
Shelter & Care of Persons with Dementia



Edited by
Gloria Gutman



**SHELTER AND CARE OF PERSONS WITH
DEMENTIA**

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INTRODUCTION

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

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

While Alzheimer's disease and strokes are known to occur in younger persons, dementia is primarily a disorder of the elderly, with an estimated 4% to 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 the authors' age-specific prevalence rates to Canada, McEwan, Donnelly and Robertson (1989) estimated that in 1991 there were 72,348 cases of dementia among persons aged 65-79 and 117,637 cases among those aged 80 and over. Because of the changing age structure of the population (i.e. greater growth among the very old) these authors project that the number of Canadians with dementing disorders will more than double over present levels by 2006.

The impact of dementia on society is even greater than these numbers would suggest because the disease, by its very nature, has a significant, often devastating effect not only on the afflicted individual but also on his/her family. For this reason, Aronson and Lipkowitz (1981) 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 illness 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 dementia then the treatment aim should be to maximize the person's functioning level and quality of life.

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

THE CONTENT AND GOALS OF THIS BOOK

This book begins by examining the number and characteristics of dementia victims currently in institutions in Canada and the services these settings provide. In the first chapter in Part I, McEwan, Maxwell and Gutman provide a rationale for examining institutional settings. They point out that even if home care were to be significantly expanded over the next 20 years, to the extent that institutionalization of persons below the age of 85 is prevented, a substantial increase in the number of beds (e.g. 18% in British Columbia) would still be required. Key questions that have been debated for some time and which are addressed in subsequent chapters in this section are whether, and if so, in what proportion, new and existing beds occupied by persons with dementia should be located in segregated settings and how best to configure these settings.

As regards segregated settings, Holmes, Teresi and Monaco (1992) estimate that 11% of nursing homes now provide care for some of their residents with dementia in speciality units . Special Care Units are also proliferating in Canada.

While there is some information available about the characteristics of Special Care Units in the United States (Gutman, 1989; Mace, 1991; Sloane & Mathew, 1991) to date only very limited information has been available concerning such units in Canada (cf. Vancouver Health Department, 1986).

As a beginning step in filling this information gap, in chapter 2, Gutman and Killam describe the characteristics of residents of six Special Care Units currently in operation in British Columbia. Information is also presented on the extent to which these units offer special environmental design features, have specially trained staff and offer special programs and activities. In chapter 3, Flett and Davis describe the residents and the facilities and services offered in 71 Special Care Units in Ontario Homes for the Aged. Care practices in these units are compared with those offered in the Homes to residents with dementia living outside Special Care Units. In chapter 4, Lahaie and Theroux describe the conceptual framework and evolution of "an alternative unit" developed for persons with dementia living in rural Manitoba. A key feature of this latter unit is "generic staffing" in which caregivers assume some tasks and responsibilities traditionally assigned to other departments.

While the identification of key environmental design and behaviour management issues and innovative and effective non-medical solutions to these are underlying themes in Part I and throughout the book, in Part II they are the main topics of discussion. In chapter 5, which begins this section, Teri describes the theoretical underpinnings and a protocol for behavioural treatment of the depression and depressive symptoms that so frequently accompany dementia, adding "excess disability". In chapter 6, Dobbs and Rule present findings from an important series of studies concerned with where, when and with what frequency "problem behaviours" occur in an institutional setting. While staffs' perceptions of the frequency and management difficulty of these behaviours are presented in the chapters in Part I, data reported in chapter 6 derive from *systematic behavioural observations* conducted in both segregated and non-segregated nursing home settings. In showing that dementia patients are inactive much of the time, display more appropriate than inappropriate behaviour and are mobile only a small percentage of the time, the findings challenge the traditional concept of dementia patients. Data reported by Milke, in chapter 7, also challenge convention wisdom, in this case, as regards the efficacy, ethicality and most importantly, the safety of wandering paths and such equipment as "walking machines". The section concludes with a description (chapter 8) of the contents, guiding principles and goals of a

new publication from Health and Welfare Canada containing design guidelines for facilities for persons with dementia.

While Parts I and II of the book tend to focus inward on institutional settings, examining their environmental design and services to residents, Part III takes a broader perspective. In chapter 9, which opens this section, Shulman and Cohen present a set of emerging principles that underlie the provision of specialized psychiatric and mental health services for the elderly, whether community-based or in institutional settings. These include: comprehensiveness; accountability; ensuring that the elderly person who experiences a change in mental status is first assessed by his/her general practitioner who continues to be closely connected with the patient even after the psychiatric assessment; ensuring that patients, especially those with dementia, are assessed in their familiar home environment; and ensuring that older persons with dementia or other psychiatric illness, receive the psychiatric treatment they need. Examples are provided as to how these goals may be reached through cooperation and coordination, in an urban setting where there often are multiple community-based agencies and services as well as hospital-based geriatric psychiatric services.

Chapter 10, in contrast, deals with issues of organization and coordination of services in rural settings where staff with specialized training and expertise in dementia care tend to be in short supply. In this chapter, Sarchuk and Wiebe describe one response which involved the opening of a Special Care Unit in Winkler, Manitoba which, rather than being used for permanent admissions, serves as a resource for surrounding Personal Care Homes. Using behaviour modification as a means of managing disruptive behaviours, the goal of this unit is to devise a plan that will treat the problem behaviour and be transferrable to the referring facility.

Turner and Graham, in chapter 11, describe another response of the Manitoba government to meeting the needs of the increasing numbers of elderly persons with mental impairment. This response involved the establishment of Special Care Resource Teams which provide weekly or biweekly consultative services to Personal Care Homes in the Winnipeg area. These services range from informal advice concerning the behaviour of a particular client to the development of formal, intensive behavioural management programs. Three case studies are presented which illustrate the way in which behavioural approaches are applied and the success that has been achieved.

While one goal in compiling this volume was to identify environmental design features and non-medical interventions that would facilitate management and, more importantly, enhance the quality of life of persons with dementia living in institutions, a second goal was to facilitate the development and delivery of appropriate and effective shelter and care to dementia victims living in the community. Some of the material presented in Parts I, II, and III is applicable to this second goal. It is explicitly addressed, however, in Part IV which begins with chapter 12. In this chapter, Gnaedinger describes findings from a three-part cross-Canada study in which key informants, 1000 members of the Alzheimer Society of Canada and 25 other individuals, the latter interviewed in-depth, were asked about physical adaptations they had made to their home to accommodate a family member with dementia. Attention turns next to adult day care. In chapter 13, Keith and Rutman describe the Alzheimer's Family Care Centre, a specialized adult day care centre in Victoria, B.C., designed to assess and stabilize dementia patients living in the community. Part IV, and the book, conclude with chapter 14 in which Rapelje discusses three types of respite programs: institutional, in-home and what he terms "responsibility respite" in which the caregiver is relieved of some of the chores of daily living.

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The chapters that make up this book originated as papers presented at a workshop by the same title held in conjunction with the 19th Annual Meeting of Canadian Association on Gerontology/Association canadienne de gerontologie (CAG/Acg) held in Victoria, B.C., October 25-28, 1990. The workshop was organized by the editor of this volume, Dr. Gloria Gutman, Director of the Gerontology Research Centre at Simon Fraser University and four individuals from the B.C. Ministry of Health: Dr. Kim McEwan, David Maxwell and Dr. Kathy Montgomery, from Mental Health Services and Norma McAllister from the Continuing Care Division.

It should be noted that this volume builds on three previous joint publications of the Simon Fraser University Gerontology Research Centre and the CAG/Acg: *Innovations in housing and living arrangements for seniors* (Gutman and Blackie, 1985); *Aging in place: Housing adaptations and options for remaining in the community* (Gutman and Blackie, 1986) and *Housing the very old* (Gutman and Blackie, 1988).

The workshops from which the three earlier volumes originated as well as the one preceeding this volume were partly funded by the Canada Mortgage and Housing Corporation under Part IX of the National Housing Act. A financial contribution to the Shelter and Care of Persons With Dementia workshop from the Pacific Health Care Society is also gratefully acknowledged. Thanks go also to the authors of each chapter for substantially expanding their papers to meet the goals of the book. Finally, appreciation is expressed to Norah Holtby, SFU Gerontology Research Centre Administrative Assistant, who took responsibility for formatting and inputting the manuscript and who coordinated production of the book.

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**PART I: SPECIALIZED CARE IN
INSTITUTIONAL SETTINGS**

1

BASIC FACTS AND FIGURES ABOUT DEMENTIA PATIENTS IN INSTITUTIONS

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INTRODUCTION

As a starting point for discussing the shelter and care requirements of institutionalized persons with dementing illness, this chapter begins with some background information concerning the number and age and sex distribution of elderly residents of institutions in Canada. Dementia as a reason for institutionalization and the prevalence of dementia in the institutional population are then discussed. Attention turns next to the nature and prevalence of "problem behaviours" exhibited by dementia patients and to the extent to which these are managed pharmacologically. Information on the physical health and functional status of dementia patients is then presented. The chapter concludes with a review of the limited information available concerning survival patterns of dementia patients. Data sources include published reports from the United States and published and unpublished works from specific geographic regions in Canada.

THE INSTITUTIONALIZED ELDERLY

NUMBER AND GEOGRAPHIC DISTRIBUTION

Forbes (1987) defines *institutional care* as the provision of 24 hour care in residential settings for older people. Of the 2,697,680 persons aged 65 and over identified in the 1986 Canadian census, 202,350 or 7.5 % are residents of institutions. Table 1 shows the elderly institutionalization rate by province and territory. As can be seen there is considerable variation - from a low of 3.5% of the elderly population of the Yukon to a high of 9.6% among the elderly in Alberta.

Table 1
PROVINCIAL RATES OF INSTITUTIONALIZATION OF THE ELDERLY, 1986*

	Pop. 65 +	# in Inst's	% in Inst's
Newfoundland	49,965	3,045	6.1
Prince Edward Island	16,080	1,210	7.5
Nova Scotia	103,835	6,095	5.9
New Brunswick	78,730	5,245	6.7
Quebec	650,640	51,945	8.0
Ontario	992,700	72,735	7.3
Manitoba	133,890	9,725	7.3
Saskatchewan	128,595	9,480	7.4
Alberta	191,320	18,300	9.6
B.C.	349,490	24,480	7.0
Yukon	860	30	3.5
N.W.T.	1,465	60	4.1
 CANADA	 2,697,580	 202,350	 7.5

Source: Statistics Canada (1987a). Population and Dwelling Characteristics: Dwellings and Households: Part 1, Catalogue 93-104; Statistics Canada (1987b). The Nation: Population and Dwelling Characteristics by Age, Sex and Marital Status: Catalogue 93-101, Table 3.

* Includes only persons aged 65 and over who were classified as residents of institutions. Elderly staff have been excluded.

SEX AND AGE DISTRIBUTION

There are more than twice as many elderly women (141,170) as men (61,200) in institutions in Canada; among those aged 75 and over, the ratio approaches 3 to 1. As shown in Table 2, the proportion of seniors in facilities rises dramatically with age. Among those aged 85 and over, 40.5% of women and 28.4% of men live in institutional settings (Stone & Frenken, 1988).

Table 2
% SENIORS IN INSTITUTIONS, BY AGE AND SEX, CANADA,
1986

Age	Males	Females
65-69	1.6	1.5
70-74	2.9	3.2
75-79	5.7	7.6
80-84	11.8	17.2
85 and over	28.4	40.5

Source: Same as for Table 1

In so far as communities are witnessing a trend toward increased home-based care, institutionalization rates would be expected to decrease. Stone and Frenken (1988) demonstrate that between the 1981 and 1986 censuses there was a decline in the proportion of institutional residents among those under age 85. Whether, they note, this is a result of more effective home care and/or more intact families in this age group, improvements in functional status or changes in policy concerning facility expansion, is unclear. What is clear is that this pattern does not hold for the old-old in Canada. Since 1976, the proportion of persons (both male and female) aged 85 and over in facilities has continued to increase (Stone & Frenken, 1988). Changes in the population age structure over the next few decades will result in even greater numbers of the old-old. The rapid growth of this segment of the population has important implications for the long-term care facility population as illustrated in the following scenario.

Currently (1986 census), in British Columbia, there are 24,480 persons aged 65 and over in residential care. Let us suppose that home care improved significantly over the next 20 years to the extent that we were able to prevent institutionalization in persons below the age of 85. Using the age- and sex-specific rates for institutionalization in Canada determined by Stone and Frenken (1988), we can estimate the number of older British Columbians in institutions in the year 2006 at 28,892 (see Table 3). In other words, an 18% increase in the number of beds in B.C. would be required over this 20 year period despite the elimination of admissions for seniors under age 85.

Table 3
NUMBER OF SENIORS IN INSTITUTIONS, B.C., 1986 vs.
2006, BASED ON SCENARIO THAT ONLY PERSONS 85+
REQUIRE RESIDENTIAL CARE

		# in Care
1986		24,480
2006		28,892
Calculation:		
85+ population forecast 2006:	Males = 23,330	Females = 55,000
Institutionalization rate:	Males = 28.4%	Females = 40.5%
Estimated number in care:	Males = 6,617	Females = 22,275

DEMENTIA AS A CAUSE FOR ADMISSION TO LONG-TERM CARE FACILITIES

There are many factors which contribute to the need for institutional care, leading Pruchno, Michaels and Potashnik (1990) to suggest that institutionalization be "examined as a process rather than an event" (p. S264). In most reports, however, the cognitive and functional deficits characteristic of dementia consistently emerge as strong predictors of placement. For example, Foley et al., (1992) in the U.S. found that persons with cognitive impairment were two to three times more likely than the non-cognitively impaired to be admitted to a nursing home. In Manitoba, Shapiro and Tate (1985, 1991) also found cognitive impairment and especially, a diagnosis of dementia, to be a strong predictor of admission to residential care.

The inability to perform self-care functions and other activities of daily living seen in the later stages of dementia, may precipitate the need for institutional care. For example, Knopman et al., (1988) found, in a longitudinal study of dementia clinic outpatients, that at one year follow-up, 12% of mild cases of primary degenerative dementia and 39% of advanced cases¹ were institutionalized. After two years, 35% of those initially diagnosed as mild and 62% of those initially diagnosed as advanced cases were institutionalized. Caregivers

¹ Classification as mild or advanced was based on the Information-Memory-Concentration test by Blessed, Tomlinson and Roth (1968).

most commonly reported incontinence, excessive patient irritability, inability to walk, wandering, hyperactivity, and nighttime disruptive behaviour as factors precipitating institutionalization.

The coexistence of dementia and depression also appears to increase the probability of institutionalization. In one report, from the Guy's Hospital/Age Concern Home Support Project in the U.K. (Lindsay & Murphy, 1989), demented out-patients with higher levels of depression were more likely than those with lower levels to be institutionalized at six-month follow-up. It is noteworthy that depression scores, as measured by the Depression scale of the CARE schedule (Gurland et al., 1977) were significantly correlated with physical disability scores based on medical staff assessments which also significantly predicted institutionalization at six months.

The need for institutional care in some cases may be mitigated by the availability of a family caregiver, particularly a spouse. Dementia patients without a spouse are consistently found to be at greater risk for institutionalization (Lieberman & Kramer, 1991). The higher rate of institutionalization among older females is considered to be directly related to higher rates of widowhood among women (Canadian Medical Association, 1987). Due to significantly different life expectancies at age 65, women are less likely to have a surviving spouse to provide home-care when their ability to live independently declines.

The predictors of institutionalization among dementia victims who reside with a caregiver have been examined by several researchers. Colerick and George (1986) found that nearly 22% of patients were institutionalized at the end of one year. Applying logistic regression to the data, *caregiver characteristics* rather than patient characteristics emerged as the most important predictors of placement. Caregivers who institutionalized their patients were more likely to be female, employed, younger than those who did not institutionalize, and to be children of the patient.

The predictors of institutionalization among spousal caregivers were studied by Pruchno, Michaels and Potashnik (1990). Twenty-two percent of a sample of 220 caregivers institutionalized their spouse within one year of enrollment in the study. The variables associated with placement of the spouse included the caregiver's stated desire to institutionalize at the outset of the study, a shorter time as a caregiver, Jewish religion, lack of positive satisfaction from caregiving, and frequent forgetful behaviours in the spouse.

Significant predictors of *desire to institutionalize* were: older caregiver age, poor marital relationship, physically demanding caregiving role, caregiver reliance on medications, a very impaired spouse and knowledge of care alternatives (associated with higher levels of caregiver education).

PREVALENCE OF DEMENTIA IN LONG-TERM CARE FACILITIES

Given the role of dementia as a reason for institutional care, it is not surprising that a high proportion of long-term care facility residents have dementing disorders. There is, nonetheless, some variation in reported rates of cognitive impairment and/or dementia-like conditions among persons in residential care. For example, the Alberta Health (1988) province-wide patient classification study showed that 30% of all long-term care facility residents had a chart recorded diagnosis of dementia or Alzheimer's disease. Bland, Newman and Orn (1988), in a study conducted in Edmonton, reported low mental test scores (MMSE < 23) in two-thirds (69%) of their sample of institutionalized persons. If *severe* mental impairment (MMSE < 17) is considered a proxy for dementia, then the same study found a prevalence rate of 39% in facility residents. However, it should be noted that Bland, Newman and Orn report that one in five institutionalized residents could not be formally assessed. As a result, the reported rate for severe mental impairment may underestimate the actual prevalence of dementia. Support for this interpretation comes from a study conducted in Saskatchewan by Robertson, Stolee and Rockwood (1981). Using a 10 item Mental Status Questionnaire validated for local use (Robertson, Rockwood and Stolee, 1982), the Saskatchewan Health Status Survey found evidence of mild dementia in 18.2% and moderate to severe dementia (score of 7 or less) in 36.1% of a sample of over 600 institutionalized elderly. Prevalence ranged from 21.3% at the minimum care level (level I) to 66.1% at the highest care level (level IV).

A more recent American study (Rovner et al., 1990) examined all consecutive new admissions to eight nursing homes during a one-year period. A rate of 67.4% with dementia syndromes among admissions was reported, based on psychiatric examination and classification of patients according to the DSM III-R criteria (American Psychiatric Association, 1987).

Table 4
PREVALENCE OF DEMENTIA IN LONG-TERM CARE FACILITIES

Study	Disorder	Method	Prevalence Rate(%)
Alberta Health (1988)	Dementia	Chart Records	30.0
Bland et al., (1988)	Cognitive Impairment	MMSE	68.8
	Severe Cognitive Impairment	MMSE	39.0
Burns et al., (1988)	Organic Brain Syndrome	Chart Records	39.0
Robertson et al., (1981)	Cognitive Impairment	MSQ	54.4
Rovner et al., (1990)	Dementia	Psychiatric Assessment	67.4

BEHAVIOURAL FEATURES OF INSTITUTIONALIZED DEMENTIA RESIDENTS

In the moderate to advanced stages of Alzheimer's and other dementias, patients often exhibit behaviours that are dysfunctional and difficult to manage. These behaviours may include hostility, aggression, sleep disturbance, wandering, agitation, incontinence, etc. The behaviour is problematic for the facility if it is:

- disruptive to the social environment;
- dangerous or harmful to the patient or other residents;
- damaging to the physical environment; and/or
- undermines or interferes with the provision of care.

Because, in many cases, patients are severely mentally impaired at the time of placement, a very high proportion display dysfunctional behaviour in facility settings. For example, Goldman, Feder and Scanlon (1986) reexamined the

records of nearly 700,000 residents included in the 1977 U.S. National Nursing Home Survey and found that only 19.7% of those with "senility with psychosis" diagnoses and 22.2% of those with "senility without psychosis" diagnoses had no behaviour problems. Rovner et al., (1986) reported that 76% of a small random sample of residents of an intermediate-care nursing home exhibited maladaptive behaviours as measured by the Psychogeriatric Dependency Rating Scale (Wilkinson & Graham-White, 1980). The Alberta Health (1988) chart review study of institutional residents found that 84.6% with dementia showed at least one problem behaviour. However, they also found that problem behaviours were not unique to dementia insofar as 70.1% of residents without a chart-recorded mental health diagnosis also displayed the behaviours. In their study of 688 elderly residents of 29 Saskatchewan long-term care facilities, Rockwood, Stolee and Robertson (1989) also found that problem behaviour was not restricted to persons with dementia. Rates were higher, however, in persons with scores of 3 or below on their 10-item Mental Status Questionnaire (29% of those scoring 0-3 showed problem behaviour daily compared with only 11% of those scoring 7 or over). Low scores were found to be associated with disorientation (87%), aggression (84%) and wandering (88%). Rockwood, Stolee and Robertson (1989) also report that residents with MSQ scores of 0-3 accounted for 75% of the wanderers.

Psychiatric features are also common in dementia. Based on a review of 30 studies, Wragg and Jeste (1989) conclude that affective (depression) and psychotic symptoms (delusions, hallucinations) occur in 30% to 40% of Alzheimer's patients and increase the need for clinical management. The frequency of depressed mood in patients with Alzheimer's Disease was found to range from 0%-87% (median = 41%). Paranoid delusions were the most common psychotic symptoms, occurring at a median frequency of 43%. Hallucinations occurred less frequently (median = 28%) with visual hallucinations occurring more often (median frequency = 22%) than auditory hallucinations (median = 13%). Rovner et al., (1986) report that such dysfunctional behaviours as wandering, aggression, and noisiness are more likely to occur among those patients with delusions and hallucinations. Florid psychiatric symptomatology is not, however, necessarily a predictable feature of dementia and may reflect an underlying medical condition.

