



**SPECIAL CARE
UNITS
FOR DEMENTIA:
Staff and Family
Perceptions**

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SPECIAL CARE UNITS FOR DEMENTIA:
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Report of a Study Undertaken for the Pacific Health Care Society

by

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PREFACE

The study described in this report and the literature review of the environmental design, programming and staffing needs of dementia victims in institutions that preceded it (Gutman, 1989) were undertaken to provide the Pacific Health Care Society with information that would assist it in evaluating the need for and feasibility of expanding its service to include a Special Care Unit.

As indicated in the Introductory section of this report, dementia is a condition whose prevalence increases dramatically with increasing age. With aging of the Canadian population, increasing numbers will be afflicted with it.

There is a need to plan now for this segment of the population; to ascertain ways in which their needs may best be met.

This study reflects the experience of the Coordinators, staff and relatives of residents of six Special Care Units currently in operation in British Columbia.

The authors gratefully acknowledge the cooperation and assistance of these individuals.

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Finally, we wish to acknowledge the financial support and encouragement provided by the Pacific Health Care Society, for whom, we trust, the information assembled will prove useful.

This information should also prove useful to existing units. It was evident on a number of occasions during the data collection that one unit had independently developed a solution to a problem that other units were still grappling with. This report may facilitate the sharing of such ideas and approaches, and it is hoped, indicate what can happen if increased opportunities for communication are developed.

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1. INTRODUCTION

1.1 BACKGROUND AND RATIONALE FOR THE STUDY

Dementia is a syndrome characterized by intellectual deterioration severe enough to interfere with occupational or social performance. Cognitive changes include disturbances of memory, language use, perception, learning, problem solving, abstract thinking ability and judgment. In some patients personality is changed as well. Some patients show paranoid symptoms and are delusional. Irritability, agitation, verbal and even physical aggression towards family members may be exhibited as the disease progresses and patients feel less and less in control of their environment (Katzman, 1986).

There are two major causes of dementia: Alzheimer's Disease, which is estimated to account for 50-60% of cases and vascular disease and multiple infarcts (strokes) which are estimated to account for 10-20% of cases (Katzman, 1986).

While Alzheimer's Disease and strokes are known to occur in younger people, dementia is primarily a disorder of the elderly, with an estimated 4-8% of those aged 65 and over suffering from moderate and severe forms (Preston, 1986). The prevalence of dementia increases markedly with age. According to Jorm, Korten and Henderson (1987), from age 65 onward the rate for moderate and severe forms doubles every 5.1 years. Extrapolating their age-specific prevalence rates to British Columbia, McEwan (1989) estimates that currently there are over 8,000 cases among persons aged 65-79 and over 12,000 cases among those aged 80 and over. As shown in Table 1, McEwan

(1989) estimates that by the year 2001, there will be over 12,000 cases among British Columbians aged 65-79 and over 22,000 cases among those aged 80 and over.

TABLE 1

ESTIMATED NUMBER OF DEMENTIA CASES (MODERATE AND SEVERE)
IN BRITISH COLUMBIA BY 5 YEAR AGE INTERVALS (1986-2001)

<u>Age Group</u>	<u>Prevalence Rate (%)*</u>	<u>1986</u>	<u>1991</u>	<u>1996</u>	<u>2001</u>
65-69	1.4	1645	1917	2034	2134
70-74	2.8	2743	3145	3637	3863
75-79	5.6	3650	4832	5454	6310
80-84	10.5	4104	5361	6962	7960
85-89	20.8	3983	5187	6597	8595
90+	38.6	4094	4320	4941	6289
Total Cases		20219	24762	29625	35151
Total Population 65+ ('000)		349.5	422.7	483.4	536.5
Total Prevalence Rate		5.8%	5.9%	6.1%	6.6%

* Age-specific prevalence rates from Jorm et al (1987); 1986 population base from Statistics Canada Census data. 1991-2001 projections from Central Statistics Bureau, B.C.

Source: McEwan (1989)

Table 2 shows corresponding figures we have calculated for the Greater Vancouver Regional Hospital District (GVRHD), where about half of B.C.'s elderly reside.

TABLE 2

ESTIMATED NUMBER OF DEMENTIA CASES (MODERATE AND SEVERE)
IN GVRHD BY 5 YEAR AGE INTERVALS (1986-2001)

<u>Age Group</u>	<u>Prevalence Rate (%)*</u>	<u>1986</u>	<u>1991</u>	<u>1996</u>	<u>2001</u>
65-69	1.4	749	849	855	836
70-74	2.8	1250	1371	1538	1548
75-79	5.6	1720	2125	2322	2602
80-84	10.5	1995	2443	3000	3286
85-89	20.8	2071	2537	3883	3793
90+	38.6	2133	2482	2881	3462
Total Cases		9918	11807	14479	15527
Total Population 65+		163371	189440	208309	191693
Total Prevalence Rate		6.1%	6.2%	7.0%	8.1%

* Age-specific prevalence rates from Jorm et al (1987); 1986-2001 population base from Extended Care Subcommittee of GVRHD's Regional Geriatric Care Planning Model (June 1987)

While these numbers are staggering, the impact of dementia on society is even greater than the numbers would suggest because dementia, by its very nature, has a significant, often devastating, impact not only on the afflicted individual but on family members and other caregivers as well. Aronson and Lipkowitz (1981), among others, therefore recommend a broad conceptual model for treatment in which attention is given to psychological, social and economic factors affecting both the dementia victim and the family.

The first priority in the treatment of dementing illnesses, however, is a comprehensive medical assessment. It is estimated that from 10 to 30% of those presenting with dementia-like symptoms have a reversible or non-

progressive illness (Bonder, 1986; Cohen, 1984; Larson et al, 1985). Treatable conditions also may co-exist with dementia. Larson et al (1985), for example, found concomitant treatable conditions such as depression and drug overuse contributed to the demented state in 31% of their subjects. If the assessment does show the condition to be one of irreversible, chronic dementia then the treatment aim should be to maximize the patient's functioning level and quality of life.

The treatment setting of choice is, first and foremost, the patient's own home. Sufferers' limited ability to cope with change makes environmental stability essential and they are more inclined to retain their functional effectiveness in a familiar and stable environment (Council on Scientific Affairs, 1986). This is one reason why home care is widely accepted to be to the advantage of demented individuals (Kahan et al, 1985; Council on Scientific Affairs, 1986). As the disease progresses, however, the point may be reached where care at home is no longer feasible and transfer to an institution becomes necessary.

The focus of the study described in this report and in the literature review that preceded it (Gutman, 1989) is on institutional settings, specifically, Special Care Units.

Five features are generally cited as criteria for designating a unit as specialized for care of dementia victims. These are that the unit:

- 1) is physically separated from the facility (nursing home, hospital) of which it is a part;

- 2) has a client population consisting mainly of individuals with dementia;
- 3) has special design features;
- 4) has special activity and/or therapeutic programs;
- 5) has staff with specialized training.

In British Columbia, Special Care Units (SCUs) have been established in both Intermediate Care facilities and in Extended Care hospitals. To the best of our knowledge, currently there are nine in Intermediate Care facilities and five in Extended Care hospitals. To date, only one has been examined in any detail (Vancouver Health Department, 1986).

The present study was undertaken to obtain a more comprehensive picture of the residents, environmental design, programming and staffing of such units, as well as to identify aspects which should and should not be included in facilities which, in future, are constructed.

The study consisted of interviews, conducted in the Spring of 1989, with the Coordinators, other staff members and relatives of residents of six SCUs in British Columbia. Three of the units were located in Intermediate Care facilities and three in Extended Care hospitals. Units located in both types of facilities were included in the study because it was felt important to ascertain whether there were major differences between them and, if so, what these were.

1.2 CHARACTERISTICS OF UNITS PARTICIPATING IN THE STUDY

1.2.1 Location

All three of the participating units in Intermediate Care facilities are located in the Greater Vancouver Regional Hospital District (GVRHD), as are the majority of units in facilities at this care level. One of the participating Extended Care hospitals is located in the Fraser Valley; the other two are in the interior of the province. These too are geographically representative since all Extended Care-based SCUs currently in operation are located outside the GVRHD.

1.2.2 Length of Time in Operation

At the time the study was conducted, one of the three SCUs in Intermediate Care facilities had been in operation for one year, one for three years and one for six years. Of the three SCUs in Extended Care hospitals, one had been in operation for five years and the other two for seven years.

1.2.3 Size

One of the three SCUs in Intermediate Care facilities cared for 31 residents; the other two, 20 each. In one of the latter units, two of the 20 residents spent only days in the unit. They spent nights and ate breakfast in other parts of the facility. Of the three units in Extended Care hospitals, two housed 25 residents and one 38 residents.

1.3 OUTLINE OF THE INTERVIEWS

1.3.1 Coordinators

The Coordinators' interview was designed to provide information concerning: the admission and discharge criteria of the unit; the number and type of

clients cared for in the unit (their level of care, sex and age distribution, diagnosis, and behavioural characteristics); the number and type of staff regularly in contact with SCU residents; the extent of special environmental design features on the unit; and the programs and activities provided for SCU residents and their families.

1.3.2 Other Staff

The interview conducted with staff other than the Coordinator contained a series of questions designed to ascertain the extent of their contact with SCU residents, whether they planned to continue working with this type of resident, and why and what specialized training, if any, they had had and what they'd like to have. The major focus of the interview, however, was on ascertaining their perception of what constituted "problem" behaviours as regards residents and their care; their experience with and opinions about various types of special environmental design features; what they perceived to be the advantages and disadvantages of SCUs for residents, their families and for staff; their opinions about families' information needs and family involvement in residents' care; and their views about programs provided to residents and their families.

1.3.3 Families of Residents

The purpose of the family members' interview was to ascertain how well they felt their relative's and their own needs were satisfied by the physical space, programming and services offered in the unit; what they did for their relative and whether they wanted more involvement in decision-making concerning their relative's care; what they wished in the way of

information and support from staff; and their perceptions of the advantages and disadvantages of SCUs.

1.4 ORGANIZATION OF THIS REPORT

This report describes findings from all three sets of interviews. Data are presented topically. Where applicable, information from the three sets of interviews is integrated.

2. METHOD

2.1 RESPONDENTS

As indicated in the Introduction, three groups of respondents participated in the study: the Coordinator - i.e. the person or persons responsible for administration of each unit, a sample of other staff regularly in contact with SCU residents, and a sample of relatives of residents of each unit. The rationale for interviewing all three groups was that it was felt that each would bring a unique perspective that when considered together, would provide a broader picture of the characteristics and needs of SCU residents than would be provided by any one group alone. Additionally, we were interested in identifying specific needs of each group in the areas of environmental design, programming and education.

In the case of staff other than administrative, each facility was asked to provide a range of respondents representing nursing, other professional groups regularly in contact with residents and/or families as well as aide level personnel.

Family members were also recruited by each facility's administration. The criterion for selection was that the family member regularly visited his/her relative and thus was knowledgeable as to his/her needs and how these were being met in the unit.

2.1.1 Unit Coordinators

In one unit three persons, in one unit one person and in four units, two persons responded to the questions contained in the Coordinator's Interview

Schedule. Most frequently, respondents consisted of the Head Nurse and/or the Director of Resident Care. All but one of the respondents was a nurse. Half had five or more years experience in working with SCU residents, one-third had from two to four years experience, the small remainder had less than one year of experience.

2.1.2 Other staff

As shown in Table 3, of the 40 other staff who participated in the study 11 (27.5%) were R.N.'s, R.P.N.'s or graduate nurses, 8 (20.0%) were other professional staff (Occupational Therapist, Social Worker, Recreational Coordinator, Music Therapist, Director of Dietary Services, Clinical Psychologist), while 21 (52.5%) were care or activity aides. Eighty-five percent of these individuals worked full-time. Forty percent had six or more years of experience in working with SCU residents, 32.5% had from 3-5 years experience, 20% from 1-2 years experience and only 7.5% less than one year of experience. Thirty-five percent worked exclusively with SCU residents while the remaining 65% worked with residents in other parts of the facility as well.

