for Unit 300 Residents

RECREATIONAL THERAPY PROGRAM OUTLINE
SPECIAL CARE UNIT

	10:30-11:30 AM	3:00-4:00 PM	6:30-7:30 PM
MONDAY	SUNSHINE CLUB	EXERCISE/ PHYSICAL GAMES	SPECIAL ACTIVITY/ MUSIC
TUESDAY	REMOTIVATION/ SENSORY	OUTINGS/ SPECIAL EVENTS	GENERAL PROGRAMMING
WEDNESDAY	CRAFT	EXERCISE/ PHYSICAL GAMES	SOCIAL/ COMMUNITY OUTING/ COGNITIVE
THURSDAY	COGNITIVE/ PHYSICAL GAMES	COGNITIVE/ REMINISCENCE	SOCIAL/ PHYSICAL
FRIDAY	EXERCISE/ PHYSICAL GAMES	COGNITIVE	GENERAL PROGRAMMING INTEGRATION
SATURDAY	GENERAL PROGRAMMING INTEGRATION	GENERAL PROGRAMMING INTEGRATION	GENERAL PROGRAMMING INTEGRATION

*THERAPISTS PLAN CONTENT ACCORDING TO BOTH THE OUTLINE AND RESIDENT NEEDS. PROGRAMS ARE EVALUATED MONTHLY FOR EFFECTIVENESS.

COGNITIVE
Reminiscence Group
Remotivation Therapy
Sunshine Club
Crafts
News and Views
Sensory Stimulation
Powder Puff
Sing-a-long
Travel Logs
Baking

SOCIAL
Tea Party
Men's Social Club
Ladies' Social Club
Happy Hour Dance
Birthday Party
Jam Session
Moms and Tots
Community Outing
Pet Visitation
Guest Entertainment

PHYSICAL
Let's Take a Stroll
Stretching
Excercise
Bowling
Fun and Games
Shuffle Board
Horseshoes
Gardening
Various Outdoor Games

Appendix J - continued

	NA #1	NA #2	NA #3	NA #4	NA #5
0700-0800	ADL	ADL	ADL	ADL	ADL
0800-0830	TABLECLOTHS	GROOMING (MON)	HAIRDRESSER (F)	TABLE SETTING	DINING ROOM
0830-0900	BREAKFAST	BREAKFAST	BREAKFAST	BREAKFAST	BREAKFAST
0900-0930	SWEEP FLOOR	REMOVE DISHES	FLOAT	TOILET	TOILET
0930-1000	TOILET	TOILET	TOILET	WALK OUTSIDE	FLOAT
1000-1030	MANICURE	HAIRDRESSER	EXERCISE	HAIRDRESSER	HAIRDRESSER
1030-1100	FLOAT	EXERCISE	HYDRATION	HYDRATION	EXERCISE
1100-1130	REST	FLOAT	REST	TOWELS	TOILET
1130-1200	TABLECLOTHS	TABLE SET	FLOAT	TOILET	REST
1200-1300	MEAL	MEAL	MEAL	MEAL	MEAL
1300-1330	TOILET	TOILET	TOILET	TOILET	TOILET
1330-1430	REST	REST	REST	REST	REST
1430-1500	TEA	TEA	TEA	TEA	TEA
1500-1530	MUSIC	WALK	MUSIC	WALK	FLOAT
1530-1600	GROOMING	TOILET	GROOMING	FLOAT	TOILET
1630-1700	TABLECLOTHS	FLOAT	DINING ROOM	FLOAT	SET TABLE
1700-1800	MEAL/CLEAN UP	MEAL/CLEAN UP	MEAL/CLEAN UP	MEAL /CLEAN UP	MEAL/ CLEAN UP
1800-1830	WALK	EXERCISE	FLOAT	TOILET	TOILET
1830-1900	FLOAT	ACTIVITY	ACTIVITY	EXERCISE	FLOAT
1930-2030	SNACKS	MUSIC	SNACKS	MUSIC	SNACKS
2030-2230	GROOM	GROOM	GROOM	GROOM	GROOM

Appendix K

GLOSSARY

Activities of Daily Living (ADL) - these refer to the activities of feeding, dressing, transferring and toileting. For the purposes of resident classification, the degree of assistance required by staff, to complete the activity, is assessed.

Behaviors of Daily Living (BDL) - for the purposes of resident classification, these refer to behaviors that place the resident at risk for injury and those that are considered ineffective coping. BDL's include: wandering, aggression, suspiciousness, hoarding and rummaging and demanding attention, for example.

Continuing Care Level (CCL) - refers to whether a resident is continent or incontinent of bladder and bowel functions.

Instrumental Activities of Daily Living (IADL) - refers to the tasks of daily living which are more complex than ADL's; these include doing housework, handling finances, preparing meals or managing medications.