PHARMACOLOGICAL MANAGEMENT OF PSYCHIATRIC AND BEHAVIOURAL SYMPTOMS

The institutionalized elderly population is one of the most heavily medicated groups. In particular, there is a very high rate of psychotropic drug use in facilities. Studies conducted in American nursing homes have reported a 60% (Buck, 1988) to 74% (Ray, Federspiel & Schaffner, 1980) utilization rate of central nervous system drugs. In a study of 850 residents in 12 intermediate care homes in Massachusetts, Beers et al., (1988) found that over half of all residents (53%) were receiving a psychoactive medication of some kind, with about one in four taking two or more. Danforth, McKinnon and McEwan (1990) replicated the Beers et al., study in British Columbia, reviewing psychoactive medication use in 1,994 long-term care facility residents. Fifty-five percent were found to be on at least one psychoactive drug and 22% on two or more. The most commonly prescribed drugs were sedative/hypnotics and neuroleptics, both of which are used for their tranquilizing effect.

While there are few studies which link prescribing patterns to patient characteristics, it is known that dementia patients who also display psychiatric syndromes are the highest users of neuroleptic medication followed by residents with uncomplicated dementia (Rovner et al., 1990). This is consistent with Ancill et al.'s (1988) finding that dementia patients in British Columbia referred from long-term care facilities to a psychiatric hospital because of behaviour problems had high rates of neuroleptic and benzodiazepine use prior to admission. Although the above reports are not definitive, it can be assumed that the management challenge presented by demented residents is one of the major factors associated with the frequent prescribing of psychotropic drugs in institutions.

PHYSICAL HEALTH STATUS OF DEMENTIA PATIENTS IN LONG-TERM CARE

The majority of patients with dementing conditions residing in long-term care facilities are of advanced age. Many have significant physical and functional disabilities. Data from the 1977 U.S. National Nursing Home Survey revealed that 61.1% of residents have both physical disorders and "senility" (Goldman, Feder & Scanlon, 1986). Residents with this combination of disorders were found to be the most dependent

of all categories, requiring assistance with many aspect of daily living. Only 3.6% of this group required no help with ADL.

The compromised physical health of institutionalized dementia residents places them at risk for acute care hospitalization. Coleman, Barbaccia and Croughan-Minihane (1990) examined hospitalization rates over a one-year period in nursing home residents with dementia. Interestingly, dementia patients in the home's Special Care Unit had a higher rate (21%) of hospitalization than dementia patients in standard wards (14%). The latter group had an identical hospital admission rate to residents without a diagnosis of dementia. The most common reasons for transfer to hospital were hip fractures, pneumonia and urinary tract infections. Fractures largely accounted for the difference in hospitalization rates among the three groups. Twenty-seven percent of the Special Care Unit patients who were hospitalized had hip fracture as their primary or secondary hospital discharge diagnosis compared with 20% of dementia patients cared for in standard wards and none of the non-Special Care Unit, non-dementia patients. The most common diagnosis in the latter group was pneumonia (68%).

SURVIVAL PATTERNS AND PREDICTORS OF MORTALITY IN DEMENTIA

For the seniors population as a whole, life expectancy has increased dramatically over the century. Currently, at age 65, males may expect to live another 14.9 years, while females may expect to live for an additional 19.2 years (Statistics Canada, 1989). There is a dearth of longitudinal research on survival of dementia patients from the point of admission to a residential care institution. Research (Knopman et al., 1988) following patients who initially entered the study in the community has reported the following trend (see Table 5).

Table 5			
SURVIVAL RATES AMONG PATIENTS WITH DEMENTIA			
	1 Year	2 Year	3 Year
Mild Dementia	98%	94%	92%
Advanced Dementia	91%	77%	69%
Source: Knopman et al., (1988)			

Heyman et al., (1984) found that patients with Mini-Mental State Examination (MMSE) scores of 12 or less, indicating severe dementia, had a five year cumulative rate of institutionalization of 79% and a mortality rate of 18%. Corresponding rates among patients with higher MMSE scores were 39% and 12%, respectively. Berg et al. (1988) report a five year cumulative nursing home placement rate of 73% and a death rate of 30% among a group assessed as having mild senile dementia of the Alzheimer type using the Washington University Clinical Dementia Rating (Hughes et al., 1982). Institutionalization and death rates at seven years were, respectively, 84% and 44%.

One difficulty in estimating survival in dementia is that most cases are not diagnosed at the time of onset of the disease. Barclay et al., (1985) report 50% survival from estimated *date of onset*, based on relatives' estimate of duration of symptoms, at 8.1 years for dementia of the Alzheimer's type (DAT), 6.7 years for multi-infarct dementia (MID) and 6.2 years for patients exhibiting features of both types (MIX). However, 50% survival *from time of diagnosis* was much lower at 3.4 years for DAT, 2.6 years for MID and 2.5 years for MIX. The mean duration of illness reported by Hier et al., (1989) for DAT was 9.7 years and 9.5 years for MID. These researchers estimated survival from the time of diagnosis at 4.3 years for DAT and 4.5 years for MID. Shapiro and Tate (1991) do not disaggregate by type of dementia but they do by age and sex. Median survival times from first diagnosis for males aged 65-74, 75-84 and 85+ were, respectively, 4.0 years, 2.8 years and 1.0 years. For females, survival time was substantially longer: 4.4. years for those aged 75-84 and 3.7 years for those 85+. No values are given for females in the age group 65-74 as the value of the survival curve had not dropped 50% in this age group by the end of the follow-up period.

CONCLUSION

Although we are beginning to know more about dementia patients and the clinical course of Alzheimer's and related disorders, systematic description of the behavioural features and psychiatric sequelae of dementia in institutional care is at an early stage of research. Fairburn and Hope (1988) charge that change in behaviour in dementia is a neglected area of research. Without reliable information on the circumstances under which specific troublesome behaviours (e.g. aggression, wandering, altered eating habits) occur, they argue, interventions which might reduce the frequency and severity of

the behaviour cannot be developed. The relationship between behaviour change and brain pathology also needs to be explored. As Fairburn and Hope point out, it may be that *specific* behavioural abnormalities are the expression of *specific* brain lesions which, once identified, may be amenable to pharmacological treatment.

Our understanding of the behavioural characteristics, needs and survival patterns of long-term care residents with dementia in Canadian institutions is minimal. The changing composition of the long-term care population, from primarily physically frail elderly to a majority with both physical disabilities and dementia or other mental health problems, necessitates a review of policies and procedures in residential care. New policies and guidelines, however, should develop out of an empirical body of knowledge concerning the resident population. To date, few large scale investigations in the long-term care environment have been undertaken in this country. Although some very pressing topics in residential care require research attention, basic descriptive studies of the numbers and nature of dementia victims requiring 24-hour vigilance are a logical starting point.

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2

CHARACTERISTICS OF SIX SPECIAL CARE UNITS IN BRITISH COLUMBIA

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INTRODUCTION

There has been much debate in the literature as to whether persons with Alzheimer's and related disorders who can no longer be cared for in the community, and who therefore must go into an institutional setting, should be located in segregated or in integrated units.

Arguments in favor of integration are that:

- cognitively impaired residents benefit from contact with cognitively intact residents who can serve as models for appropriate behaviour (Meacher, 1972);
- cognitively intact residents benefit from the humanitarian experience of assisting their impaired fellow residents (Meacher, 1972);
- the fluctuating symptoms of dementia make it inappropriate to admit individuals to a special unit as their behaviour may not continue to be problematic (Cuming et al., 1982);
- dementia is difficult to diagnose and people may be misplaced into segregated units (Rabins, 1986);
- people with reversible conditions, if placed on a segregated unit, could remain untreated (Getzlaf, 1987);

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- caring only for persons with dementia could be exhausting and demoralizing for staff (Pynoos & Stacey, 1986);
- families may find segregated units depressing and therefore curtail the frequency with which they visit their relative (Coons, 1985).

Proponents of segregated units, on the other hand, argue that:

- cognitively intact residents find the behaviour of the cognitively impaired disturbing (Ablowitz, 1983; Coons, 1985; Donovan et al., 1987; Gutman, Mercer & Fallick, 1979; Hall, Kirschling & Todd, 1986; Novick, 1985; Wolfson, 1983);
- integration of the cognitively impaired creates mental anguish for the families of intact residents (Novick, 1985);
- cognitively intact residents don't appreciate being used as "buddies" for the cognitively impaired especially when this is a staff-saving measure (Mace, 1985);
- integration may interfere with the quality of care both intact and cognitively impaired residents receive (Novick, 1985);
- it is unrealistic to expect the cognitively impaired to be able to model the behaviour of those who are unimpaired (Coons, 1987);
- efforts to control the wandering of confused clients in integrated settings may result in excessive use of physical and chemical restraints (Coons, 1987b; Hall, Kirschling & Todd, 1986; Rodenburg, 1986);
- special units permit special exterior and interior design that facilitates the functioning of cognitively impaired persons (Brice, 1986; Clarke, 1982; Mace, 1987; Rodenburg, 1986);
- special units allow the development of special programs and expertise in patient care (Brice, 1986);

- there is greater acceptance of "extreme" behaviour by patients and staff in special units (Roberts, 1984).

While this debate has been going on, as Ohta and Ohta(1988) point out:

...There appears to be an ever growing belief that special units should be established for nursing home patients who suffer from Senile Dementia of the Alzheimer's Type (SDAT). Indeed, the proliferation of such units based on this belief has been enormous (p.803).

As evidence of this the Institutional Population Component of the 1987 National Medical Expenditure Survey indicated that there were 22,064 nursing homes in the United States with 1.6 million beds. Of these, Leon, Potter & Cunningham (1990) estimated that 1,668 or 7.6% had specialty units for persons with Alzheimer's disease or related disorders, accounting for almost 53,800 or 3.3% of the total number of nursing home beds. They projected that the number of facilities with such units would nearly double by 1991. A recent study by Holmes, Teresi and Monaco (1992) estimates that currently 11% of American nursing homes provide some form of separate or special care for persons with dementing illness.

Despite the prevalence of Special Care Units, as Ohta and Ohta (1988) and more recently, Riter and Fries (1992) have pointed out, there is little empirical data concerning the characteristics of residents nor concerning the factors that lead to their placement. There is also only limited information available concerning the extent to which existing units manifest the five features generally cited in the literature (Gutman, 1989) as criteria for designating a unit as specialized for care of persons with dementia, vis. that the unit :

- is physically separated from the facility (nursing home, hospital) of which it is a part;
- has a client population consisting mainly of persons with dementia;
- has special design features;
- has staff with specialized training;
- has special activity and/or therapeutic programs.

Data concerning Special Care Units in Canada is even more limited than that from the United States. As one step toward filling the information gap, a study was conducted, in the Spring of 1989, of six of the 14 Special Care Units in operation in British Columbia. Three of the study units were in Intermediate Care facilities and three were in Extended Care hospitals.¹ In each, semi-structured interviews were conducted with the Coordinator(s), a sample of other staff, and with relatives of residents.

The primary objectives of the interviews were to ascertain the characteristics of residents, admission and discharge criteria, and the extent to which the units employed special design features, had specialized staff and offered special programs. The study was also designed to ascertain whether there were major differences between Special Care Units based in Intermediate as compared with Extended Care facilities.

LOCATION, AGE AND SIZE OF PARTICIPATING UNITS

All three of the Intermediate Care facilities participating in the study were located in the Greater Vancouver Regional Hospital District as were the majority of facilities at this care level with Special Care Units (n=9). One of the participating Extended Care hospitals was located in the Fraser Valley; the other two were in the interior of the province. These too were geographically representative of Extended Care-based Special Care Units in operation at the time the study was conducted (n=5).

¹ The BC Long Term Care (LTC) Program defines five levels of care, each of which can be provided either at home or in a facility. The levels, from lowest to highest, are: Personal Care (PC); three levels of Intermediate Care (IC_I, IC_{II}, IC_{III}); and Extended Care (EC). PC clients are independently mobile and are able to eat and use a toilet without assistance but may need minimal help with bathing or dressing. Such clients may be mildly confused or forgetful, but in general their medical conditions are stabilized to the point where they do not require daily professional supervision. IC clients are usually independently mobile but may require assistance with toileting, may have mild to moderate mental impairment, and often require daily professional supervision of medications, application of special appliances, etc. EC clients are not independently mobile and often require a high degree of professional care. Care levels are assigned on the basis of a standard assessment performed by trained LTC Program staff. The primary aim of the LTC Program is to enable those who qualify for service to remain in their own home for as long as it is possible and practical for them to do so. Placement in an approved community-care facility or admission to a hospital-based Extended Care Unit is arranged when home care is no longer possible.

Two of the Intermediate Care-based units cared for 20 residents; one cared for 31. Two of the Extended Care-based units cared for 25 residents; the other, 38 residents.

One of the Intermediate Care-based units had been in operation for one year, one for three years and one for six years. One of the Extended Care-based units had been in operation for five years; the other two for seven years.

All six of the units were physically separated from the facility of which they were a part. Unit A was located in one wing of the first floor of a two-storey building. Unit B was on the lower floor of a three-storey building. Unit C was in a wing of the third floor of a three-storey building. Units D, E and F, the three units based in Extended Care hospitals, occupied one wing of one-storey buildings. All except Unit D, where most residents were non-ambulatory, were separated from the rest of the building by a locked door.

RESPONDENTS

In five of the six units, more than one person responded to the questions contained in the Coordinator's interview. Most frequently, respondents consisted of the Head Nurse and/or Director of Resident Care.

Of the 40 other staff who participated in the study, 27.5% were R.N.'s, R.P.N.'s or graduate nurses; 20.0% were other professional staff (Occupational Therapist, Social Worker, Recreation Coordinator, Music Therapist, Director of Dietary Services, Clinical Psychologist); and 52.5% were care or activity aides. Forty percent had six or more years of experience in working with Special Care Unit residents; 32.5% had from three to four years of experience. Thirty-five percent worked exclusively with Special Care Unit residents while the remaining 65% worked with residents in other parts of the facility as well.

Thirty-nine relatives of residents were interviewed. Of these, 53.8% were children of residents, 33.3% were spouses, 7.7% were siblings and 5.1% were in-laws. Two-thirds had had primary responsibility for their relative's care prior to institutionalization while another 23.1% had shared the responsibility with another family member.

CONTENT OF THE INTERVIEW SCHEDULES

The Coordinator's interview was designed to provide information concerning: the admission and discharge criteria of the unit; the type of clients cared for; staffing; special design features and programming provided to residents and families.

The staff interview contained a series of questions designed to ascertain respondents' feelings about working with Special Care Unit residents; their training and training needs; what they perceived to be "problem" behaviours as regards residents and their care; their experience with and opinions about various special design features described in the literature; their perception of the advantages and disadvantages of Special Care Units for residents, their families and staff; their opinions about families' information needs and family involvement in residents' care; and their views about programs provided to residents and their families.

The purpose of the relatives' interview was to ascertain how well they felt their relative's needs and their own were satisfied by the physical design, programming and services offered in the unit; what services they performed for their relative and whether they wanted more involvement in decision-making; the type of information and support they wanted from staff; and their perception of the advantages and disadvantages of Special Care Units.

ADMISSION AND DISCHARGE CRITERIA

Verbal responses of the Coordinators and examination of print materials indicated that five of the six units considered as eligible for admission persons who exhibited behaviour or social habits disturbing to others. These included wandering uninvited into another's room, 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 eating habits; messy toilet habits; and sleep reversal. Five units also admitted persons who were a danger to themselves, particularly as a result of wandering.

As shown in Table 1, four units, including one based in an Extended Care hospital, required clients to be assessed at the Intermediate III level in order to be eligible for admission. An Extended Care classification was required by one of the two remaining Extended Care-based units. The other accepted

persons classified either as at the Intermediate III or at the Extended Care level.

Table 1
ADMISSION CRITERIA FOR PARTICIPATING SCUs

	Intermediate Care based Units			Extended Care based Units		
	A	B	C	D	E	F
Assessed level of care:	*	*	*		*	
IC ^{III}				*		
EC						*
IC ^{III} or EC						*
Diagnosis of irreversible dementing illness	*	*			*	*
Behaviour/social habits disturbing to others	*		*	*	*	*
Behaviour dangerous to self (e.g. wandering)	*	*	*		*	*
Unable to provide self-care		*				
Resistant to care					*	
Physically aggressive				*		*
Non-violent/non-destructive/non-aggressive	*	*			*	
No acute physical or psychiatric disorder	*				*	

Four units specified a diagnosis of an irreversible dementing illness as a criteria for admission although one of these also admitted younger persons with traumatic brain injury on a temporary basis until appropriate long term rehabilitation settings became available.

Two units, both based in Extended Care hospitals, admitted persons who were physically aggressive. Three others, two based in Intermediate Care facilities and one in an Extended Care hospital, stated explicitly that persons who frequently displayed aggressive behaviour would not be admitted. Among others ineligible for admission to at least one of the six units were persons suffering from an acute physical or psychiatric disorder, persons with sociopathic personality disorders and the developmentally handicapped.

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 do not admit physically aggressive persons discharge residents who, after entering the unit, exhibit violent or destructive behaviour that cannot be controlled with medication. As shown in Table 2, most live discharges were to "regular" wards in the same facility or to other facilities.

	Intermediate Care based Units			Extended Care based Units		
	A	B	C	D	E	F
No. residents in unit	31	20	20	25	25	38
No. admitted in previous 12 months	8	2	10	9	10	15
No. discharged in previous 12 months	11	2	10	9	10	18
Reasons for discharge	(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 or at risk for wandering	0	1	3	0	4	7
If discharged alive, discharge destination	(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
Care at home	0	0	1		1	0
Psychiatric hospital	0	0	1		2	1

RESIDENTS' CHARACTERISTICS

LEVEL OF CARE

As shown in Table 3, a majority of residents in five of the six units has been classified by the B.C. Long Term Care Program as at the Intermediate III level. The admission of Intermediate Care level clients to two of the Extended Care-based units may reflect a lack of Special Care beds in Intermediate Care facilities in the geographic area in which these hospitals were located.

Table 3						
RESIDENTS' CHARACTERISTICS						
	Intermediate Care based Units			Extended Care based Units		
	A	B	C	D	E	F
No. 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				12.0	32.0	52.6
Multi-infarct dementia				16.0	0.	13.2
OBS/CBS (etiology unsp.)				20.0	36.0	21.1
Alcohol-related dementia				8.0	4.0	2.6
Huntingdon's disease				0.0	0.0	7.9
Psychiatric disorder				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

AGE AND SEX DISTRIBUTION

There was considerable variation across units in the age and sex distribution. In one of the Intermediate-care based units 80% were aged 80 and over; in the other two at this care level and in one of the Extended Care-based Units, the proportion aged 80 and over ranged from 64.0% to 67.8%. Corresponding figures for the other two Extended Care-based units were 40% and 47.4%.

While in two of the Intermediate-care based units, over 80% were female, the proportion female in the other four units ranged from 47.4% to 60%.

AMBULATORY STATUS

From 85% to 100% of residents of the three Intermediate Care-based units were independently ambulatory. In one of the Extended Care-based units, only 8% were ambulatory and then, only with assistance. The proportion ambulatory was much higher in the other two units (66% and 75%), which is consistent with the greater proportion in these units classified as at the Intermediate Care level.

DIAGNOSIS

Residents of the Intermediate Care-based units were described by their Coordinators as predominantly dementia victims, with over two-thirds thought to be suffering from Alzheimer's disease. More specific information, available for the Extended Care-based units, suggests a broader case mix including persons with psychiatric disorders (schizophrenia; manic depression), head injuries, Huntington's disease, and alcohol-related dementia.

PROBLEM BEHAVIOURS

In the staff interviews, respondents were asked about the 21 "problem" behaviours shown in Table 4. They were asked to indicate whether each was exhibited by "most" "some" or "few" of the Special Care Unit residents they worked with and whether the behaviour was "very difficult", "moderately difficult" or "not difficult" to manage.

The behaviours 50% or more thought most Special Care Unit residents exhibit were: difficulty wayfinding, trespassing and resistance to care. Behaviours 25% to 49% thought most residents show were: inappropriate eating behaviour, repeated chattering and physical aggression towards staff. Behaviours fewer than 10% of respondents thought were characteristic of most Special Care Unit residents were: verbal and physical aggression towards visitors, public sexual behaviour, sexual behaviour towards staff, anguish/crying, screaming, other inappropriate verbalizations, spitting and smearing feces. Spitting, however, was one of the five behaviours most often

Table 4
PERCEIVED FREQUENCY AND MANAGEMENT
DIFFICULTY OF SELECTED "PROBLEM" BEHAVIOURS

	Number Showing Behaviour			Difficulty of Management		
	Most %	Some %	Few %	Very %	Mod. %	Not %
Unauthorized exiting	24.1	20.7	55.2	10.3	48.3	41.3
Difficulty wayfinding	61.3	22.6	16.1	12.9	25.8	61.3
Trespassing	58.1	12.9	25.8	20.0	50.0	30.0
Resistant to care	56.7	30.0	13.3	33.3	53.3	13.3
Inappropriate voiding/ defecating	22.2	29.6	48.1	14.8	25.9	59.3
Smear feces	7.4	22.2	70.4	23.1	46.2	30.8
Verbally abusive to:						
other residents	13.3	46.7	40.0	20.7	41.4	37.9
staff/volunteers	13.3	26.7	60.0	6.7	40.0	53.3
visitors	0.0	10.0	90.0	14.3	28.6	57.1
Physically abusive to:						
other residents	10.0	36.7	53.3	33.3	50.0	16.7
staff/volunteers	30.0	30.0	40.0	26.7	50.0	23.3
visitors	0.0	6.7	93.3	16.7	33.3	50.0
Repeated banging	10.3	41.4	48.3	25.0	25.7	39.3
Repeated chattering	31.0	31.0	37.9	20.7	24.1	55.2
Screaming or yelling	3.4	37.9	58.6	17.2	31.0	51.7
Anguish/crying	3.4	20.7	75.9	17.9	42.9	17.9
Public sexual behaviour	0.0	3.4	96.6	13.0	21.7	65.2
Sexual behaviour						
towards staff	0.0	3.4	96.6	0.0	16.0	84.0
Spitting	3.4	20.7	75.9	40.7	18.5	40.7
Inappropriate eating						
behaviour	42.9	10.7	46.4	18.5	37.0	44.4
Try to get out of bed/ wheelchair	15.4	11.5	73.1	19.2	30.8	50.0

judged to be very difficult for staff 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 analyzed by facility level of care, it was found that a significantly ($p < .05$) higher proportion of Intermediate than Extended Care staff thought most Special Care Unit residents attempt to leave the unit without permission, have difficulty wayfinding and eliminate in inappropriate locations. There was also a greater proportion among the Intermediate Care facility staff who judged smearing feces and repeated banging as very difficult to manage.