TABLE 3

STAFF OTHER THAN THE COORDINATOR(S) WHO PARTICIPATED IN THE STUDY

	<u>Location of Unit</u>						Total
	<u>Intermediate Care</u>			<u>Extended Care</u>			
	A	B	C	D	E	F	
R.N./RPN/LGN	1	1	1	3	3	2	11
Other professional staff (O.T., Social Worker, Recreation Coordinator, Music Therapist, Director of Dietary Services, Clinical Psychologist)	2	1	2	1	1	1	8
Care/activity aide	4	2	4	4	3	4	21
	--	--	--	--	--	--	--
Total	7	4	7	8	7	7	40

2.1.3 Family Members

Thirty-nine relatives of residents were interviewed. Approximately half (53.8%) were children of residents, one-third (33.3%) were spouses, 7.7% were siblings and 5.1% were in-laws (one sister-in-law, one daughter-in-law). Two-thirds had had primary responsibility for their relative's care, while another 23.1% had shared responsibility with another family member. Approximately 20% (20.6%) had cared for their relative for six or more years prior to his/her admission to any care facility, 41.2% from 3-5 years, 23.5% from 1-2 years and 14.7% for less than one year.

2.2 PROCEDURE

All Coordinators' and other staff interviews were conducted by the junior author, herself a nurse (B.Sc.N.) and graduate of SFU's Diploma Program in Gerontology. The interviews with family members were conducted by four

individuals trained by the junior author. One was male; three were females, two of the latter were nurses.

The Coordinator's interviews ranged in duration from one to two hours; the interviews with other staff and with families took from 50 minutes to one and three-quarter hours.

The Coordinators' and the staff interviews were conducted in the facility in which they worked. The family interviews were conducted in the respondent's home, the facility his/her relative lived in or in a mutually convenient location in the community. Ninety-six percent of the Coordinators and staff interviews took place during working hours.

2.3 ANALYSIS

In analyzing the data, all variables were examined for differences between the six units. Where the data lent themselves to quantitative analysis, variables from the staff and family interviews were crosstabulated by type of facility (Intermediate vs. Extended Care). In addition, variables on the staff questionnaire were crosstabulated by staff position (nurses vs. other professional staff vs. aide level personnel). The results of the crosstabulations are reported only when the chi square statistic indicated that there was a statistically significant difference (i.e. $p < 0.05$).

In the case of open-ended questions in the staff and family interviews, the general rule followed is to report only those answers given by three or more respondents.

III. FINDINGS

3.1 ADMISSION AND DISCHARGE CRITERIA OF THE PARTICIPATING UNITS

3.1.1 Admission Criteria

At the outset of the Coordinator's interview, respondents were asked to describe their unit's admission criteria and, if available, to provide printed material outlining these.

Examination of verbal responses and printed materials indicated that five of the six units consider as eligible for admission persons who exhibit behaviour or social habits which are disturbing to others. These include wandering uninvited into others' rooms, violating their privacy, and possibly tampering with their possessions; exhibiting episodic, erratic control of emotions; spitting; undressing in public; repetitive speech; inappropriate sexual behaviours; messy table habits; messy toilet habits; and/or sleep reversal (night to day).

Five units also consider as eligible persons who are a danger to themselves, in particular as a result of wandering.

As shown in Table 4, an admission criterion for four units was that the individual be assessed by the B.C. Long Term Care Program as at the Intermediate III level. An Extended Care classification was required by one of the remaining units. The other accepted persons classified either as Intermediate III or Extended Care.*

* See Appendix for a description of classification criteria for Intermediate and Extended Care in British Columbia.

Four units specify a diagnosis of an irreversible dementing illness such as Alzheimer's or multi-infarct dementia as a primary criterion. One of these units also admits younger persons with traumatic brain injury who otherwise meet the admission criteria. These individuals are admitted on a temporary basis until appropriate long term rehabilitation settings become available.

Two units stated that they will admit persons who are physically aggressive. Three others, two based in Intermediate Care facilities and one in an Extended Care hospital, stated explicitly that persons who frequently display aggressive behaviour will not be admitted.

Among others deemed ineligible for admission by at least one of the participating units were persons suffering from an acute physical or psychological disorder which may contribute significantly to their disturbed behaviour, persons with sociopathic personality disorders and mentally retarded persons who have simply grown old.

TABLE 4
ADMISSION CRITERIA FOR PARTICIPATING SCUs

	<u>Location of Unit</u>					
	<u>Intermediate Care</u>			<u>Extended Care</u>		
	A	B	C	D	E	F
Level of care:						
Assessed at IC _{III}	*	*	*		*	
Assessed at EC				*		
Assessed at IC _{III} or EC						*
Diagnosis of irreversible dementing illness such as SDAT or multi-infarct dementia, OBS/CBS	*	*			*	*
Behaviour/social habits which are disturbing to others e.g. trespassing in others' rooms; episodic, erratic control of emotions; spitting; undressing in public; repetitive speech; inappropriate sexual behaviour; messy table habits, messy toilet habits; sleep reversal (night to day)	*		*	*	*	*
Behaviour which is dangerous to self -- in particular, wandering	*	*	*		*	*
Inability to provide self-care		*				
Resistant to care					*	
Physically aggressive				*		*
Non-violent/non-destructive/ non-aggressive	*		*		*	
No evidence of an acute physical or psychiatric disorder	*				*	

3.1.2 Discharge Criteria

When asked about their discharge criteria, Coordinators of all three units located in Intermediate Care facilities said they would discharge (back) into the general facility population persons whose behaviour improved to the extent that they no longer needed the services of the unit. Persons

whose condition deteriorate so they no longer wander and/or who qualify for Extended Care are also discharged.

The cessation of noisy, disruptive, aggressive or resistive behaviour (either because of improvement or deterioration in the resident's condition) was a criterion for discharge in three units.

The three units that would not admit persons exhibiting physically aggressive behaviour included in their discharge criteria persons who, after living on the unit for a while, became "unmanageable" i.e. exhibited violent or destructive behaviour that could not be controlled with medication.

Other reasons for discharge included "if the family requests a move to another facility", "if suitable alternate placement is found" and, of course, death.

3.1.3. Number Discharged In Previous Twelve Months, Reasons For Discharge And Discharge Destination

The units participating in the study were home to from 20 to 38 residents. Table 5 shows the number of current residents of each unit who had been admitted in the previous 12 months and the number of discharges (which was approximately equal to the number of new admissions).

As can be seen, the reasons for discharge paralleled the discharge criteria described by the Coordinators. The only category that bears explanation is "family wish". It should be noted that one of the four individuals

discharged for this reason had been admitted for respite purposes. Once the family were refreshed the individual was returned to their care at home. Of the remaining three, two were discharged to facilities in closer geographic proximity to their family.

TABLE 5

NUMBER OF NEW ADMISSIONS AND DISCHARGES IN PREVIOUS TWELVE MONTHS,
REASONS FOR DISCHARGE AND DISCHARGE DESTINATIONS

	<u>Location of Unit</u>					
	<u>Intermediate Care</u>			<u>Extended Care</u>		
	A	B	C	D	E	F
No. of residents currently in unit	31	20	20	25	25	38
No. of new residents admitted to unit in previous 12 mo.	8	2	10	9	10	15
No. discharged in previous 12 mo.	11	2	10	9	10	18
<u>Reasons for discharge</u>	(n=11)	(n=2)	(n=10)	(n=9)	(n=10)	(n=18)
Death	3	1	5	9	3	7
Improved	1	0	0	0	0	1
Couldn't be managed in unit	7	0	1	0	2	1
Family wish	0	0	1	0	1	2
No longer ambulatory/at risk for wandering	0	1	3	0	4	7
<u>If discharged alive, discharge destination</u>	(n=8)	(n=1)	(n=5)	(n=0)	(n=7)	(n=11)
"Regular" IC ward/facility	1	1	0		0	1
"Regular" EC ward/facility	7	0	3	n/a	4	8
Mental health group home	0	0	0		0	1
To care at home	0	0	1		1	0
To Valleyview	0	0	1		2	1

In general, live discharges were to "regular" wards in the same facility or in other facilities. Only a small minority were discharged to care at home, to a mental health group home or to other destinations such as

Valleyview Hospital, a Provincial Mental Health facility specialized in care of psychogeriatric patients.

3.2 CHARACTERISTICS OF CURRENT RESIDENTS

In addition to providing information on their unit's admission and discharge policies and practices, the Coordinators were asked to provide a description of its current residents. Areas enquired about included their level of care, age and sex, ambulatory status, diagnosis and behavioural characteristics.

3.2.1 Level of Care

As shown in Table 6, while most of the residents of the three SCUs located in Intermediate Care facilities were classified by the B.C. Long Term Care Program as at the Intermediate III level, a small number were at the Extended Care level. Intermediate III clients also constituted the majority in two of the three SCUs located in Extended Care facilities. This may reflect bed supply: there are no SCU beds in Intermediate Care facilities in the area in which these two units are located.

3.2.2 Age And Sex Distribution

From 65-80% of residents of the three SCUs in Intermediate Care facilities were aged 80 or over. The Extended Care-based units had a younger population (only 40-64% aged 80+). Unit E, for example, cared for three brain impaired residents under age 40. The Extended Care units also differed from the Intermediate Care units in having a more equal sex distribution (47-60% female). The predominance of women in the

Intermediate Care-based units is particularly noticeable in Units A and C where females constituted approximately 85% of the population.

TABLE 6

RESIDENTS' CHARACTERISTICS

	<u>Location of Unit</u>					
	<u>Intermediate Care</u>			<u>Extended Care</u>		
	A	B	C	D	E	F
No. of residents in Unit	31	20	20	25	25	38
Level of Care (%)						
IC II	0.0	0.0	0.0	0.0	8.0	0.0
IC III	96.8	100.0	85.0	0.0	80.0	73.7
EC	3.2	0.0	15.0	100.0	12.0	26.3
Age (%)						
< 65	3.2	0.0	0.0	4.0	16.0	13.2
65-74	9.7	10.0	20.0	16.0	16.0	10.5
75-79	19.4	10.0	15.0	16.0	28.0	28.9
80-84	35.5	60.0	40.0	24.0	24.0	23.7
85+	32.3	20.0	25.0	40.0	16.0	23.7
Sex (%)						
Male	16.1	45.0	15.0	40.0	44.0	52.6
Female	83.9	55.0	85.0	60.0	56.0	47.4
Ambulatory (%)	100.0	100.0	85.0	8.0	66.0	75.0
Diagnosis (%)						
Alzheimer's disease		pred-		12.0	32.0	52.6
Multi-infarct dementia		omin-		16.0	0.0	13.2
OBS/CBS (etiology unsp.)		ant-		20.0	36.0	21.1
Alcohol-related dementia		ly		8.0	4.0	2.6
Huntingdon's disease		dem-		0.0	0.0	7.9
Psychiatric disorder		entia		8.0	8.0	0.0
Behaviour problem				4.0	4.0	2.6
Head injury				0.0	16.0	0.0
Undiagnosed				28.0	0.0	0.0
Other				4.0	0.0	0.0

3.2.3 Ambulatory Status

From 85-100% of the residents of the three SCUs located in Intermediate Care facilities were independently ambulatory.

In Unit D, one of the three units located in an Extended Care hospital, only 8% were ambulatory and then, only with assistance. The proportion ambulatory was much higher in Units E (66%) and F (75%), which is consistent with the greater proportion in these two units classified as in need of Intermediate Care.

