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SPECIAL CARE UNITS: The Policy Practice Interface

by

Ellenor M. Frost
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We accept this thesis as conforming
to the required standard

[redacted]

Dr. Brian Wharf, Supervisor (Faculty of Human and Social Development)

[redacted]

Dr. Carolyn Attridge, Departmental Member (School of Nursing)

[redacted]

Dr. Howard Brunt, Departmental Member (School of Nursing)

[redacted]

Dr. Tim Diamond, External Examiner (Research Affiliate, Centre on Aging)

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University of Victoria

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Supervisor: Dr. Brian Wharf

ABSTRACT

This is a study of practice and policy in Special Care Units. Special Care Units (SCU's) are planned therapeutic environments in long term care facilities. These units are designed for the particular needs of elderly residents with moderate to severe cognitive impairment, principally those with Alzheimer's Disease and Related Disorders (ADRD).

The problem addressed by this study is that the knowledge and experience of staff working in Special Care Units has received little attention in the research and from policy makers. Special Care policy is developing without benefit from practitioner experience. The purpose of the study is to provide information about Special Care Units from the standpoint of front-line nurses, to describe the interface between the nurses' knowledge and experience and the larger policy context and to suggest the policy implications for Special Care Units arising from practitioner knowledge.

There are three research questions: 1. What are the key features, characteristics and components of Special Care Units? 2. What are the congruencies and incongruities between the nurses' knowledge and experience and the larger policy context? 3. What are the policy implications for Special Care Units suggested by the data?

A research perspective (rather than a theoretical framework) has guided the data selection and how the data is viewed. Two concepts make up the research perspective: standpoint and policy/practice interface. The principle data used in the study are interviews with nurses working in Special Care Units, supportive literature and policy documents. The study uses a flexible research design which combines interpretive and policy oriented methods. The interpretive, policy oriented approach is based on the perspective that reality is both constructed and contextually embedded. The knowledge thus created is a function of the researcher interacting with the participants and the participants bringing their own perspective into the process.

Interpretive analysis identifies four main categories (and several sub-categories) which describe the key features and characteristics of Special Care Units. The four categories are: Clients Created Elsewhere, The Dumping Ground, Coping as Care, and Creating a Community. The four categories are a construction and interpretation of the interface between the larger policy context and front-line Special Care practice. The congruencies and incongruencies between nurses' knowledge and experience and the larger policy context are described. The policy implications (problems, goals/objectives, strategies and resources) suggested by the findings conclude the study.

Examiners:

[redacted]

Dr. Brian Wharf, Supervisor (Faculty of Human and Social Development)

[redacted]

Dr. Carolyn Attridge, Departmental Member (School of Nursing)

[redacted]

Dr. Howard Brunt, Departmental Member (School of Nursing)

[redacted]

Dr. Tim Diamond, External Examiner (Research Affiliate, Centre on Aging)

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DEDICATION

This thesis is dedicated to Special Care front-line staff:
May practice wisdom be a catalyst for change.

Special thanks to:
My husband and children who have endured my shadow presence and obsessive focus long enough; Elaine Gallagher who suggested one way; Marie Campbell who pointed out several ways and several more; Howard Brunt who showed me the way not taken; Brian Wharf whose mirth and policy intelligence helped keep things in perspective; and Tim Diamond whose stories about the work of caring (even though it came from a man) inspired this project.

Barb Egan for her warmth, support and attention to detail that nobody else seems to understand and who deserves to be paid more; and to Barb Isaac for her equanimity and smarts, well developed sense of the ridiculous and the safe haven of friendship offered through it all.

CHAPTER ONE

BACKGROUND AND POLICY CONTEXT

Introduction

Many issues are interrelated and relevant to the care of cognitively frail elderly. An overview of these issues is presented in order to appreciate the multiple challenges presented by this growing population. Taken together these issues have influenced the development of Special Care Units. This section provides both background information and a brief discussion of the complexity and scope of the problems associated with planning and implementing specialized care for the cognitively frail elderly.

Background

Caregiving for the elderly with irreversible dementia within a formal care setting poses difficult problems for administrators, front-line staff, family and for the elder him/herself. Although the etiology and clinical features of dementia differ, the combination of cognitive impairment, behavioral problems and diminished capacity to perform activities of daily living characterize this population (Lieberman & Kramer, 1991; Mahurin, DeBettignes & Pirozzolo, 1991; Spector, 1991; Gold et al., 1991; Berg et al., 1991). Wandering, agitation, incontinence and poor hygiene, inappropriate social/sexual behaviours, repetitive behaviours in addition to affective (ie depression) and psychotic (ie delusions, hallucinations) behaviours are associated complications in over 1/3 of this population (Health & Welfare Canada, 1988; 1991). Because of these associated characteristics, managing behaviour and providing security and protection for these elderly and non-cognitively impaired residents has been the traditional focus of caregiving. However, devising approaches to care which, in addition to ensuring the safety and security of residents, also enhances residents' quality of life has proven to be an elusive and difficult challenge. Problems associated with this traditional approach have been identified: a) increasing injuries to staff and other residents, b) increased use of physical and chemical restraints, c) high staff stress and turnover, d) family distress and dissatisfaction, and e) deterioration in functioning and well being of the elder (Brody, Lawton & Liebowitz, 1984; Gold et al., 1991; Health & Welfare Canada, 1988; 1991).

Although most conventional Long-Term Care facilities attempt to individualize care plans for their residents with dementia who reside among the non-cognitively impaired in non-specialized settings, the impact of these efforts has limited effect on difficult, inflexible behaviours attributed to profound short-term memory loss. For example, behaviour modification has no effect on people with little or no short-term memory. Short-term memory loss means these elderly cannot learn anything new (Coons, 1991; Ronch, 1987; Rabins, 1986; Rovner et al., 1990).

It is now recognized that behaviours related to short-term memory loss and cognitive impairment such as wandering, pacing, inflexibility in decision making, sleep disturbances, catastrophic reactions, yelling, hoarding activity, aggression, inappropriate sexual and eating behaviour are not easily addressed in traditional, "integrated" institutional environments. Research further indicates that integration of the cognitively impaired with the cognitively well impacts negatively on both groups (Cluff, 1990; Coons, 1991; Ohta & Ohta, 1988). Segregated environments with specially trained staff, environmentally sensitive designs and highly specialized therapeutic approaches to care have been identified as critical factors in improving safety and quality of care and quality of life for cognitively impaired residents (Nehrke, Morganti, Hulicka & Cohen, 1987; Riley & Kahana, 1985; Cluff, 1990; Ohta & Ohta, 1988). The pressing need to develop alternative, effective and humane approaches to care has resulted in the development of SCUs across Canada and the United States.

Scope and Significance

Health care in British Columbia is undergoing profound and large scale change. An aging population, changes in family structure and work patterns especially among women, anticipated shifts in federal/provincial cost-sharing in health care, an economic climate of restraint, new patterns of immigration, and shifting ideology and knowledge about health and health care organization are profoundly influencing health care policy and planning in British Columbia (Aronson, 1986; Evans, 1987; Royal Commission on Health Care and Costs, 1991). Effective policy and planning for a changing and aging population depends on developing a range of services which are innovative, appropriate, accessible and cost effective.

People over 65 years now comprise almost 13% of the total population within British Columbia. This percentage is expected to rise to 14.5% over the next 20 years (British Columbia Ministry of Health, 1989). The most rapid increase within the elderly population is the old-old, those 85 years and older whose members will increase by 51% between 1990 and the year 2000 (Royal Commission on Health Care and Costs, 1991).

Demographic trends, in combination with other significant social and economic indicators, suggest the need for change in the type and quality of health and social services for the elderly. Included among these services are residential and institutional facilities within the British Columbia Long-Term Care (LTC) Program.

Presently, institutional care for the elderly consumes 75% of the resources allocated to the elderly (British Columbia Ministry of Health, 1989). Roos, Shapiro and Roos (1987) in a study of nursing home utilization patterns found that advanced age was the greatest risk factor for nursing home placement. Additionally, Kraus et al. (1976) and Shapiro and Tate (1985) found living alone and low family income were associated with higher rates of admission to institutions. While most elderly remain in good health and continue to live in the community, a small proportion or 5% of those 65 years and older, account for a disproportionate utilization of these formal health resources (Angus, 1985). In 1990/91 the British Columbia Ministry of Health spent **$597 million** on 25,000 residents in Intermediate and Extended Care facilities (Royal Commission on Health Care and Costs, 1991). Increased longevity and a growing population of old-old requiring intensive, specialized health and social resources poses a serious challenge to government and service providers.

Considerable controversy exists about the appropriateness and associated costs of institutionalization of a relatively small segment of the elderly population (Aronson, 1986; Chappell, 1988; Evans, 1987; Forbes, Jackson & Kraus, 1987). The current health policy shift towards regionalization and community-based programs of care reflects this concern. However, until alternatives to institutional care are implemented, residential facilities will continue to assume this important role.

Facilities at the Intermediate and Extended Care level primarily care for a population of elderly with multiple and complex health care needs (Royal Commission on Health Care and Costs, 1991). Among this population are the cognitively frail elderly, those with psychiatric and dementing illnesses (Health & Welfare Canada, 1988; 1991).

By far the largest and fastest growing group among the cognitively frail elderly are those with dementia. While the spectrum of innovative community-based programs have begun to reduce total admissions to long term care institutions, the rate of admission for those with dementia remains high and growing (Health & Welfare Canada, 1988; 1991). Health and Welfare projections, based on current demographic trends, estimate that by the year 2006 the total cases of dementia will exceed 325,000. Of the 203,000 elderly (65+) currently residing in Canadian institutions, at least half have a dementing illness (Forbes, Jackson & Kraus, 1987; Health & Welfare Canada, 1991; Lynaugh & Mezey, 1989). On the basis of these conservative estimates and with the expected increases in the British Columbia population, the number of people with dementia will increase from 24,905 in

1992 to 45,987 in 2006 - an increase of 85% (McEwan, 1991). Although a larger percentage of elderly with early stage dementia (all ages) live in the community despite severe mental, physical and behavioral challenges posed by the illness, those entering an institution in the very near future will be both older and more frail (Roos & Shapiro, 1987; Schwenger, 1987; Health & Welfare Canada, 1988; 1991). The combined impact of an aging population and the risk of dementia escalating dramatically with age (1.4% prevalence in those 65-75 years compared to 21% prevalence in the 85-89 year age group) has important implications for health and social service policy, program planning, clinical research and front-line practice (Health & Welfare Canada, 1991).

Policy Context

The evolution of care services for the frail elderly in British Columbia, culminating in the development of Special Care Units for the cognitively frail, demonstrates a tension between differing policy initiatives; institutionally based care and community based care. Often the approaches to care have been developed in isolation from each other rather than in harmony. Gradually, institutional modes of care delivery, fashioned after the acute hospital model, gained ascendence. Standards for care and safety (supported by legislation), increasing government control over residential services (contractual arrangements with service providers, funding formulas and staffing) created a policy environment which organized and structured care.

Although locales, funding, type and proportion of various service arrangements for the frail elderly have fluctuated over time, nurses and nurse aides continue to be the main care providers.

The following section describes both the evolution of care for cognitively frail elderly within the LTC system and situates the development of Special Care Units as the terminal point on this policy continuum. The section outlines how Special Care policy has evolved and is being shaped by present government initiatives. These policy initiatives, based on available evidence, have excluded participation by front-line Special Care nurses.

Historical Outline

The policy context of facility based care in British Columbia can be traced back to 1947. At that time, public health nurses (principally the Victorian Order of Nurses) provided nursing services in the home. An organized "Home Care Program" was formally introduced as a component of the public health nursing program in British Columbia. Between 1947 and 1976, a series of provincial government initiatives were undertaken to reduce use of acute hospital bed days (and the associated costs) by patients with chronic long-term disabilities. Formal home nursing units were established in several regions along with the appointment of public health physiotherapists who would teach public health nurses how to set up and implement community activation programs.

The Hospital Insurance Act (passed in 1948) was expanded to cover persons receiving **medical care** in Extended Care facilities. The Act did not include similar funding support to persons receiving **nursing care** in community programs. In 1976 the responsibility for the delivery of home nursing care services was absorbed by the Ministry of Health. During this same period the "Established Program Funding" was introduced by the Federal government to replace cost sharing for health services. Additional cash grants targeted for nursing home coverage were also included.

In 1978 the government of British Columbia implemented a Long-Term Care Program to provide services to clients requiring long-term support. Physiotherapists who had provided agency based services in a similar manner to the Victorian Order of Nurses were merged with Home Nursing Care to become the Long Term Care/Home Care (LTC/HC) program in 1980. Interestingly, in 1982 the Home Care Program name was changed back to Home Nursing Care Program to emphasize the main provider of services - nurses - whose practice had been systematically absorbed into government run programs since World War II.

The LTC/HC Program was renamed again in 1983 as the Continuing Care Program. Although the name change emphasized the growing, broad institutional/home support system, it de-emphasized the central role of nurses who continued to be the main care providers. The name change additionally signalled the growing institutionally based side of LTC services. In the 1980's, there was a proliferation in building of long term facilities. Not surprisingly, there was a parallel increase in the institutionalization of elderly requiring continuous supportive nursing services for chronic disabilities (Government of British Columbia - Ministry of Finance and Corporate Relations, 1991). The growth of institutional facilities paralleled, if not superseded, the government's policy direction to establish standardized home nursing care services to prevent or delay institutionalization.

The original 1950's policy to decrease acute hospital bed days through the expansion of government administered community nursing service programs was only partially successful. Large, expensive hospital-like chronic care institutions continued to be built in British Columbia. Care of chronically disabled clients, principally the elderly, was primarily achieved through shifting clients from one total institution to another; from acute hospital care to chronic hospital care. The mode of care which developed in these residential facilities was no less hospital-like, standardized and routine than acute hospital care. Operational procedures in long term facilities perpetuated administrative structures and care practices originating with the acute care medical model. The facilities both looked and operated like hospitals and in some instances were called hospitals. "Residents" retained their patient status and illness and treatments became the organizing principle of care.

What did change was the amount of funding allocated to residential facilities. Long term care facilities were funded and staffed at a considerably lower level than hospitals.

In 1990, the Continuing Care Act was passed along with the introduction of service provider contracts eg the government contracted with residential facilities to provide chronic care services in accordance with the Act. The Continuing Care Act defines Continuing Care and provides the Ministry of Health with the authority to:

- Establish certain operating and program standards.
- Intervene in crisis situations.
- Establish a written agreement with each funded service provider.

The Community Care Facility Act (1979; 1989), also administered by the Ministry of Health, established licensing requirements for the operation of community care facilities (adult and child care). Specific regulations within this Act detail the requirements for adult care facilities. The Continuing Care Act (1990) and the Community Care Facility Act (1979) give the Ministry of Health the legal authority to establish environmental, care and safety standards for facility based care. The Acts give the Ministry authority over licensing and funding to long term care facilities. The provisions of the Acts frame caregiving to fit with standardized nursing care, cleanliness and safety features to be applied across the board to all community facilities. The standards are meant to protect the public from unacceptable conditions and practices. Administrators and nursing supervisors are answerable to provincial authorities for ensuring that the standards are met (Parker, 1992).

Most facilities today are either wings of hospitals converted to chronic care units or have been built using a hospital model which conform to the Acts. Most facilities (except in rural areas) are large, functional and impersonal and have been built according to standards which focus on physical care (Pallen & Young, 1992, p.41).

In summary, a review of the history of LTC suggests that although the Ministry recognized in the late 1940's the need to provide more appropriate community based care for the chronically disabled population, it did so by building large institutions which have effectively re-institutionalized most of the target population. A rather inflexible set of options emerged: the choice between institutional or home-based care. In contrast to Mental Health, LTC did not appear to consider other residential options such as group homes to meet the environmental and care needs of this population.

Additionally, professional control of practice for nurses (and physiotherapists) was weakened when the Ministry took control over long term facility and community care programs. Nurses, once agency based practitioners, became employees of homecare programs/agencies and chronic care facilities which contracted services with the government. Care standards, as defined in the service provider contracts, took precedence over professional influence, experience and discretion in setting care standards. Service provider contracts, negotiated between facility administrators and the Ministry, were drawn up in accordance with the Acts. Funding provided by the Ministry was tied to a facility's conformity to the contract. Provider contract negotiations did not include professional or non-professional caregiver representatives. Funding formulas were determined by the Ministry in consultation with agency administrators. Nurses and care aides had no representation in the policy process which both organized and funded their work, and a similar omission occurred with respect to development of Special Care Units. This process is discussed in some detail in the following section which outlines the policy context in which Special Care Units have developed.

Present Policy Context

The Continuing Care Division (CCD) has primary responsibility for providing a range of residential and community based services for handicapped and infirm or frail individuals, especially the elderly. The CCD determines policy and acts as both a funding and direct service agency for all provincial LTC programs. Since 1978, facility and community services have been planned, coordinated, implemented and funded through this division of the Ministry.

Continuing Care contracts with (purchases services from) over 600 service agencies across the province on behalf of eligible clients. These services include homemaker agencies, adult day care centres, group homes, family care homes, meals on wheels, short stay assessment and treatment centres and Personal/Intermediate Care facilities.