SPECIAL DESIGN FEATURES

In the Coordinator's interview, respondents were asked whether they employed any of the design features shown in Table 5 in their Special Care Unit. As can be seen, only one unit used electronic sensors as a means of preventing unauthorized exiting, none had a multiple latching mechanism on the unit door although one had previously had such a device, two had alarmed doors, and one had masked the exit door. In all but the unit in which virtually all residents were non-ambulatory (Unit D), the unit door was kept locked. In two units it could only be opened with a number code; in three, a key was needed.

When asked about indoor space to accommodate wandering, no special design features were mentioned. All units, however, had secured outdoor space. In one unit it consisted of two fenced patios and in four units, a fenced garden area was directly adjacent to and accessible from their ground floor location. The sixth unit, which was located on the top floor of a three storey building, had access to a secured courtyard at ground level. Only one of the units had anything resembling the wandering paths described in the literature. It consisted of a circular walkway in its secured outdoor area.

In general, use of environmental aids to facilitate wayfinding and orientation was minimal. Although five of the six units had clocks and calendars, only three had extra large signs, only three had reality orientation boards and only one placed pictures on the resident's door. The pictures were of something of special interest to the resident (e.g. picture of a horse for a man who loved horses) since, one Coordinator noted, "many do not recognize pictures of themselves."

When asked if they used pastel colours or background music to reduce sensory overload or calm residents, the Coordinators of four units reported using background music. In three units pastel colours were used.

Other environmental techniques these units used to restrict exiting, accommodate wandering, facilitate wayfinding and orientation, and reduce sensory overload or calm residents included: video monitoring from the nurses' station, putting coded locks on doors leading to the fenced yard, using dimmer lighting in hallways at night than during the day to help residents differentiate night and day, reduced lighting levels and using small rooms for individual activities and/or to isolate

Table 5
PREVALENCE OF SPECIAL DESIGN FEATURES

	No. units with feature
To restrict exiting	
Multiple latches	0
Alarmed doors	2
Masked exit door	1
Locked door	5
Electronic sensors	1
To manage wandering	
Indoor wandering space	0
Outdoor wandering space	5
To facilitate wayfinding/ orientation	
Extra large signs	3
Picture signs	0
Colour coding	0
Textured walls	0
Special landmarks	0
Pictures on resident's door	1
Clocks/calendars	5
Reality orientation board	3
To reduce sensory overload/calm residents	
Background music	4
Pastel colours	3

noisy residents. Additionally, one Coordinator noted that her unit was T-shaped with doors 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", a practice several of the family respondents commented negatively about.

A need to enclose the nurses' station in plexiglass was also noted since, with an open design, "patients answer the phone, *savage* charts, play with the oxygen equipment and go through drawers."

Additionally, placement of call bells was commented on by one Coordinator. She noted that many residents with dementia don't know what call bells are for and "play with them, particularly in the morning when they wake up. This jams the system." She recommended that there only be an emergency bell in the bathroom of each bedroom to enable staff to call for help if needed. A related problem with fire alarms was noted by several Coordinators.

STAFFING PATTERNS AND ISSUES

STAFF-RESIDENT RATIOS

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

As shown in Table 6, during the day shift the staff-resident ratio ranged from a high of 1:3.5 (Unit E) to a low of 1:8.9 (Unit A). The range for the evening shift was from 1:6.3 (Unit F) to 1:12.4 (Unit A) and for the night shift, from 1:12.7 (Unit F) to 1:40 (Unit C).

In all six of the participating facilities, the staff-resident ratio was higher in the Special Care Unit than in other units. Among staff respondents, the proportion who thought the number and/or type of staff working on the Special Care Unit was sufficient to meet residents' needs ranged from 25.0% to 83.3%. Generally, satisfaction with the number and type of staff was higher in the three units located in Extended Care hospitals. The most common types of additional staff recommended were: care aides; activity/recreation workers and an RN or equivalent on the unit at least during the day and evening shifts.

Table 6
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						
<u>Day</u>						
RN/RPN/LGN	0.6	1	0.5	1	1	3
CARE AIDES	3.5	2	2.5	2.5	2.5	4
ACTIVITY WORKER(S)	(SHARED)		(SHARED)	1	2.5	1.5
<u>Evening</u>						
RN/RPN/LGN	(SHARED)	(SHARED)	0.3	1	1	2.5
CARE AIDES	2.5	2	2.5	2.5	2.0	3
ACTIVITY WORKER					0.5	0.5
<u>Night</u>						
RN/RPN/LGN	(SHARED)	(SHARED)	0.3	(SHARED)	(SHARED)	2
CARE AIDE	1	1.2	0.5	0.3	1	1
b) Shared with rest of facility						
	Dietician	Dietician	Dietician	Dietician	Dietician	OT
	OT/PT	Music	Social	OT	OT	PT
	Social	Therapist	Worker	Chaplain	PT	Social
	Worker	Activity	Music	Pharmacist	Activity	Worker
	Music	Coord.	Therapist		Coord.	Rec.
	Therapist		Recreation Dir.		Speech	Therapist
					Therapist	Ward
					Psychologist	Clerk
					Ward	
					Clerk	
% of respondents feeling number of SCU staff 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.)

STAFF'S TRAINING AND TRAINING NEEDS

Almost all (94.4%) of the staff respondents from Intermediate Care-based Special Care Units and 72.7% from Extended Care-based units indicated that they had received some special training prior to or while working on the unit.

As shown in Table 7, the training most commonly received provided: general information about dementia; information concerning management of disorientation; management of such behaviours as catastrophic reactions, anxiety, restlessness and wandering and management of aggressive and abusive behaviour. The vast majority of those who had received special training had found it to be useful.

Table 7
SPECIALIZED TRAINING

	Have Had	Useful (n = Have Had)	Would Like (n = Have Not Had)
n	%	%	%
General information on dementia	33	93.9	100.0
Management of behaviours such as catastrophic reactions, anxiety, restlessness and wandering	33	75.8	95.8
Management of aggressive and abusive behaviour	33	63.6	90.5
Management of disorientation	33	78.8	96.0
Communicating with patients	33	57.6	100.0
Communicating with/assisting families	33	42.9	92.9
Family dynamics	33	54.5	87.5
Stress management - patients	33	42.4	92.9
Stress management - families	33	24.2	100.0
Stress management - staff	33	51.5	93.3
Reminiscence therapy	23	13.0	100.0
Validation therapy	29	58.6	100.0
Reality orientation	26	38.5	62.5

Of topics staff had not had instruction on, demand was greatest for information about: dementia; management of disorientation; management of aggressive, abusive and other "problem" behaviours such as catastrophic reactions, anxiety, restlessness and wandering; communicating with and assisting families and, management of their own stress level.

PROGRAMMING

FOR RESIDENTS

According to the Coordinators, in all six units residents were offered an exercise program. Music was also a regular feature in all six units. In all except Unit E in which few residents were ambulatory, bus trips and outings were a regular offering.

Five units had a pet visitors program; three of the five also had animals in residence.

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

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

While a slightly greater number of programs were offered in units based in Extended Care hospitals, there appeared to be no direct relationship between the number of programs offered and the number of residents living there. The number of programs also did 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 task. 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 received some special training in program planning for persons with dementia).

FOR FAMILIES

The Coordinators of five of the six units stated that their facility offered programs for families of residents. In four units, family counseling was said to be provided, in three of these, specially for families of Special Care Unit residents. Four units' Coordinators said their facility offered a family support group, in two of these units, specially for families of Special Care Unit residents. Two units offered, exclusively to relatives of Special

Care Unit residents, information about dementia; one offered them training in stress management.

Interestingly, 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, had all attended the unit's Special Care Unit Family Support Group; 77.7% reported having found it helpful.

Among the three respondents associated with other units who were aware of programs for families, one had attended an orientation session for families of new residents, one had attended weekly meetings offered by the facility and one reported knowing a program was offered but had not attended it.

When asked if there were any (other) services or programs that would be useful to them, 43.6% of the family respondents identified one or more. These included: information concerning the stages of the disease and/or reasons for their relative's behaviour which, they felt, would increase their acceptance of it; regular meetings with direct care staff and/or the administration; and practical information (e.g. how to apply for power of attorney; how to get labels for their relative's clothing). Several also commented on the need for more information and support *prior* to the admission of a relative to a care facility.

OUTREACH

None of the six facilities offered a special day program or other outreach services to persons with dementia living in the community. One, however, accepted community-dwelling Alzheimer's patients into its regular hospital day program.

SUMMARY AND CONCLUSIONS

As indicated in the Introduction, five features are generally cited as criteria for designating a unit as specialized for care of persons with Alzheimer's and related disorders. These are that the unit is physically separated from the care facility or hospital of which it is a part, serves mostly persons with dementia, has staff with special training, has special design features and has special activity and therapeutic programs.

The study described in this chapter was conducted to ascertain the extent to which these features were characteristic of Special Care Units in British Columbia. It was also designed to ascertain if there were major differences between units located in Intermediate Care facilities and those located in Extended Care hospitals.

All six units met the criterion of being physically separate from the facility of which they were a part. The vast majority of residents of each unit suffered from a dementing illness. Most of the staff of each unit had received some special training. Other than having a locked unit door and fenced outdoor area, however, there was little in the way of special environmental design features in the participating units. This is an area that could bear expansion. As indicated in the literature review that preceded the study (Gutman, 1989), other jurisdictions have implemented a variety of special design features. Some staff respondents had had experience with some of these in other facilities in which they had worked and recommended their implementation. In particular, "quiet rooms" were mentioned as an aid in the management of residents. Persons who are disturbed/disturbing can be segregated in these rooms in order to calm them and prevent their behaviour from impacting negatively on other residents. The two units in the study having such rooms reported them to be very effective for this purpose. Larger than average common areas and halls were also recommended by study participants. They noted that many persons with dementia seem highly sensitive to being jostled by others or having their "space" invaded. Lack of space in which to move about freely was thought to contribute to "problem" behaviours such as agitation and physical aggression.

Also noticeably absent was much in the way of special programming. Most of the programs offered were the same as can be found in standard nursing home units albeit, we were told, they were offered to smaller groups than is usually the case and with recognition of residents' limitations. While as indicated in the literature review that preceded the study (Gutman, 1989) the efficacy of such therapeutic programs as validation therapy, reminiscence/life review, milieu therapy or reality orientation has yet to be established in the treatment/management of dementia, perhaps greater application to this population than was found to be the case should be considered.

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, we were told, has different needs. These include instruction on how to make the most of visits, how to cope with the probability their relative will exhibit behaviours they find disturbing when exhibited by other Special Care Unit residents and how to solve such practical problems as applying for power of attorney.

Day programs and respite beds for community-dwelling dementia victims should also be considered. None of the participating units offered the former, and only one, the latter. Implementation of one or both types of programs would further utilize the expertise of Special Care Unit staff and perhaps enable small facilities to employ specialized staff they might not otherwise be able to afford.

While not reported here, data from the study clearly showed that the six Special Care Units were valued both by staff and by families. For example, in their answers to questions regarding the pros and cons of such units from the point of view of unit residents, other residents of the facility, staff and families (see Gutman & Killam, 1989) both staff and family respondents cited substantially more advantages than disadvantages. Further, when asked whether they planned to continue working with Special Care Unit residents, all but one staff respondent said "yes."

Finally, as regards differences between Special Care Units based in Intermediate as compared to Extended Care facilities several were noted. These included a more equal sex distribution in the Extended Care-based units (47.4% to 60% female compared with over 84% female in two of the three Intermediate Care-based units), a higher proportion of residents under age 65 (4% to 16% compared with 0% to 3.2% in Intermediate Care-based units), a wider-case mix, more two- and four-bed rooms, a slightly greater variety of activities and programs offered to residents, and a greater readiness of units in Extended Care facilities to admit and retain physically aggressive residents. Perhaps even more striking than the differences between Intermediate and Extended Care-based units, however, was the variation between units within the two care levels. Diversity between units is certainly not unique to British Columbia (cf. Mace, 1991; Ohta & Ohta, 1988). Rather, it appears to be the hallmark of this ever increasing care modality causing Coons (1991) to refer to Special Care Units as "a concept in search of standards"(p.1).

The establishment of standards for Special Care Units is perhaps the next stage of development that we will witness occurring in Canada or that we should be advocating for.

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3

COMPARISON OF CARE PRACTICES FOR PERSONS WITH DEMENTIA LIVING ON AND OUTSIDE SPECIAL CARE UNITS IN ONTARIO'S HOMES FOR THE AGED

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INTRODUCTION

Elderly persons with dementia have formed an increasing proportion of admissions to Ontario's Homes for the Aged¹ during recent years as a result of changing patterns of community-based and institutional care. With the support of government programs and help from family and friends, greater numbers of seniors have been enabled to defer admission to long-term care facilities until community-based programs no longer meet their needs. When admitted to long-term care, these seniors are more likely to have dementia and other health problems requiring staff attention than were seniors admitted in the past.

Long-term care professionals have been challenged by the increasing numbers of elderly with dementia in their care and by the care needs of these residents. These needs arise from the symptoms of their disorders and their interactions with other persons. More specifically, the special needs of residents with dementia are related to problem behaviours, competency to make decisions, functional deficits, psychotic symptoms such as hallucinations, and suffering related to depression and anxiety (Health and Welfare Canada, 1990).

¹ Homes for the Aged in Ontario are under the auspices of either a municipality or a charitable organization. The Ontario Ministry of Community and Social Services has jurisdiction over them through the Homes for the Aged Acts of 1947 and 1949 and subsequent amendments. Anyone over the age of 60 is automatically eligible for admission; younger persons may be admitted under special circumstances. All Homes are funded to provide residential care (which can include some personal care in carrying out activities of daily living) and the majority also provide extended care to residents who require more than 1.5 hours of personal and/or nursing care per day.

Homes for the Aged in Ontario and other long-term care facilities in North America have responded to the needs of their residents with dementia by developing approaches to care and Special Care Units. In 1990, the Ministry of Community and Social Services in Ontario contracted with the authors for a survey of all 181 Homes for the Aged to describe their residents, care practices for those with dementia, and the role of Special Care Units.² The survey results provide a demographic portrait of Home residents and estimate the prevalence of dementia, thereby contributing to the small amount of literature on characteristics of residents in long-term care.

More significantly, the survey results allow for comparison between care practices for residents with moderate or severe dementia living on Special Care Units and those living on other units in the facilities. This approach departs from the typical discussion of Special Care Units in the literature which reviews issues associated with segregated settings. Given the increasing numbers of elderly with dementia in long-term care within and outside Special Care Units, issues concerning segregated care may be losing their relevance.

WHAT ARE SPECIAL CARE UNITS AND WHY ARE THEY "SPECIAL"?

Special Care Units are defined in the literature as separate units or wards offering specialized programs, trained staff and incorporating physical design and technologies that compensate to some degree for residents' deficits and support their remaining abilities. In practice, units for residents with dementia vary considerably and the term "Special Care" may simply indicate some variation from the facility's standard practice (Gutman and Killam, 1989; Hiatt, 1987; Ohta and Ohta, 1988; Ronch, 1987; Weiner and Reingold, 1989).

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Recent reviews of the literature have found no consistent research data on the benefits or disadvantages of Special Care Units (Hepburn et al., 1989; Mace, 1987; Ohta and Ohta, 1988). Effects of segregated care on residents, family members and staff have been the focus of much debate. Proponents of segregated care believe cognitively intact residents are disturbed by the behaviour of residents with dementia while proponents of integration believe cognitively intact residents benefit from the humanitarian experience of assisting them (Gutman, 1989).

In terms of effects on staff, proponents of integration believe staff could become exhausted and demoralized if caring only for residents with dementia (Pynoos and Stacey, 1986). Those favouring segregated care believe special programs allow for development of specific expertise that is beneficial to residents and rewarding to staff.

Different views are held concerning effects on families. One view holds that families of residents on segregated units find the units depressing and therefore reduce the frequency of visits. However, families of cognitively well residents may be upset by contact with residents with dementia living in integrated settings (Gutman, 1989).

THE STUDY OF ONTARIO'S HOMES FOR THE AGED AND THEIR SPECIAL CARE UNITS

The data presented here are part of a larger study, *A Study of Care Practices for Persons with Dementia in Ontario's Homes for the Aged*.³ As part of the study, all 181 Homes for the Aged in Ontario were surveyed to obtain information on residents' characteristics and policies and care practices pertaining to residents with dementia living outside any Special or separate units in the Home. The Homes were asked to complete a parallel survey for residents living on Special or separate units in the Homes, completing one survey form for each such unit.

A total of 133 completed surveys were received, yielding a response rate of 80% after the sample base was adjusted to remove Homes that did not admit residents with dementia.

³ *A Study of Care Practices for Persons with Dementia* is available from: Residential Services Branch, Community Health and Support Services Division, Ontario Ministry of Community and Social Services, 80 Grosvenor Street, 5th Floor, Toronto, M7A 1E9

Completed questionnaires concerning Special Care Units were received from 67 Homes. Two Homes had two Special Care Units and one Home had three, resulting in a total of 71 responses.

Although Special Care Units are well-established in Ontario's Homes for the Aged, with half the Homes reporting one or more, the units care for only about 10% of the Homes' total residents and 23% of residents with dementia.

The discussion that follows compares the results of the survey of general practice with residents with dementia in the Homes and practice on Special Care Units along several lines, including: residents' characteristics; use of design technology and the physical environment; aspects of the social environment including the organization of daily activities, programs, and the use of restraints; and staffing issues such as training, staff/resident ratios and the use of external resources.

TYPES OF SPECIAL ARRANGEMENTS HOMES MAKE FOR RESIDENTS WITH DEMENTIA

Respondents were asked to choose from a list of five possible options those that best described the physical arrangements made for residents with moderate or severe dementia. The options were: caring for residents on a separate or Special Care unit; special groupings in various areas throughout the Home; planned integration where residents are cared for throughout the Home but where no special space is allocated for them; residents are placed as beds become available (in other words, no special arrangement); and some other type of arrangement or combination of arrangements.

While most (77.7%) Homes had only one type of arrangement, almost one-quarter (22.3%) indicated two or more types. Overall, a separate ward or unit was the most frequent arrangement. One-third of the Homes (34.7%) said they had this type of arrangement exclusively; 8.4% had a separate unit in combination with another arrangement. About 10% of the Homes placed residents with dementia in special groupings in various areas throughout the Home. Fewer residents were cared for in each group than was the case in a typical separate or Special Care unit.

AGE, LOCATION AND SIZE OF SPECIAL CARE UNITS

Special Care Units are not a recent phenomenon in Ontario. While 40% of the Homes with Special Care Units reported the unit was established during the last 10 years, 44% said their unit was established before 1970.

Most units (67.1%) are located on ground level, although a substantial proportion (27.1%) are located on upper levels of the Home. A few units can be found in basements or on more than one level.

The literature indicates that the size of Special Care Units usually is determined by available space and budgets, rather than by theoretical considerations of optimal size. While units of fewer than 20 beds are viewed as optimal, in practice units typically range in size between 20 beds and 34 beds (Gutman and Killam, 1989; Hepburn et al., 1989; Johnson, 1989; Ohta and Ohta, 1988; Wagner, 1987).

The survey indicated that the number of residents living on Special Care Units in Ontario ranged from 14 to 80 or more. As shown in Table 1, while 9.8% reported fewer than 20 residents on each unit, 28.2% reported between 20 and 29 residents, 26.8% reported 30 to 39 residents, and 35.2% reported 40 or more residents.

No. of Residents	No. of Units	%
Less than 20	7	9.8
20-29	20	28.2
30-39	19	26.8
40-49	12	16.9
50-59	5	7.0
60+	8	11.3
Total	71	100.0

RESIDENTS' CHARACTERISTICS

Age, Sex and Marital Status

With the exception of a survey of six Special Care Units in British Columbia by Gutman and Killam (1989), there are virtually no Canadian data on the characteristics of residents living on Special Care Units. As indicated in chapter 2 of this volume, Gutman and Killam found no consistent trend in age or sex distribution. However, levels of dementia and the presence of problem behaviours were high on all six units.

The present study, in contrast, found that most residents of Special Care Units were women, although there was a greater proportion of men on the units (37%) than in the total population of the Homes (27%).

Residents of Special Care Units also tended to be younger than the total population of the Homes. As shown in Table 2, while 31.8% of the Units' residents were 85 years of age or older, the corresponding proportion for all residents of Ontario's Homes for the Aged was 49.4%.

Age Groups	Special Care Units %	Homes for the Aged %
Under age 60	1.1	0.8
60-64 years	2.0	1.9
65-74 years	16.5	11.1
75-84 years	48.6	36.8
85-94 years	26.0	42.5
95 or older	5.8	6.9

Number of Units responding = 61
Number of Homes responding = 131

The data also show that while a majority of residents living on Special Care Units (78.9%) were single and/or widowed the proportion not married was smaller than for all residents in Ontario's Homes for the Aged (86.2%). Almost twenty per cent (17.4%) of residents living on Special Care Units, a higher proportion than for the total population of residents (7.5%), were married and had spouses living elsewhere. Only 3.8% of Special Care Unit residents had spouses living in the same Home - proportionately half as many as in the total resident population (6.3%).