3.2.4 Diagnosis

Residents of the three units in Intermediate Care facilities were described by their Coordinators as predominantly dementia victims, with over two-thirds thought to be suffering from Alzheimer's disease. There appeared to be a wider case mix in the units based in Extended Care hospitals. These included a small proportion with psychiatric disorders (schizophrenia; manic depression), with head injuries, with Huntingdon's disease, with alcohol-related dementia or who were described simply as having "behaviour problems".

3.2.5 Behavioural Characteristics

When asked to describe the behavioural characteristics of residents in their SCU, the Coordinators of all six units stated that they were a danger to themselves. In five of the six units, the Coordinators also described them as being disturbing to others. In two units, both in Extended Care facilities, the Coordinators said some residents were a danger to others. Some Coordinators also described specific "problem" behaviours their

residents exhibited such as trespassing in others' rooms, eloping from the building, defecating on the floor, screaming constantly, pacing and/or being very restless.

As indicated below "problem" behaviours were explored in greater detail in the interviews with other staff.

3.3 "PROBLEM" BEHAVIOURS

3.3.1 Perceived Frequency and Management Difficulty

In the staff interviews, respondents were asked about the 21 "problem" behaviours shown in Table 7. For each of the behaviours enquired about, the respondent was asked to indicate whether it was exhibited by most, some or few of the SCU residents he/she worked with and whether he/she found the behaviour to be very difficult, moderately difficult or not difficult to manage.

The "problem" behaviours that 50% or more of the respondents felt most SCU residents show were: difficulty wayfinding, trespassing and resistance to care.

Behaviours 25-49% of respondents felt most residents show were: inappropriate eating behaviours, repeated chattering and physical aggression toward staff.

Relatively rare behaviours, on the other hand, (that fewer than 10% felt most residents exhibit) included: verbal and physical aggression towards visitors, public sexual behaviour, sexual behaviour towards staff,

anguish/crying, screaming or yelling, other inappropriate verbalizations, spitting and smearing feces.

TABLE 7
FREQUENCY AND MANAGEMENT DIFFICULTY OF SELECTED BEHAVIOURS

	Base	<u>No. Showing Behaviour</u>			<u>Difficulty of Management</u>		
		<u>Most</u>	<u>Some</u>	<u>Few</u>	<u>Very</u>	<u>Mod.</u>	<u>Not</u>
Elopement/unauthorized exiting	31	24.1%	20.7	55.2	10.3%	48.3	41.3
Difficulty wayfinding	31	61.3	22.6	16.1	12.9	25.8	61.3
Trespassing	31	58.1	12.9	25.8	20.0	50.0	30.0
Resistant to care	30	56.7	30.0	13.3	33.3	53.3	13.3
Inappropriate voiding/defecating	27	22.2	29.6	48.1	14.8	25.9	59.3
Smearing feces	27	7.4	22.2	70.4	23.1	46.2	30.8
Verbal aggression - towards other residents	30	13.3	46.7	40.0	20.7	41.4	37.9
Verbal aggression - towards staff/volunteers	30	13.3	26.7	60.0	6.7	40.0	53.3
Verbal aggression - towards visitors	30	0.0	10.0	90.0	14.3	28.6	57.1
Physical aggression - towards other residents	30	10.0	36.7	53.3	33.3	50.0	16.7
Physical aggression - towards staff/volunteers	30	30.0	30.0	40.0	26.7	50.0	23.3
Physical aggression - towards visitors	30	0.0	6.7	93.3	16.7	33.3	50.0
Repeated banging	29	10.3	41.4	48.3	25.0	25.7	39.3
Repeated chattering	29	31.0	31.0	37.9	20.7	24.1	55.2
Screaming or yelling	29	3.4	37.9	58.6	17.2	31.0	51.7
Anguish/crying	29	3.4	20.7	75.9	17.9	42.9	17.9
Public sexual behaviours	29	0.0	3.4	96.6	13.0	21.7	65.2
Sexual behaviour towards staff	29	0.0	3.4	96.6	0.0	16.0	84.0
Spitting	29	3.4	20.7	75.9	40.7	18.5	40.7
Inappropriate eating behaviour	28	42.9	10.7	46.4	18.5	37.0	44.4
Trying to get out of bed/wheelchair	26	15.4	11.5	73.1	19.2	30.8	50.0

It should be noted, however, that spitting was one of the five behaviours judged by 25% or more of respondents to be very difficult to manage: the

other four were resistance to care, physical aggression towards other residents, physical aggression towards staff and repeated banging.

When the data were examined by type of facility, three significant differences ($p < 0.05$) in the reported frequency of problem behaviours were apparent: a higher proportion of Intermediate Care-based SCU staff than Extended Care-based SCU staff reported that most residents exhibit elopement/unauthorized exiting behaviour, have difficulty wayfinding and void/defecate in inappropriate locations. Further, the two behaviours of smearing feces and repeated banging were judged by Intermediate Care-based SCU staff to be more difficult to manage than they were by Extended Care-based SCU staff. The latter difference is difficult to explain. The former most likely reflects the higher proportion of residents in Intermediate Care facilities who were ambulatory and thus able to engage in these behaviours.

When the data were examined according to staff position, only one significant difference emerged. Aides were more likely than nurses (73.3% vs. 45.5%) to report that most patients show resistance to care. In most facilities, aides perform most of the personal care provided to residents (e.g. bathing, toileting, feeding). It is situations of these types which frequently evoke resistive behaviour in long term care populations.

3.3.2 Variation By Time Of Day

Respondents were asked whether there are certain times of day when specific behaviours that pose management problems for them tend to occur. Eighty-five percent said "yes". Of these, 82% cited the late afternoon and/or

evening as particularly problematic. By far the most frequently mentioned behaviour thought to be subject to variation by time of day was "being noisy". Other behaviours mentioned by a minority of respondents were pacing, agitation, aggression and resistance to care. Several of the units have addressed this situation by increasing staff, either adding another care aide for half a shift or by scheduling an activity worker to be on the unit in the late afternoon or evening. Some success in reducing "problem" behaviour was reported following increasing staffing in these ways.

3.4 SPECIAL DESIGN FEATURES

3.4.1 In The Participating Units

In the Coordinator's interview a series of questions was asked concerning special design features used in their unit to: restrict unauthorized exiting, accommodate wandering, facilitate wayfinding and orientation or reduce sensory overload/calm residents.

3.4.1.1 To prevent unauthorized exiting

A number of possibilities for restricting unauthorized exiting from the unit were enquired about. These included: multiple latching mechanisms, alarmed doors, masked doors at the unit exit, locked unit door, electronic sensors and personal restraint devices.

None of the units currently has a multiple latching mechanism although one had previously had such a device. Two have alarmed unit doors. One unit has masked the exit door. In all but the one unit in which virtually all residents are non-ambulatory (Unit D), the unit door is kept locked. In

two units the door can only be opened with a number code; in three a key is needed.

Only one unit employs electronic sensors. None employ personal restraint devices as a means of preventing unauthorized exiting. Most, however, do use restraints, usually lap restraints in chairs, as a means of preventing falls. As one Coordinator pointed out, however, these are used only if "the doctor insists" because of risk of injury.

3.4.1.2 To accommodate wandering

The Coordinators were asked whether their facility had secured wandering space within the building and/or outside.

In three units the Coordinators indicated that residents were free to wander in the corridors and/or the activity area or lounge. The Coordinator of one unit responded by saying "It's a locked unit. They can wander wherever they want to within it."

As regards outdoor space, all units reported having a secured area. In one unit it consists of two fenced patios and in four units a fenced garden area directly adjacent to and accessible from their ground floor locations. The sixth unit, which is located on the top floor of a three storey building, has access to a secured courtyard at ground level. One unit has a circular walkway in its secured area. In describing it, the Coordinator noted that the surface needs to be very smooth as residents are vulnerable to stumbling and falling. Another Coordinator recommended that enclosed

areas be constructed so residents "can see the world" and not feel "shut away".

3.4.1.3 To facilitate wayfinding and orientation

The Coordinators were asked if their unit facilitated wayfinding and orientation by employing: extra large signs, picture signs, colour coding, textured walls, special landmarks, picture(s) on residents' doors, clocks and calendars, or a reality orientation board showing, for example, the date, place and weather.

In general, use of these aids appeared to be minimal. Although five of the six units have clocks and calendars, only three have extra large signs, only three have reality orientation boards and only one has pictures on the residents' doors. The pictures were reported to be of something of special interest to the resident (e.g. picture of a horse for a man who loved horses) since, the unit Coordinator noted, "many do not recognize pictures of themselves".

3.4.1.4 To reduce sensory overload/calm residents

The Coordinators of each unit were asked if they used pastel colours, background music or any other environmental design features to reduce sensory overload and/or calm residents.

In four units background music was used; three were decorated in pastel colours. Several respondents mentioned that their unit is considering current research which suggests that colour may have an impact on emotion and on behaviour and spoke about "calming" colours. Two other techniques

mentioned were to use small rooms for individual activities/to isolate noisy residents (2 units) and to use reduced lighting (1 unit).

3.4.1.5 Other design features tried

In response to the question "Are there any other design features you've tried?", the following were mentioned:

"TV monitor in Nursing Station so that staff can see the area of the Unit not visible from it."

"Dimmer lighting in hall at night than during the day -- helps residents differentiate night and day."

"Got permission to put coded locks on previously unlocked fire doors to fenced yard. Prevents residents going out inadequately dressed in poor weather; reduced upper respiratory infections."

Additionally, one Coordinator noted that theirs is a T-shaped unit with a door at each point of the T. "Residents", she noted, "walk to the door and don't know to turn around so they congregate there waiting to get out. Agitation is high, they wander into adjacent bedrooms so we sometimes lock bedroom doors." She suggested providing a continuous circuit for wanderers. Such a circuit is, in fact, included in the unit's plans for a new dining room and garden.

The unit also plans to enclose the Nursing Station in plexiglass. Currently, the nursing station is open. "Patients answer the phone, 'savage' charts, play with the oxygen equipment and go through drawers."

This Coordinator also felt that the unit needed a quiet, homelike room for families to visit in. "The unit sometimes distresses families because of its plainness (to reduce stimulation and for safety)."

Finally, she pointed out that call bells in the rooms are required for licensing but these create a problem. "Many residents don't know what they're for and play with them, particularly in the morning when they wake up. This jams the system." She felt that there should only be an emergency bell in the bathroom of each bedroom "to allow staff to call for help if they need it."

A related problem, with fire alarms, was noted by several Coordinators. One commented "Residents set them off and the law doesn't permit us to lock them. As a temporary solution, we've fastened an oxygen mask over them. These can be removed quickly by staff but not by the residents."

3.4.2 Special Design Features That Staff Had Had Experience With

The Special Design Features section of the interview with staff explored the same areas covered in the Coordinator's interview - i.e., environmental techniques to prevent unauthorized exiting, to accommodate wandering, to facilitate wayfinding and orientation and to reduce sensory overload. However, rather than focussing only on techniques used in the unit in which they were currently working, respondents were asked to indicate those items they had ever had experience with and whether they'd found them to be effective most times, sometimes or never.

3.4.2.1 To prevent unauthorized exiting

As shown in Table 8, 100% of staff had worked in facilities with fenced areas for confused residents, more than 70% in facilities with alarmed doors, with locked unit doors and which used patient personal restraint

devices; 40.6% in facilities with multiple latching mechanisms, and less than 16% in those with electronic sensors and masked unit exit doors.