Organizational Structure

The CCD central office, located in Victoria, provides policy direction to community LTC program offices in each of the 21 provincial Health Units. (16 Health Units plus 5 Municipal Health Departments of Victoria Capital Regional District, Vancouver, Burnaby, Richmond and North Shore comprise the 21 provincial Health Units). The office staff in the 16 Health Units are provincial employees whereas staff of the 5 municipal departments are employed by the municipality.

LTC programs are coordinated and administered by the 21 Health Units (referred to as "field offices") by a Continuing Care Manager. The 21 Provincial Health Units are currently organized within 5 Provincial Health Regions - roughly encompassing discrete geographical areas eg Vancouver Island, the North, Metro Vancouver/Sunshine Coast etc. Each health region is under the administrative direction of a CCD regional director located in central office. (A CCD organizational shift in now underway to move the regional director positions from central office to regional locations.)

Policy and planning originates in central office and programs are delivered by the health units. The organizational structure is one of centralized policy and decision making authority located in Victoria with programs administered through a decentralized structure.

Entry into the System: Client Eligibility

A person is eligible for the LTC program if that person:

- is a Canadian citizen, landed immigrant or holds a Minister's permit approved by the British Columbia Ministry of Health's Medical Advisory Committee;
- is 19 years of age or older;
- has a progressive or chronic health condition or health problem which generally lasts for at least three months.

(Ministry of Health, Continuing Care Division, Service Provider Handbook, 1992).

Persons seeking services at the Personal/Intermediate Care Level must additionally:

- have lived in British Columbia continuously for 12 consecutive months immediately prior to making application for benefits under the program.

(Ministry of Health, Continuing Care Division, Service Provider Handbook, 1992).

Point of Entry into the Long Term Care Program

There is a single point of entry into the LTC Program. A client's entry into the Program typically begins with a call to the local Health Unit by any concerned person eg neighbour, relative, physician etc. A client is referred to a Case Manager (LTC Assessor) who then contacts the referred client. The LTC Assessors are the gatekeepers of the LTC Program. Typically their backgrounds are in nursing and social work and they are responsible for determining the client's eligibility for benefits under the Program.

The formal application for benefits under the LTC Program is contained within the Program's Application and Assessment Form (LTC 1-5). The form is completed following the Assessor's home visit when they evaluate the referred client. It is the Assessor's job to determine the need for services and work with each client and/or family (or other relevant parties) to determine the most appropriate and cost effective services within available resources. At any time an average caseload for an assessor in an urban area may be as high as 300 clients (Personal communication with Capital Regional District LTC Assessor, 1993). The goal of the LTC Program is to provide a coordinated plan of supportive services to ensure that each client continues to receive appropriate care/support as health status and circumstances change (Ministry of Health, Continuing Care Division, Service Provider Handbook, 1992). Whenever possible services are provided within the client's own community. The initiation of LTC services begins only after the Assessor determines that personal and family resources are unable to meet health care needs: the program recognizes the right and responsibility of the individual to remain at home for as long as it is reasonable, safe and practical to receive health services in the home setting. (Ministry of Health, Continuing Care Division, Service Provider Handbook, 1992).

The Continuing Care Division establishes the rates paid to individual service providers for each purchased service such as day care, homemaker, home nursing care, meals on wheels and eventually, residential services.

Special Care Clients Entry into the Long Term Care System

Cognitively frail elderly, principally those with a dementing illness, may require few supportive services at the early stages of their illness. Maintaining someone with dementia at home without supportive services becomes more difficult as the illness progresses. Variations in the elder's functioning and behaviour, familial circumstances (economic, social and cultural) strongly influence the utilization of external supportive services. Unpaid caregiver perception of need for help, cultural barriers to accessing help, client resistance to receiving external help, the type and availability of service desired and cost are all barriers to timely access to community LTC services (Pittaway, 1992). Each service has a standard contract limiting the nature, extent, duration and cost of service. These criteria are determined solely by the LTC Program and any deviation or discretion in program benefits that falls outside of the standard contract is controlled by the Continuing Care Administrator in the local Health Unit. Deviation in service contract is unusual, although discretion by Assessors at the local level is common practice (Personal communication LTC Assessor, 1993).

For families coping with dementia, client reassessment is typical. As the illness progresses a family's capacity to cope diminishes as the care requirements intensify. The Assessor, while adjusting the package of services to reflect changing needs, will usually reassign the client to a different Care Level. Benefits and extent of services in the community and facility care is tied to each Care Level.

The documentation process involves completion of a lengthy Application and Assessment Form (LTC 1 - 5) which is the standardized interviewing tool used by all Case Managers. The LTC Form was developed in late 1970 and has remained unchanged. The information gathered on this form provides the documentary evidence of a client's need for services within the LTC program. It is also the evidence used to support the Assessor's recommendation to the Continuing Care Administrator concerning eligibility, Level of Care and the service delivery plan.

Care Levels

Care Levels provide a means for the Program to classify and compare clients by functional abilities. The five Care Levels range from lighter care requirements through 3 Levels of Intermediate Care to the heavier care requirements of Extended Care. The criteria for determining the Level of Care are independent of the client's place of residence. The Assessors determine Care Levels by evaluating functional needs they identify on the LTC 1 Form against the Care Level criteria developed by the Ministry of Health. Care Level criteria was also developed in late 1970. The criteria used in the LTC program include the following:

Personal Care (PC)

This level of care recognizes the person who is independently mobile with or without mechanical aids, requires minimal assistance with the activities of daily living, and requires nonprofessional supervision and/or assistance.

Intermediate Care 1 (IC1)

This level of care recognizes the person who is independently mobile with or without mechanical aids, requires moderate assistance with the activities of daily living, and requires daily professional care and/or supervision.

Intermediate Care 2 (IC2)

This level of care recognizes heavier care and/or supervision requiring additional time. The basic characteristics of this level of care are the same as for Intermediate Care Level 1.

Intermediate Care 3 (IC3)

This level of care recognizes the psychogeriatric person who has severe behavioral problems on a continuing basis. However, this level of care may also be used for persons requiring a heavier level of care involving considerably more staff time than at the Intermediate Care 2 level but who are not eligible for Extended Care.

Extended Care (EC)

This level of care recognizes the person with a severe chronic disability which has usually produced a functional deficit which requires 24-hour-a-day professional nursing services and continuing medical supervision, but does not require all the resources of an acute care hospital. Most persons at this level have a limited potential for rehabilitation and often require institutional care on a permanent basis. (Ministry of Health, Long Term Care Program, 1992).

The following provides an example of how Care Levels are tied to service benefits for Home Support:

Service Benefits for Home Support by Care Level

Level of Care	Maximum Hours per month
Personal Care	40
Intermediate Care 1	46
Intermediate Care 2	64
Intermediate Care 3	98
Extended Care	120

In the above example, a client assessed at IC3 (the majority of people with middle stage Alzheimer's disease) can receive 98 hours per month (4 days) of Home Support services in addition to limited Day Care and short term respite placement in a facility. Community night services are not included in the policy.

Funding Mechanisms for Facility Care

Care Levels are integral to the funding formulas for Intermediate Care Facilities. Most facilities participate in the LTC Program. Originally, a two tier payment scheme was developed for profit and non-profit facilities. Due to rapid inflation, difficulties arose between the two payment schemes. Now, both profit and non-profit facilities who have opted to belong to the LTC Program, are reimbursed using a formula based on industry cost standards. The challenge to the government is to maintain a two sector industry in which the often competing forces of cost and quality can be both identified and audited. The current system has attempted to address these dimensions through the following mechanisms:

- The same reimbursement formula is applied to profit and non-profit organizations.
- Financial accounting procedures are built into the reimbursement system.
- Quality of care is monitored to ensure an adequate standard is maintained.
- LTC Program's financial, administrative and quality of care requirements for facilities will be formalized into a contractual agreement with facilities.

(Ministry of Health, Continuing Care Division, Facility Reimbursement System, 1985).

In addition to per diem costs for each resident in facility care there may be additional accommodation costs such as equipment and other medical supplies some of which are paid by the client and some paid by the government.

The greatest single cost to government, in both profit and non-profit facilities, is reimbursement for staffing costs. Staffing costs for non-profit facilities are based on the existing Non-profit Staffing Guidelines and the average full time equivalent (FTE) salary of the particular facility. For-profit facilities belonging to the LTC Program should staff according to these guidelines but may also charge client fees in excess of the reimbursement by Care Level. These Staffing Guidelines were developed in tangent with the 1977 Care Levels and were revised once in 1979. The Staffing Guidelines recommend the number and type of staff which may be used to maintain care levels in facilities. The Staffing Guidelines are the primary source of data used to establish yearly budgets for non-profit facilities. The Guidelines, based on occupied bed and Care Level of resident determine the number of staff a facility may use and be paid for.

The funding calculation follows a set mathematical formula to determine FTE's per resident. Staffing is directly tied to Care Levels. The number of staff allocated results from a calculation based on Level of Care X Number of Occupied Beds X a Multiplication Factor to arrive at the allowed (funded) staff FTE's. To calculate the actual number of FTE's in a facility, the Total Number of scheduled hours of work in a given time period is divided by a 37.5 hour week.

The only way a for-profit facility can make money is by keeping their beds occupied, cutting expenditures in other areas such as dietary and activity programs and charging clients large monthly fees.

Special Care Client Entry into Residential Care

A person with progressive functional deterioration and increasingly difficult behaviours (eg wandering and elopement, incontinence, socially inappropriate sexual and eating behaviours) will receive 24 hour care at home. The maximum hours allowed for Home Support - in addition to other services such as day care and respite bed use - is soon exhausted. The care requirements rapidly exceed policy limits for hours of service and are currently more expensive than care in an institutional residential setting. The cognitively frail elder, at this stage, requires constant supervision and daily professional care. Frequently the person is at risk in the community due to their physical and mental deterioration.

Within the LTC program there is only one type of residential setting available to elderly clients with a dementing illness. All residential facilities for this client group are institutions. These institutions are long term care hospitals called residential care facilities.

Placement in a LTC facility is considered when caregiver supports are exhausted and because no alternatives to institutional placement exists for this client group. Final consideration for residential care is usually reduced to two factors: 1) It is not possible or appropriate to provide an adequate program of home support services, and 2) the costs of home support services have become prohibitive. If a LTC Assessor decides a client requires residential care, the client's Care Level is determined. This decision is communicated to the client and the family and/or sponsor and client's physician.

Moving a client from the community to residential care is based on the Care Level needed, the family's preference and the availability of a facility bed. For this client group, placement on a waitlist for the first available bed is common. Waitlist times vary according to regional resources and demand. In large urban areas a client may wait for a bed for up to a year and in very rural areas the wait for a bed in or near the elder's community may be as long as two years.

For this type of client, a family's choice of Long Term Care residential facility includes:

- Intermediate Care facilities.
- Multilevel Care facilities.
- Licensed Private hospitals.
- Extended Care facilities.

Extended Care facilities are administered under Hospital Programs not LTC. Group homes, Personal Care residences and Family Care Homes, also administered by the LTC Program, do not accept cognitively impaired elderly clients. Intermediate Care (IC) facilities are used most frequently for these clients. IC facilities are designed to care for clients assessed at the Intermediate Care Levels 2 and 3. Clients assessed at the heavier Extended Care Level (EC) may reside in these facilities but most IC facilities refuse EC clients.

Once institutionalized in an IC facility, a demented resident's capacity to function independently will decline as the disease progresses. This decline frequently necessitates reassessing the client from IC to EC Level. The change in health and functioning often means the client is physically moved from an IC facility to an EC facility. The logic of this policy can only be explained in terms of program design and administrative control. Extended Care is still under the funding and administrative umbrella of Hospital Programs whereas clients, in the most frail stage of life, are required to move because the organizational structure in the Ministry separates Extended Care from other LTC Programs.

In early 1990, the Ministry initiated a policy shift to integrate IC and EC clients within one residential facility. These facilities are called Multilevel Care (Ministry of Health, Facilities Planning and Construction, 1992). Clients admitted to these facilities are not required to physically move because their functional health has deteriorated.

Multilevel Care

Multilevel Care (ML) is the new policy model for residential care facilities. The explicit objective of Multilevel Care is to minimize transfer trauma for the resident enabling them to age in place and reduce/eliminate the administrative layer and costs associated with transfers. Multilevel facilities have mixed Care Levels, although within the facilities clients are usually segregated according to level and care requirements. (It should be noted that Extended Care clients living in ML facilities continue to be funded through Hospital Programs, while ML facilities are administered and funded through the LTC Program.)

All new Long Term Care residential facilities are now built according to ML Design Guidelines and Standards (1992). For the most part, these continue to be large, hospital like institutions. Facilities requesting funding for upgrading and renovations must attempt to incorporate, wherever possible, ML Care Design Guidelines.

Current government thinking about Special Care clients, and the residential environments they require, are reflected in the ML Guidelines. The Guidelines outline primarily environmental recommendations related to: resident behaviours, environmental design, separation/integration, size of units, overall space requirements - room size, walking/wandering area, dining/activity, bathing, storage, staff area, corridors and loops, outside wandering area - way finding cues, acoustics, lighting, flooring and other sources to minimize extraneous stimuli, and alarm devices on exits.

Special Care Unit Guidelines

The Multilevel Care Guidelines (1992) were the first government policy initiative directed toward the Special Care client population. In July 1992, the Continuing Care Division developed a "Special Care Unit Resource Manual for Facility Caregivers" (1992). The manual was developed principally by a CCD Program Analyst, a Psychogeriatric Psychiatrist, and the Unit Manager of a well established Special Care Unit in an Intermediate Care facility. The Resource Manual ("Draft for Discussion") was intended to provide policy and program guidance to facilities currently providing or planning to provide a Special Care component for cognitively impaired elderly. The Resource Manual was sent to all the Health Units in the province to be distributed to target facilities. The Resource Manual for Special Care Units (1992) was written in the absence of knowledge of Special Care Units currently operating or planned. The Resource Manual was distributed **prior** to the Special Care Unit Survey which will be discussed in a subsequent section. Thus, without the benefit of data about operating SCU's, policy direction emerged from CCD central office. Direct care staff, families, agencies, professional organizations, unions and other key stakeholders were not consulted in the development of the Resource Manual. The Ministry took the initiative to:

- identify the target population,

- provide a definition of a Special Care Unit,
- provide recommended functions of an SCU,
- determine guidelines for admission and discharge criteria and process,
- outline considerations for staff coverage,
- provide guidelines for training and education of SCU staff,
- provide guidelines for unit design and construction planning,
- recommend SCU activity/therapy program principles,
- suggest the role of Mental Health services in relation to Special Care.

Parallel Policy Initiatives

Special Care is being shaped by other policy initiatives in addition to the ML Guidelines and the Special Care Resource Manual. The reintegration of elderly psychiatric clients from Riverview Hospital into the community has coincidentally paralleled the ML Guidelines and Resource Manual. Riverview is the largest psychiatric hospital in the province, resourced and funded under Hospital Programs. Many of the elderly Riverview patients differ markedly from dementia clients. Many elderly Riverview clients have long term psychiatric histories and often difficult and sometimes dangerous behaviours. Acute episodic symptoms are commonly associated with their illnesses. Additionally, many of the elderly with chronic mental illnesses are now experiencing increasing somatic health problems as they age. Most of the Riverview clients have lived for years in a controlled hospital milieu, with their care provided by specially trained psychiatric staff.

The current Riverview initiative involves placing patients requiring 24 hour security and professional supervision in LTC facilities. The complexity of care required by elderly chronic psychiatric clients is significant - as is the associated cost. The cost of maintaining a patient at Riverview is much more expensive than funding the same patient in a LTC facility. The Special Care Unit Resource Manual ("Draft for Discussion") specifies that psychiatric clients are to be part of the Special Care population. The Special Care Resource Manual (1992) states that, "clients with a chronic psychiatric disorder **ARE** eligible. However, SCU's are **NOT** intended for those individuals whose unmanageable behaviour is attributable to an acute exacerbation of a psychiatric disorder" (p.3).

Riverview Hospital, in order to curb health care costs, is downloading its psychogeriatric population to community LTC facilities. There are no other secure, residential environments to accommodate the psychogeriatric group being discharged from Riverview. Mental Health Group Homes do not accept psychogeriatric clients, although no formal policy could be found to explain this practice. Already, over 100 Riverview clients have been transinstitutionalized into Long Term Care facilities across the province.

Special Care Unit Survey

The final government Special Care policy initiative was to develop a survey of all existing and planned Special Care Units in the Province. The explicit intention of the survey was to:

- Identify one or more units as resources within each Health Unit/Department.
- Determine useful admission discharge criteria.
- Establish therapeutic environment and programming guidelines.
- Establish rational and equitable funding for service providers.

(Ministry of Health, Special Care Unit Survey, 1992).

The survey was developed by central office staff and distributed to the 21 Health Units in the province. The 14 page survey instrument was not piloted and was distributed **after** the Special Care Unit Guidelines were developed. Health Unit Managers were asked to complete the survey (in consultation with their staff and service providers) for all existing and planned Special Care Units. The survey was **not** distributed to Special Care Unit front line staff. The survey results were analyzed and compiled in Spring 1993.

In summary, the ML Guidelines, the Special Care Resource Manual, the Riverview downloading and the Special Care Unit Survey are shaping policy for Special Care. The shaping process has taken place with no evident coordination, strategic planning or broad consultation with key stakeholders.