There was very little difference in age, sex, and marital status between all residents of the Homes and residents with moderate or severe dementia living outside Special Care Units.

Proportion With Moderate or Severe Dementia

Four studies reviewed by Health and Welfare Canada (1990) found that between 52% and 94% of residents of long-term care facilities had psychiatric disorders. Organic mental disorders (primarily dementia) were the most prevalent. In the present study, staff of the Homes were asked to classify each resident, into one of four categories: no dementia, mild, moderate or severe dementia. The following standard assessment definitions were used to classify residents:

- **no dementia** - fully oriented to time, person and place;
- **mild dementia** - loss of memory and learning abilities with preservation of feeling, perception and movement; Resident needs - can function without direction only in familiar surroundings and by virtue of environmental clues (minimum supervision is required);
- **moderate dementia** - pronounced loss of memory and moderate impairment of psychomotor and neurological functioning; Resident needs - can follow some verbal direction but needs assistance with dressing, hygiene and safeguarding of personal effects. Residents may exhibit a range of behaviours such as wandering, sexual disinhibition etc. (24-hour supervision is required);

- **severe dementia** - profound loss of all higher mental functions; **Resident needs** - personal care is totally assisted by a care provider and incontinence is often present. Residents are often immobile and the emphasis is on physical care (24-hour supervision is required).

As shown in Table 3, 40.8% of all residents in the Homes were rated as having moderate or severe dementia. This proportion increased with the total number of residents in the Home; about half in Homes with 200 or more residents were thought to have moderate or severe dementia.

Level of Dementia	Special Care Units %	Homes for the Aged %
No dementia	.9	33.4
Mild dementia	5.6	25.8
Moderate dementia	41.0	20.2
Severe dementia	52.5	20.6
Number of Units responding = 62		
Number of Homes responding = 133		

Prevalence of Problem Behaviours

As shown in Table 4, while there were no differences in proportion between Special Care Unit residents and all residents of the Homes with dementia with respect to incontinence, agitation or wandering, residents of Special Care Units were far more likely than the Homes total population of residents to be abusive or aggressive (69.9% vs. 29.4%) and to display hoarding or rummaging behaviours (74.1% vs. 17.5%).

Table 4
PREVALENCE OF PROBLEM BEHAVIOURS ON SPECIAL CARE UNITS AND IN HOMES FOR THE AGED

Problem Behaviours	Special Care Units %	Homes for the Aged %
Incontinence	68.8	61.9
Agitation (pacing, chatting)	48.4	47.4
Abusive or Aggressive	69.9	29.4
Wandering	30.4	29.3
Hoarding, rummaging	74.1	17.5
Other (i.e. refusal to eat or drink, undressing, unhygienic, sexually aggressive)	19.6	18.6
Number of Units responding = 67		
Number of Homes responding = 117		

Need for Assistance With Activities of Daily Living

Not surprisingly, residents of Special Care Units required more help than the Homes' total population with activities of daily living (bathing, dressing, toileting, transferring from bed to chair, continence and feeding). As shown in Table 5, more than 80% in Special Care Units required assistance with three or more of these activities compared to half the total population of the Homes.

Table 5
ADL ASSISTANCE NEEDED BY RESIDENTS WITH DEMENTIA

Assistance Needed	Special Care Units %	Homes for the Aged %
No assistance needed	0.7	14.0
Assistance with 1 or 2 activities	15.8	35.7
Assistance with 3 or more activities	83.5	50.3
Number of Units responding = 64		
Number of Homes responding = 132		

Ambulation

As shown in Table 6, compared with all residents living in the Homes a greater proportion on Special Care Units were independently mobile without the need for a cane or walker (63.3% vs. 38.2%). This may be explained by the fact that the ability to ambulate was an admission criteria to the Special Care Unit in about two-thirds of the Homes and is commonly cited in the literature as an important factor for admission (Hepburn et al., 1989; Weiner and Reingold, 1989).

Table 6
DEGREE OF AMBULATION OF RESIDENTS WITH
DEMENTIA

Degree of Ambulation	Special Care Units %	Homes for the Aged %
Independently mobile	63.3	38.2
Independently mobile with cane or walker	4.6	22.0
Use a wheelchair	6.0	15.6
Mobile only with staff assistance	26.0	24.2

Number of Units responding = 51

Number of Homes responding = 133

DIFFERENCES IN CARE PRACTICES AND STRATEGIES

As a group, 93.5% of residents of Special Care Units had moderate or severe dementia; 69.9% showed abusive or aggressive behaviour; 74.1% hoarded or rummaged through others' belongings, and 63.3% were independently mobile without cane or walker. This combination of characteristics presents many challenges for the administration and direct care staff. Their ability to respond to these challenges through unique care practices determines the success of Special Care Units. The following section compares care practices and strategies implemented on Special Care Units with approaches employed on general care units in the Homes.

ENVIRONMENTAL MODIFICATIONS

Surveys of Special Care Units have found a range of approaches to environmental modifications, ranging from no modifications through to sensitive attention to many aspects of the environment (Gutman and Killam, 1989; Hepburn et al., 1989; Ohta and Ohta, 1988; Weiner and Reingold, 1989). The Ontario survey found that Special Care Units were more likely than other units to adopt measures to increase security and visual access; to create spaces to reduce jostling and accommodate wandering; and to employ a greater variety of safety measures. However, the Special Care Units and other units made the same use of measures to enhance reality orientation and wayfinding by residents with dementia and few clear differences were observed in measures to compensate for sensory deficits or overload.

Table 7
ENVIRONMENTAL MODIFICATIONS AND TECHNOLOGICAL AIDS USED ON AND OUTSIDE SPECIAL CARE UNITS

Strategies intended to:	Special Care Units %	General Care Units %
a) increase security and improve visual access		
Alarmed/coded/secured door exits	100.0	83.1
Secured outside areas	71.0	52.2
Modified nurses' stations	46.4	46.1
Secured elevator openings	45.8	36.5
Wide-angle mirrors	20.6	10.4
Video camera surveillance	4.4	8.8
b) increase reality orientation to time/place		
Symbols/signs marking resident's door	85.9	82.9
Reality orientation materials	84.1	88.5
Extra large signs or picture signs	78.9	73.0
Removed misleading stimuli	37.3	21.1
c) reduce jostling and accommodate wandering		
Outdoor spaces for wandering	82.9	43.9
Indoor spaces for wandering	72.5	33.3
Increased size of lounges	48.5	25.7

Table 7 (cont'd)**d) control noise to reduce sensory overload**

Planned background music	49.3	38.6
Eliminated intercom/public address system	31.4	28.1
Carpeting/sound-absorbing finishes	29.6	40.0

e) compensate for sensory deficits

Colour/other contrast	81.4	74.8
Reduced glare from floors/windows	63.4	61.4
Increased lighting	60.6	60.2
Textured finishes	56.5	52.7
Even lighting levels	52.2	59.5
Eliminated contrast	50.7	41.7

f) increase safety/security

Key/combo door locks	83.8	48.3
Identification bracelets	64.2	55.8
Controlled access/key to elevators	40.7	16.7
Electronic sensors on doors	39.4	35.6
Electronic sensors on elevators	5.2	12.0

g) assistive aids

Special bath aids	68.2	64.9
Specially designed eating utensils	55.2	52.1
Emergency response systems	25.8	19.1

Number of Units responding to each item = 59 to 71.

Number of Homes responding to each item = 106 to 120.

Security and Visual Access

As shown in Table 7, compared with other units in the Homes, Special Care Units were more likely to have alarmed, coded or secured door exits (100.0% vs. 83.1%); secured outside areas used by residents (71.0% vs. 52.2%); secured adjacent elevator openings (45.8% vs. 36.5%) and to use wide angle mirrors (20.6% vs. 10.4%). Special Care Units were less likely to use video cameras, although very few Homes reported using this option. No differences were found with respect to modifications to the nurses' stations to improve staffs' ability to view residents.

Reality Orientation and Wayfinding

All but one of the strategies enquired about to increase residents' orientation and wayfinding had been adopted by most Special and general care units. For example, 84.1% of the Special Care Units and 88.5% of the general care units reported the use of reality orientation boards or other materials orienting residents to time and place. Most Special (85.9%) and general care units (82.9%) also used symbols or signs marking each resident's door, and extra large signs or picture signs in general (78.9% and 73.0% respectively). However, compared with general care units more Special Care Units had purposely removed misleading stimuli such as artwork (37.1% vs. 21.1%).

Wandering

While most Special Care Units had adopted one or more strategies to reduce jostling and accommodate wandering, fewer than half the Homes reported such measures for their residents with dementia on other units. For example, 82.9% of the Special Care Units reported outdoor spaces for wandering, compared with 43.9% of the general care units. Almost three-quarters (72.5%) of the Special Care Units reported indoor spaces for wandering, compared with 33.3% of the general care units. About half (48.5%) of the Special Care Units had increased their square footage for lounges, compared with 25.7% of the general care units.

Sensory Overload

About half (49.3%) of the Special Care Units made use of background music, compared with 38.6% of the Homes reporting practices with residents with dementia on other units. Special Care Units and the Homes' other units were equally likely to have eliminated their intercom or public address system (31.4% and 28.1% respectively). Special Care Units were less likely, however, to use carpeting or other sound-absorbing finishes (29.6% compared with 40% of Homes reporting on other units).

Sensory Deficits

Most Special and general care units had implemented some strategies to compensate for sensory deficits in residents. For example, 81.4% of the Special and 74.8% of the general care units reported the use of contrast to show where differences occur (e.g. different colours or other contrasts between floors and walls, doors and door knobs, dishes and table surfaces). Half of the Special and 41.7% of the general care units had eliminated contrasts where no differences occur, such as eliminating patterns or lines on the floor.

Safety Measures

More Special Care Units than elsewhere in the Homes reported having doors that lock with a key or combination (83.8% vs. 48.3%), had a controlled access system or key to elevators (40.7% vs. 16.7%) and used ID bracelets (64.2% vs. 55.8%).

Technological and Assistive Aids

Approximately two-thirds of both the Special Care Units (68.2%) and other units (64.9%) had installed bath aids such as grab bars and shower stools and over half of the Special (55.2%) and general care units (52.1%) used specially designed eating utensils. However, more Special Care than general care units had installed an emergency response system (25.8% vs. 19.1%).

SOCIAL ENVIRONMENT

The survey included questions that looked at how daily activities were organized, what types of programs were provided, the use of restraints, staffing arrangements, and use of external resources.

Organization of Daily Activities and Programs

Respondents were presented with a series of statements about the organization of daily activities for residents with moderate or severe dementia living on and outside Special Care Units. For each statement, they were asked if their unit was "very much like this", "somewhat like this", or "not at all like this." Table 8 lists the statements and shows the percentages of Special and general care units that indicated they were "very much like this."

Table 8
ORGANIZATION OF DAILY ACTIVITIES FOR RESIDENTS
WITH DEMENTIA

Statements	Special Care	General Care
	Units %	Units %
Meals provided at regularly scheduled times.	97.2	97.5
Residents encouraged to decorate their rooms with their favourite belongings.	77.5	90.2
Provisions made for residents to have privacy during bathing.	85.9	88.5
Provisions made for residents to obtain snacks when they wish.	73.2	66.1
Residents offered a choice of clothing.	49.3	63.9
Meals served one course at a time.	70.4	58.7
Residents toileted every two hours.	64.8	57.9
Residents must be clean/dressed before meals.	36.6	51.6
All residents with moderate or severe dementia eat the same meals.	47.9	45.9
Residents with moderate or severe dementia spend more time in group than individual activities.	33.8	40.8
Staff spend a good deal of time interacting with residents on an individual basis.	52.1	37.7
Staff spend considerable time organizing group activities for these residents.	36.6	37.5
School children are encouraged to pair up with residents.	18.3	28.1
Most of the residents go to bed when they wish.	29.6	21.3
Residents go walking outside on a daily basis.	24.3	16.4
Residents toileted in a group.	5.6	4.9
Residents get up when they wish.	21.1	4.9
Residents with moderate or severe dementia are allowed to keep pets.	15.7	4.1

Number of Units responding to each statement = 70 to 71.

Number of Homes responding to each statement = 120 to 122

As can be seen in Table 8, almost all Special (97.2%) and general care units (97.5%) said they "provided meals at regularly scheduled times." Most Special (85.9%) and general care units (88.5%) indicated that "provisions are made for residents to have privacy during bathing." While 77.5% of Special Care Units indicated that "residents are encouraged to decorate their rooms with their favourite belongings" this practice was more widespread outside Special Care Units and was reported by 90.2% of the Homes. The general care units were also more likely than the Special Care Units to maintain personal grooming practices such as offering a choice of clothing (63.9% vs. 49.3%) or insisting that residents be clean and dressed before meals (51.5% vs. 36.6%). Special Care Units were more likely to serve meals one course at a time (70.4% vs. 58.7%) and to toilet residents every two hours (64.8% vs. 57.9%). Special Care Units were also more likely to allow residents to get up in the morning when they wished (21.1% vs. 4.9%), go to bed when they wished (29.6% vs. 21.3%) or to keep pets (15.7% vs. 4.1%).

Differences were also noted in the way staff were reported to interact with residents. Special Care Units were more likely to say their staff spent a good deal of time interacting with residents on an individual basis (52.1% vs. 37.7%) and less likely to say that residents with moderate or severe dementia spend more time in group than in individual activities (33.8% vs. 40.8%). Respondents' perceptions here may vary from actual practice, since almost two-thirds of the programs offered on Special Care Units were group programs - the same percentage as on other units.

Palliative Care

Palliative care was offered by 56.3% of the Special and 57.4% of the general care units. Special Care Units were more likely than other units in the Homes to offer this care in the resident's bedroom rather than in a sick bay on the unit (75.0% vs. 61.4%).

Frequency of Client Reassessments

Most Special Care Units (95.7%) reported conducting more than one reassessment annually and 82.1% conducted up to four annually--comparable to the 82.8% of Homes that conduct up to four reassessments annually. Two-thirds of the Units (64.8%) indicated their residents are assessed as frequently as residents with moderate or severe dementia living

elsewhere in the Home; one-third (33.8%) thought they were reassessed more frequently, usually to monitor and address problem behaviour.

Families are more likely to be involved in reassessments on Special (62.3%) than on general care units (50.4%).

Care Plan Reviews and Unit Meetings

Although most Special Care Units (81.7%) reported reviewing their residents' care plans as frequently as elsewhere in the Home, half (50.7%) of the Special Care Units reported they reviewed individual care plans once each month compared with only 33.0% of the general care units.

Special Care Units were also more likely to hold unit meetings to plan programs and services and met more frequently for this purpose than elsewhere in the Homes. Almost two-thirds of the Special Care Units (63.4%) hold such meetings, compared with 47.5% reporting this practice on other units, and 80.0% meet once each month, compared with 69.1% of the general care units.

Most Effective In-house and Outreach Programs

The Special and general care units identified the same in-house programs as being the most effective for residents with moderate or severe dementia. While more than 30 programs were identified by the Special Care Units, those most frequently mentioned as being most effective fell into eight categories: exercise related (53.5%); music related (53.5%); food related (40.8%); crafts and games (31.0%); social groups (26.8%); activities of daily living (18.3%); reality orientation (18.3%); and lifeskills (18.4%).

About one-third of the programs listed by the Special Care Units (each unit could indicate up to four programs) were held once each week and included music or food-related programs plus reality orientation. One-fifth of programs (21.6%), such as crafts, were offered two or three times each week and 18.0% were offered five days per week. The Special Care Units had a larger proportion of programs offered daily compared with units elsewhere in the Home (15.0% vs. 9.7%), and most that offered exercise did so daily.

Approximately two-thirds (61.1%) of programs offered by Special Care Units are held on the unit itself rather than elsewhere in the Home, compared with 38.1% of programs offered by general care units. Most programs for residents with moderate or severe dementia on Special Care Units and elsewhere in the Homes are group programs (69%) and fewer than 20% are strictly one-to-one programs.

Most programs offered by general care units (64.9%) involve residents with moderate or severe dementia as well as other residents. On Special Care Units, 43.5% of programs included both groups of residents.

Fewer Special than general care units provided outreach programs (40.8% vs. 68.1%) and fewer believed this role would increase in the future (64.8% vs. 81.9%). Both groups believed the most beneficial outreach programs for residents with dementia were adult daycare, respite programs and meal programs.

Management of Problem Behaviours

The same types of interventions were used on Special and on general care units, although a larger percentage of the Special Care Units indicated they used each intervention. Also, the Special Care Units were less likely to use an alarm to control wandering and far more likely to create spaces for wandering than other areas of the Homes.

The most frequently mentioned intervention for *wandering* on Special Care Units was provision of secure areas (73.2%); for general care units it was alarms (45.5%). Other interventions used included increasing staff (43.7% on compared with 36.6% outside Special Care Units) and diversion tactics (35.2% on and 32.4% outside Special Care Units).

In response to *abusive or aggressive behaviour*, Special Care Units most frequently increased staff (74.6% compared with 66.7% outside Special Care Units), or used a diversion tactic (40.8% compared with 25.2% outside Special Care Units).

The most frequent responses to *agitated behaviour* on and outside Special Care Units were increased staff (69.0% and 44.7% respectively), diversion (63.4% and 53.7%), and chemical restraints (19.7% compared with 23.6%).

Hoarding or rummaging on and outside Special Care Units were addressed through frequent room checks (56.3% and 51.2% respectively), locked closets (36.6% compared with 23.6%) and diversion (29.6% compared with 23.6%). About one-quarter (23.9%) of the Special Care Units also reported increased monitoring as a way of dealing with hoarding and rummaging; very few of the general care units reported this intervention.

Most Special (98.6%) and general care units (91.1%) indicated they used regular toilet routines as a preventive measure for *incontinence*, although 40% of Special and general care units also reported use of diapers.

Use of restraints

Few differences were reported between practices on Special and general care units with respect to use of restraints. Virtually all of both types of units reported using restraints under certain circumstances, usually as a safety measure. Half of the Special and general care units said restraints are used only under a doctor's orders. One-third of the general (31.6%) and 21.5% of the Special Care Units said they used a policy of least restraint.

The proportions using each of four types of restraints were similar for the Special and general care units. As shown in Table 9, 93.8% of the Special and 86.5% of the general care units reported use of chemical restraints; 84.4% and 88.4% respectively used the geri chair; 71.0% and 74.3% respectively used the lap belt, and 38.3% and 41.8% used the jacket restraint.

Type of Restraint	Special Care Units %	General Care Units %
Chemical Restraint	93.8	86.5
Geri Chair	84.4	88.4
Lab Belt	71.0	74.3
Jacket Restraint	38.3	41.8

Number of Units responding to each item = 60 to 65
 Number of Homes responding to each item = 109 to 112

The Special Care Units were asked whether, compared with other units of the Home caring for residents with moderate or severe dementia, certain types of restraints were used more or less often. One-third (35.3%) believed *chemical restraints* were used more often on the Special Care Unit while 22.0% believed they were used less frequently. One-third believed *jacket restraints* were used less frequently. Most units (62.8%) agreed that *lap belts* are used about as frequently on the Special Care Unit as elsewhere in the Home.

Most (81.2%) Special Care Units reported consulting the family each time a restraint was used compared with 63.1% of the general care units.

STAFFING ISSUES

Staffing Ratios and Rotation

According to the literature, the staff-resident ratio has an effect on staff stress levels and staff rotation patterns. Ohta and Ohta (1988), for example, believe that units with a high staff-resident ratio generally experience less stress and are able to maintain a consistent staffing pattern in which the same staff work on the unit rather than rotating off. A wide variation in ratios are reported in the literature and there appears to be no clear norm (Gutman and Killam, 1989; Weiner and Reingold, 1989).

Most Special Care Units (72.1%) believed the ratio of direct care staff to residents is higher on Special Care Units than elsewhere in the Home. Half the Special Care Units were able to calculate staff/resident ratios. The most frequent ratios reported were between 1:6 and 1:8 (range 1:2 to 1:17). A ratio of 1:9 was typical for Homes caring for residents with dementia outside Special Care Units, but ranged as low as 1:20.

About 80% of the Special Care Units reported using a specialized team that stayed on the unit, with about half of the units staffed by teams that stay on the same shift (i.e., only days or only nights) and the other half staffed by teams that rotate two or more shifts within the unit. The remaining units used another form of rotation, usually having staff rotate throughout the Home.

Table 10 displays a list of staffing-related statements and the percentages of Special and general care units that said their direct care staff-resident ratio does not allow them to

address these work-related activities. Almost all Special (80.3%) and general care units (80.4%) agreed that their staff/resident ratio did not allow them to provide programmed activities in the evening. However, slightly more general than Special Care Units said their ratio was insufficient to allow responsiveness to residents' needs for individual attention (47.7% vs. 42.3%), or to make appropriate response to problem behaviours (39.8% vs. 31.0%).

Table 10
WORK NOT PERMITTED AS A RESULT OF RATIO OF DIRECT CARE STAFF TO RESIDENTS

Type of work not permitted	Special Care Units %	General Care Units %
Monitoring residents in the evening to ensure their safety	26.8	23.2
Appropriate responses to problem behaviour	31.0	39.8
Completion of daily routines at a comfortable pace for residents	33.8	35.1
Sufficient variety in activities offered in the daytime	36.6	35.5
Ability of residents to perform activities of daily living as independently as possible	38.0	40.2
Ability of staff to be responsive to residents needs for individual attention	42.3	47.7
Provision of programmed activities in the evening	80.3	80.4
Number of Units responding to each statement = 71.		
Number of Homes responding to each statement = 108 to 114.		

Staff Training

According to the literature, provision of training on the care of residents with dementia varies considerably among Special Care Units, with some providing little or none and

others providing orientation before work on the unit and ongoing in-service training (Gutman and Killam, 1989; Weiner and Reingold, 1989).