TABLE 8
EXPERIENCE WITH AND ASSESSMENT OF
VARIOUS SPECIAL ENVIRONMENTAL DESIGN FEATURES

	<u>Base</u>	<u>Have Had Experience</u>	<u>Effective</u>		<u>Never</u>
			<u>Most Times</u>	<u>Some Times</u>	
<u>To restrict unauthorized exiting</u>					
multiple latching mechanisms	32	40.6%	33.3%	50.0	16.7
alarmed doors	32	93.8	50.0	30.0	20.0
masked unit exit door	32	12.5	66.7	33.3	0.0
locked unit door	32	87.5	89.3	3.6	7.1
personal restraint device	31	71.0	40.9	59.1	0.0
electronic sensors	32	15.6	33.3	66.7	0.0
fences	32	100.0	81.3	15.6	3.1
<u>To manage wandering</u>					
secure wandering space in building	32	96.9	58.1	41.9	0.0
secure wandering space outside building	32	96.9	77.4	22.6	0.0
<u>To facilitate wayfinding and orientation</u>					
extra large signs	31	74.2	18.2	72.7	9.1
picture signs	31	29.0	11.1	88.9	0.0
colour coding	31	22.6	28.6	57.1	14.3
textured walls	31	0.0		n/a	
special landmarks	31	22.6	0.0	85.7	14.3
picture of resident on door	31	19.4	16.7	83.3	0.0
clocks/calendars	30	96.7	6.9	82.8	10.3
reality orientation board	31	61.3	11.1	88.9	0.0
<u>To reduce sensory overload</u>					
use pastel colours	30	53.3	73.3	26.7	0.0
background music	31	93.5	51.9	48.1	0.0

Two-thirds or more of the respondents who had experience with them felt fences, masked unit doors and locked unit doors were effective in preventing unauthorized exiting most of the time. Forty to fifty percent felt alarmed doors and personal restraint devices were effective most of

the time. Only a third of the respondents were convinced of the general effectiveness of electronic sensors and multiple latching mechanisms.

Among comments made concerning these devices were the following:

multiple latching mechanisms

- some residents figure out how to open them (3)*
- they break a lot (1)

alarmed doors

- create stress for staff and residents (e.g. staff bothered by noise; residents become agitated. Sometimes staff turn off the alarm when they go to find missing resident and forget to turn it on again. If another resident goes out, he/she could be in cold/bad weather for a long time before being noted as missing) (5)
- already too late when alarm goes off; takes time to respond; resident has a good head start by the time the alarm sounds (4)
- residents can still get off the unit but it resulted in behaviour modification in some i.e. they stopped when buzzer went off (1)

locked unit door

- locked doors, fences, gates, anything that keeps them in attracts and distresses/frustrates them. They rattle the doors, bang on them, play with handles, etc. (5)
- causes less agitation than buzzer alarms (1)
- greatly decreases need for restraints (1)

personal restraint devices

- safety sometimes requires their use, for example, if a resident is unsteady on his/her feet. Should only be used selectively/if really needed (8)
- prevents exiting but is not pleasant for them/causes anxiety, restlessness/agitation (3)

fences

- some go over them, fence needs to be strong, high (more than 6 feet) and unclimbable (8)
- some have dug under fence (2)
- keeps them in and safe but they know they're confined and rattle gate (2)

* bracketed numbers indicate number of respondents giving the comment

When asked if there were any other techniques they'd had experience with, two staff members mentioned covering the elevator buttons which one said was effective most of the time and the other, some of the time. Two others spoke of using strong magnets to keep the unit door shut. One noted, however, that some residents are able to press hard enough to open the door.

3.4.2.2 To accommodate wandering

Most respondents had had experience in working in facilities with secured wandering space in and outside the building. Three-quarters felt the secured outside space was effective most of the time compared with only 58.1% feeling this way about the inside space. The main concern regarding inside wandering space was that it usually was not large enough or sufficiently well designed to prevent congestion and residents jostling one another.

Aside from recommending that more space be provided inside for wanderers, staff suggested that there should be no dead ends "since residents don't think to turn around and staff must redirect the flow".

As regards outside space, specific recommendations included:

- covered continuous walking area
- fence with guard bar, smooth so can't be climbed
- artificial turf or grass rather than cement so residents are less likely to be hurt if they fall.

3.4.2.3 To facilitate wayfinding and orientation

Almost all respondents (96.7%) had worked in facilities having clocks and calendars to facilitate wayfinding and orientation, approximately three-quarters (74.2%) had worked in facilities with extra large signs and approximately two-thirds (61.3%) in facilities with reality orientation boards. Fewer (from 19-29%) had worked in facilities employing picture signs, colour coding, special landmarks or pictures on residents' doors to facilitate wayfinding and orientation. None had experience with textured walls.

While from 57.1% to 88.9% felt these devices were effective some of the time, less than one-third felt they were effective most of the time. A number of staff commented that their effectiveness depended greatly on the level of functioning of the resident. For example, extra large signs and reality orientation boards were reported to "work" only in the early stages of dementia; in the later stages, reading and comprehension skills are seriously compromised both by cognitive and visual deficits.

When asked about other wayfinding and orientation aids they'd had experience with, one staff member recommended leaving a light on in the bathroom at night. She said this was very effective for those able to do their own toileting who otherwise "just void in the hall".

3.2.4.4 To reduce sensory overload/calm residents

Almost all respondents had worked in facilities having background music; half felt it was effective most of the time and half some of the time. Several staff respondents commented that music had to be carefully selected as some music seems to agitate and overstimulate residents. Quiet,

soothing music was recommended. Several also commented that music was more effective if used selectively (e.g. at times of change such as mealtime or bedtime) rather than being constantly on. One unit has taped music they feel is appropriate for given situations. These tapes are played rather than relying on what happens to be available on the radio at the time.

Only approximately half of the staff respondents had worked in facilities decorated in pastel colours; approximately three-quarters of these individuals (73.3%) felt that such colours were effective in reducing sensory overload/calming residents.

Other techniques for calming residents two respondents had had experience with were dimming the lights/turning them out at "quiet" time. One said this was effective most times; the other, only sometimes. Several respondents, both here and at other points in the interview, spoke of the advantage of having a place to take noisy residents "so they don't set off others".

3.5 ASSESSMENT OF THE UNIT'S LAYOUT, INTERIOR DESIGN AND FURNISHINGS

In the staff interviews, a series of questions were included which asked for respondents' assessment as to whether the facilities' layout, interior design and furnishings met the needs of SCU residents, their families and staff and what improvements or modifications would better meet the needs of each group.

Family members were asked where on the unit they usually visited their relative and whether this arrangement was satisfactory. They were also

asked to evaluate and to make recommendations in terms of modifying the physical space to better meet their or their relative's needs. Finally, they were asked how they would describe the atmosphere of the unit.

3.5.1 For Meeting Residents' Needs

Approximately half of the staff respondents felt the layout, interior design and furnishings of the unit they worked in met residents' needs.

With respect to potential improvements, the following suggestions were made:

Layout

- quiet rooms to withdraw to/ for privacy/ to calm agitated or disruptive residents (some recommended they be nicely decorated and furnished and/or have soft lighting) (19)
- bigger lounge/ more lounges/ separate lounge and dining room (11)
- specifically designed activity room(s) and/or activity kitchen on unit (9)
- large outside area totally secure/ accessible from unit/ entirely visible from unit (8)
- continuous walking area (avoid dead ends) (7)
- improved ventilation (preferably windows that open) (7)
- more windows (to provide natural lighting/ more light, to allow residents to view the outside/ for better ventilation) (6)
- wider hallways (5)
- more room for wandering (5)
- nursing station located so whole unit can be seen (5)
- wheelchair accessible toilets (with grab bars) (4)
- dining room on unit (3)
- solarium (for feeling of being outside) (3)
- more one and two bed rooms (3)

Interior Design

- more homelike appearance (e.g. aquarium, pictures) (7)
- provide things to touch (e.g. wall hangings, mobiles) (6)
- provide more light (as natural as possible) (4)
- camouflage exit doors (2)
- non-glare flooring (reflections on floor cause confusion) (2)
- uniform floor colour (if there are lines on the floor residents think they have to step over them) (2)

Furniture

- build in or bolt down furniture (residents tend to move and pile it) (6)
- provide more rocking chairs (4)
- avoid cloth furniture (4)
- strong furniture with arms/gives good support (3)

3.5.2 For Meeting Staff's Needs

Approximately two-thirds (65.6%) of the staff respondents felt the layout of their unit, its interior design and its furnishings met their needs. With respect to improvements or modifications for the benefit of staff, suggestions included:

- central nursing station with view of whole unit (6)
- staff lounge/dining room on unit (5)
- enclosed nursing station (secure from residents) (3)
- larger bathrooms - not enough space for wheelchairs; need space even if residents are ambulatory so staff can help them (3)
- bigger medication room/ locked room secure from residents (2)
- cameras to monitor exit door (1)

Three of the Coordinators also pointed out a need for more locked areas for storage of supplies, office equipment and residents' personal belongings and clothing. As one Coordinator noted:

"We take them out in all seasons. They therefore need boots, winter coats, hats and clothes for all seasons. There's no room to store these."

One Coordinator noted a need for a room in which to offer inservice education and hold case conferences.

3.5.3 For Meeting Families' Needs

Forty percent of the staff respondents thought the layout, interior design and furnishings of the unit met the needs of residents' families, 34.3%

felt it did not and 25.7% felt they didn't know enough about families' needs to respond.

The primary improvement suggested by staff for the benefit of families of SCU patients was to provide a special lounge for visiting.

When the families were asked where they usually visit their relative, it was apparent that multiple locations are used: these included the resident's bedroom (76.9% of family respondents), the unit's main lounge (35.9%), the dining area (20.5%), as well as rooms in other parts of the facility, the garden and locations away from the facility.

More than two-thirds of the family respondents (64.1%) were clearly satisfied with these arrangements; about one quarter (23.1%) were satisfied but with qualifications (e.g. "visiting in the unit is best for mother although it's a little noisy at times"); 12.8% were dissatisfied.

When asked whether the layout of the unit, its interior design and furnishings met the needs of their relative, two-thirds (61.5%) said "yes", one-quarter (23.1%) gave a qualified "yes", while 15.4% said "no". There was more dissatisfaction with units in Intermediate Care facilities than with units in Extended Care hospitals (26% vs. 5% saying the layout was not satisfactory). Mentioned as disliked features were hard chairs, small lounge area, long corridors and insufficient space for walking. Suggestions for improvement included softer chairs, larger lounge, more space for walking, better ventilation, more large windows, a dining room on the unit, toilets visible and in proximity to common areas and more colour

and visual stimulation. One family member suggested that if pictures and wall-hangings are a problem, they could be secured out of reach of residents.

With respect to the needs of the family, 68.4% felt that the layout clearly met their needs, with the remainder giving a qualified "yes" (e.g. "furnishings are sparse but functional"). Suggestions for improvement included provision of a visiting room and more comfortable seating.

A final question in this section asked family respondents how they would describe the atmosphere in the unit. The most commonly used adjective (35.9% of respondents) was "noisy", followed by "institutional" (28.2%), "calm" (25.6%), "homelike" (28.2%), "quiet" (20.5%) and "tense" (7.7%).

"Noisy" was used more frequently by those with relatives in Extended Care hospitals (60.0%) than by those whose relatives were in Intermediate Care facilities (10.5%).

Other descriptors commonly used included "friendly", "caring" and "pleasant".

3.6 RECOMMENDED UNIT SIZE AND ROOM TYPE

In the literature on design of SCUs, one finds a continuing debate as to whether it is preferable to build single, double or multi-bed rooms. Also under debate is the question of how large SCUs should be.

Questions on both these topics were included in both the staff's and the families' interviews.

3.6.1 Unit Size

When asked what they consider to be the ideal number of residents in a SCU ward, there was a difference between the responses of Intermediate Care-based SCU staff and Extended Care-based SCU staff. For Intermediate Care staff the ideal maximum number of residents ranged from 6 to 30, with a mean of 18, and a median and mode of 20. Extended Care staff, on the other hand, believe the ideal maximum number to range from 12 to 38, with a mean of 26, and a median and mode of 25. In relation to the size of the unit in which they currently worked, as shown in Table 9, approximately half of the staff respondents (46.7%) felt there should be fewer residents, approximately half (46.7%) felt there should be the same number as currently, while 6.4% felt there could be more than currently. Several respondents added, however, that the actual number does not matter as long as staffing is adequate. The reasons most frequently given for desiring a smaller number of residents were "too many together increases agitation", "smaller numbers produce a cohesive 'family' group" and "noise level would be lower".