Special Care Units in B.C. began as a practice response to a complex and difficult care situation involving increasing numbers of elderly clients with dementia. However, there is no available evidence to suggest that knowledge and experience of front-line caregivers informed any of the government initiatives. Front-line Special Care staff have been systematically excluded from each step in the policy process. The policy vacuum is slowly being filled from the top-down. The government is poised to finalize a policy framework for this complex area of facility based care without benefit of the experience, knowledge and concerns of nursing staff working in Special Care.

CHAPTER TWO

REVIEW OF THE LITERATURE

The following review of the literature is organized according to major themes and trends identified with Special Care Units. The literature broadly focused on four key elements: person-environment congruence, physical/environmental features and adaptations, policy context/administrative organization and staffing issues.

Person-environment congruence is the degree of fit between the SCU care environment with the needs and characteristics of the residents and with the practice concerns of staff (Lawton, 1970). The concept is significant in that it captures the intent of Special Care Units to develop a care environment which meets the needs of cognitively impaired residents.

Physical/environmental features and adaptations are those design elements which have developed in Special Care Units which are associated with or impact upon person-environment congruence. Much of the Special Care literature is devoted to studies and discussion of environmental design features.

Studies of policy context/administrative organization focus on the relationship between the policy environment and the development of Special Care Units. To date this has been the weakest area of research.

Staffing issues broadly cover all aspects of staffing: training/education, deployment and numbers, and workload/working conditions associated with Special Care. The literature did offer prescriptive suggestions in regard to staffing issues but no studies were uncovered which were informed by practitioner experience and knowledge.

As Kane and Kane (1987) have noted a residential home is not a single program but a setting for a package of services. Special Care Units are a subsetting of the larger facility community. The key features and nature of Special Care services are emerging but not well understood. The eclectic nature of the research and the predominance of opinion pieces characterize the uncertain nature of these specialized therapeutic programs.

In broad terms, the available Special Care literature is divided between environmental and program elements, with the vast majority of studies speaking to the American experience. Of particular concern is research which addresses both the Canadian or provincial experience and which focused on the relationship between the larger policy environment and the development of Special Care Units. Additionally, studies were sought which captured front-line practitioner knowledge and experience. As the literature review indicates, there is a paucity of Canadian publications and an absence of studies or opinion pieces dedicated to identification and analysis of the larger policy environment, practitioner experience or the linkages between the two.

Key features and characteristics of Special Care Units identified in the literature were useful in developing some of the interview questions. The gap in the literature, in terms of policy environment and practitioner perspective, guided the development of other interview questions. The literature provides a backdrop against which the results and analysis of this study may be discussed.

Person-Environment Congruence

Previous research has established that the environment is a critical factor affecting the elderly individual's behaviour and sense of well being. Nehrke, Turner, Cohen, Whitbourne, Morganti and Hulicka (1981) reported on the development and testing of the Environmental Perception, Preference and Importance Scale (EPPIS) designed to measure person-environment (p-e) congruence, psychological well-being and adjustment of the elderly in long-term care facilities. The study demonstrated that the impact of the environment could be empirically measured by this tool. The results could be used to enhance and alter critical environmental factors affecting p-e congruence. A weakness of the study was the exclusion of the cognitively impaired elderly in the sampling frame. Further studies are needed to develop tools to measure p-e congruence with the cognitively impaired elderly.

Cohen, Lyman and Pynoos (1991) described a two year project involving the development of training materials for staff in adult day care centres. The aim of the study was to increase awareness of the effect of the physical environment on persons with Alzheimer's disease and related disorders. Three major areas of the physical environment were included in the training: 1) environmental cues to promote recall, 2) safety and accessibility and, 3) surveillance and wandering. Through pre and post-test evaluation, the findings indicated that awareness of the effect of the environment on persons with Alzheimer's was significantly increased in all staff participants. Significant reduction in staff stress and improved functioning of the elderly (based on staff perceptions) following the educational intervention was demonstrated.

Randall, Burkhardt and Kutcher (1990) examined program considerations for the design of exterior space for Alzheimer's elderly in facilities. Design schemes were outlined based on the cognitive and behavioral symptoms manifested with the disease. The study presented various concepts and suggestions for creating outdoor activity and garden space for this population (ie looped wandering paths to decrease necessity for directional decision making, minimal shadow areas to decrease perceptual distortion, use of non-toxic and edible plants). Architectural modifications suggested by the authors were designed to be responsive to the lack of adaptability of these elders to their environment. The authors suggest that many of the behavioral problems seen with Alzheimer's elderly are environmentally induced. Consequently, physical environmental modifications were conceptualized as a source of therapeutic treatment. Moos, Gauvain, Lemke, Max and

Mehren (1979) reported on the concept and assessment of social climate in sheltered care settings. The Multiphasic Environmental Assessment Procedure (MEAP) was developed to evaluate sheltered care settings for the elderly using four approaches: 1) physical and architectural features, 2) policies and procedures, 3) the human aggregate (characteristics of residents and staff) and, 4) social climate. The theoretical basis of the MEAP assumes that environments have unique "personalities" that can regulate and direct behaviour. The authors build on a theory developed by Murray (1938). The theory suggests that social climate is created by the dual interaction between personal needs and the demands or press of the environment. The MEAP appears to be sensitive to certain aspects of nursing home environments which are not assessed by the type of data usually collected on organizational policies, staffing, resident characteristics etc.

Smith and Whitbourne (1990) reported their research testing the validity of the Sheltered Care Environment Scale (SCES), which is the section of the MEAP scale designed to measure social climate. The SCES and a parallel open-ended interview were administered to 25 non-cognitively impaired residents of a long term care facility. A multi-method/multi-trait validity matrix was generated which contained intercorrelations among the seven SCES subscales and the interview ratings. Lack of validity for three of the SCES subscales was revealed. The research suggested that the SCES subscales were not sufficiently sensitive to measure major aspects of the environmental factors they are purported to measure. Although a small sample size was used the findings were significant because the SCES has become a popular tool to assess the quality of nursing home settings.

Moos and Igra (1980) examined the relation between the social environments of sheltered care settings to the type of setting and three other aspects of environmental domains: 1) physical and architectural features, 2) organizational policy and programs and, 3) aggregate resident and staff characteristics. Data from 90 sheltered care settings was collected as representative examples of the three environmental aspects. Through multiple regression analysis the findings indicated that focusing on several domains of environmental variables in evaluation of sheltered care settings is most effective. The study further demonstrated that those factors most salient to the formation of social environments in sheltered care settings were policy and architectural features.

Lemke and Moos (1987) reported on data gathered from 244 nursing home facilities representing a variety of residential settings. The Sheltered Care Environment Scale (SCES) (one of four of the Multiphasic Assessment and Environment tool) was used to assess the social climate in congregate residential settings for the elderly. The sample population excluded the cognitively impaired elderly. The SCES was found to reflect actual and agreed upon qualities of a setting not just characteristics of the respondent. The SCES was found to contribute unique information about these residences by tapping into the common perceptions of a setting held by participants. Significantly, the SCES was found to be useful to contrast the views between residents and staff in a facility. The results of the SCES can be depicted graphically to examine the social environmental factors related to resident well-being and functioning and how residents' families perceive a setting. In this respect, the SCES appears to be a useful measure (with staff acting as surrogate informants) for the cognitively impaired who are unable to self-report.

Sommer (1970) contends that it is necessary to teach people how to design and alter care environments to promote human relations as well as serve the goals of the organization. He suggests that opinions of residents, staff and families must be solicited prior to design, building or alteration of a residential environment. Based on his experience in designing care environments he contends that therapy, comfort, privacy, interaction, ambience need not be dismissed by overriding concerns with efficiency, maintenance and economy. He found in his study that institutions frequently arrange the environment to express administrative and service provision which, in turn, appears to control the social relations of residents.

Lawton (1970) suggests that the elderly are particularly sensitive to environmental variation. He hypothesized that with diminishing competence an elderly person is more susceptible to the effects and constraints of their environment. This susceptibility is due to their diminished capacity to adapt and respond to the environment. Because almost every policy, program or service for older people involves an environmental factor, he suggested the need to make these factors explicit in formative and impact evaluations. Citing previous empirical studies he concludes that when older people have a variety of environmental alternatives to choose from they tend to match their own competence with the appropriate environmental resources. He hypothesizes that limited or unavailable environmental resources can contribute to the docility and deterioration seen in many older persons residing in institutions.

Physical and Environmental Features

Much of the literature on Special Care Units emphasizes the importance of the physical environment in relation to behaviours of demented residents. Most of the literature is descriptive and speculative based on observation and of practitioners and administrators working with the demented elderly. No controlled studies reporting the effects of isolated environmental features on the functioning of the elderly with dementia have been reported. The methodological difficulties of isolating and testing the effects of only environmental features within a therapeutic environment is cited repeatedly in the literature.

Ohta and Ohta (1988) in a descriptive, exploratory study to identify and describe a range of variables in Special Care Units emphasized that a diversity of environmental features were evident in the units they studied. The size of unit was considered significant. Smaller units (around 10-12 residents) appeared to promote improved socialization and spatial orientation of residents and created a more "home-like" setting according to observations reported by staff. This view is supported in descriptive articles and studies by Coons (1991), Mace (1991), Gold et al. (1991). A "homelike" environment is one that resembles in as many ways as possible, the environment in which the person lived before the onset of the disease (Calkins, 1988).

In a 1992 statewide study of 203 long-term care facilities in Nebraska, which included both urban and rural settings, Sand, Yeaworth and McCabe found the average size of SCU was 19.5 beds. According to Berg et al. (1991) in a descriptive study of published material and visits to five SCU's the average SCU contained approximately 30 beds, despite the recommendation of many studies indicating a smaller size for dementia units. The reality of 30 beds appears to be at variance with the recommended size.

Type of room is frequently reported in the existing SCU literature. However, rare among special units is the private room. Most units utilize shared rooms based on economic rather than therapeutic considerations (Ohta & Ohta, 1988; Berg et al., 1991, Mace, 1989). These findings underline the importance of exploring the policy and funding context in which dementia units develop. Therapeutic and regulatory goals frequently conflict according to these authors.

Special Environmental Adaptations

Most of the descriptive and exploratory literature on SCU's discussed the environment as a therapeutic aid rather than a neutral entity (Berg et al., 1991; Coons, 1991; Mace, 1989, Coons & Weaverdyck, 1986; Peppard, 1986; Hyde, 1989). Physical adaptations such as colour coding, camouflaging of elevators and exits, labelling familiar pictures, large lettered signs and outside wandering space were observed across diverse programs (Schultz, 1987; Ohta & Ohta, 1988; Coons, 1991; Mace, 1989). Grossman, Weiner, Salamon and Burros (1986) explored and described how a home for the aged developed an SCU and its potential applicability to provide appropriate care for demented elderly in other settings. They reported on various physical adaptations including colour coding of doors and hallways, pictures and signs, and labelling they believed to be useful to assist residents' wayfinding.

Sand, Yeaworth and McCabe (1992), noted in their descriptive study of SCU environments, that labels, colour cues, pictures and signs for communication problems were common across the sites studied. Ohta & Ohta (1988), describing salient SCU features, reported on the unique environmental features ranging from simple security measures to elaborate decoration in pastel colours, sound absorbent material, non-glare floor to diminish visual distortion; names, photographs and biography of each resident adjacent to their doorway. Weiner & Reingold (1989) in a survey study of 42 U.S facilities, noted that in the majority of environmental modifications (N=26), the largest number were for increased security and visual access, orientation and wayfinding, modification of communal space and noise control. Cluff (1990), an architect specializing in design for dementia care, described the dilemma and challenge of environmental design for the cognitively impaired. She noted design elements cannot rely on residents' learning and mastery of a particular setting or situation. Lighting, use of colour, diverse orientation cues were emphasized as well as wandering space. Hyde (1989) reporting on a tour of eight Alzheimer's facilities in eastern Massachusetts and on information gained from interviews with administrators and staff, noted that the use of pictures, colour, word labelling as wayfinding cues and reduction in auditory stimuli were frequently used environmental modifications.

Policy Context/Administrative Organization

Few studies have dealt with the relationship between policy context/administrative organization and the development of SCU's, and the studies are largely based on the U.S.

experience. As noted by Ronch (1986), there is asynchrony between the care needs of the demented in American long-term care facilities and the policy structures and the resource allocation paradigm currently in place. American nursing homes are run for profit, thus pitting the needs of residents against market forces. As Diamond (1991) described, American nursing homes are an industry in which the human requirements of the residents become secondary to profit margins. Berg et al.(1991) in an article on SCU definitional issues, noted that existing units vary in almost every respect including philosophy, design, staffing, staff training and ratios, activity programs and treatment practices. Standards, if they exist at all, vary from state to state. Free market forces, reimbursement and payer mix play a significant role in the development and economics of operating an SCU (Koff, 1986; Kane, 1987; Berg et al., 1991; Cameron et al., 1987).

Gold et al. (1991) and Rabins (1986) note the associated higher costs of providing care over increasingly longer periods of time will influence policy and regulatory decisions which may conflict with therapeutic aims of caregivers.

Maslow and Mace (1991) reported on public policy issues relating to provision of dementia care. They cited the impact of free-market forces on a for profit industry (eg American nursing homes) and fragmentation of funding as critical factors affecting the development and quality of dementia units. These observations reflect that in the U.S., funding for health services in Long-term care is tied to poverty.

Coons (1991) noted that governmental regulations and funding schemes are often in direct conflict with the best current thinking about quality dementia care. Coons (1991) additionally noted in a separate source that regulations frequently ignore the fact that the goal in nursing homes is not cure and that inflexible and restrictive acute care settings have fostered the development of inappropriate regulations for long-term care facilities. Kane and Kane (1982) in an analysis of the American long-term care system noted that developing criteria to define and measure quality of life is exceedingly difficult. Regulatory measures, it was noted, discourage innovation and risk taking in approaches to care.

Staffing Issues

Staffing issues (selection, training, organization of work, staff to resident ratios, working conditions) was a topic central to many studies and descriptive essays on Special Care Units.

Coons (1991) in an analysis of quality of care in dementia units noted that low pay scale and the inadequacy of staff training programs is incongruent with the expectation of developing specialization in dementia care. The work of staff (notably nursing aides) is usually strenuous and tedious and the job is exhausting. Ronch (1986) in describing approaches to care of elders with dementia noted that staff who are trained, supervised and supported in a way to encourage residents' autonomy will reinforce their own autonomy and creativity. Gold et al. (1991), after rating 55 nursing homes in five states created a typology of rated care settings. Using grounded theory approach in combination with quantitative data, they developed a coding system to reach consensus about a range of variables in SCU's. The researchers found the "ideal type" of SCU expresses genuine concern for staff, staff is well trained and staff to resident ratio is high. Staff autonomy and flexibility in decision making is strongly supported on "ideal" units.

Berg et al. (1991) describing definitional issues of SCU's noted that key indicators using staff as the unit of analysis would include training, experience, attitudes, continuing education, numbers and deployment. They omitted mentioning pay scale as did most authors discussing staff issues. Sand, Yeaworth and McCabe (1992) in a sample of 203 Nebraska nursing homes identified that staffing and staff training were crucial if a program were to be identified as special. However, it was concluded that in units which offered specialized dementia care staff education and training was not in keeping with the demands of the work.

Robinson and Spenser (1991) in an article on reducing staff burn-out noted that working with people with dementia is exceedingly fatiguing and stressful both physically and emotionally. Kane and Kane (1982) in an analysis of long-term care facilities noted the high rate of stress and staff turnover in nursing homes and that the vast majority of staff were care aides. Weaverdyck and Coons (1988), in a case study of one specialized dementia program, noted that specific, well trained and supported staff helps to produce a familiar and consistent environment. This can improve staff morale through producing closer relationships with staff and residents and help to form a knowledgeable, cohesive team.

Weiner and Reingold (1989), in their survey of 42 U.S. facilities, reported that staffing level was related to reported severity of patient condition. Additionally, flexibility and autonomy in work was mentioned by respondents as critical for job satisfaction. Schultz (1987) emphasized, in an overview analysis of program and design considerations of SCU's, that there is a desperate need for personal care assistants to work with the demented elderly. Creative scheduling and the importance of a staff dedicated to the unit was stressed. Ohta and Ohta (1988) discussing critical features and dimensions of SCU's noted that in the published reports and in the five sites the authors visited staff-patient ratios varied greatly. The implications for staff stress should be apparent. Units with high staff-patient ratio reported no staff stress and turnover. Consistency of staff (dedicated to the unit) varied greatly across settings.

Benson et al (1987) in pre and post test design study (where residents were assessed at admission, at six months and twelve months on the unit) noted that prior to establishing a specialized unit staff must receive special training to effectively deal with the unique problems of this population and to foster high staff morale.

SUMMARY OF THE LITERATURE

Environmental factors which impact on the behaviour, well-being and functioning of the elderly in formal care settings have been the focus of many studies undertaken by social and environmental psychologists. The rich theoretical and research base suggests that the elderly are particularly sensitive to environmental influences. Diminishing physical and psychological capacity in an older person suggests that they are more susceptible to environmental influences which can adversely affect well-being and functioning. This assertion has stimulated much research to develop tools to empirically measure the impact of the environment on the elderly individual. The results of these measures can then be used to make recommendations for change thereby enhancing the quality of life for these people. Most of these environmental measurement tools have established their validity and reliability as measures of person-environment congruence. Some research has indicated that further refinement of these tools is warranted. The testing and refinement of these tools has demonstrated that the environment should be viewed using multiple indicators or domains. This suggestion is congruent with another theoretical approach which suggests that residential environments are social systems in which alteration in one domain affects the others. Although the cognitively impaired elderly were excluded from all study samples, it has been demonstrated that staff, administrators and families can be used as surrogate respondents (speaking on behalf of the elder with dementia) in measuring person-environment congruence.