About three-quarters (77.3%) of the Special Care Units said their staff receive the same number of hours of in-service training as staff elsewhere in the Home who care for residents with moderate or severe dementia; one-quarter (22.7%) said their staff receive more hours of training.

Respondents were asked to list and describe three topics presented through in-service training in the last 12 months that were the most useful and relevant to the care of residents with dementia. Many topics were listed but most belonged to three groups: understanding and management of Alzheimer's Disease; dealing with the behavioural manifestations of dementia; and communication with the cognitively impaired. The types of topics were the same on and outside Special Care Units.

When asked about barriers to staff training, 67.9% of the Special Care Units indicated there were "no funds to facilitate training courses" and 61.1% said "the expertise needed to lead sessions is unavailable" in their area. This barrier was identified more by Special than by general care units. The Special Care Units also reported "few relevant training resources such as booklets or videotapes available" as a training barrier.

Involvement of External Resources

Special and general care units differed with respect to the involvement of external resources such as psychogeriatricians and the use of community services to support staff. Where available in the community, Special Care Units were more likely than general care units to report using the services of a psychogeriatrician (59.1% vs. 45.0%) or a social worker (62.5% vs. 45.0%). However, the general care units reported greater use of physiotherapists (75.7% vs. 64.7%), speech therapists (23.4% vs. 8.6%) and chiropractors (12.0% vs. 7.8%).

While Special Care Units had less involvement than other units with such community services as footcare clinics (41.4% vs. 60.5%); private nursing services (14.5 vs. 25.7%) and adult day programs (11.8% vs. 22.1%), they had more involvement with the Alzheimer's Society (50.7% vs. 40.7%), family counselling (30.4% vs. 22.6%), and home support agencies (24.6% vs. 17.9%).

Volunteer Involvement

Most (94%) of the Special and general care units reported involvement of volunteers (including family members) in activities with residents with dementia. However, when asked whether volunteer involvement on the Special Care Unit was more, the same, or less than with those living elsewhere in the Home, more than half the Special Care Units believed volunteers spend less time with individual residents (58.7%) and less time assisting with activities of daily living (51.9%).

Residents with dementia living in the two types of settings receive about the same number of social visits. Few receive daily visitors (11.0% of SCU residents; 12.9% residents' elsewhere); one-third receive visitors about once a week; most receive visitors less often.

PERCEIVED SUCCESS OF SPECIAL CARE UNITS

Areas of Special Expertise

As shown in Table 11, both types of units agreed that Special Care Units are more successful in such areas as ensuring residents' safety (85.9% vs. 75.4%), responding to problem behaviours (74.6% vs. 68.6%) and providing appropriate programming (73.2% vs. 66.9%). Not unexpected, the Special Care Units were slightly more optimistic about their role.

Care Practices	Special Care Units %	General Care Units %
Ensuring residents' safety	85.5	75.4
Responding to problem behaviour	74.6	68.6
Providing appropriate programming	73.2	66.9
Completing daily routines with residents at a pace that is comfortable for them	63.4	59.3
Allowing residents to perform activities as independently as possible	57.7	55.9
Effectiveness of incontinence management	38.0	36.2

Number of Units responding to each statement = 71.
Number of Homes responding to each statement = 116 to 118.

Advantages and Disadvantages of Integrated and Segregated Care Arrangements

The literature on the advantages and disadvantages of integrated and segregated care settings for persons with dementia produces very little consensus and, so far as we are aware, no systematic study of long-term benefits of either physical arrangement has ever been conducted. Table 12 shows the mean scores for a series of statements presented to respondents about the perceived advantages and disadvantages of integrated and segregated care. The original response categories were: strongly agree (score=1), moderately agree (score=2), neither agree or disagree (score=3), moderately disagree (score=4) and strongly disagree (score=5). The mean response thus summarizes general agreement (mean score closer to 1), disagreement (mean score closer to 5) or indifference (mean score around 3) for each statement.

For most statements, the Special and general care units were in agreement. However, Special Care Units were more likely to agree that "The needs of residents with dementia are different from those of other residents and are best met in a special separate unit" (mean score 1.5 vs. 2.0); "Residents with dementia are sensitive to rejection from cognitively intact residents" (1.7 vs. 2.1) and that "a therapeutically-designed environment can best be created in separate units for residents with dementia" (1.5 vs. 1.8).

Table 12
PERCEIVED ADVANTAGES OF INTEGRATED AND SEGREGATED CARE FOR RESIDENTS WITH DEMENTIA (Mean Scores)

Statements	Special Care Units X	General Care Units X
Cognitively intact residents benefit from contact with fellow residents with dementia in an integrated setting.	4.1	4.0
Families find segregated settings depressing.	2.5	2.4
Residents with dementia are sensitive to rejection from cognitively intact residents and find greater acceptance in segregated settings.	1.7	2.1

Table 12 (Cont'd)

Special Care Units are inappropriate for rural areas and small urban centres, since the population is too small to support them.	4.3	4.0
Diagnosis of dementia is difficult and segregation of residents believed to have dementia increases the chances that misdiagnosis will be undetected.	3.5	3.3
All residents have much the same care needs that can best be met in an integrated setting focusing on quality care.	4.2	3.8
Residents with dementia benefit from contact with residents without dementia who provide a model for behaviour and increased social stimulation.	3.3	3.1
The needs of residents with dementia are different from those of other residents and are best met in a special separate unit.	1.5	2.0
Turnover among staff who care only for residents with dementia is no different than it is among staff who care for residents without dementia.	2.7	3.0
Cognitively intact residents are often upset by the behaviour of fellow residents with dementia and therefore prefer segregated care.	1.5	1.4
Segregated care increases the potential for inappropriate care for those with dementia as they cannot speak for themselves.	4.3	4.0
A therapeutically - designed environment can best be created in separate units for residents with dementia.	1.5	1.8
Special Care Units are appropriate outside urban areas since families will travel considerable distances to maintain a relative in a Special Care Unit.	2.9	3.2

Number of Units responding to each statement = 71.

Number of Homes responding to each statement = 116 to 118.

SUMMARY AND CONCLUSIONS

The survey of Ontario's Homes for the Aged documents the high levels of residents with dementia living in these facilities. Fully 40% of all residents in the Homes were believed by staff to have moderate or severe dementia. While Special Care Units have an established tradition in Homes for the Aged, with half the Homes reporting one or more of these units, they care for only 23% of the Homes' residents with moderate or severe dementia and most residents with dementia live on general care units. This finding bears out the comments of the Subcommittee on Institutional Guidelines (Health and Welfare Canada, 1990):

In practice, the demography of long-term care does not permit "segregation" in any rigorous sense: cognitive impairment and behavioural disturbance are matters of degree and residents who are affected to some extent by such problems are likely to be the majority in most facilities. Only a fraction of the residents in this group could be accommodated in separate, specialized units or programs. The needs of the less seriously impaired must be addressed by adapting the regular programs and physical environment of the facility (p. 52).

While the Special Care Unit was the most frequently reported type of arrangement made by the Homes for the care of residents with dementia, it is worthwhile noting that almost one-quarter of the Homes have tried two or more types of physical arrangements. Although Special Care Units care for only a small proportion of the Homes' residents with dementia, these residents form a unique group within the Homes.

Almost all of the residents living on Special Care Units were believed to have moderate or severe dementia and, compared with residents of other wards, were far more likely to be abusive or aggressive and to display hoarding or rummaging behaviours. Also, residents of Special Care Units required more help than other residents with activities of daily living. More than 80% of the Special Care Units' residents required assistance with three or more activities of daily living compared to about half of all residents of the Homes. Residents living on Special Care Units, however, were more likely than the total population of the Homes to be independently mobile without the need for a cane or walker.

The same types of interventions for problem behaviours are used on Special and general care units in the Homes, although a larger percentage of the Special Care Units indicated they used each intervention, particularly increased use of staff. Also, the Special Care Units were less likely to use an alarm to control wandering and were more likely to create spaces for wandering than other areas of the Home.

Special Care Units may be more apt to respond to problem behaviours using environmental design, compared with other units, perhaps because they may be more current on technological aids or may have a better understanding of the effects of cognitive impairment. Special Care Units were more likely than other units to adopt measures to increase security and visual access, to create spaces to reduce jostling and accommodate wandering, and to employ a greater variety of safety measures. However, the Special Care Units and other units made the same use of measures to enhance reality orientation and wayfinding by residents with dementia and few clear differences were observed in measures to compensate for sensory deficits or overload.

The findings on the use of restraints showed few differences between practices on Special and general care units. However, the results do suggest that Special Care Units are more likely to avail themselves of psychogeriatricians and to use chemical restraints for residents with moderate or severe dementia.

Staffing is enriched on Special Care Units compared with other units caring for residents with dementia and the amount of staff training is reported to be higher. While only half the Special Care Units were able to provide figures, the most frequently indicated staff-resident ratio was between 1:6 and 1:8. The typical staff-resident ratio on other units with residents with moderate or severe dementia was 1:9. In addition, most of the Special Care Units maintained a consistent staffing pattern in which the same staff worked on the unit without rotating off.

With respect to the organization of daily activities for residents with moderate or severe dementia, the differences between Special and general care units suggests the Special Care Units were more flexible and aware of residents' limitations. For example, the Special Care Units were more flexible on dress requirements for meals and the times residents arose and went to bed. Their routine toileting procedures and one-course-at-a-time approach to serving meals

also suggests a greater awareness of residents' limitations and abilities.

More respondents believed staff on Special Care Units spend a great deal of time with residents compared with staff on other units, and fewer believed residents on Special Care Units spend more time in group rather than individual activities. In practice, almost two-thirds of the programs offered on Special Care Units and other units in the Homes were group programs.

Both Special and general care units find exercise and music-related programs to be the most effective with residents with dementia, with most programming occurring with groups. However, most programming for Special Care Unit residents occurs on the unit itself, whereas most programming for residents with dementia outside Special Care Units occurs away from the residents' unit. Also, most programs offered in general care units (64.9%) involve residents with moderate or severe dementia as well as other residents. On Special Care Units, 43.5% of programs included both groups of residents.

IMPLICATIONS OF THE FINDINGS

Although this study was designed to gather descriptive information and not to assess the quality of care provided in different settings, it does suggest lines for consideration in developing good care practices for elderly persons with dementia. Increasingly, the arrangements long-term care facilities make for their residents with dementia should be characterized by flexibility and combinations of approaches. Homes for the Aged are making more than one arrangement for their residents with dementia. Although the Special Care Unit has a role in many of these Homes, issues should not be defined in terms of segregation or integration, given the large numbers of residents with dementia.

In many respects, Special Care Units could be viewed as pilots for innovative and flexible approaches to resident care that could be adopted throughout the facility. Ideally, these approaches would include monitoring and assessment of their effects on residents, staff and family members, as an aid to identifying the approaches most effective in serving the needs of residents with dementia. With their enriched staff resources, Special Care Units are well equipped to serve as the incubator for developing approaches to care.

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4

LE CHEZ NOUS ACCOMMODATION WITH A DIFFERENCE FOR COGNITIVELY IMPAIRED PERSONS IN RURAL MANITOBA

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INTRODUCTION

Victims of cognitive impairment need appropriate accommodation. As research contributes to our knowledge and understanding of the relationship between cerebral function and behaviour, health care providers acknowledge that individuals with cognitive deficits have unique needs requiring unique solutions.

The traditional conceptual framework for care delivery to the elderly focuses mainly on physical needs. In this model, the allocation of nursing care, measured in units of time, does not factor levels of cognitive function appropriately. While the model serves a major segment of the institutionalized elderly, it ignores the needs of cognitively impaired individuals, an increasingly significant group.

Response to the shelter requirements of a cognitively impaired population is best managed within the parameters of a conceptual framework. With the help of a conceptual framework, a long term care facility can use existing financial and human resources to develop a program that accommodates the needs of mentally frail persons.

This chapter describes our unit's evolution. It includes geographic and demographic data, a historical overview, an elaboration of its conceptual framework, a description of the physical space, discussion of staffing, education, programming and the role of the family, and an evaluation of the unit's progress.

*The authors wish to thank the staff of Le Chez Nous and the following individuals who contributed to this chapter: Marcie Plaitin, Recreational Therapy student; Darcy Mosquin, Pharmacist; Gerard Rioux, Social Worker; Simone Comte, Unit Coordinator, Gail Snider, head Nurse and Muriel Deleurme, typist.

GEOGRAPHIC AND DEMOGRAPHIC DATA

Notre-Dame de Lourdes lies amidst the rolling hills of the Pembina Mountains in southwestern Manitoba. It is surrounded by rich agricultural land and provides a picturesque setting that inspires local artists. Farming, education and health care are the mainstays of the economy.

Notre Dame has a population of 708, 24% of whom are aged 65 and over. This contrasts with the provincial rate of 12.8% and the national rate of 10.7%.

The majority of inhabitants are of Swiss and French ancestry. Some neighboring communities share a similar lineage; others claim Dutch and Belgian extraction. This ethnic mosaic is reflected in the Foyer and Le Chez Nous resident populations.

FOYER AND CHEZ NOUS RESIDENT POPULATION

The Foyer Notre-Dame is a 61 bed long-term care facility. Admission is open to anyone meeting eligibility requirements determined by Manitoba Health Services Commission guidelines.

Our alternative care unit, Le Chez Nous, comprises 12 of the Foyer's 61 long term care beds. The term "Chez Nous" translates as "my home" and connotes an ambiance of comfort, trust, and a sense of belonging and being at ease in one's environment.

As shown in Table 1 the mean age of the Foyer's general resident population is 85 (range 66 to 101). The gender split is 57% female and 43% male. Thirty four (69%) of the Foyer's general area population claim French as their mother tongue. Most residents come from southern Manitoba communities but some are from outside the province.

While the mean age (85) and age range (74-96) is similar in Le Chez Nous, the gender split is different. In Le Chez Nous males outnumber females by 2:1. Most male residents were farmers and most females were homemakers. Other occupations noted in the care plans are mechanic, clerk and restaurant owner. Le Chez Nous is home to four Francophone residents.

Table 1
CHARACTERISTICS OF FOYER NOTRE DAME RESIDENTS

	GENERAL AREA		LE CHEZ NOUS	
	(n=49)		(n=12)	
Mean Age	85		85	
Age Range	66-101		74-96	
% Female	57.1		33.3	
Level of Care	<u>n</u>	<u>%</u>	<u>n</u>	<u>%</u>
1	5	10.2	1	8.3
2	20	40.8	2	16.7
3	15	30.6	7	58.3
4	9	18.4	2	16.7
% Francophone	69.4		33.3	

The Manitoba Health Services Commission's Personal Care Home Program is based on four levels of care with an assignment to level one indicating minimal dependence on staff and an assignment to level four indicating maximum dependency. In the Foyer's general area, five residents are assessed at level one, 20 at level two, 15 at level three and nine at level four. In comparison, Le Chez Nous has one resident at level one, two at level two, seven at level three and two at level four. All Chez Nous residents suffer some degree of cognitive impairment due mainly to dementia-related illness.

HISTORY/BACKGROUND

Several events prompted us to consider establishing an alternative care unit. In a broad context, changes occurring at the national level set the stage for new approaches to the care and shelter of cognitively impaired persons. For example, in the early 1950s, as the number of mental hospital beds decreased, older patients with cognitive impairment were transferred to long term care facilities as part of the deinstitutionalization movement. Today, home care maintains elderly persons in their homes longer. But individuals with attendant mental health problems exhaust their home supports sooner than those with only physical problems and seek facility care earlier. The result is a higher rate of facility admissions for this group. Finally, as the demographics of aging change, so does the prevalence of age-related mental health problems. Today, people are living longer and the Canadian population is aging rapidly, resulting in

greater numbers of persons with mental health problems (Health and Welfare Canada, 1990).

Locally, the precipitating events included:

- a significant rise in the Foyer's cognitively impaired population. We were admitting more cognitively impaired individuals and more residents within the Foyer were becoming impaired;
- a growing number of staff and resident injuries caused by acts of physical aggression. Abuse to various staff included an eye injury, a concussion and a fractured nose. Aggressive acts among residents, resulting in several fractured hips and a skull fracture were also documented, as were many incidences of physical fighting. Several staff injuries resulted in extensive use of income protection benefits;
- numerous complaints from lucid residents expressing fear of violent attacks and fear of having their privacy invaded;
- several incidences of aggressive acts toward confused residents in attempts to scare them away or preempt attacks;
- an alarming increase in elopements and injuries that jeopardized residents' safety and raised fears of litigation;
- deterioration of staff morale. Many staff members experienced stress from physical and verbal abuse, fear of losing an impaired resident or seeing residents harmed. High stress levels were also manifested in increased sick time usage;
- a significant rise in complaints from families of lucid residents concerned about their relative's safety;
- an unfavourable image in the community, with visitors misinterpreting impaired residents' behaviours and questioning the staff's response to them.

Collectively, these events highlighted the need for a solution that would improve quality of life for all residents, enhance families' perception of the care rendered, reduce staff stress and reconcile problems generated by an environment that failed to accommodate persons with cognitive limitations.

TO SEGREGATE OR INTEGRATE?

A search of the literature indicated that the notion of segregation, although not popular initially, is now gaining currency. Novick (1988) for example, cites four studies in which segregation of lucid and confused individuals has proved mutually beneficial. Coons (1987a) cautions against an integration model. She argues that intact persons cannot serve as role models for those with severe memory loss. It is unrealistic she contends, to assume that the cognitively impaired have the capacity to use the behaviour of others as a prototype for their own response. Also, alert persons who find themselves angry, frustrated and unable to cope with their impaired neighbours will probably provide poor behaviour models.

In deliberating the segregation option, we felt success or failure would be determined by our purpose. If we pursued segregation solely to enhance the quality of life of lucid residents by removing the problem (i.e. the impaired resident), the program would fail its disadvantaged population. But if the philosophy guiding segregation focussed primarily on meeting the needs of cognitively impaired individuals, the attendant needs of lucid residents for personal security and privacy, would also be met. The Foyer opted to pursue a segregation model featuring a conceptual framework designed specifically to answer the shelter needs of its mentally impaired population.

LE CHEZ NOUS' CONCEPTUAL FRAMEWORK

Le Chez Nous' conceptual framework is analogous to the structure of a home and comprises three principles:

- 1) **To enhance residents' lives, we must first consider past lifestyles and plan care accordingly.** This principle is our home's foundation and the basis of all decisions that affect our residents. It is the groundwork upon which all policies rest and the root of all planning.

- 2) **Individuals with cognitive deficits should not be held accountable for their behaviour.** This second principle frames our home and supports our contention that the burden of behavioural ownership must not be borne by impaired persons.
- 3) **Losses must be compensated for and residents helped to function within their remaining capacity.** This last principle shelters the frame and foundation of our home and protects the integrity of the first two principles.

These principles are reflected daily in case conferences; in admission, discharge and transfer decisions; in programming and in developing, implementing and revising care plans.

UNIQUE FEATURES OF LE CHEZ NOUS

Alternate care units are becoming commonplace in Canada. Most are linked to research centres, universities, hospitals and large long term care facilities. In contrast, Le Chez Nous is a local product, created by in-house talent, developed with available resources and operated within existing staffing levels.

FUNDING

Most new concepts in accommodation for the elderly originate as research projects, are funded by endowments from benevolent foundations, or are financially supported by one or more government agencies. We received many words of encouragement from health care funding agencies but financial assistance was unavailable. This motivated us to develop a simple, practical and affordable model. Through fundraising campaigns, we solicited financial support from employees, families, friends and the community. In fact, charitable donations account for all of Le Chez Nous' development costs.

STAFFING

An increase in personnel was not required. Rather, nursing staff who opted to work on the unit assumed duties that were traditionally the domain of other job classifications such as housekeeping, activities and dietary. This shift of tasks was negotiated with the supervisors from each department and the staff selected to work on the unit.

A RURAL PERSPECTIVE

Almost all alternative care units for the elderly cited in the professional literature are based in urban settings, but the needs of cognitively impaired persons extend well beyond urban perimeters. Le Chez Nous, a rural unit, offers succor to a mostly rural population.

DEVELOPMENT

A final point to note is that in contrast to units initiated as university projects or developed in larger urban health centres that benefit from the expertise of several professions and disciplines, Le Chez Nous was inaugurated by our Director of Resident Services together with a nursing supervisor, staff nurses and nursing aides.

ADMISSION TO LE CHEZ NOUS

Le Chez Nous admissions are processed by a team comprising the nursing supervisor, unit coordinator, social worker and physician. The team functions as an autonomous unit unless disagreement or controversy arises. The Director of Resident Services may then intervene in order to reach a consensus.

THE ADMISSION PROCESS

When a room in Le Chez Nous becomes available, first priority is given to candidates from within the Foyer's general population. Where an outside applicant is considered, members of Le Chez Nous' selection team visit the applicant in his/her residence and conduct a behavioural and cognitive assessment. At this time, team members discuss with families Le Chez

Nous' philosophy and goals. Families must then decide if their needs can be met within that framework.

Most applicants are easily assessed. Others, however, present potential problems. In such cases, admission is conditional. The admitting physician agrees, in writing, to a trial period. After three months, the candidate may become a permanent resident. But if Le Chez Nous determines that it cannot meet the candidate's needs or, if the candidate is not seen to benefit from the experience, he or she may either return to previous accommodations or be discharged to an available room in the Foyer.

Knowing that challenging candidates are admitted with this proviso, Le Chez Nous staff make extra efforts to accommodate them. The written agreement also serves as a morale booster. Staff know they will not be taxed beyond the resources they have to care for individuals they cannot safely accommodate.

ADMISSION CRITERIA

To qualify for admission to Le Chez Nous, individuals must be ambulatory but impaired to the degree that if they were to leave the building unescorted, they would not be able to return safely. We then ask "Which candidate would best benefit from admission to Le Chez Nous?" The level of cognitive function is not the deciding factor. Rather, it is the candidate's potential to adapt to Le Chez Nous' environment that determines admissibility.