The majority of family respondents (89.7%) felt that the number of residents in the unit in which their relative resides is "about right". Only a small proportion (10.3%) felt there were too many persons in it.

3.6.2 Room Type

With regard to the residents' rooms, 69.2% of the Intermediate Care-based SCU staff thought that there should be no more than one resident per room, the remainder said there should be no more than two per room. Among Extended Care-based SCU staff, on the other hand, only 15.8% felt there should be one to a room, 57.9% recommended two per room, 5.3% recommended three per room while 21.1% believed four per room is the ideal size.

TABLE 9
RECOMMENDED UNIT SIZE AND ROOM TYPE

	<u>Intermediate Care</u>			<u>Extended Care</u>		
	A	B	C	D	E	F
No. of residents currently in the Unit	31	20	20	25	25	38
Staff's perception of ideal unit size relative to current size:						
More	0	1	1	0	0	0
Same	0	0	3	5	4	2
Fewer	3	2	3	1	2	3
Staff's perception of ideal no. per room:						
One	3	0	6	1	2	0
Two	1	3	0	5	3	3
Three	0	0	0	0	0	1
Four	0	0	0	1	1	2

Among the residents whose relatives were interviewed, only one, in an Intermediate Care facility, was in a two-bed room; the remainder were all in single rooms. Among those in Extended Care facilities, 40.0% were in single rooms, 20.0% in two-bed room and 40.0% in four-bed rooms. Despite this variation, the vast majority (94.9%) of family members interviewed felt that the number of beds currently in their relative's room was about

the right number. Only two respondents (both with relatives in Extended Care-based SCUs) felt there were too many in the room. The main reasons given for feeling single rooms were appropriate for their relative were that the relative was used to and/or valued privacy, that he/she may disturb or be disturbed by others, that in multi-bed rooms clothing and belongings "get mixed up" and that a private room facilitates visiting. Those preferring more than one bed in the room cited "companionship" and "good roommate" as the reasons. The two who felt there were too many beds in their relative's room said it was because the room was too noisy and their relative did not get enough privacy and rest.

3.7 SEGREGATION VS. INTEGRATION

There has been considerable debate in the literature over whether, in residential care, it is best to segregate the cognitively impaired or to integrate them with other residents.

Among arguments given in favour of integration are that caring for dementia patients could be exhausting and demoralizing for staff (Pynoos and Stacey, 1986) and that families may find segregated units depressing (Coons, 1985).

In an effort to explore these and other arguments for and against SCUs, in the staff interview respondents were asked whether or not they planned to continue working with SCU residents and why. They were also asked to describe what they felt were the advantages and disadvantages of SCUs from the point of view of SCU residents, families, other intermediate/extended care residents and staff. A description of the advantages and

disadvantages of segregation vs. integration for each of these groups was also requested from family members.

3.7.1 Staff Plans And Reasons For Continuing/not Continuing To Work With SCU Residents

Of the 40 staff members interviewed, only one planned to discontinue working with SCU patients. This individual finds the work frustrating, stressful and unchallenging. The remaining 39 all plan to continue. Their reasons for wishing to do so are shown in Table 10. As can be seen, these are varied, with the most frequently mentioned being that they "like the residents". It is interesting to note that while the job is viewed as challenging, rewarding and interesting, it is also perceived, by a few individuals, to be less stressful and less demanding than jobs in other hospital settings.

TABLE 10

REASON FOR WISHING TO CONTINUE WORKING WITH SCU RESIDENTS
(MULTIPLE RESPONSES ALLOWED)

REASONS	FREQUENCY	PERCENT
like residents	18	46.2
patient need	9	23.1
challenging	7	17.9
rewarding	6	15.4
interesting	5	12.8
varied work	4	10.3
learn a lot	4	10.3
less demanding	3	7.7
necessary job	3	7.7
now confident	2	5.1
patients open	2	5.1
less stressful	2	5.1
psychiatry background	2	5.1
physically less demanding	1	2.6
nice place	1	2.6
other reasons	4	10.3

3.7.2 Perceived Advantages And Disadvantages Of SCUs

3.7.2.1 Staff respondents

Responses given by three or more staff members to the question "What do you think are the advantages and disadvantages of Special Care Units?" are listed below. It will readily be seen that, for this group of respondents, far more advantages than disadvantages were perceived.

Advantages for SCU Residents

- not ridiculed/ostracized/rejected by other residents (11)
- secure, safe (for example, from elopement) (10)
- free to move around at will (7)
- their special needs can be better met (5)
- safer from physical retaliation from other residents (4)
- sense of belonging/feeling of closeness in unit (patients, staff and family) (4)
- often improve when come to unit (4)
- continuity of staff/recognize staff/change in staff increases agitation (4)
- decreased need for physical and/or chemical restraints (3)
- more attention/one-to-one care can be given (3)

Disadvantages for SCU Residents

- level of functioning drops because continually exposed to inappropriate behaviour, lack of opportunities to use remaining skills and/or because of decreased staff/family expectations (8)
- sense of isolation from other residents (5)
- tend to be treated as a homogeneous population (3)

Advantages for Families

- can be sure relative's needs are being met; he/she is safe/secure (8)
- although some are angry/critical at first, most people prefer it once they see how it functions (5)
- see staff as caring about residents; sense of "family" in unit (4)
- not embarrassed by relatives' behaviour or nasty reactions/remarks of alert residents (4)

Disadvantages for Families

- depressed/upset by residents more deteriorated than their relative (5)
- feel relative is isolated/stigmatized (5)

Advantages for Other Residents of the Facility

- not disturbed/bothered by behaviours of SCU patients (27)
- safer -- "frail elderly are very vulnerable to physical actions of confused residents" (9)
- not fearful for their own safety (4)
- their rooms are more secure/don't have to worry about trespassing of confused residents (3)

Disadvantages for Other Residents of the Facility

- no opportunity to see/realize there are others who have "worse" problems than they do (4)
- fear they may develop the same condition/end up on the unit (4)

Advantages for Staff

- because unit is locked, don't have to worry about elopement and therefore have less stress and more time to provide care (10)
- easier to care for one type of patient rather than having to change back and forth from the confused to the alert (5)
- with similar types of patients grouped together, can concentrate on providing appropriate care and programming (5)
- incentive to learn more about/develop skills in caring for SCU-type residents (5)
- fewer negative reactions/comments from other residents to have to deal with (3)

Disadvantages for Staff

- stress/potential burn-out because of low staffing ratios and type of care that needs to be provided (5)
- feeling of isolation from rest of facility (3)

3.7.2.2 Family respondents

As shown below, except for their more frequent mention of over and understimulation, family respondents' perceptions of the advantages and disadvantages of SCUs were generally similar to those of staff. For them too, the advantages appear to outweigh the disadvantages. This is particularly true in regard to the perceived impact of SCUs on families and

on other residents of the facility. While a number of advantages for both of these groups were mentioned by three or more respondents, fewer than three mentioned any one disadvantage for families; no disadvantages were mentioned for other residents of the facility.

Advantages for SCU Residents

- special needs better met (11)
- safer (10)
- sense of acceptance/comfort from being with similar others (8)
- not overstimulated (6)
- free/safe to wander (3)

Disadvantages for SCU Residents

- understimulation (8)
- constant exposure to persons exhibiting inappropriate behaviour (4)
- lack of opportunity to observe/model behaviour of higher functioning residents (3)

Advantages for families

- family not upset by relative upsetting/being upset by alert residents (7)
- less concern about relative's safety (5)
- confident relative is well cared for (3)
- "don't have to hear comments about 'crazies' from other residents"/other families more accepting of their relative's behaviour (3)

Disadvantages for families

- disturbed by exposure to residents more deteriorated than their relative (2)
- noisy (2)
- concerned about residents' lack of stimulation (1)
- disturbed by institutional feeling of unit (1)

Advantages for other residents of the facility

- aren't frightened or made to feel uncomfortable by the presence of demented persons (13)
- privacy and personal possessions safe from trespassing (4)
- if dementia victims are segregated, the rest of the facility is quieter (3)
- are surrounded by individuals of comparable mental functioning level (3)

Disadvantages for other residents of the facility

None articulated.

Advantages for staff

- easier to monitor/keep track of residents (10)
- smaller number of residents facilitates getting to know them as individuals/provide personalized care (8)
- staff know what to expect and/or have/get specialized training (6)

Disadvantages for staff

- could be stressful to be continually with SCU residents (6)

3.8 PROGRAMMING**3.8.1 For Residents****3.8.1.1 Coordinator's description of programs now offered**

According to the Coordinators, in all six units residents are offered an exercise program. In one of the Intermediate Care units, higher level SCU residents join with other residents of the facility in a "Fun and Fitness" program.

Music is also a regular feature in all six units, in three taking the form of a music therapy program and in the other units, presented in a more informal manner.

In all of the units except the one Extended Care unit in which few residents were ambulatory, bus trips and outings to various locations in the community are a regular offering.

Five units have a pet visitors/pet therapy program; three of these five also have animals in residence.

Four units offer a crafts program. Validation therapy, reminiscence therapy/life review and reality orientation programs are also offered in four units, although one Coordinator noted that the reality orientation in her facility was not offered "in a big way".

Other programs/activities mentioned by one to two units consisted of milieu therapy, outdoor walks, baking, gardening, bingo, woodworking and "mini-vacations".

While a slightly greater number of programs are offered in SCUs located in Extended Care facilities, there appears to be no direct relationship between the number of programs offered by a unit and the number of residents living there. The number of programs also does not appear to vary as a function of the discipline or mix of disciplines of the person(s) in charge of programming. (In five units one person was responsible for programming; in one unit four persons shared the job. The range of disciplines represented included one nurse, three occupational therapists, four recreationists and one psychologist. All but two of those in charge of programming had some specialized training in program planning for dementia victims.)

It should also be noted that in all of the participating facilities some SCU residents are mixed with other residents for at least one activity. Most frequently this occurs when outside groups provide entertainment (four

units), although at least one unit mentioned music groups, movie showings, church services, parties for special occasions, daily exercise programs, bus trips, baking programs and meals as programs in which residents are mixed. The latter was the one situation in which a Coordinator expressed a negative note. In her facility (and in one other unit), SCU residents must take their meals in the same dining room as other residents, which she feels is disruptive for both groups. Mentally intact residents are upset by the noise and inappropriate eating behaviours of SCU residents; SCU residents must be moved as a group to the dining room three times a day which tends to increase their agitation. An attempt to secure funds for a separate dining room for the SCU is currently in progress.

3.8.1.2 Program goals and planning considerations

In the staff interviews, respondents were asked to describe the goals of the programs offered to SCU residents. Some of the more frequent responses were:

- to keep them busy (7)
- maintain/optimize functioning (7)
- fun/enjoyment/provide quality of life (6)
- maintain/optimize physical status/mobility (5)
- decrease stimulation/avoid overstimulation/calm (5)
- socialization (to interact with others) (4)
- stimulate/activate (4)
- set individual program goals (4)
- orient them to what is going on (3)

When asked what factors are taken into consideration in planning/delivering programs for SCU residents, the most frequent responses were "their interests and likes", as well as "their previous skills". Other factors mentioned by three or more respondents included "recognition of residents'

short attention span", "the need for small groups or 1:1 interaction" and "daily fluctuations in functioning".

Respondents were also asked how they deal with different levels of impairment when planning/delivering programs. Responses given by three or more individuals included "observe what they can and cannot do", "group by ability and/or goals", "adapt to how they are", "individualize programs", and "do 1:1 or small groups".