Educational programs designed to increase staff understanding of environmental influences on the cognitively impaired has been reported to be an effective measure to improve well-being and adjustment for this population. Architectural and design considerations for the Alzheimer's elderly illustrate a growing body of research concerned with matching components of the physical environment to the behavioral manifestations of this illness.

The literature on SCU's ranged from modified "case study" (where a particular unit was described in terms of the environmental components and program characteristics), exploratory and descriptive articles (based on available literature of SCU's), survey studies (of a limited sample of SCU's) using limited environmental indicators, a combination of survey, on-site descriptions and analysis of available literature. It is noteworthy that few studies have been undertaken to evaluate impact of environmental and program variables on demented residents' actual functioning and behaviours.

The literature indicates that environmental adaptations invariably parallel changes in therapeutic programs and staff approaches to care of demented elders. The convergence of many program features to create a therapeutic environment across diverse settings suggests that the design of evaluative and impact studies on resident functioning need to be multi-dimensional to capture the context, both the processes and effects of an entire social culture created for those with dementia. This contextual approach suggests other methods such as ethnography, grounded theory and case study may be more appropriate to gain a holistic, contextual understanding of Special Care Units and their benefits to residents, staff and families. Controlled studies which attempt to isolate and measure the effects of single or very limited variables appear inappropriate to the study of dementia units. Alternate approaches would also include experience of front-line staff, analysis of the policy environment and the relationships between policy structures and organization and development of dementia care. Few studies have undertaken an analysis of the relationship between the larger policy context and the development of SCU environments and programs. Yet, the variety of design and program modifications reported on SCU's have developed in specific policy contexts and from practice-based knowledge of the cognitive and behavioral changes associated with a dementing illness. Few studies, however, focused on the policy issues or the experiential accounts of caregivers working in these environments. Key features and characteristics of SCU's were researched by a variety of methods but policy issues and practitioner perspectives were marginalized. There is, in effect, an interesting gap in the literature. While SCU's are reported to be a practice-based response to the problem of caring for the elderly with dementia, the knowledge of direct caregivers is not visible in the research about SCU's. And, the policy forces impacting on practitioners working in SCU's has not been explored. Although practice-based knowledge has inspired the development of SCU's a policy vacuum nonetheless exists. Elmore (1979) and Berman (1984) have noted, in other areas of policy design, that practice "wisdom" frequently does not find its way back to inform policy. The Special Care literature indicates that nursing practice "wisdom" is not finding its way back to inform policy in specialized dementia care. Both practitioner knowledge and the influence of the policy context on SCU's has been, based on the available literature, short changed.

The diversity of programs and services offered for the elderly with dementia **does occur** within differing policy contexts. The array of services reported across diverse settings under the name "specialized dementia care" reflects, based on the American literature, both free-market forces and lack of guidelines about what constitutes effective and quality care for this population of elderly. This literature, however, speaks primarily to the American "health care" system. In particular, resource allocation and funding mechanisms tied to payment schemes originating with the medical model rather than current thinking about dementia care, appear to powerfully influence the development and diversity of SCU's in the United States. No similar analyses have been done relative to the Canadian experience. Standards of care, if they exist at all, do not appear to guarantee quality but rather the capacity to provide quality care. Current funding and resource allocation schemes in the American system inhibit creativity and flexibility in approaches to care. Again, few studies concerning funding and resource allocation included front-line perspectives and an analysis of how these economic policies actually impact on practice.

Many sources reported that staff working in dementia units should possess an understanding and appreciation of the uniqueness of the illness, its progression, and the profound effect it can have on the patient, the family, and other caregivers. To achieve this level of sensitivity the literature emphasized that personnel should have the ongoing opportunity to participate in educational programs. Interestingly, while many studies emphasized the importance of education for staff, none explored the connection between policy and the priority given to and availability of quality educational opportunities for staff.

Much of the research indicated that staff to resident ratios must be high for staff to implement care approaches appropriate for those with dementia. Few studies indicated that staff require substantial administrative support and funding to enable autonomy and flexibility in approaches to care. The availability of resources which accompany this aim were, according to my review of the literature, taken for granted.

Most authors agreed that staff should be dedicated to the unit and not "pulled" to staff other areas of the facility - but again few studies explored the funding implications (and profit loss in proprietary facilities) associated with this goal. Wages, the literature suggested, must be significantly improved to attract motivated and qualified staff - an objective with significant policy implications.

Overall, the literature suggests that along with environmental modifications, caregivers are the critical link to enable person-environment congruence between the elderly and their environment. Caregivers must be well trained, flexible and creative in their approaches to care. However, the literature does not even raise the issue of the practice wisdom of practitioners and their contributions to policy.

Finally, the caregivers of interest in dementia care, without exception, were presented as genderless and faceless entities in spite of the fact that the overwhelming majority of caregivers in LTC are women. However, the policy (and social) implications of a primarily female workforce were not mentioned in the literature.

CHAPTER THREE

METHODOLOGY

Introduction

This chapter presents an overview of the research design and methods used in the study. A flexible research design was developed which incorporates both qualitative and policy oriented methods and is congruent with the research purpose.

Research Problem

The problem addressed by this study is that the knowledge and experience of staff working in Special Care Units has received little attention. Although Special Care Units started as a practitioner response to an increasingly complex care problem, practitioner experience is not being utilized by researchers or policy makers. Special Care programs and policy issues impacting on the development of Special Care have not been identified in the Canadian long-term care literature.

Research Purpose and Questions

The research purpose, as Patton (1990) notes, is the controlling force in research. Decisions about design, methods and analysis have been shaped by the purpose of this study.

The purpose of this research is to: 1) provide information about Special Care Units from the standpoint/experience of nurses, 2) describe the interface between the nurses' knowledge/experience and the larger policy context and, 3) suggest the policy implications for Special Care arising from practitioner knowledge.

There is an explicit policy purpose to this research. That is, the intent of this study is not only to describe the key features and characteristics of Special Care Units but to seek knowledge for social change. Practical application rather than theory development have guided the approach to this study. The research problem indicates that the knowledge of experienced Special Care nurses has received little attention. A social change perspective supports the inclusion of practitioner experience in the research and policy process.

Therefore, the research questions are:

1. What are the key features and characteristics of Special Care Units identified by Special Care nurses?
2. What are the congruencies and incongruencies between the nurses' knowledge and experience and the larger policy context?
3. What are the policy implications for Special Care Units suggested by the data?

Research Perspective

Special Care Units are an emerging area of care and a new area of gerontological investigation. No theoretical frameworks related to Special Care research have been developed. Therefore, a research perspective was developed to guide both data selection and analysis (Miles & Huberman, 1984).

The research perspective consists of two concepts. The first concept is standpoint. Standpoint is a term used to denote the position or location of a person viewing a particular phenomenon (Smith, 1990). Standpoint speaks to the location from which a viewer sees the world. A person's account of the world is tied to the context in which and from which they view the world. A viewer is always located somewhere. Seeing or knowing about something is grounded, situated in a local reality (Smith, 1990). The reality or context in which someone is situated influences both what is known and how it is known. As noted by Miles and Huberman (1984) qualitative research is usually focused on the words and actions of people that occur in a specific context. Standpoint provides a conceptual tool to focus the research on practitioner experience and the context of that experience. Nurses' standpoint, their experience and knowledge, is central to the study. To address the purpose of the study the standpoint of front-line nurses is examined within a two tier context: the larger policy context and the specific context of each individual Special Care Unit.

The second concept is the policy/practice interface. Special Care Units have developed from the interface between resident needs, the Special Care environment, the practice of nurses and the policy context in which each of these elements are situated. A dynamic interface is created when these elements come together. Policy/practice interface is defined as the quality of fit between these elements. The quality of fit is identified as either junctures or disjunctures. Junctures are derived from data suggesting reasonable congruence or harmony between all or some of these elements and disjunctures are created when there is a lack of congruence or disharmony between all or some of these elements.

Taken together, standpoint and the policy/practice interface helps focus the research on the experience of practitioners and the context of their practice.

Research Design

Chapter Two provides an overview of the background to the study, scope of the problem, and the policy context surrounding Special Care. The literature review indicates what is known and not known about Special Care. The critical missing piece is attention to and inclusion of practitioner knowledge/experience of Special Care and the interface between practitioner knowledge and the larger policy context. Different methods have been combined to provide these pieces of the Special Care picture.

The research purpose and questions indicate the need for a flexible research design. As Patton (1990) notes, "design flexibility stems from the open-ended nature of qualitative enquiry as well as pragmatic considerations...the point is to do what makes sense" (p.62).

What makes sense in terms of design for this study is a mixed method approach. A mixed method approach is typical of policy oriented research and is supported by Bulmer

(1986), Patton (1990), and Miles and Huberman (1984). As Putt and Springer (1989) note "the pluralistic nature of public policy requires a pluralistic research approach. Policy research must accomodate multiple perspectives on issues, and this has implications for the organization and conduct of policy research" (p.2).

There are two main sources of data used for this study. The first source is semi-structured interviews with front-line Special Care nurses. The second source is Ministry of Health policy documents supplemented, wherever possible, with informal interviews with CCD central office staff. A research design incorporating both descriptive and interpretive methods was developed to establish linkages between macro-policy forces (policy context) and the everyday practice of Special Care nurses. This study, therefore, uses an interpretive policy oriented design.

Interpretive policy oriented research differs from deductive positivist methodologies. First, the researcher is an active participant in a research process whereby knowledge is created rather than discovered. The approach is based on the perspective that "reality" is constructed and the knowledge thus created is a function of the researcher interacting with the participants. Additionally, the participants bring their own perspective into the process. Secondly, interpretive policy oriented research, rather than minimize the influence of contextual variables so the results of the study may be generalized, identifies how the variables interact with and are part of the knowledge. Policy research is a complex, inexact and contextually embedded process. As Tinkle and Beaton (1983) note, "research findings resulting from methodologies that ignore the importance of person-situation interactions are of limited utility in the formulation of social policy" (p.32).

The choice of this design also reflects my perspective that research design decisions involve more than methodological and academic considerations. The design decisions I have made for this study reflect my view that research is not a neutral exercise but is value laden and political. This view is supported by Moccia (1988), a nurse researcher, who states, "research methods are contingent on the questions asked and are controlled and evaluated by the bureaucratic processes through which the researcher reveals/discovers knowledge" (p.3). My choice of studying front-line practitioners, with a view to inform policy, was made by identifying a researchable problem evident in gaps in the literature and from my own nursing experience. My choice of what to study and how to study it is explained by Thomas' (1993) view that "institutions of power lie behind behavior and cultural meanings that construct and limit choices, confer legitimacy and guide our daily routine" (p.6). Special Care nursing experience is embedded in sociohistorical and power relations which affects nursing practice. The literature review of Special Care demonstrates the dominance of certain academic preferences in terms of the questions asked and the methodologies selected. These preferences for research questions, purpose and data selection illustrate as Thomas (1993) states " the academic outer rim of practices and process that constrains research and how we talk about it" (p. 7). Through this design, practitioner experience is given a voice in the development of Special Care research and policy. In order to answer the research questions and address the purpose of the study, the dynamics between the nurses' accounts and the policy context in which their work is situated had to be considered within the design. Methodological considerations for this study were influenced by and adapted from the following sources: Critical ethnography: Diamond (1992), Smith (1990), Campbell (1988), Thomas (1993) and Rosen (1991); Policy analysis and implementation research: Elmore (1979), Lipsky (1980), Patton (1990), Miles & Huberman (1984) and Berman (1984). The following sections demonstrate how the study has integrated these methods.

Research Process

Data Collection

Seven Intermediate Care facilities with Special Care Units, (distributed among 5

Provincial Health Units), were selected and contacted by introductory letter. The purpose of the letter was to: 1) inform the facility about the study, 2) request facility consent and participation in the study and, 3) request voluntary participation of 1 nurse working full-time in the Special Care Unit. (Appendix A). After receiving verbal consent from the both the facility and nurse volunteers, interviews were arranged by telephone with the nurses. During the telephone contact, the nurses were informed again of the purpose of the study and encouraged to clarify any questions they had. All interviews were conducted within a nurse's home or place of work and each interview lasted approximately 2 hours. Prior to the interview, participants were again informed about the purpose of the study and asked to sign a Consent Form consistent with University of Victoria Research/Human Subjects policy (Appendix B.) All the interviews were taped and anonymity of both the facility and participants was reaffirmed. I was the sole interviewer.

A limited, purposive sample of nurses was used to maximize diversity in terms of provincial Health Units and Special Care Units. Constraints on sample size was imposed by research cost and travel time to different provincial Health Units.

Participants

6 Registered Nurses (RN), 2 Registered Psychiatric Nurses (RPN) and 1 unlicensed Graduate Nurse (GN) were interviewed (n=9). (For two facilities a pair of nurses were interviewed.) The interview participants were all self-selected introducing a potential source of bias. All nurses interviewed are women. All but one nurse had between 5-15 years clinical nursing experience and all had worked at least 1 year in Special Care.

Instrumentation

A semi-structured interview guide was developed. Almost half of the questions correspond to the main Special Care topics identified in the literature review:

1. Design and Security Features.
2. Admission Criteria and Clients Served.
3. Activity and Therapeutic Programs.
4. Specialized Staffing and Staff Training.
5. Involvement of Mental Health Services/Resources.
6. Philosophy of Care.

One third of the questions addressed policy issues arising from the provincial policy context data. The remaining questions arose within the context of discussion as probes or clarifications. All the questions were framed to capture each nurse's specific practice and experience. The inclusion of practice focused questions addressed the gap identified in the Special Care literature and policy context information. The nurses were encouraged to talk about issues underlying, associated with or in addition to the main topics. The rationale of this semi-structured approach was to provide some boundaries to the data collection while not controlling or limiting the content to researcher generated categories.

One faculty member reviewed the interview guide to assess question structure and development prior to interviewing. The interview guide was pilot tested with one nurse working in a local Special Care Unit not included in the sampling frame. Revisions in question order and wording were made following the pilot testing. Revisions increased the utility of the interview schedule.

Data Analysis

Data analysis proceeded in several stages. Data analysis methods are consistent with those described by Patton (1990), Miles & Huberman (1984) and Putt & Springer (1989), in addition to recommendations by an experienced qualitative researcher.

- Each tape was listened to four times to become familiar with the complete data and the linguistic nuances eg tone, laughter etc.

- Each interview tape was transcribed and initially organized under each interview question.
- Four copies of each transcribed interview was made.
- Open coding proceeded in two ways: First, each individual interview was coded page by page by making margin notes and key words. Second, coding was then done across SCU's, question by question, using a second transcript copy. Margin notes and key words were made. The rationale for this was to provide "depth/context" from the individual interviews and "breadth" by data from the same questions across interviews. Margin notes were compared. Comparison of the two approaches indicated that individual interview margin notes provided more detailed information. Each individual interview created a picture of the Special Care Unit. During the interviews the nurses often added to previous answers, referring to a previous question, anecdote or remark. On this basis, I determined that coding across interviews lost this context information and therefore rejected across SCU coding.

Using the interview-by-interview process a review of margin notes revealed similar key words and groups of key words. Word patterns associated with specific questions and content areas began to emerge. Word patterns provided the initial main categories. Each category was color coded and then named for easy reference. The margin notes, key words and actual text (coded by Special Care unit/page number) were then assigned to a main category using a clean transcript. For example, design as a main category might contain the words corridor, wandering loop, reference to resident behaviors such as "continuous wandering" "crowding" or "increased confusion" and a reference to practice such as "increased workload" or "poor visability". Each complete interview was coded in this way. When all the interviews were coded for main categories, the categories were compared along with the key words and actual text. In some cases, two main categories were collapsed into one. The collapsing was done after reviewing the key words, margin notes and actual text in which I identified that the same thing was "said" in a different way.

Once the first level coding was done, subcategories emerged. For example, admission criteria and admission process was influenced by factors common to all Special Care Units. However, other factors emerged which were associated with for-profit facilities. The differences associated with for-profit facilities became a subcategory.

A final copy of each transcript was then coded by main category (color), subcategory (color/number) and textual examples were marked (previously coded by SCU and page number) to have a clean working copy from which to write up the results. This working copy was invaluable to retain the contextual/holistic identity of each Special Care Unit.

Final analysis involved reflection and critical analysis of the categories and subcategories in relation to the policy context data. Working back and forth between the categories (and actual quotes) and the policy context I interpreted linkages, patterns and connections between macro policy issues and practice knowledge/experience. This phase moved a descriptive coding process to an interpretive (and policy oriented) coding process. The last stage established connections between policy and practice.

The final coding resulted in four main components of Special Care Units described in the results section. To validate the analysis, the preliminary results were sent to all the nurse participants for review and comment. This step was particularly important to determine if the analysis and final results represented the nurses' views. The nurses were asked if the results adequately described and represented their practice and experience within Special Care. The comments from the nurses were uniformly positive and supportive of the results as written. Based on their feedback, few revisions were required.