In the trial period, staff look for clues to positive response to the environment. These may include a decrease in aggressive behaviour, pacing or agitation; better nutritional intake and/or improvements in sleep pattern.

Family input complements the admission process. Families must feel secure that admission is in their relative's best interest. If an individual is assessed as a good candidate for Le Chez Nous but the family disagrees, the individual is not admitted.

PHYSICAL SPACE

Le Chez Nous' physical design incorporated existing structures and required only minor remodeling. A rarely used lounge became a kitchen, dining area and living room. A hairdressing shop was relocated, freeing space for a multipurpose service room. Door hardware was installed for additional security. New furniture, enhanced lighting, fresh paint and wallpaper completed the desired ambiance.

During Le Chez Nous' design and development stage, it was helpful to exercise the home analogy. One question we posed was: *"How is the division of labour structured in a home?"* Managing a home requires the exercise of many talents and most family members develop skills in several areas. Accordingly, our staffing model allows employees to perform various duties in housekeeping, dietary and activities. As we expect family members to pull together to fulfill their assignment, staff are also encouraged to rely on each other to complete their tasks. This doesn't, however, preclude the need to accommodate the many disruptions common to the nature of the unit. Resident care is always given at the expense of other tasks.

"Do homes run on schedules?" Homes may have routines but most do not have schedules. We extend our routines accordingly. Bath times and mealtimes are now more flexible. If a resident chooses to eat outside of a regular time, his or her meal is reheated and served later.

Le Chez Nous' design attempts to recreate the easygoing informality we enjoy in our own home. The kitchen is the favoured room for visiting family and friends and they are encouraged to make and serve themselves coffee and snacks. To promote congregation, the kitchen and day living areas are combined. Baking is a regular activity and residents enjoy participating in food preparation, an activity that promotes reminiscing and stimulates conversation. There is a self-serve cookie jar on a shelf within easy reach, and residents have free access to the refrigerator. They often open the refrigerator doors out of curiosity, but unfortunately, they lack the cognitive skill to serve themselves.

"How do we furnish a home?" Considering the residents' past lifestyles, we sought sturdiness, comfort and familiarity in wooden tables and chairs. Families also participate in furnishing rooms to their relative's taste. Working outdoors was a constant feature of many of our resident's lives. A wall of windows facing

the inner court draws in the environment and contributes to a sense of intimacy with nature. Lithographs on other walls depict old time harvest scenes. A variety of plants accent the area.

As in a private home, there is free access to the outside in our enclosed, ground level inner court where residents are protected from wind, glare and temperature extremes. A circuitous path winds by a small elevated garden, fountain and pond. Several rest benches, trees, shrubs and a fragrant garden serve as cues to wayfinding. The inner court is used in spring, summer and fall. A smaller enclosed patio is used in all seasons.

Adequate lighting is important. Incandescent lights in the kitchen, dining and living room area were installed for resident comfort. In residents' rooms, staff and residents can choose between incandescent and fluorescent illumination. Hallway lights are evenly distributed to reduce shadows and glare.

The traditional nursing station - inconsistent with our concept of a home -- was omitted in Le Chez Nous' design. Nursing staff chart in the dining room. Files are stored in a locked cupboard, as are pharmaceuticals.

STAFFING

Staffing is a critical feature of an alternative care unit. How staff are selected, how their roles are defined and how they are supported in caregiving efforts determine the success or failure of the unit.

STAFFING PATTERN

Le Chez Nous' staffing pattern consists of an RN unit coordinator and a nursing aide on weekdays, and two nursing aides on staggered shifts on evenings. The Unit coordinator is accountable to the Foyer's nursing supervisor but Le Chez Nous nursing aides are accountable to the Le Chez Nous unit coordinator. On evenings, nights and weekends, when the unit coordinator is absent, Le Chez Nous' nursing aides work with the Foyer registered nurse in charge. Night shifts in the Foyer are covered by one RN and two nursing aides and Le Chez Nous serves as the base for nursing functions during the night. This allows close resident supervision when staffing is at a minimum.

GENERIC STAFFING

One method of effectively distributing personnel and resources is through generic staffing. Generic staffing means that caregivers chosen to work in Le Chez Nous assume some tasks and responsibilities traditionally assigned to other departments. Our nursing budget could not accommodate two nursing staff positions on 24 hour duty, the coverage required to operate Le Chez Nous safely. Therefore, housekeeping duties and some dietary and activity functions were transferred from their respective departments to Le Chez Nous. This transfer of hours and tasks allowed appropriate staff coverage to meet fluctuating resident needs. Sweeping, dusting, snack preparation and one-on-one activities are now carried out by Chez Nous staff. It is the Le Chez Nous unit coordinator's responsibility to ensure that all non-nursing tasks are performed to each departmental supervisor's standards.

We favor the generic staffing concept for several reasons. Chez Nous residents are exposed to fewer personnel; this reduces traffic flow, reduces noxious stimuli, and lessens confusion and agitation. Residents see the same faces, hear the same voices, experience the same routines, see the same smiles and feel the same reassurance from caregivers. This enhances feelings of security and tempers emotional stimulation levels. When residents are awake, staff give basic health care but they also involve residents in performing simple environmental tasks that are part of everyday life such as setting and clearing tables, sweeping floors and folding linen. This approach helps staff, accomplish their duties, fulfills some of the residents' programming needs, and validates their contribution to their home's operation. Generic staffing also mitigates regimentation by allowing flexible scheduling. The more complex environmental tasks that residents are unable to participate in are effected when they sleep or rest.

Generic staffing occasionally serves as a safety valve. When staff experience stress in coping with difficult behaviours, they can seek refuge in 15 to 20 minutes of time out performing routine environmental tasks that are emotionally less demanding.

CAREGIVER PROFILE

Coping with the demands of caring for persons with dementia presents unique challenges for caregivers. Careful

selection of personnel counts as a major determinant of success in ensuring empathetic and compassionate response to resident needs. Selection is partially based on one's possession of desirable attributes or characteristics. The following profile is representative of Le Chez Nous caregivers. They:

- have easy going dispositions;
- are creative problem solvers;
- seek humour in daily events;
- respond calmly to catastrophic reactions;
- adapt easily to an unstructured environment;
- are people oriented rather than task oriented;
- work well with minimal supervision yet exercise their obligations to a team approach to caregiving;
- can readily adapt to immediate and sometimes dangerous behavioural changes.

APPROACHES

Probably the most valuable characteristic to seek in selecting staff to work with dementia victims is the ability to problem solve. The key feature in effective problem solving lies in selecting appropriate approaches to resident care. Coons and Weaverdyck (1986) offer a repertoire of techniques that staff can use. These include gentle cajoling, affectionate encouragement, diversion, humour, and withdrawing to return later to try again. These techniques are consistent with our concept of behaviour ownership. When staff accept that a moderate or severely impaired resident cannot own his or her behaviour, they free themselves of restrictive and failure-prone approaches such as coercion, rigid application of routines and habitual use of uniform methods such as controlling and enforcing conformity and obedience.

BURNOUT

Although staff burnout is a potential workplace hazard in an alternative care unit, simple safeguards can mitigate the risks. In Le Chez Nous, staff are allowed a trial employment period during which they and the employer determine their suitability for full time or part time work. The trial period

contains a proviso that allows staff to return to their previous job if their experience is not positive.

Unit size plays an important role in stress management. With a small group of employees, irritants surface faster but are handled sooner; decision - making is enhanced and changes relating to resident care and quality of worklife are easily initiated. The responsibility for managing change rests mostly with the individual staff member. However, if one experiences a problem, it is quickly felt by others; group awareness then stimulates the need for timely resolutions. Regular case conferences allow opportunities to voice concerns and help to determine appropriate response to specific problems. A teamwork approach also serves to boost morale.

RESOURCES

Le Chez Nous benefits from the expertise of various health professionals. A local physician visits the Foyer once a week and sees Le Chez Nous residents requiring medical care. A geriatrician is available for consultation on program development and staff education. A psychogeriatric nurse consultant visits on a regular basis as do a music therapist and an occupational therapist. We also turn to a regional psychogeriatric assessment unit for advice on behavioural management issues and for occasional temporary admission of Chez Nous residents with behavioural problems requiring intensive therapy. These services are available to all long term care facilities in our area.

Our experience with Le Chez Nous brought to light a variety of unmet resident needs. Integration of confused and lucid individuals tended to obscure behaviour problems. Within the general population, the nature and extent of the requirements of the confused elderly were not evident. Segregation exposed several needs, in particular our need for the services of a social worker, a recreational therapist, a behaviour therapist and a separate and specific program of activities.

PROGRAMMING

Programming for persons with cognitive losses must be flexible, individualized and promote self esteem. A program's suggested characteristics include simple activities that offer a reasonable chance for success, programs that are integrated

with all activities of daily living and opportunities to participate in off-unit events. Involvement of family, friends and volunteers and a range of approaches such as music, dance, pets, crafts and exercise are also advised (Health and Welfare 1990). Activities should be meaningful, enjoyable, give satisfaction, sustain old roles, and significantly reduce the number of empty hours the resident experiences (Mace, 1987).

Le Chez Nous' programming philosophy is to provide a balance between understimulation and overstimulation. In lieu of *coping* with maladaptive behaviours, we seek to *prevent* their development through appropriate program activities.

BENEFITS.

Programs of activity are also designed for therapeutic benefits. Planned activities will help alleviate confusion and provide active and passive stimuli that will make the resident feel useful and active (Kromm and Kromm, 1985) and help maintain manual dexterity and cognitive status (Hall, Kirschling & Todd, 1986). Activity programs may also incite positive behaviour change in persons with dementing illness such as a decrease in wandering, agitation and screaming; improved orientation; weight gain; a reduction in drugs used to control behaviour; and a greater ability to sleep through the night (Mace, 1987).

Weaverdyck and Coons (1988) suggest that programming be designed to reflect, as much as possible, activities and routines typically incorporated in each resident's life prior to entering the dementia program and prior to the onset of the disease. This advice is consistent with Le Chez Nous' conceptual framework. Indeed, all Le Chez Nous activities consider the resident's past interests and abilities and are documented in the nursing care plan. For example, previous occupational roles are reflected in physical activities like wiping tables, sweeping floors or box gardening and wood sanding.

The generic staffing concept allows simple routine tasks to be incorporated into an activities of daily living program. As staff perform their duties, residents are encouraged to help. Thus, setting tables, clearing dishes, baking and making beds add to the residents' daily repertoire of meaningful activities.

LIMITATIONS

We encourage specific activities requiring simple instructions and few rules. Most Le Chez Nous residents have limited concentration spans and are easily distracted. Some are unable to move from one activity to the next. Many disassociate events and fail to perceive the whole. For example, in group activity, they will see their role but not that of the group. Our response is to design a program that elicits positive experiences in a non-threatening environment. For example, as staff perform tasks in crafts or food preparation, some residents watch and are encouraged to offer advice or reminisce. This provides opportunities for participation and praise without taxing attention spans.

Le Chez Nous residents have difficulty analyzing alternatives and making decisions. Games such as checkers or cards are inappropriate for moderate or severely impaired residents but carpet or table bowling and tossing horse-shoes, beach balls or bean bags offer a minimum of alternatives. Simple exercises are also well tolerated since mirroring the facilitator's movements requires few decisions.

Severely impaired Le Chez Nous residents do not tolerate off unit activities well. A different, overstimulating environment can trigger agitation and sometimes aggression. Upon return to the unit, agitated behaviour promotes similar conduct in other residents. For these reasons, unit activities are carefully selected and participation is closely monitored.

INDIVIDUAL VERSUS GROUPS

One-on-one interactions are more successful than group activity in Le Chez Nous' environment. Examples of popular one-on-one activities are looking at old photos, listening to music, dancing, doing household tasks, walking, cuddling pets, gardening, tossing horseshoes, bowling, exercising, talking and visiting, reading, outings and reminiscing.

CHOICES

Direct statements or commands tend to promote negative reactions from most Le Chez Nous residents. Efforts at manipulating behaviour are met by resistance and subsequent agitation. But some residents, especially those suffering mild impairment, respond well to simple choices that give them

control over an event. For example, a statement like "Come, Mr. Jeanson, it's time to go for a walk" may alienate the individual. It is better to offer a choice like, "Mr. Jeanson, would you like to go for a walk?" Giving information first about the activity is even more persuasive: "Mr. Jeanson, it's a sunny day and it's warm outside. Would you like to come for a walk and show me the new flowers?" Offering choices to residents with moderate or severe impairment may be perceived as threatening and should be avoided.

Consistency in scheduling helps to minimize confusion. Activities like making beds, sweeping floors, wiping tables and folding linen occur regularly. Residents come to expect these tasks which reinforce a time order in their lives and reduce the bewilderment often caused by new and unexpected responsibilities. Time order is reinforced even if residents do not participate but watch caregivers perform the tasks.

Consistency of scheduling is also influenced by a resident's emotional level. Another advantage of generic staffing is that staff can easily gauge resident's moods and schedule activities accordingly.

PROJECTS

Two projects developed by our programming department are particularly noteworthy: lifepanels and junior volunteer visits.

LIFEPANELS

Constructed by maintenance personnel of cork board and oak frames, our lifepanels measure 28 inches by 38 inches and hang on the wall adjacent to each door. A resident's lifepanel serves as a pictorial biography for relatives and friends and a constant reminder to all staff of the richness and fullness of each resident's personal history.

Each panel celebrates major milestones in a resident's life and includes general information on: place of birth, school attended, life's work and family history. Events are highlighted with photographs, ribbons, lace doilies, even three dimensional objects. For example, one carries a golf ball, another shows a favorite dance record and knitting needles and yet another displays pliers and a set square.

Family members were asked to supply materials, ideas and labour while our staff coordinated the project. Some embraced the concept and made it a family project while others chose to remain aloof and relied on Le Chez Nous staff to develop the panel.

The project yielded both expected and unexpected benefits. As anticipated, family and friends studied the panels and learned to appreciate the individual in each montage. Consequently, some family members now consider many Le Chez Nous residents their relative's extended family. Some members were grateful of the opportunity to temporarily reconvene the family unit to reminisce about good times and revive waning relationships.

We had not anticipated that residents would enjoy looking at their own and each other's panels, yet they do. One gentleman gets up three or four times a night to inspect his panel, touches it and then returns to bed. We've observed that when residents pause to view them, their wandering behaviour is interrupted. Staff capitalize on these pauses to initiate conversation.

JUNIOR VOLUNTEER PROGRAM

Our junior volunteer program began as a response to one resident's love of walking outside for lengthy periods but for whom, we could not provide appropriate supervision. The program has since grown to include other residents. Every day, after school, several 11 to 13 year old students meet in Le Chez Nous and engage selected residents in a 15 minute to one hour activity such as going out for ice cream, coffee or a stroll. The duration of activity varies for each resident but at some point before fatigue becomes evident, our volunteer redirects the resident back to Le Chez Nous. We've noticed that some residents in the program no longer require chemical restraints or sedation at night.

Resident tolerance of junior volunteers has been remarkable. We surmise that this favourable response is attributable to our young volunteers' lack of assertiveness. Residents are not intimidated by the students and are amenable to follow their direction.

EDUCATION

Establishing an alternative care unit carries with it the responsibility to ensure staff are appropriately trained. Coons (1987b) used a variety of training methods in her Wesley Hall training programs. We adopted several.

LECTURES

The education program began with a series of six mini-lectures dubbed "Brown Bag" inservices. They were presented over dinner and open to all Foyer staff. Each session lasted 30 minutes and was repeated twice to accommodate as many employees as possible over dinner break. Topics included were: Mental Illness; the Jargon of Mental Illness; the Brain: Normal Anatomy; the Diseased Brain; Alzheimer's: Its Cause and Progression; and New Theories, New Causes, New Treatments. The "Brown Bag" inservices were successful to the credit of most staff who participated during their breaks without remuneration. Learning packages were compiled for those unable to attend.

Supervisors from activity, housekeeping and dietary departments also presented informal inservices on specific tasks transferred from their departments to Le Chez Nous.

VIDEOS

Numerous videotapes on topics relating to dementia serve to sensitize Foyer employees to the unique needs of its cognitively impaired population.

WORKSHOPS

The Foyer hosted two workshops with guest speakers of national reknown. One addressed the topic of supportive therapy for the mentally impaired elderly; the other focussed on response to difficult behaviours in cognitively impaired persons. Both were day long workshops. The publicity generated by these events boosted staff morale and self-esteem.

CONSULTANTS

Some resident management problems require extramural expertise. Le Chez Nous staff participate in the problem solving process with the consulting person or agency in such circumstances. This presents unique educational opportunities and staff involvement is encouraged.

VISITS

Tours of other alternative care units stimulate interest, invite comparison, and promote sharing of ideas and resources. Staff return to Le Chez Nous with a greater appreciation for what has been accomplished in their own community, reinforcing a sense of pride and self-esteem.

The goals of an education program in an alternative care setting are to assist staff in effecting a role transition from caretakers to enablers, help them expand their repertoire of therapeutic approaches, and promote positive attitudes towards persons with cognitive impairment. The training methods described above create favourable circumstances for achieving these goals.

FAMILY ORIENTATION

An orientation program, implemented by our social work department, serves as a learning experience for interested relatives and enhances support for Le Chez Nous' goals. Understanding and accepting Le Chez Nous' philosophy is critical to family satisfaction.

Family attitudes and perceptions are best developed in the early stages of their relationship with us. Several key themes are stressed during orientation. We discuss:

- the importance of the environment and how it influences affect and behaviour;
- why aberrant behaviour in cognitively impaired individuals does not necessarily reflect the quality of pre-admission relationships;
- how an individual loses control of feelings, attitudes and behaviour as a result of physical

deterioration of the brain, and the stress this exacts on family relationships;

- the necessity of physical freedom and how eschewing restraints enhances the quality of life;
- the relevance of circadian rhythms and how we strive to accommodate each resident's internal time clock;
- why we spurn nagging and negativism as these tend to escalate frustration and aggression;
- how we attempt to create a home atmosphere that approximates family life.

We emphasize to families that resident needs come first and other duties assume lesser importance. They must understand that an unmade bed at 1100 hours doesn't reflect neglect; it means that other, important needs took precedence. Families are also cautioned to expect misplaced items as all residents are free to wander and may enter another's room, pick up objects of interest and forget to return them.

EVALUATION

FAMILY SURVEY

Our social worker interviewed 8 families (2 by phone and 6 one-to-one) to determine how they perceived their relative's well-being after admission to Le Chez Nous. The relatives length of residency in Le Chez Nous ranged from five months to 30 months.

When asked if they had noticed changes in their relative's behaviour, all responded with favourable comments such as "seems happier, more relaxed, more socially active, smiles more, more talkative, memory is better". Families attributed the changes to the environment, programming and quality of staff.

We also asked families if they felt at ease contributing to their relative's care. Some families enjoyed the opportunity to assume a partnership in care, others did not wish to be involved except for occasional calls from staff advising of a change in

health status or requesting approval or support for decisions made on their relative's behalf. Some families were still coping with grief and their comments reflected their distress. Others had rationalized their contributions and felt comfortable with what they could offer.

The desired outcome of family involvement in resident care is a partnership between friends and relatives and caregivers. Each partnership may vary in the degree of involvement but all contribute in some measure to the resident's well-being.

DRUG USE AND BEHAVIOUR CHANGE

Assessing our experience with Le Chez Nous was done both formally and informally. We collected data on drug use, elopements and acts of aggression. Also, six months after Le Chez Nous' inauguration, we polled all Foyer staff on their perception of the benefits of the new unit to all residents. Informally, we interviewed Le Chez Nous personnel on their impressions of their work environment.

- a) **Drug Use** Our pharmacy department monitored psychotropic drug use for six residents, over a period of three months prior to Le Chez Nous' opening and for two years thereafter. After sixteen months on the unit, three of the six residents no longer required antipsychotic medications. The data suggest a relationship between the environment, therapeutic intervention and psychotropic drug use.
- b) **Elopement** Elopements were tracked by the Foyer's Quality Assurance program. We witnessed a dramatic decline in elopements shortly after Le Chez Nous opened. Several variables may account for this:
 - most residents prone to wander and elope were admitted to Le Chez Nous;
 - the unit is smaller and easily supervised;

- residents are free to walk outside in the enclosed inner court and the enclosed patio;
- families take the residents out more;
- junior volunteers also take some residents out for short excursions. The energy consumed in these activities probably satisfies the need to wander;
- with less noise and traffic in Le Chez Nous, residents no longer feel compelled to wander to avoid noxious stimuli.

c) **Aggressive Behaviour** Aggressive acts were numerous when residents were integrated. A decrease in the incidence of aggression accompanied segregation. Some reasons why this occurred are:

- the more aggressive residents suffered from dementia and were admitted to Le Chez Nous;
- Le Chez Nous staff know the residents well enough to anticipate aggressive behaviour and preempt it through diversion, withdrawal and other approaches;
- the unit is smaller and residents are not as frustrated since they don't get lost as easily or as often;
- the balanced stimuli environment exerts a calming effect;
- a smaller population presents fewer opportunities for interactions that trigger aggressive acts.

STAFF SURVEY

In a staff survey conducted six months after Le Chez Nous opened, we sought feedback on two main questions: "Is the Foyer's general resident population benefitting from Le Chez

Nous?" and, "Are the residents in Le Chez Nous benefitting from their new environment?"

Almost all staff members concurred that Foyer residents benefitted from the change. Some identified a return to a peaceful and relaxed atmosphere as the greatest benefit; others cited the absence of wanderers. Greater security with personal possessions, a sense of relief from the constant threat of physical aggression, and the return of respect for individual privacy were highlighted as important improvements in the Foyer's residents' life. Some staff members expressed relief at no longer having to protect lucid and confused residents from aggressive acts. Finally, a decline in elopements meant fewer disruptions and more nursing time to devote to resident care.