3.8.1.3 Staff's experience with and perception of the effectiveness of specific therapeutic programs

The staff interview contained a series of questions in which respondents were asked which of the eight therapeutic techniques shown in Table 11 they had had experience with and whether these were felt to be effective with SCU patients most times, sometimes or never.

Eighty percent or more reported having had experience with music, exercise, pet visitors, outdoor walking and crafts programs. Fifty to 68.6% had had experience with plant therapy, validation therapy and reality orientation.

Among those having had experience with them, music programs, outdoor walks, exercise programs, pet visitor programs and validation therapy were all judged to be effective most of the time by 50% or more of the respondents. Reality orientation, plant therapy and crafts were thought by most respondents to be effective only some of the time and only with higher functioning residents.

TABLE 11
EXPERIENCE WITH AND PERCEIVED EFFECTIVENESS OF
SELECTED THERAPEUTIC PROGRAMS

	<u>Base</u>	<u>Have Had Experience</u>	<u>Effective</u>		<u>Never</u>
			<u>Most Times</u>	<u>Some Times</u>	
music therapy	37	97.3%	91.3%	8.3	0.0
validation therapy	34	50.0	52.9	47.1	0.0
reality orientation	34	67.6	5.6	77.8	16.7
pet visitors	35	97.1	61.8	38.2	0.0
plant therapy	35	68.6	21.7	78.3	0.0
outdoor walks	35	82.9	85.7	10.7	3.6
crafts	34	91.2	6.7	76.7	16.7
exercise	36	97.2	57.1	42.9	0.0

In commenting on the specific therapeutic programs, several staff respondents noted that the plants used in plant therapy programs should not be kept on the unit or, if they are, they need to be placed out of reach. Otherwise, lower functioning residents may pull them out, eat them and/or "dump over the pots".

As regards crafts programs, several respondents commented that they must be kept simple. One respondent noted, however, that it was "hard to break them down into easy enough tasks without making them child-like". Several respondents also mentioned that crafts programs must be carefully supervised as residents' attention span tends to be short and they may wander away. Supplies also need to be carefully monitored to ensure residents' safety (e.g. they may eat glue, stuff paper in their ears, etc).

Several respondents also noted that exercise programs need to be carefully thought out. Comments included "if in a group, most don't follow the leader", "if too complicated they get agitated". Several respondents also

mentioned that games or exercises involving throwing balls should be avoided as these upset some residents, and that exercise programs "work best if music is involved".

A theme running through many of the comments about specific therapeutic programs was that programmers need to recognize that, in addition to having cognition problems, many residents have poor vision and poor eye-hand coordination.

When responses from staff in SCUs based in Intermediate Care facility were compared with those from staff based in Extended Care facilities, only one statistically significant difference emerged. A significantly higher proportion of Intermediate Care staff than Extended Care staff had had experience with validation therapy (70.6% vs. 29.4%). However, there was no difference in their assessment of the effectiveness of this technique.

3.8.1.4 Other programs found effective

When asked whether there were any other programs they'd had experience with that they'd found to be effective, only two were mentioned by three or more respondents. One of these was food-related activities such as baking or cooking. In one unit, residents make food for family meetings which, according to the staff respondent, "makes family members proud and pleased". This unit also has a "muffins program". Residents make and sell muffins to the rest of the facility. "Staff", the resident noted, "are often surprised at what the SCU residents can do". Another unit has a "cook-in". Here, six to eight residents eat with the Activity Worker.

Those who can, help to prepare the meal. The others watch the food being prepared.

The second activity mentioned with any degree of frequency was bus trips, although one staff respondent noted that some residents have difficulty (mentally, not physically) getting in and out of the bus.

3.8.1.5 Perceived advantages and disadvantages of mixing SCU and other residents in programs and activities

Staff respondents were asked to describe the advantages and disadvantages for SCU residents, other Intermediate/Extended Care residents and for staff of mixing SCU and other facility residents in programs and activities.

Many commented that only the higher functioning SCU residents were able to go to integrated activities. Among the most frequently cited advantages and disadvantages for each group were:

Advantages for SCU Residents

- improves level of behaviour/can model others' behaviour (14)
- time off unit/change of surroundings (11)
- increases variety of activities that can be provided (4)
- feel a part of/involved with rest of facility (4)
- enjoyment/fun (3)

Disadvantages for SCU Residents

- disruptive/confusing/stressful for them (7)
- other patients react negatively to them/verbally abuse them/don't accept them ("SCU patients are very sensitive to others' feelings") (6)
- not all able to go (3)

Advantages for Other Residents

None mentioned

Disadvantages for Other Residents

- upset/frightened by them (15)
- complain about the noise (5)

Advantages for Staff

- like to see SCU residents enjoy selves/functioning at optimal level (4)
- like the change (see other residents and staff in facility) (3)

Disadvantages for Staff

- harder to manage toileting, inappropriate behaviours (4)
- feel badly when there are disagreements/belittling between general facility population and SCU residents (3)

3.8.1.6 Families' perception of residents' care and programming

The first question in this section asked what aspects of the physical care given to his/her relative the family member particularly appreciated.

Almost all comments concerned that fact that the patients were kept clean and tidy. Some also mentioned "good food".

In terms of aspects that could be improved, some family members mentioned that they would like to see more frequent baths and several mentioned the problem of clothes going missing. One individual said that being locked out of one's own bathroom during the day may lead to increased incontinence.

When asked whether there were things about the way staff related to their relative that were particularly appreciated, patience, warmth, hugs and touching were all commonly mentioned. In terms of improvements they would like to see, more familiarity with Alzheimer's disease on the part of staff was mentioned by several. Other suggestions were a greater knowledge of the individual resident's history and more one-to-one care.

Another question asked what programs and activities offered in the hospital their relative especially enjoyed or benefitted from. While one or two family members thought their relative did not get any activities*, most mentioned music, singing, dance and outings. Eighty-three percent felt that the programs provided met the needs, preferences and interests of their relative. When asked whether there were programs or activities not now offered that the relative might enjoy, the only suggestion made by more than one individual was "more outings". Those dissatisfied with current program offerings suggested that there were an inadequate number for those whose functioning had declined to a low level. Other specific preferences included children, pets and kitchen activities.

Another question, included in both the staff and the family interview, concerned opportunities to make choices.

When staff were asked "Within the limits of their abilities, in what areas do you feel Special Care Unit residents can or should make choices?", the following responses were given:

- choice of food (12)
- choice of clothing (10)
- whether or not to participate in activities (9)
- when they want to get up and/or go to bed (8)

* Several staff members noted that some families visit mainly in the evening and on weekends. These individuals may be unaware of programs and activities provided for their relative. To bridge this gap, staff of one unit suggested that it might be useful to provide such families with a videotape of their relative, showing him/her engaging in various activities. Such videotapes might also be appreciated by families unable to visit on a regular basis.

Five staff respondents, it should be noted, said "they aren't capable of making choices". Several also pointed out that offering choices is "time consuming and therefore difficult given current staff-resident ratios."

Among family respondents, 70% believed their relative was offered choices. Examples given paralleled those described by staff.

When those who said their relative was not offered choices were asked in what areas choices might be offered, almost all stated that their relative cannot make any choices.

3.8.2 For Families

3.8.2.1 Coordinators' description of programs now offered

The Coordinators of five of the six participating facilities stated that their facility offered programs for families. In four units, the coordinator said that family counselling is provided; in three of these four facilities specially for families of SCU residents. In four facilities, there is a family support group. It is specifically for relatives of SCU residents in only two of the four. Two facilities offer, exclusively to relatives of SCU residents, information about dementia; one facility offers them training in stress management.

3.8.2.2 Staff's experience with and perception of the effectiveness of programs provided for families

As shown in Table 12, approximately half of the staff respondents had had experience with family support groups, only one-third with family

counselling and fewer than twenty percent with information sessions or stress management programs.

While two-thirds of those who had had experience with family support groups felt they were effective most of the time, the proportion dropped to half for information sessions and to just over a third (37.5%) for family counselling. None felt stress management programs were effective most of the time.

TABLE 12

STAFF'S EXPERIENCE WITH AND PERCEPTION OF
THE EFFECTIVENESS OF PROGRAMS PROVIDED FOR FAMILIES

	<u>Base</u>	<u>Have Had Experience</u>	<u>Effective</u>		<u>Never</u>
			<u>Most Times</u>	<u>Some Times</u>	
information sessions	27	18.5%	50.0%	50.0	0.0
family counselling	28	32.1	37.5	62.5	0.0
family support groups	28	46.4	66.7	33.3	0.0
stress management programs	25	12.0	0.0	100.0	0.0

3.8.2.3 Families' participation in and satisfaction with programs provided for them

Although, as indicated above, the Coordinators of five of the six participating units said they offer programs for families, when family respondents were asked "What special services or programs does this hospital offer for families of Special Care Unit residents?", only those associated with Unit C responded in substantial numbers. These individuals, who constituted 100% of the family sample from Unit C, all had attended the Family Support Group the unit puts on especially for SCU

residents' relatives. When asked if they'd found the Family Support Group useful, 77.7% said "yes". Among their reasons for saying so was that it:

- "provided a good opportunity to bring up suggestions concerning the needs of residents"
- "provided an opportunity for identifying with and understanding the issues with others, finding out about common concerns and hearing about practical ideas"
- "demonstrated the staff have a caring attitude and provided an opportunity to express grievances (e.g. got keys to relative's room after requesting them at a support group meeting)".

Among the small number (3) of respondents associated with other units who were aware of programs for families, one mentioned that the unit had provided an orientation session to families of new residents, one said he/she had attended weekly meetings put on by the facility, and one said that he/she knew a program was offered but had been unable to attend it.

Two of the relatives from Unit C and two from two other units had attended support groups sponsored by "outside" agencies. Their reaction to these was mixed.

Also mixed were respondents' reactions to the expression of personal feelings at support group meetings. For example, one respondent said she enjoys the group meetings but "doesn't like people complaining about their own worries". Some participants, she felt "worry more about themselves than their relatives". Another respondent, however, said she was "grateful for the opportunity to express personal concerns and feelings".

When asked if there were any (other) services or programs that would be useful, 17 of the 39 respondents identified one or more.

These included:

- information about Alzheimer's e.g. stages of the disease/reasons for their relative's behaviour (to increase their acceptance of it) (5)
- regular meetings with staff and/or administration (3)
- practical information (e.g. how to get labels for relative's clothing/power of attorney information) (2)
- more information/support prior to admission of relative (2)

3.8.3 For Dementia Victims Living In The Community

None of the participating facilities offers a special day program for dementia victims living in the community. One, however, accepts Alzheimer's patients into its regular hospital day program.

3.9 FAMILY INVOLVEMENT AND NEEDS

3.9.1 Staff's Perceptions Of:

3.9.1.1 the nature and degree of information that should be provided to families

In the staff interview, respondents were asked what information they thought the family should receive regarding the condition of and treatment being given to their relative.

Eleven of the forty respondents (27.5%) declined to answer this question because they felt it was not part of their job to respond to relative's requests for information.

Among those who did respond, approximately half (51.5%) felt families should be given as much information as possible. This included information concerning their relative's diagnosis, the stage of the disease he/she was at and the prognosis. Such information, they felt, would help families to "not think their relative is crazy" and to "know what to expect". Other staff cautioned, however, that discretion should be exercised in providing information. For example, one individual pointed out that how much information and what was given depends on the family.

First -- look at the family history. If they've been close in the past, share a lot of information. However, sometimes there is a history of friction and some families may not have the best interests of the resident in mind -- it's important to question their motivation when they ask questions.

Other staff respondents cautioned against giving information that might be very upsetting to the family and/or recommended placing emphasis on the resident's positive rather than negative behaviours.

One respondent felt families should be fully informed about the medications his/her relative was receiving and, in particular, concerning any change in these; three others felt information about medications should be kept confidential.

Three felt relatives should be informed about any change in the resident's medical condition and, in particular, if he/she had had a fall or sustained an injury.