Limitations

The research design uses a mixed method approach. Although policy oriented research requires the use of a mixed method approach, there is some risk of spreading the research net too wide making study replication difficult. However, policy oriented research can never be exact.

Study participants were self selected. Choosing to participate in this study suggests a different informant sample than might be available through a randomized selection procedure. Self-selected participants might represent a sub group of the Special Care nurse population. However, use of randomized selection would require informed consent of the participants who could still self select on the basis of particular perspectives and interests.

Although nine nurses provided abundant information for the purpose of the study, the small sample size somewhat limits the scope and impact of the results. There are currently 43 existing Special Care Units in British Columbia, with a total of 71 SCU's anticipated within 2-5 years (Ministry of Health, Special Care Survey, 1993).

The interview guide was developed to be congruent with key topics in the literature and include questions addressing gaps in the literature. The questions were researcher generated. The use of questions which prompted and influenced the thinking of the nurses provided necessary boundaries to the data collection. In some cases, the questions had to be reworded for the nurses to answer. This indicated that the some of the wording I chose was based on language familiar to me as a researcher but unfamiliar to the nurses. This aspect was most evident with policy oriented questions. The few wording problems were not discovered during the pilot but arose sporadically with different participants. The questions were rephrased but the content and objective of the questions were not altered.

Another unanticipated limitation was that the nurses worked different shifts and consequently were most familiar with Special Care life experienced in their shift period.

Nursing practices differed between day, evening and night shifts. Although having participants who worked different shifts enriched the data it detracted from the specificity of some of the interview answers.

As the sole interviewer I provided consistency to the process and learned from previous "mistakes". Some of the nurses were more articulate than others, able to express themselves effectively with words. To balance these differences in verbal ability I always asked the nurses to give an practice example to clarify their answer.

There are many approaches and perspectives from which to examine the data. The methodological decisions, (and the overall design which was used), represent a particular research perspective. There are other designs and methods which could have been used. Nonetheless, every effort was made to focus on the research purpose and develop congruency between all stages of the research process.

Time and economic constraints limited the inclusion of an auditing resource for the data analysis. However, an experienced qualitative researcher in another faculty provided expert advice prior to and during the coding and content analysis. His experience and information assisted the coding process and determining how to proceed with the raw data. I am confident that another researcher could follow the decision trail and the coding process I used. By providing the nurses with a draft of the preliminary results I was able to support that the study adequately represented and interpreted their experience.

Finally, I recognized that design and methods decisions in qualitative research are never "final". The process is evolutionary and ongoing, involving self-critique and constant questioning and comparision. The nature of inductive research requires a degree of open-mindedness in the researcher to identify a wrong direction taken, a forced fitting between concepts and raw data and a frustrating tendency to become attached to material that is actually irrelevant to the study. Letting go of data which is beyond the boundaries and limitations of the study is a necessary task which I frequently faced.

CHAPTER 4

RESULTS AND DISCUSSION

The following section presents the analysis results from the seven interviews with Special Care front-line nurses. The perspective described in this section are those of Registered Nurses only. The purpose of the study is to add to the knowledge about Special Care Units through inclusion of practitioner knowledge and explore the relationship between practitioner knowledge/experience and the policy context. Results are presented and discussed in relation to the research perspective and research questions.

Interpretive analysis revealed four interrelated dimensions within which the key features, characteristics and components of seven Special Care Units (identified by nine front-line nurses) are revealed. The following section describes and discusses the four dimensions: Clients Created Elsewhere, The Dumping Ground, Coping as Care, and Creating a Community.

Dimension I. Clients Created Elsewhere.

This dimension refers to the Long Term Care Levels, developed by the Ministry in late 1970, which describe and classify clients and control the type and level of service received in a facility. Care Levels are integral to the funding and staffing formulas for Intermediate Care facilities. The Care Levels are used by the Case Managers in the Long Term Care Program to classify and compare clients by functional abilities. Funding and staffing levels in residential facilities are determined on the basis of the classification assigned to each resident. The Care Levels and formulas apply equally to all Intermediate Care facilities and to the Special Care Units. Clients admitted to Special Care Units are assigned a Care Level, usually IC3. Many of the regular (non-SCU) facility residents are assigned the same level. When a client is admitted to a Special Care Unit, their functional abilities have been defined by Case Managers primarily in terms of the criteria designated on the Long Term Care Form. In effect, they are admitted to a facility with an identity created on the basis of the LTC form and the assigned Level. They are clients created elsewhere.

The interviews revealed that the Care Levels are a crucial determinant of care for all seven Special Care Units. The Ministry Care Level assigned to Special Care clients give them a documentary identity (usually IC3) which controls the money and staffing the Special Care Unit will receive. The behavioral indicators in the criteria frame the client's identity but, according to the nurses, the fitting between the Care Level and the real person do not match. The documentary identity bears little resemblance to the actual persons known to the nurses. As one nurse stated, "IC3 describes Special Care people in such broad terms. But these clients differ so much! They require very different care." Another noted, "IC3 absolutely does not reflect clients in the Special Care Unit. So many things...It doesn't include. We have IC3's who should be Extended Care." She goes on to state, "Special Care clients, their needs increase but the staff doesn't increase to accommodate their needs. Nor does the funding. So...they get poor EC care." These sentiments were restated by another nurse who said, "we don't get more money if someone is reassessed Extended Care. They may wait for as long as a year to go elsewhere". Another stated, "Nothing happens to staffing. Staffing stays the same. One year we had 6 EC! Staffing didn't change." The nurses claimed that because the facility's formal designation is Intermediate Care, if a client is actually reassessed the facility does not receive more money to provide the level of care the client actually requires. As the nurses' comments indicate, the staff frequently provide make-shift Extended Care "for free" while the client is waiting to be transferred to an EC facility. As one nurse said, "We hold them as IC3's because we are licensed at Intermediate Care. What happens if you **actually** have an Extended Care patient and they don't get Extended Care placement? They get worse. We actually accelerate their death."

A disjuncture is created when "documentary" clients interface with the real clients known by the nurses. The effect of this disjuncture may have profound consequences as, for example, when a client requires palliative care (specialized care and attention because the person is dying). One nurse described this situation stating, "There's no funding for palliative care. If you're an IC3 and you're dying and we have to have somebody sit with you. There's no funding for that. The rest of the people just go undone. We do less with the others."

Clients created elsewhere affects Special Care Units in a significant way. The disjuncture created between the Ministry assigned Levels/funding/staffing and the actual behaviours, needs and care required by Special Care clients, as identified by the nurses, was a consistent theme across the interviews. The levels, funding and staffing formulas have created one reality, the client as document, which is incongruent with the other reality, the client as experienced by front-line staff.

The client created elsewhere, (different than the client as experienced), is an example of a control mechanism common to many large service organizations. The levels, and the accounts of clients as described by the levels, serve the purposes and policies of the Ministry. Smith (1990) has described how organizational forms, such as the LTC classification Levels, "separate those who formulate, conceptualize and make policy from the front-line workers who experience the actual ways in which the organization interrelates with its objects. Those in actual contact with those who are the objects of action are not those who frame policies, categories and concepts that govern their work" (p.95). Campbell (1988) demonstrated the same phenomenon. Her study described how nursing documentation (charting) is constructed into systematic information useful for management purposes and detrimental to nursing practice.

Front-line SCU nurses do not frame the categories that govern their work. There is no mechanism available to the nurses to demonstrate and to document the incongruence they experience. They have no authority to redesignate a client and describe that client in terms which are meaningful to them. In any case, as the interviews demonstrated, redesignation within the official LTC Levels changes little in terms of funding and staffing. The disjuncture between the LTC Level client and the experienced client is too large. According to the nurses, redesignation will not capture the real dimensions of behaviour and care required for the Special Care clients. There is no "other form" or "other Level" available to the nurses which will more accurately depict Special Care clients and bring the SCU more staff.

Ministry staff who lack ongoing direct contact with some of the most difficult to manage clients in the LTC residential system, have settled on a description of clients which misses the mark in Special Care. The Special Care client simply does not exist on any of the levels. One nurse summarizes their view of the system stating, "the whole system is a facade. It is so outdated. The levels, it just doesn't fit. There needs to be a Special Care classification for sure...what happens as a result of using these Care Levels is that the mental status and care required together are taken at the expense of other people. Everyone needs, demands so much, but the staffing is for another era, another client population which no longer exists in these facilities." The disjuncture between the two realities, the created client (and the associated funding/staffing) and the experienced client (and the funding/staffing needed), was identified as a source of constant frustration to the nurses.

<u>Clients created elsewhere</u> is a component of Special Care Units not identified in the literature except in respect to the suggested need for enriched staffing. <u>Clients created elsewhere</u> is an aspect of the policy/practice interface known to all the Special Care nurses in this study.

Dimension II. The Dumping Ground.

The dumping ground dimension refers to SCU's being used by mental health services to unload or "dump" elderly psychiatric patients who have no where else to go. Generally these patients are those discharged from Riverview, over 65 years and deemed inappropriate for placement in any Mental Health community residential setting. SCU's have become a convenient, secure facility setting for difficult to manage, aging psychiatric clients. According to the nurses, these clients are admitted to Special Care although they do not fit the admission criteria. The dumping ground dimension of Special Care was well known to all the SCU nurses. In several instances, different nurses used identical terminology to describe the dimension. The dumping ground phenomenon was common to all but one of the Special Care Units. (This particular unit accepted and mixed all types of clients with differing behaviours, diagnoses and care management problems. However, the admission criteria of this SCU specifies that a diverse client population is accepted - dementias including Korsikoff's, psychiatric disorders, and other organic brain syndromes. Further details cannot be disclosed in order to protect the identity of the facility.)

Each Special Care Unit has admission procedures and admission criteria. The purpose of admission criteria, (used in conjunction with the LTC forms and physician information), is to screen clients to ensure appropriate placement. Admission criteria are used to match the needs of the client to the resources of the Special Care Unit. The admission criteria described by the nurses, in all but one of the Special Care Units, specified that clients with Alzheimer's Disease and Related Disorders (ADRD) were the target client group. The SCU clients suitable for admission were described as those who had "severe behaviour problems related to a dementing illness," and who were a "wandering and elopement risk." Additionally, clients needing "constant supervision and direction" in a "secure (locked) unit" and a "supportive therapeutic environment" to compensate for "loss of life skills and dysfunctional behaviours" were the most common admission criteria. There were differences between the seven SCU's in terms of the formality of the admission process but few differences were evident in terms of the actual admission criteria used by all the units.

All the nurses described a similar admission procedure, with some differences indicated in personnel involved in the process. In all seven facilities, admission decisions involved the recommendation of the LTC Case Manager in consultation with the facility Director of Care/Administrator and sometimes the Social Worker and Head Nurse. No SCU has established a formal Admissions Committee.

All community clients assessed by a Case Manager are placed on a facility waitlist maintained within each Health Unit. A previously assessed client must be in a preferred position on the Health Unit facility waitlist and a bed must be available in the Special Care Unit. The LTC Case Manager and admission personnel in the SCU facility then determine the prospective client's suitability for placement in the Special Care Unit. The admission procedure involves comparing the waitlisted client's functional and cognitive abilities (documented on the LTC Form) to the admission criteria of each SCU.

However, the admission situation described by the nurses differed from the (presumed) official procedure established by the LTC Program. According to the nurses, clients not fitting the admission criteria of the SCU were being admitted because of pressure from the LTC Case Manager and, in some cases, the facility administration. The clients of most concern to the nurses are elderly clients with long-term psychiatric histories not related to a dementing illness. The dumping ground dimension was described by one nurse who stated, " [we take] dementia. And then we get the ones from Riverview. We are a catch-all." All but one of the nurses described, with considerable intensity, the problems related to placing psychiatric clients among the designated Special Care population. One nurse with several years psychiatric nursing experience stated, "if there is someone who is psychotic, they can trigger off the others. They can be a threat to demented residents. The psychotic resident [in turn] becomes more bizarre and violent as the demented residents react to them. Having schizophrenics, those with bi-polar disease - no! It just doesn't work." This nurse went on to describe some of the differences in care required by the demented elderly and those with psychiatric problems, "psychotic patients need a psychogeriatric setting, with particular professional assistance from a psychogeriatrician. They need particular medications for their particular illness." Another nurse also with extensive psychiatric experience described the situation in her unit saying, "we have 1 client with a history of psychiatric problems and 15 end stage dementia. The psychiatric client agitates the other residents. He sets them off. **He** is also frightened by **them**! He's quite loud and quite vulgar. He's got a mouth that offends the other people. Whereas that particular age group, a lot of those people come from a very rigid society, especially the women, who are just not used to having men around who swear at them like that."

The dumping ground dimension captures a dysjuncture between the explicit SCU admission criteria and the actual admission of clients not fitting the criteria. The explicit criteria designates elderly clients with Alzheimer's disease and related disorders as the target population. However, elderly clients with long term psychiatric illnesses such schizophrenia and bi-polar disease, clients with head injuries, Korsikoff's disease, HIV dementia are being admitted. The nurses know from experience what happens when clients with different problems, needs and behaviours are mixed with those with a dementing illness. The SCU environment, and the approaches to care, has evolved to address the particular characteristics and needs of dementia clients - not psychiatric or other brain injured clients. The SCU literature supports their experience. Special Care Units initially developed because practitioners recognized that dementia clients should not be integrated with the cognitively well. Neither group appeared to benefit. The dementia client's functional and cognitive capacity is so limited that they require a controlled and subdued environment to compensate for their losses. The environment must be flexible and sensitive to their particular behaviours and needs.

Elderly clients with psychiatric problems still retain much of their higher cognitive functions. They can adjust to change, learn new things and negotiate their environment in spite of affective and ideational distortion. Integrating psychiatric clients into the controlled SCU environment appears, from the nurses' accounts, to have disruptive, negative consequences for the dementia clients. As one nurse described the situation, "in the face of these psychiatric clients the frail demented are sitting ducks." Another remarked, "those who are untreatably violent - untreatable in the sense of their placement in a therapeutic environment - has minimal effect on their behaviours, violent and aggressive behaviours. They need something else which we don't provide." Another described the disjuncture stating, "we have Alzheimer's here. Those on the move all the time. We also have a male resident who is extremely violent who doesn't fit."

The dumping ground dimension originates in the larger policy context. The disjuncture created at the interface between policy (dementia specific admission criteria) and practice (admitting psychiatric clients) results from gaps in the provision of mental health services. There are no Mental Health community residential services for elderly psychiatric patients requiring a locked environment. Nonetheless, these clients are being discharged to "the community." Special Care Units provide a convenient camouflage to hide poor policy and planning for elderly psychiatric clients.

Nurses were not consulted about the effect of mixing these client groups. The reasons for the pressure to integrate psychiatric clients may lie with the Ministry's intent to reduce the costs of hospital care by shifting services from hospitals to the community. Recommendations to reduce psychiatric tertiary (hospital) services is outlined in the 1992 Royal Commission Report, Closer to Home. Riverview Hospital was an obvious target for "downsizing." However, relocation planning did not appear to include elderly psychiatric patients. Some of these patients have been institutionalized for decades and would be unlikely candidates for unstructured, unlocked community boarding homes (personal interview with Riverview discharge personnel, 1993).

The fiscal and political interests of the Ministry are served by the downsizing and dumping ground approach to deal with elderly psychiatric clients. LTC facilites are cheaper than hospital tertiary care. Special Care Units are in place, are secure and locked. One of the SCU nurses referred to SCU's as becoming "baby Riverviews."

The policy gaps in Special Care are a policy opportunity for mental health services. The pressure being placed on Special Care Units to accept elderly psychiatric clients is incrementally reshaping SCU admission criteria. Front-line Special Care nurses are resisting the pressure to change the designated client group. As one nurse vehemently stated, "we are not a psychogeriatric unit! We are dealing with Alzheimer's. These [Alzheimer's] are clients who respond to a therapeutic environment. People whose aggression and behaviours can be modified by the environment. In a lot of cases clients with mental health problems can't be helped here." Another summarized the dilemma stating, "with Korsikoff's and severe mental health patients - they will never fit in! We are looked at more and more like a dumping ground for the system's problem clients. Well we're not! They won't be able to be managed. They cause constant turmoil. Mental Health can't dump their problems on Long Term Care. Its not fair to anyone - for the demented resident or mental health patient. They haven't developed any options for mental health clients requiring residential care. Well, it **isn't here**!"

The dumping ground dimension has a subcomponent. The subcomponent applies only to two Special Care Units and is not representative of the other five SCU's. These two SCU's are for-profit facilities. The subcomponent was sufficiently and strongly represented in the two interviews to warrant inclusion as a unique feature of this type of Special Care.

The subcomponent is called **Care for Sale.**

Care for sale represents the profit motive which appears to dominate SCU admission policy and admission criteria in for-profit facilities. By the nurses' accounts, the profit motive overrides explicit SCU admission policy. SCU clients in for-profit facilities are selected on the basis of filling the bed rather than appropriate placement. Clients are placed in the unit because the owners will lose money if the bed remains empty. According to the nurses working in for-profit facilities, admission criteria means little in the face of profit loss. Admission policies and admission criteria, within a for-profit facility, have become marketing devices to attract clients. As one of the nurses stated, "the owners were so desperate. It [admission criteria] really doesn't matter. We'd take anybody." Clients whom the nurses consider inappropriate for Special Care are being admitted. As one nurse said, "if there's an empty bed drives admissions...our criteria? Almost $3,000 a month." In one for-profit unit, the nurse described how a mildly confused but well functioning resident was pulled from another area of the facility and placed in the empty SCU bed in order to admit a higher functioning client from the community to her bed. Neither the resident, nor the resident's family nor the nurses were consulted by the owner as to the appropriateness of the move.