When asked if residents in Le Chez Nous benefitted from their new environment, most responses were affirmative. If the advantages of Le Chez Nous could be reduced to one word, it would be freedom: freedom from paternalism, freedom from regimentation, freedom from restrictions on movement and freedom from noise pollution. Le Chez Nous' benefits were readily apparent to staff. They cited, as a direct result of these freedoms, a safer environment for both staff and residents, diminishing incidences of aggressive acts, less agitation and confusion and a happier resident. Voicing a sentiment on worklife in Le Chez Nous, one staff member noted, "It's what I thought nursing was going to be like when I first started in the profession".

ENVIRONMENT

Some aspects of Le Chez Nous experience were unsuccessful. Most pertained to the physical structure.

Water taps were a problem. Occasionally, residents would open water taps and wander away, leaving sinks to overflow. The problem was resolved by installing spring loaded handles that close upon release of hand pressure.

The water fountain in the inner courtyard proved a source of intense interest for residents but their safety was compromised when they approached the small pool out of curiosity. The fountain water jet was disconnected, eliminating the distraction.

While entry and exit to the unit must allow ease of transit for staff and visitors, Le Chez Nous residents must be

deterred from leaving. Ordinary door hardware and a disguised bolt action lock requiring simultaneous use of both hands to open the door, discourages moderate and severely impaired residents but does not deter mildly impaired residents. We are still seeking a satisfactory solution to this problem.

CONCLUSION

As we approach a new millennium and experience a shift in the demographic curve towards longer lifespans, the percentage of elderly in the general population will rise dramatically. A high risk of cognitive impairment accompanies longevity, especially in the 85 and over age group (Health and Welfare Canada, 1990). Initiatives are required now to ensure health care environments can adjust to these needs.

Our model offers several attractive features:

- it is adaptable to many existing long term care environments;
- it can be implemented with homegrown talent and expertise;
- it can be developed without government funding yet comply with standards of care;
- it can become a focus of community involvement and a source of community pride.

For the smaller long term care facility, Le Chez Nous' conceptual framework offers an innovative, practical and cost effective model that enjoys a wide range of application yet meets present and future accommodation needs of individuals with cognitive losses.

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**PART II: BEHAVIOURAL INTERVENTIONS AND
ENVIRONMENTAL DESIGN ISSUES**

5

NON-PHARMACOLOGICAL APPROACHES TO MANAGEMENT OF PATIENT BEHAVIOUR: A FOCUS ON BEHAVIOURAL INTERVENTION FOR DEPRESSION IN DEMENTIA

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INTRODUCTION

This chapter provides a framework from which to understand and work with behavioural problems in demented adults. Although a growing body of clinical knowledge is available in this area, empirical studies are much less plentiful. Consequently, both clinical and empirical literature concerning assessment and treatment of behavioural problems in demented older adults are presented. In particular, an intervention is described which relies on the application of behavioural theory to treat depression in demented adults.

Although depression represents only one type of behaviour, its conceptualization, assessment, and treatment from a behavioural framework may offer a model from which to investigate and treat other behavioural disturbances of demented older adults. Because the theoretical rationale to behavioural intervention is straightforward and based on the application of operant and classical conditioning, it can be applied across a broad range of settings. This potential for effective application in clinical as well as non-clinical environments heightens the significance of this approach.

BACKGROUND

Before discussing the specific rationale for behavioural assessment and treatment of depression in dementia, the importance of identifying and working with behavioural problems from a non-pharmacological perspective must be addressed. A wide range of behavioural problems have been

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found to be prevalent in demented older adults. These include, but are not limited to, depression, agitation, aggression, wandering, anxiety, inappropriate sexual behaviour, hallucinations, delusions, paranoia, suspiciousness, and problems of daily living, such as trouble with personal hygiene, dressing and eating (Reisberg, 1987; Merriam et al, 1988; Swearer et al., 1988; Teri et al., 1989, Teri, Larson & Reifler, 1988). Such problems frequently are a primary source of stress for families and staff (Barnes et al., 1981; Deimling & Bass, 1986; Drinka, Smith & Drinka, 1987; Greene et al., 1982; Haley, Brown & Levine, 1987; Niederehe et al., 1983) and represent a primary reason families seek to institutionalize the patient (Chenoweth & Spenser, 1986; Sanford, 1975). Consequently, effective management of behavioural problems has far reaching implications.

Abundant clinical material is available to suggest methods for dealing with these behavioural problems (Mace & Rabins, 1981; Powell & Courtice, 1983; Zarit, Orr & Zarit, 1985). Oftentimes, behavioural techniques are included in such suggestions. For example, it is often recommended that care providers change patient behaviour by modifying the environment (such as putting labels on drawers and removing dangerous items from view) or changing their response to patient behaviour (such as suggesting care providers substitute simple, concrete directions for complex instructions in order to facilitate patient compliance). Clinical wisdom suggests these techniques are advantageous, even when applied on a trial and error basis, yet very little research exists on the efficacy of such suggestions. There is a disappointing lack of theoretically based, clinically sound, and scientifically evaluated methods of behaviour management with demented patients.

This is not to suggest that no research is available. A growing body of literature suggests that a variety of behavioural techniques can be successfully employed for a range of behaviours, including (but not limited to) depression, independent eating, social interactions, social conversation, wandering and exit-seeking. Successful techniques have included full system interventions, such as token economies, and more individualized strategies, such as shaping, stimulus control, and social reinforcement (Baltes & Zerbe, 1976; Blackman, Howe & Pinkston, 1976; Hussian, 1981, 1983; Hussian & Brown, 1987; Hussian & Davis, 1985; Hussian & Lawrence, 1981; Konarski, Johnson & Whitman, 1980; Linsk & Pinkston, 1984; McClanahan & Risley, 1974, 1975; McDonald, 1978; Panella, 1986; Patterson & Jackson, 1981; Teri, 1986; Teri & Uomoto, 1986). A number of programs have also been

reported in which caregivers are provided with a broad-based approach to assist them in a multitude of patient management issues and these often include behavioural strategies (e.g., Aronson, Levin & Lipkowitz, 1984; Zarit & Anthony, 1986; Mohide et al, 1990; Lazarus et al., 1981).

There are a number of advantages to non-pharmacological rather than pharmacological management of behavioural problems in dementia patients. One of the most important is avoiding the difficulty of managing medications in cognitively impaired adults. The fewer medications prescribed, the fewer chances there are for problems associated with medication interactions or misuse. Medications which are contraindicated for some patients because of coexistent medical conditions can be avoided. Finally, the potential for central nervous system toxicity is reduced when drug intake is reduced.

DEPRESSION IN DEMENTIA

Depression is widely recognized as a significant problem among patients with dementia. Although estimates vary, it is generally agreed that 30% of patients with dementia have a coexistent depressive disorder (Teri & Reifler, 1987). In addition, an equal and often higher percentage of patients exhibit depressive behaviours such as tearfulness, feelings of worthlessness, suicidal ideation, and lack of interest in previously enjoyed activities (Teri, 1986). Depression and depressive symptoms can add "excess disability" to the clinical picture of such patients, causing additional difficulties which hinder proper care. For example, dementia patients with depression have more functional disability than those with comparable levels of dementia but without depression (Pearson et al., 1989). Depression and depressive symptoms are also highly associated with caregiver stress and burden (Drinka et al., 1987; Greene et al., 1982; Niederehe et al., 1983; and Teri et al., 1989). Thus, depression adversely impacts both the patient and care provider. Treatment may assist both.

BEHAVIOURAL TREATMENT OF DEPRESSION IN DEMENTIA

Behavioural intervention for depressed patients with dementia is based upon the social-learning theory of depression proposed for non-demented adults by Lewinsohn and his colleagues (Lewinsohn et al., 1984). Depression is viewed as a

behaviour. As with any behaviour, it is learned and maintained through positive and negative reinforcement contingencies. Depression is maintained by a series of person-environment interactions characterized by a deficit of positive experiences and an excess of aversive experiences. Consequently, the central aim of intervention is to modify these contingencies by increasing the level of positive and decreasing the amount of negative ones (Lewinsohn et al., 1984).

This is not to imply that behavioural intervention is simplistic, nor that it ignores the affective and cognitive components of intervention. Because the modification of interactions involves the careful analysis and treatment of depressive *behaviours*, these behaviours are the focus and emphasis of intervention. This subsumes, but does not deny, the emotional and cognitive aspects of the disorder. Rather, it stresses that depression can be reduced or eliminated by altering the contingencies that maintain depressive behaviours and introducing new contingencies to stimulate and maintain non-depressive behaviours. This pattern of response to environmental contingencies suggests the cycle of depression can be interrupted. Once interrupted, it can be redirected toward remission.

This theoretical formulation and its related treatment techniques have been extrapolated to depressed demented patients (Teri, 1986). Depression in patients occurs and is maintained by the same system of positive and negative reinforcers as in non-demented patients. To wit, the absence of pleasant experiences and/or the presence of aversive experiences maintains depression: patients can no longer do many of the activities they once enjoyed; they can no longer function as independently as they once could and, therefore, they experience more aversive events. A pattern of learned maladaptive behaviours is initiated, and the subsequent interaction between behaviour and environment exacerbates and perpetuates depression. This formulation takes into account the affective and cognitive aspects of the disease. Patients with dementia, especially in the early stages, may realize their memory and level of functioning are impaired, they may disproportionately focus on their problems and experience an over abundance of negative thoughts to the exclusion of positive ones. Thus, intervention may need to address these maladaptive cognitions as well as actual behaviour much as it does in non-demented depressed adults (Beck et al., 1979). Behavioural intervention is tailored to the individual and also takes into account the larger biopsychosocial environment. In

order to effectively manipulate contingencies to alter behaviour, understanding the full context of that behaviour is necessary.

SEATTLE PROTOCOL FOR BEHAVIOURAL TREATMENT OF DEPRESSION IN DEMENTIA

The Seattle protocol for the behavioural treatment of depression in dementia includes the patient and the caregiver, who meet with a trained geropsychologist for nine weekly one-hour sessions. The goal of each session is to teach caregivers behavioural strategies for improving the patient's depressed mood based on the theoretical model described above.

The first step of intervention is to fully explain the behavioural rationale of treatment to be sure both caregiver and patient understand and agree. Realistic and explicit treatment goals are established. Behavioural change principles are taught to the caregiver, and to the extent possible, to the patient. Caregivers learn how to identify and prioritize problems, specify what behaviours occur under what conditions, plan a behavioural intervention, evaluate the success of that intervention, and modify the original intervention to accommodate changing abilities and needs. After learning strategies for changing behaviours, caregivers and patients identify pleasant activities that are to be increased. The Pleasant Events Schedule - Alzheimer's Disease (Teri & Logsdon, 1991) is often used to assist them in doing so. This instrument lists 53 potentially enjoyable activities for dementia patients. Subsequent sessions focus on identifying, planning, and increasing pleasant events.

Each day, the caregiver is asked to rate the patient's mood and record the frequency and duration of pleasant events that took place. The therapist works closely with the caregiver and patient to identify pleasant activities that are realistic to attempt to increase. The therapist then helps the caregiver plan and carry out these activities. Often, in order to increase activity, patients and caregivers must learn the prerequisite skills to accomplish that goal. Various techniques are taught, including strategies for identifying and confronting behavioural disturbances that interfere with engaging in pleasant activities, methods to decrease the occurrence of problem behaviours, and ways to increase the occurrence of incompatible behaviors. The caregiver's own role in determining patient behaviour is also addressed. Ways to alter negative cognitions, engage in effective problem-solving, and identify and address sources of caregiver

burden are all discussed. The patient is encouraged to participate in treatment and contribute as much as feasible, given his/her level of cognitive impairment.

RESEARCH FINDINGS

Currently, this protocol is being used in a clinical setting and evaluated as part of a controlled, randomized trial in which it is compared to traditional clinical care (treatment-as-usual) and a wait list control. Pre-, post-, and one, six, and twelve month follow-up assessments are scheduled. In these, patient and caregiver characteristics are assessed, including cognition, affect, behaviour and health. Preliminary results look quite promising.

In the first report of this intervention, Teri (1986) reported that caregivers were successfully able to understand the principles behind behavioural treatment of depression in dementia patients and learn to increase patient pleasant activity. In each case, an increase in pleasant activity was accompanied by a decrease in depressed mood. Expanding upon this, Teri & Uomoto (1986) described two cases in which the association between depressed mood and pleasant events was investigated. Significant relationships were obtained between patient depressed mood and the number of pleasant events engaged in (frequency) and the amount of time spent in such activity (duration). A higher frequency and longer duration of pleasant activities were significantly related to less depressed mood. Once again, caregivers were successful in increasing the frequency and duration of pleasant events and decreasing the patients' level of depressed mood. Data from other cases support this association between mood and pleasant activity, and the ability of caregivers to increase both. One such case may help illustrate these findings (Teri & Uomoto, 1991).

Mrs. B. was a 74-year-old Caucasian female with Alzheimer's disease. Over the previous three years, her memory difficulties, confusion, and disorientation had worsened, to the point where she needed assistance with complex tasks (such as banking) but was able to care for herself and live alone. At intake, her Mini-Mental State Exam (Folstein, Folstein & McHugh, 1975) score, an index of global cognitive functioning, was 21, placing her in the mildly to moderately impaired range. In addition to being demented, Mrs. B. was clinically depressed. She was often tearful and sad, and complained of fatigue and feeling worthless and lonely. She had trouble sleeping, had a poor appetite, and was psychomotorically slowed. At intake, her

Hamilton Depression Rating Scale (Hamilton, 1967) and Beck Depression Inventory (Beck et al., 1961) scores, of 22 and 24 respectively, indicated moderately severe levels of depression.

Mrs. B's primary caregiver was her 47-year-old son. He was unmarried and although he did not live with her, saw her every day and spent at least one hour each time. He was also in daily contact with a paid homemaker-companion who lived with the patient.

Table 1 presents the means, standard deviations, and *p* values for the patient's mood ratings, level of pleasant events and depression scores for three phases of observations: pre-treatment, post-treatment, and one month follow up.

**Table 1:
MEANS AND STANDARD DEVIATIONS
FOR MOOD RATINGS AND PLEASANT EVENTS
FOR MRS B.**

Measures	Pre-Treatment A	Post-Treatment B	One Month Follow-Up C	F ^a	Post Hoc Analysis
Daily Mood Rating	3.0 (0.68)	5.3 (1.50)	7.1 (0.90)	19.80**	B,C > A
Pleasant Events					
Duration (Hours)	0.0 (0.0)	4.1 (1.97)	4.7 (0.95)	35.18**	B,C > A*
Frequency (#/Day)	0.0 (0.0)	2.0 (1.00)	2.4 (0.54)	33.18	B,C > A*
Hamilton Depression					
Rating Scale	22	12	N/A	N/A	
Beck Depression					
Inventory	24	9	N/A	N/A	
^a df = 2,56	*p < .05	** p < .001			

As can be seen, the patient's mood, depression, and level of activity improved from pre- to post-treatment and continued to improve at one month follow-up. Although statistical analysis of the depression measures is not feasible, the changes obtained are clinically significant and were verified by the caregiver's subjective report. Since mood and activity ratings were collected each day, analyses of these ratings were conducted. A one-way ANOVA across the three phases was significant. Neuman-Keuls

post-hoc analyses revealed ratings significantly increased from baseline to treatment. This improvement was maintained at follow-up.

Preliminary group data from the controlled clinical trial support these positive findings (Teri, 1990). Pre- and post-treatment gains have been found on measures such as the Beck Depression Inventory and the Hamilton Depression Rating Scale. Improvement on other indices of function (such as troublesome behaviours and caregiver affect) are also evident.

While the ultimate utility of this approach cannot be established until further data from the controlled clinical trial are available, it appears that caregivers are able to alter both the patients activity level and their depressed mood.

Three aspects of this intervention are especially worthy of note. First, the intervention is very structured and involves a gradually increasing approach to re-involving the patient in pleasant activities and altering the contingencies which maintain depression. Each strategy is integrated into a structured and well thought out intervention aimed at the particular complaint or constellation of complaints that seem most relevant for a given patient. Second, the caregiver, who is often a family member, is enlisted to assist with these efforts, which are accomplished in a natural setting. Although many activities patients previously enjoyed are no longer available to them (due to a variety of factors, including their degree of cognitive impairment, physical limitations, and/or limited community access), therapists assist the caregiver in identifying "new" and realistic enjoyable activities. Third, few contraindications exist. Behavioural intervention is a benign treatment which can be offered instead of or in conjunction with other medical interventions. The main requirement is that caregivers and patients are willing and able to devote the time and effort necessary to successful intervention. This last point is not trivial. Indeed, for patients without involved caregivers, behavioural intervention may possess unique problems in implementation. Thus far, however, this intervention offers an optimistic approach to reducing depression in patients with dementia.

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6

BEHAVIOUR AND USE OF SPACE BY RESIDENTS OF SPECIAL CARE AND INTEGRATED NURSING HOME UNITS

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INTRODUCTION

The greying of Canada and other countries has resulted in a dramatic increase in age-related diseases. Dementia is one of the most costly, both in terms of financial burden and human suffering. Recent estimates (Evans et al., 1989) are that one in four community dwelling people aged 80 and over is demented. Since the 80 and over age group is the fastest growing segment of the population, current problems are only a warning for what is coming if advancements in knowledge from research are not forthcoming.

The most prevalent form of dementia among the elderly is Alzheimer's disease, which accounts for as much as 50% to 60% of all dementia cases (Katzman, 1986; Mortimer & Hutton, 1985; Weiler, 1987). Research from many different perspectives is being pursued concerning causes, cures and medical interventions for this and other dementias. As with other neurological and brain disorders, however, it is unlikely that a cure will be found in the near future, even if the causes of dementia are identified (U.S. Congress, Office of Technology Assessment, 1987). In the meantime, we must deliver services and care for increasing numbers of demented persons. Delivering adequate services and providing appropriate care presupposes knowledge about the symptoms and attributes of the disorder.

The care of dementia patients presents an interesting anomaly within the traditions of the health care system. This is because these patients ordinarily are healthy, perhaps even

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inordinately healthy (Wolf-Klein et al., 1988). Thus their care is outside the usual context of nursing care. Instead, it focuses on managing behaviour associated with progressive decline in intellectual functions. This means that behaviours of cognitively impaired patients must be known in order to tailor management programs appropriately. The behaviours displayed by dementia patients do not, however, occur in a vacuum: they occur in physical and social environmental contexts. There is now growing recognition (Coons, 1985; Gutman, 1989; Lawton, 1980) that an understanding of person-environment interactions can contribute to improving the functional abilities of both cognitively impaired and non-impaired patients. Cluff (1990) notes the need to identify and foster supportive physical environments that compensate for functional limitations and disabilities while at the same time dealing with related programming, staffing and operational issues.

Rule, Milke & Dobbs (in press) have reviewed the effects of a variety of physical and social aspects of the environment that can enhance the functioning and well-being of residents. The purpose of this chapter is to review empirically based descriptions of behaviour and the influence of the psycho-social environment. First, studies delineating the behaviours of institutionalized residents will be presented. Next, the use of space and its relation to behaviour will be considered. Finally, the impact of Special Care Units will be reviewed.

BEHAVIOUR OF DEMENTED RESIDENTS

The development of appropriate programs for in-home and institutional care of dementia patients depends on knowing the behaviour patterns of these patients. There has, however, been surprisingly little systematic documentation of their behaviour.

The clinical lore describes the demented person as aggressive, absconding, wandering, trespassing, gathering objects and generally antisocial (Pynoos & Stacey, 1986). The reported lore among caretakers (Bartol, 1979; Hoffman et al., 1985; Langman & Panieveci, 1982) focuses on the Alzheimer patient's lack of communication skills and asocial nature, as well as their gathering and wandering. Some of these negative behaviours may contribute to the decision by informal caregivers to institutionalize the patient (U.S. Congress, Office of Technology Assessment, 1987), and they can present serious problems for formal caregivers (Morishita, 1990). Important questions for daily management of demented residents include:

- What are these problem behaviours?
- When and where do they occur?
- To what extent do problem behaviours represent the repertoire of resident behaviours?
- To what extent does the physical and social setting affect the frequency of such behaviours?

Only a few studies have provided systematic observations of daily activities of nursing home residents. Although some pioneering studies did use observational techniques, the researchers themselves note that they utilized relatively gross measurement procedures, examined global categories of behaviour and did not assess behaviours that are of special relevance to demented residents (e.g. Brent, Brent & Mauksch, 1984; Kahana & Kiyak, 1984; McClannahan & Risley, 1975; Lawton, Patnaik & Kleban, 1980; Lawton, Liebowitz & Charon, 1970). It is only recently that more comprehensive and systematic measurement schemes have been developed.

AGITATED BEHAVIOUR

An extensive program of research by Cohen-Mansfield and her colleagues has focused on agitated behaviour in institutions. These researchers (Cohen-Mansfield & Billig, 1986) define agitation as "socially inappropriate verbal, vocal or motor activity that is not a necessary by-product of a medical condition" (p.712)].

Cohen-Mansfield, Werner and Marx (1989) observed and directly recorded selected behaviours of 24 cognitively impaired nursing home residents during each hour of the 24 hour day for 2-3 months. These residents were selected on the basis of their high levels of agitation as well as cognitive impairment, and were undesignated cognitively impaired, physically impaired residents, and from Alzheimer units. The Agitation Behavior Mapping Instrument (ABMI) used to record their behaviour included the following items considered symptomatic of agitated behaviour: negative verbalizations, throwing things, disrobing or exposing oneself inappropriately, repetitious movements, pacing, aimless walking, requests for attention or help, asking questions, making strange noises, rigidity, and getting out of restraints. The results revealed that agitated behaviours, particularly making strange noises, requests for attention, repetitious mannerisms, picking at things, making

strange movements and pacing, occurred at very high frequencies. Daytime agitation was positively associated with nighttime agitation. The particular patterns of agitation were idiosyncratic, however, to each resident.