Three felt relatives should be informed of any change in the care plan.

3.9.1.2 areas of decision-making families should be involved in

When staff were asked what areas of decision-making concerning the care and treatment of their relative they felt families should be involved in, several commented that it depends on the family's degree of acceptance of the disease and their involvement with their relative. Six said "as much as possible/in all decisions" while three felt there were no areas they should be consulted about "because families are not realistic about their relative's condition". More specific responses included:

- when knowledge of the resident's history/likes and dislikes might be helpful (e.g. in care planning, in choice of appropriate activities) (12)
- when decisions need to be made regarding how aggressive treatment should be/whether to transfer a resident to an acute care hospital/whether to resuscitate (family and physician should discuss) (5)
- concerning the use of restraints to prevent falls (2)
- concerning living arrangements/number of beds per room (2)

In responding to this question and to one concerning how families are involved in decision-making in their unit, a number of staff respondents stressed the importance of ascertaining, from the family, the resident's past history and, in particular, his/her likes and dislikes.

In virtually all units this is done as part of the pre-admission process or immediately subsequent to admission. Respondents from several units indicated it was an ongoing process. In two units, families are invited/can sit in on case conferences. In one unit, if the resident is unable to take part in the Residents' Council, a family member may take his/her place.

3.8.1.3 what families should/should not do for their relatives

In response to a question asking whether there were things now being done by staff that they thought families could or should do, the most frequent answers given by staff respondents were that families should visit more/be more involved with their relative (8 respondents), that they should keep their relative's clothing repaired (6 respondents) and that they should provide more or more suitable clothing (3).

Additionally, one or more respondent stated that they could

- assist in getting residents to the dining room and/or with feeding (3)
- straighten up his/her room/decorate room with personal belongings (2)
- take their relative to the doctor (1)
- take their relative for a shampoo/hair cut or for a ride (2)
- shop for him/her (1)

Things staff felt families should not do for their relative centered primarily around personal care. A small number of staff respondents stated families should not attempt to toilet their relative; give baths; or wash, get them up and dress them. One respondent also noted that family "should not feed when the person doesn't need it". Apparently, this individual had encountered a situation where staff were trying to encourage the resident to feed him/herself. The family either was unaware of staff's intentions or chose to ignore them.

3.9.1.4 behaviour that is supportive and helpful to families

This section of the staff interview began with the question: "Do you feel most staff understand the stress which relatives of SCU residents

experience?". More than three-quarters (78.1%) of the staff respondents felt they do.

When asked in what ways staff are supportive and helpful to relatives, staff respondents stressed the importance of good communication.

- "Talk to the family when they visit - tell them how the patient is. Some staff ignore families, and don't answer questions."
- "Explain what went on during the day."
- "Keep them aware of changes in their relative."
- "Talk to them - give reassurance (e.g. your mother is eating better than last week)."
- "Be open - form trust. The family is reassured if they believe staff really care about their relative."

Several also noted the importance of attempting to understand family members' feelings and to interpret their behaviour in light of the stress they are experiencing rather than taking it personally.

- "Understand their feelings. Families can be demanding because they are upset. Put yourself in their place. How would you feel if it was your mother?"
- "Accept criticism - understand they're mad at the situation, not you."

Another major theme in the staff interviews was the importance of making family feel welcome on the unit and that they can come to staff with their questions or just to talk.

- "Make it as unhospital-like as possible e.g. 24 hour visiting. Welcome the family and involve them."
- "Encourage them to come to visit, participate in activities, special meals, bus trips, etc."

3.9.2 Family's Perception Of/Satisfaction With

3.9.2.1 amount and type of information provided to them

In the relative's interview, respondents were asked whether they felt they were kept sufficiently informed as to the condition and treatment being given to their relative. Those answering "yes" (80.6%) were then asked "What information do you appreciate receiving?" Those answering no (19.4%) were asked what information they would like to receive.

Appreciated/desired, in order of frequency of mention, was information regarding:

- relative's medical condition/health/any changes (e.g. falls, seizures, flu) (18)
- medications (e.g. what getting, changes) (11)
- his/her current condition (e.g. how has been eating, how is today, things he/she has said or done) (8)
- need for clothing (3)

Several respondents said they appreciated the ready way in which staff gave them information when they asked for it. A small minority complained that staff seldom volunteered information. Rather, they only received it when they specifically asked for it, and sometimes they received conflicting information from different staff members. One respondent remarked he/she would like to receive an accounting of or bills for money spent from the resident's account.

3.9.2.2 degree/way they are involved in decision-making

Families were asked if they have as much input as they would like concerning the care and treatment of their relative. Those indicating they

had enough (89.5%) were asked to describe how they were involved in decision-making for their relative.

The most frequent response was "If I don't like something, I speak up". Other responses were: "staff talk to me when I visit", "they phone and involve me" and "they try to have meetings".

It is interesting to note that one of the four respondents not satisfied with his/her degree of input into decision-making stated explicitly that regular meetings with the staff and the administration should be scheduled, especially for relatives of new residents. Such meetings would serve the needs of one of the other dissatisfied respondents, who felt that access to staff was essentially limited to one person: the Activity Coordinator.

3.9.2.3 areas of family/staff responsibility

This section of the family interview began with a question asking respondents what they do for their relative in the hospital and on his/her behalf outside the hospital. In an attempt to ascertain whether there were areas of responsibility families felt they, rather than staff, should be involved in, they were asked "Are there things you feel you could or should do for your relative that are now being done by staff?" They were also asked whether they were now doing things for their relative they felt staff should do.

The most frequent service performed by family in the hospital related to mealtimes. More than one-third (35.9%) of the family respondents reported feeding their relative breakfast, lunch, supper or juice at snack-time;

taking him/her to the dining room; and/or encouraging him/her to eat. About one-quarter (23.1%) reported activities related to the resident's clothes. These included checking them to see if they needed cleaning or repair, bringing new clothes, changing their relative's clothes or sorting laundry. Other activities frequently performed by the family respondents for their relative included:

- talking/visiting/sitting with him or her (14)
- shaving, washing and/or cutting hair, manicuring nails, massaging with lotion (10)
- walking with him/her (in or out of the facility) (9)
- bringing food/flowers (9)
- taking him/her out (e.g. for drives) (8)
- decoration/tidying bedroom or closets (6)
- brings him/her up to date on family/showing photos (4)
- toileting/changing undergarments (4)
- taking to another part of the facility (3)
- checking condition of glasses, dentures, etc. (3)

The most frequent activity performed by family members on their relative's behalf outside the hospital consisted of taking care of financial matters. More than two-third (69.1%) reported doing their relative's banking, paying bills, etc. More than half (59.0%) reported purchasing, cleaning or repairing goods for their relative. These activities included buying, repairing, washing and labelling their relative's clothes; buying/seeing to the repairing of his/her glasses or hearing aid; and purchasing toiletries or other needed items. Another service provided by several respondents was to transport their relative to the doctor, dentist or, in one case, the hairdresser

Only one person felt there were things he/she could be doing for the relative that were now being done by staff. These were bathing, feeding and cutting the resident's hair.

Only four individuals felt there were things they now do for their relatives that should be the staff's responsibility. In one case a relative was bathing the resident "since she was difficult for staff to handle". Two felt staff could keep their relative and/or his/her things "a bit cleaner". One family respondent was concerned that his relative might not eat enough fresh vegetables if he wasn't there to assist her at mealtimes.

3.9.2.4 staff behaviour that is supportive and helpful to families

As in the staff interview, this section began with the question "Do you think most staff understand the stress relatives of Special Care Unit residents experience?" This was followed by the question "In what ways are staff supportive and helpful to you?" and "What else could they do?"

More than three-quarters (83.8%) of the family respondents felt staff understood their stress.

In terms of being supportive and helpful, more than one-quarter (28.2%) noted that staff were "nice", "friendly and cheerful", "pleasant and encouraging", one respondent stating "they always recognize me and call me by name". Twenty percent reported that staff offered sympathetic comments and try to understand if they are upset. Small proportions commented that:

"Staff are always willing to listen and are there to talk when I need them"

"Keep an eye on me to make sure I don't over-exert myself while caring for my wife"/"suggest I 'take a day off' and sometimes bring a cup of tea if I've been there several hours"/"offer services when I visit"

TABLE 13

STAFFING OF PARTICIPATING SCU'S

	A	B	C	D	E	F
No. of Residents in Facility	150	64	130	150	200	113
No. of Residents in SCU	31	20 (day) 18 (night)	20	25	25	38
Ratio of Direct Care/Nursing Staff to Residents*						
Day	1:8.9	1:8.5	1:6.6	1:7.1	1:3.5	1:4.5
Evening	1:12.4	1:8.5	1:7.1	1:7.1	1:7	1:6.3
Night	1:31.0	1:15	1:40	1:25	1:20	1:12.7
Staff Breakdown						
a) Regularly on duty in SCU	> 2/3 RN/RPN/LGN 3.5 Care Aides < 1 Activity Worker shared	1 RN/RPN/LGN 2 Care Aides	0.5 RN/RPN/LGN 2.5 Care Aides shared Activity Worker	1 RN/RPN/LGN 2.5 Care Aides 1 Activity Worker	1 RN/RPN/LGN 2.5 Care Aides 2.5 Activity Worker	3 RN/RPN/LGN 4 Care Aides 1.5 Activity Worker
Evening	shared RN/RPN/LGN 2.5 Care Aides	shared RN/RPN/LGN 2 Care Aides	0.3 RN/RPN/LGN 2.5 Care Aides	1 RN/RPN/LGN 2.5 Care Aides	1 RN/RPN 2.0 Care Aides 0.5 Activity Aide	2.5 RN/RPN/LGN 3 Care Aides 0.5 Activity Worker
Night	shared RN/RPN/LGN 1 Care Aide	shared RN/RPN/LGN 1.2 Care Aide	0.3 RN/RPN/LGN 0.5 Care Aides	shared RN/RPN/LGN 0.3 Care Aides	shared RN/RPN 1 Care Aide	2 RN/RPN/LGN 1 Care Aide
b) Shared with rest of facility	Dietician OT/PT Social Worker Music Therapist	Activity Coordinator Dietician Music Therapist	Dietician Music Therapist Recreation Dir. Social Worker Ward Clerk	Chaplain Dietician OT Pharmacist	Activity Coord. Psychologist Dietician OT PT Speech Therapist Ward Clerk	Activity Worker OT PT Recreation Therapist Social Worker
% of staff respondents feeling no. of SCU staff is sufficient	60.0	25.0	42.9	75.0	50.0	71.4
% feeling type of SCU staff is sufficient	60.0	25.0	57.1	75.0	83.3	57.1

* Note: Staff-resident ratios are approximate as they vary between weekends and weekdays. Also, some workers overlap the three standard shifts (e.g. 7a.m. - 7p.m.; 12 noon to 8 p.m.)

"Have her cleaned up and ready to go when I come"

"Appreciate my frequent visits and the assistance I give my wife"

"Talk about dad"/"keep me posted on mom's condition"/"volunteer information".

In terms of additional things staff could do to help families, respondents noted that some staff need to be more open and honest; others need to make them feel more welcome on the unit.

"Some need to be more upfront, honest about what is going on"

"I quit visiting in the evening because I didn't feel welcome as staff were 'closing up' even as early as 7:30 p.m."

3.10 STAFFING PATTERNS AND ISSUES

3.10.1 Staff-to-patient Ratios Of Participating Facilities

In their survey of 17 SCUs in the United States, Ohta and Ohta (1988) found that staff-patient ratios varied from a high of 1:3 to a low of 1:12+. They also noted that staff-to-patient ratios can vary considerably within a given unit over a 24 hour period.

Table 13 shows the staff-patient ratios of the six SCUs participating in the present study. Staff included in calculating ratios consist only of direct care and nursing staff (i.e. R.N.s, R.P.N.s, LGNs and Care Aides).