Making a profit appears to fast track admissions. The explicit admission policy of both SCU's focused on dementia clients. The implicit policy, captured in the **care for sale** component, is described by both nurses as "whatever the owner decides" and "if there's a bed drives admissions."

The **care for sale** component within for-profit SCU's compounds the complex policy forces already influencing SCU admissions. This component was described by the nurses as a feature of Special Care completely beyond their control. One nurse sighed and then laughed, saying, "we are a catch-all. Private pay...they'd take the devil himself!" Generally, the fill-the-bed-clients are the most ill psychiatric elderly, difficult to manage, whom nobody wants. It appears that in addition to the pressures created by Mental Health, the pressure exerted by profit margins may obliterate meaningful admission criteria. In the face of such fiscal pressure, the disjuncture created by official admission policy and actual admission practice appears more severe than in non-profit SCU's.

Dimension III. Coping as Care.

Coping as Care is the third and most complex dimension. The Coping as Care dimension is a collage of specific aspects of daily life in Special Care. This dimension includes features, issues, activities and effects which, taken together, characterize daily life in Special Care. As the nurses discussed the daily life and work in Special Care, it became clear that they were talking about something more difficult and complex than providing care for the residents. They were talking about coping. Coping as Care is a term I have chosen to capture the sense of constant struggle and tremendous stress which characterize the worklife of these nurses. There are five components of the Coping as Care dimension:

1. design and behaviour
2. the 48 hour day
3. activities: life or therapy?
4. nine to five
5. invisible violence

Design and behaviour captures the relationship between the physical layout/design features and the behaviours of the SCU residents. Design features described by the nurses were always discussed in relation to client behaviours. A nurse would mention a design feature and then discuss its functional merits in terms of the dominant behaviours of the residents. The most frequently mentioned and important design feature to the nurses was wandering space. Aimless wandering is a very common behaviour in many elderly suffering from dementia. As one nurse put it, the residents are "constantly on the move, endlessly pacing, on the go all the time." Wandering space is, therefore, an important design attribute when caring for someone with dementia.

Five of the SCU's were straight corridor designs. The residents' wandering area was limited to pacing up and down straight hallways. The hallways are dead end. The impact of this design element is captured by the following statement: "they congregate in rooms at the dead end of corridors and get into fights." Another nurse added, "they have no place to go, with continual pacing up and down corridors."

The significance of this design element relates to its apparent impact on both resident behaviour and staffing and workload for the nurses. According to the five nurses who work in corridor design SCU's, wandering area limited to corridors causes problems and increases their workload. The increased workload is evident in the extra surveillance required. Constant surveillance by staff is required because residents frequently have to be redirected once they reach the end of the corridor, because the corridors are usually flanked by residents' rooms which they enter uninvited, and because the wanderers don't really know where they are going and simply "get lost and frustrated, start jostling one another."

The need for surveillance by the staff means continual interruptions and time taken away from other activities. Constant surveillance is a way of coping with design limitations.

Two SCU's, new and purpose built for Special Care, have continuous indoor wandering space and unimpeded access to an outdoor wandering area. That is, residents inside can wander in a loop, go outside to another loop, and come back in without needing direction. Essentially, the indoor and outdoor wandering areas become one continuous loop. Both nurses commented how this design matched the needs of their residents and "worked very well." One added, "loops lessen the workload. You don't have to chase after them. Design and security features impact on workload."

From the nurses' standpoint, corridor design SCU's are a disjuncture between the environment, the residents' needs and nursing care. The incongruence impacts on the staff's time and appears to put demands on the residents which have negative consequences.

The SCU literature describes the importance of design adaptations to meet the needs of dementia clients. In particular, unimpeded wandering space is cited as a critical design element. Calkins (1988), Cluff (1990), Coons (1991), Gutman (1992), Mace (1991) describe the importance of adequate, well designed wandering space to fit the residents' needs.

The second element of **design and behaviours** concerns private work space for nursing staff. Several nurses indicated that both the location and adequacy of private space was important to their work. One nurse in a very large SCU described the situation saying, "there is no privacy for staff meetings. A little back office room - inadequate for the number of staff. Staff have report [communication about residents from the nurses going off shift] in the dining room at a back table. We don't have a meeting place on our floor for staff. Inservices are done downstairs." That is, staff must leave the unit for education sessions. When staff had to leave the unit, in all cases, there was no replacement staff and those left on the floor assumed responsibility for all the residents.

Inadequate private area for staff has additional elements with respect to caring for clients with dementia. In one unit the location and design of the nursing station impeded visibility of the residents. The nurses had to leave and lock the area to observe the residents - residents who are constantly on the move. As she described it, "the nursing office is mid-corridor - plexiglassed in, very poor visibility of wanderers. From the nursing station you can't see the quiet room at all. In the office there is no visibility." Another described the lack of space and privacy saying, "we have report in a dinky little room off the nursing station. There is no staff meeting area. Staff have to go off the floor for meetings." She went on talking about lack of private space saying, "we have no private space to pour meds [medications]. If you close the doors its stifling hot. If you open the doors the residents wander in and muck about." A nurse in another SCU had a similar situation, "the nursing station is very small. There is no screened off part. Residents wander in and out. The folding gate that is supposed to keep them out is continually broken. Its impossible to talk on the phone, take doctor's orders, with the constant noise level."

The availability and design of private space for the nurses to have report at shift change, pour medications, talk on the phone and have educational sessions appears incongruous with the practice demands and the behaviours of residents. Clients with dementia have, in most instances, lost a sense of social boundaries. They may wander in and out of others' rooms and the nursing station, oblivious to any sense of social intrusion. The design problems related to lack of private space for the nurses, reveal a disjuncture between what the nurses need to do their job and what the residents do because of their illness.

Nowhere in the literature is the need for staff privacy mentioned. Yet, according to these nurses, the lack of privacy impacts on their working conditions - with exasperating, sometimes humorous consequences. As one nurse said, "they were going to put a gate at each end of the nursing station to prevent residents from wandering in and mucking about with everything. One time we lost our nursing notes for about 5 days. We've lost the drug order book - it may be in the laundry bin. They often do that."

Much of the SCU literature demonstrates a growing awareness of the relationship between design and the behaviours of demented people. However, discussions of design tend to focus on the needs of residents, as though these people exist independent of the staff who care for them. The research shows little awareness of the nature of caring work. One of the SCU nurses described the problem saying, "as for the architect some people have told him he's designed a total disaster. The architect never talked with the nurses."

In the two new SCU's considerable attention had been given to the design, incorporating input by staff. The two nurses in the purpose built SCU's did not mention any significant design problems.

The third element of **design and behaviours** concerns adequate dining space. Demented residents, to varying degrees, require prompting, direction and assistance from staff when eating. All the nurses indicated that residents are subgrouped when eating. That is, those requiring a lot of assistance are placed together and those more independent are seated together. Subgrouping benefits both the residents and staff who must assist them. Subgrouping also implies adequate available space - especially space to separate those with more dysfunctional eating habits. If placed together the residents tend to upset each other.

All the nurses said that they make do with the available dining space. One of the units had two separate dining areas to subgroup residents. Most had a large area used as combined activity/dining space. The nurses' comments suggest only that the design of Special Care eating space was incongruent with the differing behaviours of the residents and the work demanded of staff. One of the new SCU's, according to the nurse, had difficulty arranging the seating to accommodate the eating behaviours of all the residents and wheelchairs.

The second component of Coping as Care, **the 48 hour day**, refers to the behaviours and needs of clients at specific periods during the day. The **48 hour day** also refers to the endless and repetitive aspects of caring for people with dementia. The day appears "longer" because these residents have diminished cognitive capacity, almost no short term memory and require continual repetition, reassurance and direction. A cup of tea taken 5 minutes ago is not recalled. A phone call from a relative an hour ago is not remembered. A prompt is required to remember where a shoe goes. A bedtime story may begin in the same place every night. Activities and events are repeated over and over to compensate for the clients' functional and cognitive decline. Yet, according to the nurses, approaches to care must remain individual and flexible based on each client's particular personality and needs. Enormous patience is required by the staff. Respectful, individualized care is integrated with repetitive, frequently mundane tasks. The routine and redundant are balanced with the individual and unique. Taken together, it makes for a very long day.

Two occurrences within the **48 hour day** are particularly significant. The first element, well known to all the nurses, was sundowning. Sundowning is a term used to describe the increased agitation and restless activity by the residents at sunset. People with dementia, for unknown reasons, are more anxious and restless at sunset than at any other time of day. According to the nurses, the impact of this daily occurrence is an increased workload for staff. The residents need more individual attention during the sundowning period.

However, staffing ratios do not address this routine aspect of Special Care life. The interviews indicate that no extra staffing is in place to cope with this daily event. The opposite appears to be the case. Staffing is reduced in the evenings. As one nurse noted, "evenings are very busy. In the evening there is no time to deal with sundowning. Staffing does not reflect the sundowning effect."

The incongruence between resident needs, care required and staffing policy around sundowning is a disjuncture. Although the literature mentions sundowning as a prevalent dementia behaviour, the care demands and the policy implications are unaddressed. The literature, taken as a whole, is written as though sundowning is an interesting clinical entity unrelated to care and staffing. From the staff's standpoint, sundowning behaviour means intense extra work.

The second element of the **48 hour day** relates to night time behaviours of demented residents. When the lights go out many things happen in Special Care. Restless sleep patterns and night wandering are common occurrences with dementia. Some residents sleep well, but many get up every night and just wander around. Some residents are sleeping and some are not. The problem is accommodating both groups - the sleepers and the wanderers. Some of the units handle the problem by sitting with the wanderers, giving them something to eat and settling them. This might happen several times during the night with different people. Other SCU's handle the problem by sedation or blocking off access to other the sleepers by gaiting. Gaiting is a half door barrier to prevent a resident from leaving their room and disturbing others. It allows the resident to see out and wander in their room but prevents them from disturbing others. Gaiting is often the preferred method to direct physical restraint or use of sedative medication. (Gaiting is also very controversial, considered by many in long term care as an unethical type of restraint.)

The nurses noted that restless activity by many of the residents impacts on staff workload. Again, the staffing ratios in the SCU's do not reflect nor incorporate this expected nighttime behaviour. Night staffing is reduced to absolute minimum in most of the units. In some of the units, the RN on duty is also responsible for all the other residents in the facility, assisted by a skeletal staff of care aides. In one SCU the nurse said, "at night there is one RN to 240 residents. If something goes wrong she must leave the unit."

The incongruence between resident behaviours, nursing responsibilities and staffing ratios is a significant if not dangerous disjuncture between policy and practice. The legal ramifications if anything "goes wrong" are self-evident. These working conditions and the demands of night care remain invisible to policy makers. Those who make the policy which effectively controls staffing ratios do not work night shifts. Policy makers located elsewhere do not see this aspect of caring work. There is no mechanism, nothing on the LTC forms, nothing on the Care Levels that gives an account of life in Special Care at night.

The third component of <u>the 48 hour day</u>, **life or therapy?**, concerns activity programs and staffing. The **life or therapy?** component describes both differences and similarities in the nurses' efforts to provide meaningful activities for their residents in the face of chronic understaffing.

All the units have activity programs. The purpose of activity programs is to improve the quality of life for the residents. Activities are meant to be stimulating and fun. All the nurses said that music and dance were the most popular and hence meaningful activities for the residents - although one nurse indicated that a few residents become agitated with music. Generally residents with significant cognitive impairment, respond positively to music. One nurse spoke for all, "they love music, they love to dance." The other popular activities include van rides, walks and special parties. The nurses said that just getting outside and watching from a van was fun for residents. Facilities often could not spare the staff for individual walks, but most had available transportation to take many residents at one time for a ride.

There were differences among the nurses around the approach to activities. The differences involved two factors: who should do activities with the residents and how should activities be done? Some of the nurses supported the use of extra activity staff to come into the unit to "do" activities. Some of the nurses felt that SCU staff should "do" the activities as part of their daily care.

Underlying these two points of view was a fundamental difference in what is meant by activities. The nurses who believed that there was no need for extra "activity personnel" felt that the residents would benefit most from spending special time with regular staff who knew them. This group of nurses believed that both the residents **and** staff would benefit from mutual involvement in activities other than the mundane and repetitive tasks of dressing-toileting-giving medications- bathing-feeding-toileting-feeding-charting and so on. Integrating activities with other parts of their work would enrich the staff's job and give more meaning to their relationship with the residents. As one of the nurses said, "I think care aides and nurses should be activity staff. The same people they see every day. We always make them [the residents] do something. Then some bright little girl comes in and she can't cope with them and brings them in. It should be the same people. Consistency, the same faces. If part of staff's job includes the fun stuff the residents wouldn't be seen as heavy or as workload. Part of their job would be to do an activity or walk. Their job would be more meaningful. Then activity and toileting would be integrated and done much faster. There would be more people on the unit and we could do things as a group."

The other group of nurses saw activities as a separate event, a discrete piece of the day done to the residents by someone not on staff.

The differences in approach to activities expressed by the nurses demonstrates differences in thinking about the nature of caring work in SCU's. One way of thinking is perhaps more traditional, defining nurse-client relationship more in terms task orientation more traditionally associated with hospital nursing eg medications, charting, care planning, client assessment etc. The more traditional approach is one in which therapists "do therapy", and nurses "do nursing." The other way of thinking implies that another type of relationship is possible between nurse and client. This latter relationship is more "be with" rather than "do for." The be with approach appears to push the boundaries of traditional job definitions. From this perspective "doing nursing" may mean a more intimate, holistic involvement with residents - something one of the nurses suggested that, "care aides have done all along."

However, the differences in thinking are, so far, theoretical since based on the interviews, there are few actual differences in activity programs. The discussion around activities inevitably focused on a more concrete challenge to their practice. In many of the SCU's, money is being taken from "Activity Programs" to add care staff. As one nurse said, "activity is not a priority because the acuity level required transfer of the money to care staff." In some cases, when budgets are cut, activity programs are cut first.

The nurses who suggest that activities be integrated into everyday life saw a way of both stopping the erosion of activity programs and increasing paid hours for care staff. Rather than doing away with activity programs these nurses see an opportunity to recreate them; to increase care staff, have activities for the residents and improve the quality of their own job. Proposing a shift from the more traditional activities-as-therapy approach to activities-as-life, the staff have seen a way to get around or cope with inadequate funding policies.

In spite of the differences in thinking about activities all the nurses believed that special, fun activities were important to the residents. The nurses' concern to maintain activities demonstrates another facet of the ongoing struggle with chronic understaffing. Although the SCU literature discusses the importance of resident activities, the discussion assumes the availability of resources to accomplish this objective.

From the nurses' standpoint, current underfunding of Special Care frames the activity programs as a frill, a service extra secondary to the instrumental tasks of "traditional" nursing care. Taking from activity programs to give to care staff does not address the real problem of underfunding. (In one for-profit SCU the staff raise money on their own to provide activities for residents.)

Developing alternative ways to provide activities to residents (and expanding the dimensions of their job), is a creative way to improve client centred care and cope with underfunded programs. However, the nurses run the risk of adding to their job responsibilities without the **actual** addition of staff. Although the activities-as-life approach has appeal (one nurse emphatically stated that it is a "proven" method), the funding formulas can ignore this innovative dimension of nursing care. It may mean adding to an already intolerable workload. The fourth dimension of <u>Coping as Care</u> is called **nine to five.** This element reflects the nurses' sense of abandonment by community Mental Health services. The term captures the sense of frustration and isolation the nurses feel trying to cope with psychiatric clients without mental health assistance. The term **nine to five** is from the following statement by an SCU nurse expressing her views about Mental Health support services, "sure, there is a crisis line in Mental Health. Just make sure these people are acting up 9-5, Monday to Friday because you get the answering machine."

In no instances did the nurses feel Mental Health was helpful. Although the SCU's are taking Mental Health clients, there is no immediate help available when a crisis occurs. The nurses are on their own. As one noted, "Mental Health wants us to take their clients because they're older. But when they have a psychiatric relapse they won't take them back. If acute episodes happen, their help is withdrawn."

The nurses expressed anger and frustration at having to cope with Mental Health clients without any supportive services from the government branch traditionally responsible for these clients. As one nurse pointed out, "the MH team - I've never seen it be effective (followed by lots of laughter). Sure, as long as the residents need a social visit and no solid diagnostics, they're fine."

The nurses' attempts to cope with increasingly difficult and complex care demands of mental health clients involved attempts to refer clients to more appropriate placement. Referrals were either unsuccessful or took months to wade through the bureaucracy and gatekeeping. The consequences were increased frustration and, in some cases, the distasteful use of high doses of tranquillizing medication know to nurses as "snowing" a patient. One nurse recounted her attempts to cope with these clients saying, "referrals don't work. We need crisis help. Their lack of availability forces us to snow somebody - you know, large doses of sedation and then cut back until you've reached the therapeutic range and they are manageable. Now, its our approach to these kinds of men." The use of chemicals to restrain clients was in direct contradiction to the Restraint Policy in all the SCU's. (The SCU Restraint Policies, in general, prohibited the nurses from using drugs as a form of restraint). However, the practice of snowing was a sporadic occurrence in most of the SCU's.

The use of drugs to restrain a client demonstrates incongruence between policy and practice. The disjuncture created by Restraint Policies, client behaviours, lack of Mental Health support and actual practice was profoundly distressing to the nurses. None of the nurses liked using drugs this way and did so only when other approaches to care were completely exhausted. Without immediate crisis help, most of the nurses admitted that the use of high dosages of sedatives occasionally occurred as a way to cope during the crisis.

The remark of one of the nurses indicates their cynicism and anger about Mental Health. She stated, "the Mobile Outreach Team? Their suggestions are really stupid. They don't know the patients. No touch with reality at all." Another summarized their efforts to cope saying, "we have no one else to turn to. We turn to each other."

The final dimension of Coping as Care concerns the violence against staff and other residents in Special Care Units. **Invisible violence** is an element of Special Care known to all the nurses. Violence is a serious and increasing problem in Special Care. According to the nurses, violence is unrecognized by facility administrators and policy makers. Other than improving education for staff, there are no policies or protocol in place to protect the nurses and other residents from assault. The violence remains invisible. The violence primarily, but not exclusively, involves male residents assaulting female staff and other residents.

It is not only the violence but the lack of support to cope with the violence that is distressing. As one nurse stated, "we have more and more men of that age group coming in. Physically healthy and very demented and aggressive. It's a chronic, chronic problem. Management is not supportive. We don't have a policy for them backing us up with these incidents."

Serious violent incidents against staff and other residents were not a daily occurrence but it happened frequently. Most often the serious violent incidents involved psychiatric clients. One nurse described the situation saying, "we had an elderly lady who was psychotic. Often the demented would come up and touch and fuss, they would do this with her and she'd strike out. She went wild at bedtime. We were not given meds to cope with her psychosis. Mostly a gentle approach would work. Not with her." The violent incidents can be serious and injuries have occurred. One nurse recalled a situation with a tall, strong male resident who had a previous history of assaults, "he grabbed me and smashed me up against the refrigerator and cupboards and did it repeatedly. I was off for three weeks with a chest wall injury." Another nurse related a story in which a female resident's arm was broken by another resident.

According to the nurses, there is no emergency or quick response help available. There are no male staff working in Special Care and there are no male security personnel to call during an emergency. There is no emergency protocol, no crisis team or back-up available to the staff. From the nurses' standpoint the problem is hidden, invisible and ignored - otherwise an emergency response procedure would be in place.

The nurses, all female, coped through various means. The following story illustrates the danger and isolation they face during a violent incident: "One evening I was alone with the 42 residents. The aides had gone for a break. On the floor was a male resident with a history of aggression. I noticed he was becoming restless and somewhat anxious. I went to the medication room for Ativan (an anxiolytic drug) and the man followed me and started to punch me. I went to the intercom to call for help and he wrapped the phone cord around my neck. If I had not been in the medication area there would have been no way to call for help. There are no other emergency call mechanisms to contact other areas of the facility." Her perception was that, "if a resident hurts staff, nothing will be done. If he hurts another resident then something will be done. If staff is hurt that is acceptable."

In one large facility the nurses were supposed to call the supervisor during an emergency. As the nurse noted, "what is a calling a supervisor going to do?" In other cases the police were called. As one stated, "we've called the police. They didn't do anything. This guy was swinging. Five care staff and one RN trying to hold him down. We've got transfer belts on this guy. The police just stood there while care staff who weighed all of 90 lbs. soaking wet struggled with this guy. The police said they weren't going near him. They stood at the elevator and watched and waited for the ambulance attendants to deal with it."

The nurses know from experience that some elderly psychiatric clients and demented clients can be violent. The lack of safety and security measures for staff and other residents is incongruent with the actual behaviours of some residents. A serious disjuncture exists between the client behaviours and the absence of policies addressing the violence. For the nurses with previous psychiatric experience this disjuncture was particularly distressing. As one psych nurse noted, "there should be emergency response protocol and support in place. One night a staff member was choked. They phoned downstairs. We have one RN and 2 LPN's on duty at night. Nobody else is there to help. If you can't get to a phone...its not enough protection and security for staff. Psych hospitals are better staffed and all the staff have been trained to deal with the violence. It happens. Its expected. We are not ready here. It happens and there is nothing in place to deal with it. In psych everyone knows what to do to take someone down. A lot of staff on other floors are afraid of our residents."

The absence of policy on violence says something about how the work of caring for demented old people is framed by administrators and government. Nursing home work is gendered as Diamond (1990), Reverby (1990) and many others writing about caring work have noted. The overwhelming majority of caregivers in residential facilities, including Special Care, are women. Violence against women nurses in Special Care has become normalized, similar to the way violence against women is normalized in larger society. (There is no reference to violence in the Special Care literature. Clients behaviours are "difficult to manage" or "socially inappropriate" but violence is not mentioned) In Special Care, violence is called "aggressive behaviour." Violence-as-aggressive behaviour is more acceptable because its perpetrators are mentally incompetent and not responsible for their actions. These people need care. "Aggressive behaviour" is just part of caring for cognitively impaired people. It goes with the territory. It is to be expected. Nurses have a professional duty to care. Therefore, the problem is one of adjusting care. Care is improved through ongoing education in the management of "aggressive behaviour." Although the nurses agree that education is very important to improve staff's approach to care, they did not see education as the single solution to the problem. They also identified the right to be protected from violence in the workplace.

Framing a policy to protect nurses against workplace violence means admitting there is a problem. Fixing the problem would likely mean more staff and implementing protective policies. More and better educated staff would mean more money. It is cheaper to frame the situation not as violence in the workplace but as part of nurses' responsibility to improve their approaches to care. There is no violence if "aggressive behaviour" is framed exclusively as inadequate staff training. And so the administrative logic goes and the disjuncture between policy and practice remains.

Dimension IV. Creating a Community.

The final dimension involves those characteristics and components which, taken together, help build a sense of community in Special Care. Creating a Community was an underlying theme of providing quality Special Care. Special Care Units are a unique type of residential community for elderly cognitively frail residents. There are several features which, from the nurses' perspective, strongly influence this community feeling. The three key elements in this process are **education**, **dedicated staff**, and **approach to care**.

All the nurses believed that staff should have a both basic **education** about the normal aging process and specialized training to understand dementia. As one nurse noted, "staff education is really important because of the approach. Individuals change, we need to understand what and why things are happening. Staff have to be flexible." Another said, "we need to know more about Alzheimer's. Its a difficult disease. The aides turn to the RN's for help." From their perspective, education was fundamental to developing a reasoned, individualized and flexible approach to each resident's care. Without understanding the etiology and progression of dementia, approaches to care could not be consistently implemented with each client. Specialized education was important to develop critical assessment skills and care planning. Most of the nurses felt that education had to be on-going to develop the sensitivity and skills required in this area of care. Most felt that basic preparation in dementia care should be required prior to working in Special Care.

The second element emphasized by the nurses was that staff should choose to work in Special Care. There were some differences expressed about whether staff should be "**dedicated**" to the unit or rotate to other areas of the facility. Most of the nurses felt staff should be dedicated because they come to know the clients well, the clients come to know them resulting in more consistent, individualized care. One nurse emphasized that using rotating staff in Special Care "increases task orientation instead of resident oriented care". Several of the nurses remarked that when staff unfamiliar with the residents came to work, the residents reacted negatively with increased agitation and disruptive behaviours. As one noted, "people who rotate through. Well, its pretty chaotic. The consistency is greatly disrupted. It affects the activity level and noise level. I can tell as soon as I walk on in the morning if the "regulars" [staff] are not on...because people [residents] are up pacing around, puttering into things and arguing between themselves. They [residents] are into somebody else's space and dressed in things that cause them discomfort and wearing things they don't like - yelling at each other to get out. Stripping out of things they don't like to wear. All the little things that make the day go smoothly are lost with inconsistent staff."

However, all of the nurses felt staff should be given the opportunity, if requested, to rotate to another area for a change. They cited the stressful nature of their work required breaks to prevent staff burn-out.

Taken together **education** and staff **dedicated** to the unit were the essential components necessary to implement an **approach to care.** The **approach to care** is characterized by philosophy-in-action of caring for cognitively impaired people. All the nurses felt that, other than adequate staffing levels, **approach to care** was the single most important element in caring for dementia clients. All the units had an approach to care which emphasized client dignity, respect for individual differences, flexibility by staff to compensate for the residents decline in functional and cognitive skills, high touch such as hugging to relate on an emotional rather than instrumental level with clients, enormous patience, and lots of humour.

Education, **dedicated staff**, and **approach to care** required policies backed by administrative support. Creating a community which was built on these elements meant staff were provided with educational opportunities, that numbers of staff were sufficient to allow for a dedicated group in Special Care, and, that the complexity of caring for demented clients meant creative, often unusual approaches to care beyond the routine instrumental tasks.

The educational level of the SCU staff varied tremendously in each unit. Some nurses had specialized training in dementia care and several years previous training and experience in psychiatry. Only one nurse indicated having specific formal education about normal aging. The type of staffing also varied: two of the SCU's have rotating staff, two have dedicated staff and three use a combination of the two. All described a similar approach to care. The interviews suggested that the smaller units, those with fewer residents, were more successful in implementing the gentle, flexible approach to care. The larger units had, as a nurse from one stated, "unbelievable workloads" which negatively influenced their approach to care. Care in the larger units was less individualized and appeared more task oriented as staff "struggle to just get through the work."

A policy structure that supports staff education, dedication to unit and specialized approaches to care was not uniformly found. In the smaller units the relations between administration and nurses appeared more positive. Nursing standpoint and administration standpoint were closer together concerning the fundamental issues of education, staffing and approaches to care. In the larger units, the nurses and administration appeared to be working at cross purposes. The larger units tended to have a management style more consistent with traditional hospital/institutional care. On the basis on anecdotal remarks, the larger facilities appeared to be managed more on the basis of organizational interests focused on efficiency and cost-accounting rather than client-centred concerns. The nurses in all units identified that government funding was inadequate to support education, dedicated staff and flexible approaches to care. Government funding policies and facility administrative decisions created conditions in which adequate education, dedicated staff and client-centred approaches to care could not be sustained. The resources simply were not there to enable staff to be well trained, remain on the unit and deliver the quality care the nurses felt the clients deserved. Creating a community was possible to the extent that the essential elements were available to the nurses to build the community. As Campbell (1988) notes "policy decisions made elsewhere in the health-care system pervade nursing care" (p.395). Education, staffing deployment and approaches to care are not fundamentally under the control of the SCU staff. In varying degrees across all units, decisions directly affecting a sense of community rarely involve the nurses. From the nurses' standpoint SCU's are not just a place of employment into which they bring their skills and labour. SCU's are a home. From the government's standpoint decisions about

SCU's are made, not on an understanding of the notion of community, but on the basis of political priorities and government fiscal policies. Decisions made by government are organized by management in relation to other facility priorities and pressures. To create a community SCU nurses must have control over the education appropriate to their work, staffing decisions and methods/approaches to care. As Campbell (1988) notes, "nurses control over their practice is lost when they no longer have a say in staffing decisions. While nurses continue to be held responsible for the outcome of their work...the conditions there are being organized without their control" (p.402). This perspective is reaffirmed by one SCU nurse who stated, "why don't they ask a nurse what is going on - before they make policy. Nobody ever asks the nurses."

In conclusion, the four dimensions represent the main features and components of Special Care Units from the standpoint of front-line nurses. Clients created elsewhere explains the disjuncture between the Long Term Care classification levels/funding/staffing by the Ministry and the needs of real Special Care clients. The dumping ground describes the disjuncture (resulting from gaps in mental health services) between SCU admission criteria (dementia focused) and admission of elderly psychiatric clients. Admission criteria are further eroded in for-profit SCU's in order to fill a bed. Coping as care describes the stress and challenges of daily life in Special Care unaddressed by the literature and policy. Creating a community describes the characteristics which, taken together, build a sense of community in Special Care.

Each dimension illuminates certain contradictions or disjunctures between the larger policy context/administrative organization and the actualities of front-line work for Registered Nurses in Special Care. The dimensions are not inclusive of the perspectives of care aides, family members nor of the residents. The four dimensions expose a tension between the reality of practice and the macropolitical forces which shape that practice

(Diamond, 1990). More importantly, the dimensions give a voice to the nurses whose experience and knowledge has been marginalized both in the literature and the policies shaping their work in Special Care.

CHAPTER 5

POLICY IMPLICATIONS FOR SPECIAL CARE UNITS

The data from interviews with nine front-line nurses identifies key features and components in Special Care. The purpose of this section is to explore the policy implications for Special Care suggested by the data. The policy implications are not prescriptive but suggestive of an alternate policy direction for the development of Special Care.

Framing policy involves identifying the problem(s) and looking among a variety of sources for problem clarification and problem solving options. Policy involves both process and product (Wharf and Cossom, 1992). The policy process is volatile, value laden, political, and involves many actors and many agencies. Research is one among many competing (and often contradictory) sources contributing to the process of policy decision making (Bulmer, 1986). Qualitative, interpretive research can play a significant role in giving the policy maker a "feel" for what is happening "out there".

Framing policy begins with identifying the policy model which will guide the process and ultimately influence the product. A policy model is the tool analysts/government bureaucrats use (consciously, deliberately or not) to think about the problem(s) and devise solutions. The Ministry has initiated a range of policy options (identified in Chapter 1) which are shaping Special Care and represent pieces of the Ministry's current model. Each policy initiative (Special Care Guidelines, downsizing of Riverview, Multilevel Care Guidelines and Special Care Unit Survey) has emerged without benefit of front-line practitioner consultation. Taken together these Special Care initiatives suggest an incremental "muddling through" policy model first described by Lindblom (1959). "Muddling through" as policy is a series of incremental (residual) but not necessarily coordinated steps which differ little from previous policy direction. Taken together the Special Care initiatives are a kind of "organized anarchy" (Thompson, 1984) - whereby incremental uncoordinated adjustments to address the problem of caring for cognitively impaired elderly are tagged to established ways of doing things in Long Term Care.

The SCU initiatives are consistent with the Ministry's traditional centralized, top-down policy approach. A top-down approach as described by Elmore (1979) begins at the top of the process, stating the policy maker's intent and proceeding through a sequence of increasingly more specific steps to define what is expected of implementers. The objectives are management oriented and frame policy goals to fit within a centralized decision making process. This approach assumes that policy making is the exclusive domain of centralized bureaucracies and "experts" (such as the Ministry of Health bureaucrats and academic researchers). The top-down approach further assumes that policy making is an "objective", "rational" and mainly technical process which can be engineered from beginning to end from central office.

If policy continues to develop in this way, based on the Ministry's Special Care menu, it will not address the challenge of bringing policy and practice together. The missing piece of all the Special Care initiatives is practitioner knowledge. A different model is required to develop policy which incorporates practitioner experience. The following discussion of policy options, therefore, focuses on those objectives (and strategies to achieve those objectives) related to and informed by front-line practice.

Front-line Issues, Policy Objectives and Implementation

Linking policy objectives and the means by which these objectives may be accomplished is a central component of policy research. As Elmore suggests (cited in Brewer & deLeon, 1983), policies cannot be understood in isolation from the means of their execution. The policy objectives suggested by front-line nurses are practitioner oriented and fit a decentralized bottom-up decision making and implementation process as described by Elmore (1979). Policy informed by practitioners turns the traditional "rational" centralized engineering process on its head and challenges the assumption that policy decisions and implementation strategies **ought** to be controlled from the top. As the nurses' accounts suggest, policy controlled from the top has resulted in severe disjunctures between policy and practice in Special Care environments. A bottom-up approach, beginning with what practitioners know, addresses "the specific behaviour at the lowest level of the implementation process that generates the need for policy. Only after that behaviour is described does the analysis presume to state an objective" (Elmore, 1979, p.604). The bottom-up approach assumes that those closest to the problem have a greater ability to identify what is wrong, suggest solutions and correct the problems. Policy makers do not solve problems, but may create the necessary resources for others in more direct contact to actually solve the problems. Identifying those closest to the problem does not mean that the **source** of the problem **is** the behaviours/experience at the lowest levels of implementation. But the behaviours are a starting place from which the problem(s) can be traced back up through the system to identify how the problem is expressed at each organizational level. The bottom-up approach begins and ultimately ends with the lowest levels of implementation eg front-line Special Care staff. Beginning with experience according to Elmore (1979),

> "emphasizes that it is not the policy or the policy maker that solves the problem, but someone with immediate proximity. Problem solving requires skill and discretion; policy can direct individuals' attention toward a problem and provide them an occasion for the application of skill and judgement, but policy cannot itself solve problems. Hence, identifying the connection between the problem and the closest point of contact is the most critical stage of analysis. After that, analysis consists of describing the most direct means of reaching the point of contact, focusing resources on those organizational units and coalitions that have the greatest likelihood of affecting delivery-level performance" (Elmore, 1987, p. 612).

The bottom-up approach allows policy goals and delivery mechanisms to be more flexible and attuned to different organizational levels (and skills of participants at each level) during the implementation process.