In all facilities staff-patient ratios are higher in the SCU than in the facility as a whole. Overall, Units E and F have higher staff-patient ratios than Units A-D.

3.10.2 Type Of Staff In Contact With SCU Residents

As shown in Table 13, there was considerable similarity across units in the number and type of direct care and nursing staff in contact with residents. Where the units noticeably differ is in the number and type of other professional staff on site and accessible to residents, even if only on a shared basis.

3.10.3 Staff's Perception Of The Adequacy Of Current Staffing Ratios And Staff Mix

In the final section of the staff questionnaire, respondents were asked whether, in their opinion, the number and type of staff in their unit was sufficient for adequate care of patients. As shown in Table 13, the proportion feeling the number and/or type of staff was adequate ranged from 25.0% to 83.3%. Although differences are not statistically significant, satisfaction with number and type of staff was generally higher in the three units located in Extended Care hospitals.

When asked what type of additional staff are needed, the following responses were obtained:

- more direct care staff/care aides (15)
- more activity/recreation workers (10)
- RN or equivalent on unit at all times/at least during day and evenings (7)
- activity staff available during evenings and weekends ("because currently there is not much going on in these time periods which are when family visit") (3)

Other suggestions made by one or two respondents included having a music therapist and a social worker available, having an RPN on the unit, having

at least one male staff member on duty each shift and having a full-time housekeeper for the unit.

3.10.4 Staff's Training And Educational Needs

In the staff interviews, respondents were asked whether they had had any special education in working with SCU patients -- for example, in the context of courses, workshops or inservice education. Seventeen of the 18 (94.4%) working in Intermediate Care-based SCUs and 16 of the 22 (72.7%) working in Extended Care SCUs indicated that they had.

Respondents were asked whether their training had covered any of topics a to j in Table 14 or had been focussed on specific therapies such as reminiscence, milieu, etc. Respondents who had had training on a particular topic were asked to indicate whether or not the information had been useful. Respondents who had not had any training on the topic were asked if they'd like information on it.

As shown in Table 14, among those who had had training, two-thirds or more had been given general information about dementia; information concerning management of disorientation; management of "problem" behaviours such as catastrophic reactions, anxiety, restlessness and wandering; or concerning management of aggressive and abusive behaviours. From a quarter to a half had had training concerning: communicating with demented persons, validation therapy, family dynamics, stress management for staff, stress management for patients, communicating with/assisting families or reality orientation. Less than one-quarter had had instruction on stress management for families or on reminiscence therapy.

The vast majority of those who had had special training have found it useful.

Of topics staff had not had instruction on, demand was greatest for general information about dementia as well as information that would facilitate: management of aggressive and abusive behaviour; management of behaviours such as catastrophic reactions, anxiety, restlessness and wandering; management of disorientation; and management of their own stress level.

TABLE 14
SPECIALIZED TRAINING

	<u>Base</u>	<u>Have Had</u>	<u>Useful</u> (Base = Have Had)	<u>Would Like</u> (Base = Have Not Had)
a) general information on dementia	33	93.9%	100.0%	100.0%
b) management of behaviours such as catastrophic reactions, anxiety, restlessness and wandering	33	75.8	95.8	70.0
c) management of aggressive and abusive behaviours	33	63.6	90.5	71.4
d) management of disorientation	33	78.8	96.0	70.0
e) communication with patients	33	57.6	100.0	52.9
f) communication with/assisting families	33	42.9	92.9	65.0
g) family dynamics	33	54.5	87.5	50.0
h) stress management - patients	33	42.4	92.9	52.4
i) stress management - families	33	24.2	100.0	53.8
j) stress management - staff	33	51.5	93.3	61.1
k) reminiscence therapy	23	13.0	100.0	53.8
l) validation therapy	29	58.6	100.0	54.5
m) reality orientation	26	38.5	62.5	36.4

4. DISCUSSION

This report has presented findings from interviews conducted with the Coordinator(s), staff and families of residents of six facilities in British Columbia having a Special Care Unit for dementia victims.

Although one unit (Unit D) does not term itself an SCU, all units generally meet the criteria for designation as SCUs. Specifically, all six are physically separated from the facility of which they are a part. In the case of facility A, the unit is located in one wing of the first floor of a two storey building. In facility B, it is on the lower floor of a three storey building. In facility C it is located in a wing of the third floor of a three storey building. In facilities D, E and F it occupies one wing of a one storey building. In all except facility D, where most of the residents of the unit are non-ambulatory, the units are separated from the rest of the facility by a locked door.

As indicated in Section 3.2.4, the vast majority of residents of each of the six units suffer from a dementing illness.

As indicated in Section 3.10, most of the staff of the six units have had at least some specialized training.

All units also have a number of activity or recreation programs for residents. While not differing markedly in type from those found in most Intermediate and Extended Care facilities, they differ in the way they are delivered. As indicated in Section 3.8.1.2, staff are sensitive to the

limitations and special needs of SCU residents. Also, programs tend to be offered to smaller groups than is usually the case. Formal therapeutic programs, on the other hand, tended to be minimal in the participating units. For example, although all units offer some type of music program, music therapy by a qualified music therapist is only offered in two units; a third provides experience for music therapy students. Few, if any, of the units offer formal validation therapy, reminiscence/life review, milieu therapy or reality orientation programs. While as indicated in the literature review that preceded this study (Gutman, 1989) the efficacy of such programs in the treatment of dementia has yet to be established, perhaps greater consideration of their application to this population should be considered.

Also noticeable by its absence was much in the way of special environmental design. Other than having a locked unit door and fenced outdoor area, few of the participating units employ special design features. This is an area that certainly could bear expansion. As indicated in the literature review (Gutman, 1989), other jurisdictions have implemented a variety of such features. Some staff respondents had had experience with some of these in other facilities in which they'd worked (see Section 3.4.2). While some were found wanting, there are many more which remain to be tried in the participating units and which should seriously be considered for new units.

In particular, new facilities should incorporate well-designed wandering space. In developing such space, designers could benefit from discussions with staff of existing units who have found, for example, that "dead ends", where residents congregate and become agitated and disruptive, are

problematic. While the ideal design for wandering areas still remains to be determined, staff now intimately involved with Special Care Units have many potentially constructive ideas which should be explored.

"Quiet rooms" were another design feature frequently mentioned as an aid in the management of residents. Agitated or disturbed/disturbing residents can be segregated in these rooms in order to calm them and prevent their distress from affecting other residents. The units in the study having such rooms found them very effective for this purpose. Larger common areas and halls were also recommended by study participants as a means of decreasing agitation. They noted that many dementia sufferers seem highly sensitive to being jostled by others, or having their "space" invaded, as well as to the level of agitation surrounding them. Lack of room to move about freely was felt to precipitate "problem" behaviours such as agitation and lashing out at others.

Findings from the study also suggest that programming for families should be expanded. While many programs are offered in the community for persons caring for dementia victims at home, once the relative enters a facility the family has differing needs. These include how to make the most of visits, how to cope with the probability their relative will exhibit behaviours they find disturbing in other SCU residents, reassurance that their relative is getting the best possible care, etc.

Day programs for community-dwelling dementia victims should also be considered. None of the units participating in this study offered these. Additionally, one or more respite beds would be useful. Currently, only

one of the participating units offers respite, and then only occasionally. One previously had a respite bed. The Coordinator of this unit noted that although occasionally use of the bed had resulted in a permanent admission, in most cases the client returned to the community with his/her family feeling better able to cope.

In addition to providing relief to family caregivers, two of the Coordinators noted another value of respite beds (and day programs) which is in familiarizing families and future residents with SCU services and staff. They feel this reduces stress when a subsequent placement is made. An additional benefit is that staff have an opportunity to observe and get to know future residents when they are still functioning at a relatively high level. This, it is felt, facilitates personalized care planning upon admission.

Both day programs and respite programs would further utilize the expertise of SCU staff. As indicated in this report, clearly the expertise and the caring approach of SCU staff are valued by the families of residents. The sections of the interview (3.9.1 and 3.9.2) concerned with staff and family responsibilities and perceptions of each group by the other show many positive areas of consensus and communication.

Equally clear is the fact that SCUs themselves are valued. In their answers to questions regarding segregation versus integration of SCU residents and the general facility population (see Section 3.7.2), respondents cited more advantages of segregation than disadvantages. There was less consensus regarding segregation for activities. All respondent

groups cited sufficient disadvantages of segregation to suggest that integration for activities should be considered, at least for some SCU residents and at least for some activities.

A more general point that should be mentioned concerns the high degree of concordance between the views of the three sets of respondents in this study. In almost all areas, Coordinators, staff and families had similar perceptions of residents' and one another's needs. Recommendations as to how these needs might better be met were also highly similar.

These suggestions, as well as the overall positive reactions of respondents to SCUs, should be taken into consideration in future policy and planning decisions for care of dementia victims.

Finally, as regards differences between SCUs based in Intermediate as compared to Extended Care facilities, at least eight were identified. These included a more equal sex distribution in Extended Care-based units, a generally younger resident population and a wider case mix; two- and four-bed rooms as compared to mainly single rooms in Intermediate Care-based facilities; a higher perceived ideal number of residents for SCUs; a slightly greater variety of activities and programs offered to residents and, fewer units in which residents' rooms were kept locked during the day. This latter practice, found to occur regularly in two of the Intermediate Care units and sometimes in the third, was instituted to prevent trespassing. Families, however, find it distressing to have their relative's door locked and would appreciate it if some other means of controlling trespassing could be developed. Another, and probably more

important difference between units located in the two types of facilities was the greater readiness of those in Extended Care facilities to admit and retain physically aggressive residents. In deciding in what type of facilities future SCUs should be located, the needs of these individuals must be taken into consideration. If the current practice of refusing them admission/discharging them from Intermediate Care-based facilities continues, with the downsizing of Valleyview there will be no place in GVRHD for them to go. Perhaps this identifies an emerging role for Extended Care-based SCUs -- that is, specializing in the care of physically aggressive dementia victims.

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APPENDIX - CARE LEVEL DEFINITIONS*

Levels of Care

The classification system used by the Long-Term Care Program to describe individuals with similar types of health care needs consists of three major groupings - Personal Care, Intermediate Care and Extended Care. Within these groupings, Intermediate Care has been further divided into levels I, II and III.

These care levels move in a progression from the lighter care requirements of Personal Care, through the Intermediate Care levels to the heavier care requirements of Extended Care. Briefly summarized, the care levels are:

Personal Care

This level of care recognizes the individual who is independently mobile, with or without mechanical aids, and whose primary need is for minimal non-professional supervision and/or assistance with the activities of daily living for the purpose of achieving or maintaining maximum personal independence in everyday activities.

Intermediate Care

The three Intermediate Care levels build on the Personal Care level and recognize a need for care planning and supervision under the direction of a health care professional by introducing a combination of professional and non-professional (lay) supervision. This professional supervision is required on a daily rather than a twenty-four hour basis. Individuals at the Intermediate Care levels are ambulant with or without mechanical aids.

* Source: Tate (1987) Long Term Care Facilities: Overview and Trends.

Intermediate Care I

This level of care recognizes the individual who requires moderate assistance with the activities of daily living and minimal professional care and/or supervision.

Intermediate Care II

This level of care recognizes the individual who has more complex care needs, and who requires additional professional care and/or supervision.

Intermediate Care III

This level of care primarily recognizes the individual who exhibits severe behavioural disturbances on a continuing basis and who presents a significant management problem.

This level also recognizes the individual who has very heavy care requirements which require significant staff time to manage.

In both instances, this level of care requires considerable supervision and/or assistance under the direction of a health care professional.

Extended Care

This level of care recognizes the individual with a severe chronic disability who requires professional nursing services on a twenty-four hour basis and regular and continuous medical supervision, but who does not require all the resources of an acute care hospital. This individual may or may not be able to ambulate independently.