Berman's (1984) adaptive implementation strategy suggests a similar policy perspective. He notes that a process that allows policy to be modified, specified and revised according to the unfolding interaction of the policy with its institutional setting addresses the inevitable difficulties arising from a large cast of implementing actors and agencies. This view has implications for Special Care. Differences in Special Care settings exist. Many actors will be involved in the delivery process. Rather than rigid goals and implementation mechanisms which ignore inevitable differences, these differences should be incorporated and used for the abilities and strengths they offer at each level and stage of the policy process. Adaptive implementation calls for the active participation of relevant actors which enhances the problem-solving during implementation. Additionally, organizational and management literature has demonstrated that people participate when they are motivated and involved to do a good job (Berman, 1984, p.211).

Active involvement of front-line practitioners in the policy process has growing support in the literature. An adaptive, bottom-up policy model will help develop a sense of policy ownership among Special Care staff and address the problems they experience as caregivers. They will not be the objects of policy decisions made elsewhere but active participants in its creation and implementation. Implicit in the adaptive, bottom-up approach is that the Ministry must share control in the development of Special Care with front-line staff. Consultation <u>and</u> collaboration between the Ministry and care staff will establish the partnership necessary to undertake new policy initiatives in Special Care. Underlying this "New Direction" is the notion that front-line workers are both capable and trustworthy to do what is best for the clients they know. The Ministry must make room for staff discretion at the Health Unit and Special Care Unit level. If Special Care staff have ownership of the policy they will be less likely, as Lipsky (1980) suggests, to develop coping strategies that subvert policy goals.

Practice Makes Policy

The intent of the following discussion is to suggest how and what kind of policies could be developed using a bottom-up approach. The four dimensions described by the nurses are rich descriptions of behaviour - actual practice issues that may be translated into policy and implementation strategies. The policy implications of the four dimensions (Clients Created Elsewhere, the Dumping Ground, Coping as Care and Creating a Community) will be outlined by: 1) Problem Definition, 2) Goals/Objectives, 3) Implementation Strategies and, 4) Potential Resources.

Clients Created Elsewhere

The Problem:

The real clients in Special Care environments do not match the descriptors and classification criteria in the Long Term Care Patient Classification Levels. Additionally, current funding and staffing formulas, tied to the Classification Levels, are seriously inadequate and do not address the workload and skill required to care for Special Care clients.

Goals/Objectives:

The goal is to identify the real needs of clients and staff in Special Care environments.

Strategy:

One way of implementing this objective is to hold focus groups of nurse practitioners in SCU's and undertake a complete review of the Long Term Care Classification Levels and Client Assessment procedures in Long Term Care. Terms of reference of the review could be determined by a *key stakeholders committee. On the basis of the findings and collaborative direction of the committee:

1) Develop a comprehensive and flexible Assessment Tool sensitive to the particular problems of psychogeriatric clients.

2) Adjust funding and staffing formulas to meet the actual workload and care required by psychogeriatric clients.

3) Develop a Health Unit controlled funding strategy that empowers Special Care Units to exercise discretionary staffing patterns.

Resources:

A key stakeholders committee termed the <u>*Provincial Care Issues Committee</u> could be formed. This committee would provide direction to the LTC Assessment and Care Level review. Committee membership might consist of Long Term Care and Mental Health representatives, SCU facility administration and SCU front-line staff representatives, Long Term Care Assessors, Health Unit Managers and family caregivers.

The Continuing Care Division could fund an independent consultant to collate the results of the review.

<u>The Dumping Ground</u>

The Problem:

Mixing diverse psychogeriatric client groups within Special Care environments is creating serious care problems. In part, these problems are due to a lack of understanding at all service levels of the differing needs, care and appropriate residential environments for different types of psychogeriatric clients. Current residential environments are inadequate and inappropriate for diverse and difficult to manage psychogeriatric clients. Unclear admission criteria and coercive admission practices in Special Care Units have contributed to the problem. Further, Special Care staff are inadequately trained to effectively and safely care for increasingly complex types of psychogeriatric clients.

Goals/Objectives:

A main objective is to improve knowledge at all service levels about the range of psychogeriatric clients requiring specialized treatment and care in secure residential environments. On the basis of improved knowledge, the Health Units/SCU's would identify the range, type and numbers (current and projected) of secure residential environments needed to accommodate increasing numbers of psychogeriatric clients. Improved psychogeriatric client assessment and placement procedures are also required. Provincial psychogeriatric emergency response services are needed.

Strategy:

To address education, a provincial education program about diagnosis, treatment, care and quality of life for different psychogeriatric client groups could be provided to all staff concerned with the care of these clients. This program could be developed and administered at the Health Unit level and tied to a regional Licensing and Quality Assurance review of facilities. Development of and participation in the program would be determined by the Health Unit stakeholders. Academic and Ministry of Advanced Training and Education representatives might be involved.

A second strategy is to approve, develop and fund through collaborative partnership programs an innovative spectrum of community based psychogeriatric residential environments across the province.

A third strategy is for a key stakeholder review the role of Multilevel care facilities (and guidelines) in relation to the range of alternative residential settings.

A fourth strategy would be a comprehensive data base (developed by central office in collaboration with Health Units) to help regions match psychogeriatric clients with appropriate residential environments province wide. This data base would enable a client centred continuum of care based on the revised LTC Assessment Tool and Funding and Staffing formulas implemented by each Health Unit. The admission criteria of each SCU would remain flexible with admissions controlled by staff discretion in both profit and non-profit facilities. Participants might include: Provincial Care Issues Committee (as above) and a computer program consultant.

A fifth strategy would involve CCD/Mental Health field staff and front-line SCU staff in the design and implementation of emergency back-up resources for SCU's. This process might involve negotiations with local tertiary service eg hospital to provide 24 hour back up emergency response for residential facilities caring for difficult to manage psychogeriatric clients. Additionally, a Health Unit based emergency response psychogeriatric staff could be developed to respond to emergencies in facilities to avoid unnecessary hospital admissions.

Resources:

Education funding could be provided through Ministry of Health/Ministry of Education and matching foundation grant.

A strategic plan outlining phased development of community based residential programs could be developed by the *Provincial Care Issues Committee.

Block funding by CCD/Mental Health/Office for Seniors and other stakeholder agencies for a pilot project (and evaluation) for alternative residential options for psychogeriatric clients in 1 urban and 1 rural Health Unit could be provided.

A contract could be established and funded through CCD central office for a computer programmer to work with the Health Units in developing a provincial psychogeriatric data base to be integrated with the revised LTC Assessment Tool and Staffing parameters.

The development and implementation of emergency response services would be jointly funded by regional budgets from Hospital Programs and Continuing Care and Mental Health.

Coping as Care

The Problem:

Residential facility designs are incongruent with client behaviours and work practices of staff in Special Care. Because client behaviours change significantly over the course of a day, existing staffing arrangements are inadequate. The working conditions and organization of work in SCU's prevents staff participation in recreational activities with clients. There is inadequate funding for activity programs. There is no emergency psychogeriatric support for Special Care staff. There are no policies and resources to protect staff and residents from violence and assaultive behaviour in Special Care.

Goals/Objectives:

A provincial objective is to build environments congruent with the needs of psychogeriatric residents and care practices of staff. Staffing formulas must be developed which are responsive to changing client behaviours which, in turn, influence staff workload. Staff should have the opportunity to develop and participate in recreational activities which: 1) expand their traditional roles, 2) enhance the meaning and satisfaction staff derive from their work and, 3) improve quality of life for residents. Safety and security of staff and residents in Special Care Units must be established through timely and appropriate treatment for clients experiencing acute psychiatric episodes.

Strategies:

Through consultation with facility administrators, architects and front-line staff, appropriate and innovative designs can be developed for new residential environments for psychogeriatric clients. The design criteria would apply to both profit and non-profit facilities. A review and redevelopment of LTC staffing and funding formulas for Special Care environments would be implemented (see above). Opportunity by staff to participate in client recreation activities might be incorporated into the staffing level review. The organization of work in Special Care would be determined by staff discretion in each Special

Care Unit. An emergency psychogeriatric response policy and procedure would be developed and funded by the Ministry. A collaborative project involving the Provincial Nurse Advisor, Mental Health, LTC program, Special Care front-line staff and union representatives, could develop security and safety procedures and standards for Special Care. Implementation of these procedures could be tied to Licensing and Accreditation of facilities.

Resources:

A decentralized Facility Design Committee, with the authority to develop design standards, could be established. Committee membership could come from stakeholder representatives at the Health Unit level. Membership might include: Ministry architects in Facilities Planning and Construction, private architect representatives, facility administration, front-line staff, families and agency and society representatives.

A legislative review of the Community Facility Act and Adult Care regulations could be planned guided by the Facility Design Committee recommendations.

A committee to review LTC staffing and funding formulas would be established (as above).

CCD, RNABC, HEU, Facility Associations, Women's Programs could provide joint funding for Provincial Nurse Advisor/CCD/Mental Health collaborative project to address violence in the workplace. Recommendations for a legislative reform of Licensing and Accreditation of residential facilities tied to staff and resident safety could be proposed.

Creating a Community

The Problem:

Many SCU staff lack basic education about normal aging and specialized education related to psychogeriatric problems. There is insufficient staffing to allow Special Care staff to be dedicated to the Special Care area. The combined lack of education and inadequate staffing negatively impacts on workload and impedes creative approaches to care of psychogeriatric clients.

Goals/Objectives:

A main objective is to improve the assessment skills and competency of Special Care staff caring for difficult to manage psychogeriatric clients. Adequate staffing must be established in Special Care Units to designate a core SCU staff who remain on the unit with options to rotate out as needed. Front-line staff should have the authority to organize care in each Special Care Unit based on experience with and understanding of individual clients.

Strategies:

Normal aging and care of psychogeriatric clients courses might be reviewed for all medical and nursing education programs. A review of LTC staffing and funding formulas would be established (as above). Core geriatric courses in undergraduate medical and nursing and social work education programs could be established through a collaborative plan utilizing experienced SCU and mental health front-line staff in both curriculum development and teaching. Union protection by contract of all LTC aides and nurses working in residential facilities could be established through collective bargaining to support front-line staff control over working conditions.

Resources:

A key stakeholder education planning committee (with equitable representation of practitioners and academic "experts") could be established to address multidisciplinary educational requirements for professional and non-professional psychogeriatric staff.

Collective bargaining for HEU and BCNU staff should incorporate contract provisions which guarantee, as well as support, workplace safety.

A psychogeriatric emergency response team would be established in each Health Unit (as above).

Concluding Statement

This study raises fundamental policy questions which involve a larger constituency of caregivers: 1. How can the care of the elderly, in general, and of those with dementia, in particular, be given priority? 2. How can those working in Special Care Units increase their influence?

Demographics of our aging society have alerted policy makers to the need for change and improvement in the delivery of care to older persons. The rapid growth of the very old segment of our population is clearly tied to the increasing prevalence of dementia. Forceful statistics, but numbers alone will not succeed in confronting bureaucratic routines imposed by above or by authorities who do not directly care for clients and who do not basically understand the problems associated with this care.

I suggest that a collective policy community can be built by a coalition of caregivers - including professional and non-professional groups, families of frail elders and societies and agencies involved with care for this population. Special Care staff representing nearly fifty Special Care Units in British Columbia can organize an association and forcefully articulate the needs of this population in a collaborative lobbying effort with family caregivers and associated societies. A policy opportunity exists in which an inclusive policy community can challenge the centralized, bureaucratic top-down decision making that has framed long term care policy. Those who confront the actual care problems are in the best position to identify and prioritize the needs, goals and strategies, both long and short term, for this population.

Secondly, a working partnership between "top" and "bottom" can only occur if decision making is decentralized. Central office bureaucrats have been given this wake-up call through the Ministry's "New Directions" policy framework which will decentralize and regionalize health care. The timing is right for community partnerships to form and actively lobby for a partnership in decision making for this dependent group of elders.

Consistent with the "New Directions" framework, Special Care policy development will require a working partnership between Special Care staff, families and concerned associations and agencies, Health Unit representatives and Ministry analysts. The caregivers (paid and unpaid) are required to identify the actual needs in Special Care Units and analysts are necessary because of the knowledge of available (and potential) resources and barriers to implementation. Bureaucrats, partnered with experienced caregivers, will come to recognize that bottom-up policy design has the advantage of a built in implementation and accountability plan - those who confront the problems help devise the solutions, map out the strategies and prioritize on the basis of full disclosure by the government of available funds and competing issues.

The development of an inclusive policy community, beginning at the Health Unit level, would establish the expertise and implementation skills and strategies necessary to address the key issues now and for the future.

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APPENDIX A.

ACCESS TO FACILITIES AND INFORMANTS

HUMAN SUBJECTS REVIEW

The following procedures were followed to gain access to facilities and interview subjects:

1. An introductory letter to each facility Director of Care was sent explaining the research project and request for facility participation. An additional request for voluntary participation by three RN's working full-time in the SCU was be made.

2. A phone call followed the introductory letter to establish whether a facility wished to participate. The call provided an opportunity to answer any questions about the research project. A request for the name of RN volunteers was made at this time.

3. When verbal consent to participate was given by a facility, a written consent form was sent. The RN's volunteering to be interviewed were contacted and additional written consent forms were forwarded to them.

4. An interview schedule was arranged at the convenience of the nurses being interviewed.

INTRODUCTORY LETTER Date

Dear (Director of Care)
(Facility Name)

My name is Lee Frost. I am a Registered Nurse completing my masters degree at the University of Victoria. My thesis is a study of Special Care Units. Specifically, I am interested in the knowledge and experience of front-line staff and how their experience might influence Special Care policy.

I am writing to request the participation of your facility in this study. I would like to visit your Special Care Unit and interview a Registered Nurse who working full-time in the SCU. The interview will last approximately two hours and will be taped. The scheduled time of the interview will be at the discretion of the nurse and will not interfere with her responsibilities at work.

Participation of the facility and the nurses is completely voluntary. The anonymity of the facility and the nurses will be maintained throughout the study. Any reference to a particular facility or informant in my final paper will be by pseudonym.
Upon completion of the study all taped interviews will be destroyed.

I will contact you by phone to determine your facility's response to my request and answer any questions you may have.

Sincerly,

Lee Frost RN, BsN.

University of Victoria
Faculty of Human and Social Development
Masters Program
Policy and Practice in Health and Social Services

CONSENT TO PARTICIPATE FACILITY/SCU

Special Care Unit Study

This research is being undertaken as part of a graduate level thesis at the University of Victoria. The aim of the study is to identify key features, characteristics and components of Special Care Units and to look at the development of policy in this emerging area of care. This study is not an evaluation of the Special Care Unit. I am looking at the potential impact on policy related to front-line nurses' knowledge and understanding of Special Care Units. The informants will include SCU staff nurses.

If your facility agrees to participate I would like to interview Registered Nurses (one or two) working full-time in the Special Care area. The interviews will be taped. Upon completion of the study the tapes will be destroyed. **The anonymity of both the facility and the nurse will be maintained throughout the study - a pseudonym will be assigned to each.**

Access to the data obtained through the interview will be restricted to the researcher and the researcher's supervisor.

If your facility agrees to participate you may withdraw at any time. If you have any concerns about any aspect of the study you may contact my thesis supervisor, Dr. Brian Wharf at the University of Victoria: 721-6297.

The signature below indicates the facility's duly authorized representative agrees to the terms of participation in the study.

RESEARCHER NAME: Lee Frost RN, BsN. SIGNATURE...............

FACILITY NAME..

NAME..........................POSITION......................

SIGNATURE.........................DATE......................

APPENDIX B.

CONSENT TO PARTICIPATE REGISTERED NURSE

Special Care Unit Study

This research is being undertaken as part of a graduate level thesis at the University of Victoria. The aim of the study is to identify key features, characteristics and components of Special Care Units based on information provided by front-line nurses. I wish to identify key features of Special Care Units from the perspective of nurses and see how the information would affect policy in this emerging area of care.

<u>This study is not an evaluation of the Special Care unit or of your work.</u>

I would like to interview you for approximately 1 - 1 1/2 hours. The interview will be taped. Your identity, and the identity of the facility where you work, will be anonymous throughout the study. Each facility and nurse participating in the study will be assigned a pseudonym. Access to the taped interview will be restricted to myself and my supervisor. Upon completion of the study the interview tapes will be destroyed.

If you agree to participate you may withdraw at any time. If you have any concerns about any aspect of the study you may contact my supervisor, Dr. Brian Wharf: 721-6297.

The signature below indicates you agree to the terms of participation in the study.

RESEARCHER NAME: Lee Frost RN., BsN. SIGNATURE.................

FACILITY NAME...

NAME OF PARTICIPANT....................SIGNATURE.................

DATE.................

VITA

Surname: Frost Given Names: Ellenor M.

Place of Birth: Kalamazoo, Michigan Date of Birth: July 5, 1948

Educational Institutions Attended:

Royal Jubilee Hospital School of Nursing	1978
University of Victoria	1989 - 1991 1991 - 1993

Degrees Awarded:

BsN	University of Victoria	1991

Honours and Awards:

Harold and Myra Thompson Memorial Bursary	1990
University of Victoria Graduate Fellowship	1991/92 1992/93

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Title of Thesis/Dissertation: SPECIAL CARE UNITS: The Policy Practice Interface

Author [redacted]
(Signature)

ELLENOR M. FROST
(Name)

January 14, 1994
(Date)