In another study (Cohen-Mansfield, Marx & Rosenthal, 1989), 408 nursing home residents were rated by nurses for frequency of 29 agitated behaviours using the Cohen-Mansfield Agitation Inventory (CMAI). Agitation was manifested most often during the day and least often at night. The agitated behaviours rated as most frequently occurring were: general restlessness, pacing, repetitive sentences, requests for attention, complaining, negativism and cursing. Three syndromes of agitation were identified by factor analysis: aggressive behaviour, physically non-aggressive behaviour and verbally agitated behaviour. These factors were stable across all nursing shifts, indicating that the syndromes were specific to individuals.

Cohen-Mansfield, Marx & Rosenthal (1990) investigated the link between cognitive functioning and agitation. They found that cognitively impaired residents were more aggressive (e.g. cursing, hitting) and physically nonaggressive (e.g. pacing) whereas cognitively intact residents were more verbally agitated, as revealed by complaints. The greatest amount of physically nonaggressive behaviour occurred in residents who were moderately unimpaired in their activities of daily living.

It is clear from these and other studies (Cohen-Mansfield, 1986, 1988; Cohen-Mansfield & Marx, 1989) that individual differences in agitation must be recognized in order to develop appropriate intervention strategies.

OTHER BEHAVIOURS

Although the above findings are very important for understanding highly agitated people, they do not provide descriptions of demented individuals who are not highly agitated nor of the non-agitated behaviour displayed by demented people.

A broader description of the activities of nursing home residents is provided by Dobbs and Rule (1991a; 1991b). In their research, both cognitively impaired and non-cognitively impaired residents were observed during a 12-hour period from awakening to bedtime. The behavioural coding scheme used included items pertaining to:

- **location of residents**
- **appropriate behaviours** (e.g. appropriate social interactions, friendly gestures, activities, ADLs)
- **problem behaviours** (e.g. gathering, unusual behaviours, verbal and physical aggression, inappropriate, incomplete ADLs)
- **mobility** (e.g. walking, wheelchair mobility)
- **inactivity** (e.g. sleeping, standing, sitting and doing nothing else)

The first nursing home studied (Dobbs & Rule, 1991a) had a separate pod for demented residents and one for relatively high functioning residents.¹ Several interesting differences between the groups were found. For example, although the demented residents *were inactive most of the time*, they exhibited more ambulatory behaviour, described anecdotally as wandering, pacing, or group walking, than non-demented residents. They also showed socially appropriate behaviour less than half as frequently as non-demented residents. Nonetheless it should be noted that they manifested far more appropriate (25% of the time) than problem behaviour (7% of the time). Further, although the higher mobility of demented persons is consistently interpreted as a sign of agitation, potentially dangerous and a negative behaviour, Dobbs and Rule (1991a) observed that group walks were very social and associated with positive behaviour.

Wandering, another index of mobility which is considered to be a dangerous attribute of the cognitively impaired, has seldom been adequately defined and researched (Morishita, 1990). A study by Milke (1989) yields some interesting findings. Defining wandering as a cluster of behaviours (including restless locomotion, absconding, having navigational difficulties, searching and group walking) Milke found that various nursing home residents engaged in significantly different amounts of wandering behaviour. She also found that staff ratings were not good predictors of individual differences in actual wandering, nor was there any

¹ Individuals with highly disruptive behaviours were not retained as residents in these facilities.

consistency in staff definitions of wandering. Restless locomotion represented a sizeable proportion of most of the Alzheimer residents' time, but was not an antecedent of absconding. Lag sequential analysis showed that a repetitive three-component-sequence characterized wanderers: restless locomotion interspersed with navigational difficulties and group walking. There were very few incidents of absconding from the floor and wanderers did not differ from non-wanderers in absconding frequency. These results certainly do not confirm expectations based on anecdotal impressions!

USE OF SPACE BY DEMENTED AND NON-DEMENTED RESIDENTS OF LONG TERM CARE INSTITUTIONS

Behaviour occurs in a context and characteristics of the physical and social environment affect residents' behaviour. Because of this, one would expect the design of long-term care institutions to be based on solid knowledge of the interaction between the person and the environment.³ Unfortunately, the design of institutions tends to be driven more by aesthetic judgements made by younger people and by government building codes based purely on physical and safety considerations. There is little empirical information relevant to understanding person-environment interactions among persons residing in long-term care institutions; even less as regards Special Care Units.

Calkins (1987) notes that the number of Special Care Units is increasing at a rapid rate because of the recognition that dementia patients may have unique needs and staff may need special training. These needs, however, have been identified almost solely as psychiatric ones. Advancements in the development of these units could be made through a better understanding of the relative effectiveness of the different physical and social aspects of the environment. This could be accomplished through documenting whether:

- demented and non-demented residents differ in their use of space,
- positive and negative behaviours occur in particular locations and are engendered by particular aspects of the physical environment, and

- the social context of Special Care or integrated units differentially affects the activities of demented and non-demented patients.

Focusing on agitated behaviour, Cohen-Mansfield, Werner and Marx (1990) recorded the physical location and specific agitated behaviours of highly agitated and cognitively impaired nursing home residents over a three - month period. Agitation occurred most frequently at particular locations, including the toilet, corridor, the nursing station and the room of another resident. Agitation was observed less frequently in their own rooms, although they spent a great deal of time in that location. Particular types of agitation were observed in specific locations. Residents paced most frequently in the corridor, around the nurses' station and in resident rooms other than their own. Verbal agitation and aggressive behaviours were manifested mainly in places where the residents might need assistance (e.g. the toilet). These findings have implications for managing the behaviour of highly agitated residents and provide information about locations in the physical environment that deserve special attention. They are limited, however, by lack of control and comparison groups, as well as by their focus only on agitated behaviours.

Dobbs and Rule (1991a) compared the spatial distribution of Alzheimer and non-cognitively impaired people, where each group was housed in segregated wings of a nursing home. The demented residents were off the floor rarely, whereas the non-demented residents were off the floor about 25% of the time. The Alzheimer patients spent three-quarters of their time in their lounge and hallway and less than a quarter of the daytime hours in their own rooms. The use of space by non-demented residents was reversed, with most of their time spent in their own rooms and little time spent in their lounge or hallway areas.

There are two very different interpretations of the heavy use of their own rooms by the higher functioning residents. On the one hand, the time spent in their own rooms may be used in constructive and adaptive ways. Perhaps they enjoy privacy with the opportunity to engage in higher focal activities (such as writing letters or reading), in low focal activities (such as watching television), or in socializing with selected other people. In this case, greater attention and resources should be directed toward furnishings and other attributes of residents' rooms. On the other hand, the choice of location could be maladaptive, indicating withdrawal and social isolation. In this case, greater attention should be directed toward programs and

attributes of other areas to increase their use and promote socialization.

An examination of the behaviours displayed by non-demented residents in their own rooms supported the maladaptive interpretation. Over 50% of the time they were inactive, doing nothing, while in their own rooms. Much less of the time was spent in activities involving higher (30%) or lower (7%) levels of skills. Social interactions occurred rarely (7%) in a resident's own room. These results are suggestive of withdrawal and add to the growing concern about depression and isolation among otherwise non-impaired residents of institutions. They also are consistent with the reports of other researchers (e.g. Lawton, 1991; McClannahan & Risley, 1975).

Despite the fact that the demented residents spent most of their day in the lounge and hall areas, whereas the non-demented spent relatively little time in their lounge, the lounge on the Special Care Unit was the smallest and the one used for storage of recreational and other materials. Clearly, the heavy use of this lounge by the demented residents means it is the area that should have received the greatest (not the least) attention. Efforts directed toward developing a supportive environment (see Rule, Milke & Dobbs, in press) could help to accommodate cognitive dysfunction and, perhaps, reduce some problem behaviours.

BEHAVIOUR IN INTEGRATED FACILITIES AND THOSE WITH SPECIAL CARE UNITS

The role of the social environment in affecting residents' behaviour and well-being has been the topic of considerable discussion lately. One focus of debate and sometimes heated discussion has been the question of the efficacy of Special Care Units. Those favouring integration emphasize that higher functioning persons provide stimulation for demented residents and that benefits accrue to the non-demented by increased responsibility in caring for demented residents. On the other hand, others believe that Special Care Units are better able to accommodate the unique needs of, and provide specialized caregivers for, demented residents, as well as allowing freedom from hassle for non-demented residents.

In their reviews of some published and several unpublished reports of the relative efficacy of Special Care Units, Ohta and Ohta (1988) and Gutman (1989) highlight the

lack of empirical assessment of the potential differences between segregated and integrated facilities. Because Gutman (1989) thoroughly reviewed the literature, giving details about the issues, they will not be reviewed here.

In our research (Dobbs & Rule, 1991b), we compared the activities and spatial distribution of behaviour of demented and non-demented people residing in two integrated and two segregated facilities. The coding scheme used, again consisted of categories for: location of residents, appropriate and problem behaviours, mobility, and inactivity.

USE OF SPACE BY DEMENTED RESIDENTS

The demented residents on integrated units spent considerably more time in their room (44%) than the demented residents on segregated units (26%). There was greater use of public areas (halls, lounge, dining area) by demented residents in Special Care Units (53%) than by those in integrated units (36%). The data clearly indicate that at least for these four facilities, demented residents in integrated social environments spent more time in private areas (own room) and less time in public areas than demented residents on Special Care Units. These findings have an interesting and potentially very important implication. They are consistent with the suggestion that in "integrated" facilities demented residents are actually segregated in their own room most of the time. If this can be confirmed by investigations of other facilities, it would provide one type of empirical evidence about the efficacy of the two kinds of social environment. Increased socializing, at least as measured by the differential use of private and public space, was not promoted by an integrated environment. This point can be further substantiated by examining the activities of demented residents in the two types of social environments. These activities will be discussed following a review of the use of space by the non-demented residents.

USE OF SPACE BY NON-DEMENTED RESIDENTS

Interestingly, the use of space by non-demented persons shows a similar, though less exaggerated pattern of results as was found for the demented residents. Similar to the demented residents, non-demented people in integrated nursing homes stayed in their rooms more than those in segregated environments (58% vs. 43%). Those on segregated units were more often in "other" areas (recreational areas, hairdressers,

etc.) and were off the floor more. The amount of time non-demented residents spent in their own rooms approached or exceeded half of the waking hours. This is consistent with Dobbs and Rule's (1991a) findings from the first nursing home studied, perhaps indicating maladaptive social isolation.

Clearly, the strong differential effects of the social environment observed for the demented residents were much less apparent in the findings for the non-demented residents. However, before it can be concluded that integration or segregation has relatively little effect on non-demented residents, it is important to point out that the designation of integrated versus segregated facilities is a very artificial distinction for the non-demented people in these nursing homes. These nursing homes were much more typical than the one from which the earlier data (Dobbs and Rule, 1991a) were collected, where the high functioning residents were a homogeneous group segregated in one wing of the nursing home. The nursing homes with Special Care Units included in this study did not have a "segregated higher functioning unit." Instead, the non-demented residents were mixed with demented residents who had not been placed on the Special Care Unit. This is the typical case for nursing homes. In contrast, Special Care Units for dementia residents almost always have a relatively homogeneous population. That is, it usually is the case that all of the residents of a Special Care Unit are cognitively impaired. The point that must be kept in mind is that the remainder of the facility is *not without demented residents*. The higher functioning residents are not segregated and located in a single area. It is more typical that a Special Care Unit houses only *some* of the demented residents, and that the remainder of them are spread throughout the facility, mixed with the higher functioning residents.

With this in mind, the reduced effects of integration and "segregation" for the non-demented residents is not surprising. It seems most reasonable that the reduced effect is less attributable to the type of population (non-demented) than it is to the reduced distinction between the two social environments.

ACTIVITIES OF DEMENTED RESIDENTS

The activities of the demented residents in the integrated nursing homes and those in Special Care Units differed in ways that indicate the Special Care Units were beneficial. The demented residents in the Special Care Units were found to be inactive a smaller proportion (33%) of the time

than those in integrated environments (45%). They also displayed almost 50% more appropriate behaviour compared to their counterparts in integrated nursing homes (34% vs. 26%). Interestingly, those on Special Care Units were twice as mobile (10% vs. 5%) and displayed somewhat more problem behaviours (12% vs. 9%). This is interesting because it suggests that environments that encourage the demented person to be active and are associated with an increase in appropriate behaviours do not necessarily reduce problem behaviours and clearly, did not reduce the amount of mobility. Although much more research is needed, the findings of a positive relationship between appropriate behaviour and the amount of mobility questions the assumption that walking by dementia patients is the result of agitation. In any case, the activity data are concordant with those on use of space. Taken together, they indicate that Special Care Units were associated with more use of social areas and reduced isolation in private areas, and with a greater activity level, including substantially more appropriate behaviour.

ACTIVITIES OF NON-DEMENTED RESIDENTS

The activities of the non-demented residents in the two types of facilities showed similar patterns. The differences were too small to be meaningful. Again, we suggest this is because the non-demented residents in nursing homes having a Special Care Unit are integrated with demented residents not placed on the Special Care Unit.

In examining our data in terms of *where* different types of behaviour were displayed, it occurred to us that one could get a quite misleading impression if one were stationed and observed the behaviour of the residents in primarily one versus another location. For example, demented residents on segregated units displayed at least as much, and perhaps slightly more, problem behaviours than residents in integrated units. However, the demented residents in the integrated units displayed almost six times as much problem behaviour around the nursing station as the demented residents on segregated units. In the segregated units, the problem behaviours tended to occur in the dining room, lounge and the resident's own room.

For the demented on integrated units, *appropriate behaviours* occurred most often in their own rooms. In contrast, the demented in segregated units display the majority of their appropriate behaviours in public areas. The point is that if

nurses' impressions of residents are formed primarily by the residents' behaviour around the nursing stations, the demented residents of integrated units would be misjudged as displaying more problem behaviours than Special Care Unit residents.

Ignoring the integration versus segregation issue and focussing only on the integrated unit, what is the outcome of this context-dependent display of behaviour on the way nurses and non-demented residents judge demented residents? The consequence is that they are likely to see the problem behaviours around the nursing station, not see the appropriate behaviours that occur in the private rooms, and conclude that demented persons are a problem and are incapable of displaying appropriate behaviour.

Use of systematic coding schemes provides a way to investigate the impact of many variables on actual resident behaviour. The behavioural observational approach taken in recent research can be a very fruitful way to approach a wide variety of questions. The integration versus segregation question is only one such example. It seems to us that part of the answer as to which type of arrangement is better should rest on objective reports of the differences in the behaviours displayed by dementia residents in the two situations. However, other factors need to be considered, such as possible differences in the training or selection of staff for Special Care Units, or the possibility that Special Care Units house the more problematic of the dementia residents. Our data are, however, a rather large step away from conjecture and retrospective reports and toward an objective, reasoned answer.

CONCLUSIONS

The pattern of behaviour observed in our research contrasts with that described in much of the literature. The major reason for this may lie in the empirical method used. It has been demonstrated that traditional survey results, relying solely on interview data and retrospective assessments of behaviour and functioning, yield different results from observational methods (Clark & Bowling, 1989). The value of on-line, systemic coding by independent raters cannot be underestimated. Clearly, the data obtained by Dobbs and Rule are in stark contrast to the clinical lore characterizing dementia patients. Based on the Dobbs and Rule findings one would characterize dementia patients as being inactive much of the time, displaying much more appropriate than problem behaviour and being mobile only a small percentage of the time.

One question, then, is why retrospective recall of the characteristics of dementia residents are so different from those abstracted from direct observation and recording of behaviour?

An obvious answer is that systematic observation by independent coders may produce more reliable results. However, more interesting are other systematic factors that may contribute to the difference.

First, normal memory phenomena may account for some results. What is remembered about an event is what is important or salient. Problem behaviours are, by definition, important events for staff. They can be highly disturbing and disruptive when viewed by non-demented residents. In contrast, inactivity or even appropriate behaviour by demented persons is less significant for the smooth operation of the facility, and, thus, may be less salient and less frequently noted. Moreover, a single disruptive behaviour may have an impact extending over a long period of time. For example, when a demented resident trespassed into the room of a non-demented person and defecated on her bed, the incident was brought up repeatedly, week after week, in residents' meetings. Each time, the staff was obliged to deal with the consequences of the single past incident. The suggestion, then, is that the salience of an incident and the potentially long-term consequences may distort memory, leading to an exaggeration of the frequency of problem behaviours and an underrepresentation of appropriate behaviours.

Second, the impressions of caregivers may be affected by biases induced by communication problems of demented residents. Normal communications, in everyday living, are more often strange or incomplete than we realize because the listener does much of the speaker's work. The incompleteness of ordinary language requires extensive interpretational and inferential skills on the part of the listener. Common simple requests provide examples, in that the straightforward literal interpretation is not at all what is meant. For example, most often when we say: "Take a chair", we would be most displeased if the person did just that. The high level cognitive skills required to comprehend common language are compromised in dementia and this creates a mismatch between the skills needed for successful communication and those available to the person. Even simple statements often require as much of the listener as they do of the speaker, perhaps making demands beyond the capabilities of a demented person. For example, one of our technicians was testing the vision of a demented patient. She asked the patient to hold the card over one eye and

to read the letters on the chart. The patient did this and read the chart as instructed. In moving on to test the other eye, the technician asked the patient to cover that eye and the patient did this with the other hand. Unfortunately, the patient was now unable to read any of the letters because one eye was covered with the card and the other with her hand. Of course, what the technician really meant, but omitted from her instruction, was "now take the card away from your eye, put the card in the other hand and cover the other eye."

Because the cognitively competent person depends upon verbal communication, there too often is the expectation that others will do so as well. But the demented person who loses verbal abilities often relies on gestural and other non-verbal forms of communication. Our coders observed a situation that illustrates the distortion that may occur when the cognitively alert and verbally dependent person fails to grasp nonverbal communication. The coders observed a woman shivering by a open window on a breezy day. When the breeze would blow the curtains over her face, she would try to blow and whisk them away. When a staff member appeared, the breeze was not blowing. The woman tried to describe her plight to the staff member through a series of gestures: she shook her shoulders, waved her arms in front of her face to mimic the curtains blowing across her face and whisking them away, then blew at her hands. The staff member rolled her eyes and shook her head, obviously viewing this as a rather bizarre sequence of behaviours. Although it was bizarre out of context, the coders who knew what the person was trying to communicate, thought of it as a fairly good non-verbal communication. From our perspective, charades is a very difficult game and one that must be even more difficult if the actor is demented. The "listener" to a gestural communication must examine the context as well as the person, and use all of the information to fill in the gaps in order to understand the communication. When this is not done, the non-demented "listener" may give an incorrect interpretation to the impaired person's behaviour. This is avoided in research studies where the coders are highly trained.

Finally, our data suggest that the vantage point of an observer may influence his/her impression of the residents' behaviour. The caution, then, is that differences in where problems and appropriate behaviours occur could strongly, and even inappropriately, influence judgements about the problems and capabilities of demented residents. This has obvious implications for the validity of studies that rely solely on staff ratings. The advantage of behavioural observation methods over those that rely on staff ratings is twofold. First, the behaviors

are recorded *as they occur*, thus avoiding misrepresentations or biases that may come into play when judgements about past events are required. Second, the behaviours are recorded *regardless of where they occur*. There are no inherent biases such as would occur if coders spent more time in one rather than another area. Staff who have other duties do not have these advantages. Nursing and other staff ordinarily cannot record behaviours as they occur and their duties bias the locations in which they observe behaviour.

The reasons described above, that appear to contribute to the different impressions people have about the "typical" behaviours of demented residents, provide some interesting leads for future research. There currently is a lack of information about gestural and other forms of nonverbal communication, as well as about the role of context in forming impressions. A better understanding of both of these factors would assist in the development of training procedures for staff and management programs for residents.

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7

WANDERING TRACKS: ENVIRONMENTAL STRATEGIES THAT MAY WORK TOO WELL

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INTRODUCTION

Wandering, typically considered an aimless or meandering walk, has become recognized as a salient feature of Alzheimer's disease and related disorders. Reports from family caregivers indicate that as many as 81% of persons with dementia wander at some time during their illness (George, 1983). Almost all long term care facilities report wanderers among their residents (95% in a study by Hiatt, 1985; 97% in the 1989 Alberta Patient Classification Database). Various researchers (e.g., Hiatt, 1985; Snyder et al., 1978) have placed the percentage of wanderers in nursing homes, at any one time, at between 6% and 18%. In 1989 an average of 15% of the residents in Alberta's long term care facilities were wanderers, but in some facilities the percentage was as high as one-quarter or one-third.

Because wanderers walk for much of their day (Milke, 1989; Snyder et al., 1978), wandering pathways have become a standard design recommendation for special care units and other facilities that care for persons with dementia (cf. Calkins, 1988; Cohen et al., 1988a,b; Health and Welfare Canada, 1989, 1991). The shape of the pathway is often prescribed. For example, in *Designing Facilities for People with Dementia* (Health and Welfare Canada, 1991), it is reported that "The preferred approach is a layout, such as a loop or figure eight, in which the pacer never comes to a dead end" (pacing is usually considered a more intensive form of wandering). Similarly, Calkins (1988) states that one solution to wandering is "creating an 'endless corridor' or racetrack in which the wanderer never comes to the end of the hall".

The notion that space should be dedicated for wandering may be evolving into a conviction that wandering and

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pacing should be promoted. One dementia ward has considered purchasing a treadmill. Gnaedinger (1989, p.15) advocates buying "a secondhand walking machine" for persons with Alzheimer's and related dementias who are being cared for at home.

It is important to note, however, that there have been no adequate evaluations of the ovals, loops and figure eight configurations that are often advocated (Cohen et al., 1988a). There is also evidence from a wide variety of research that walking, and pacing, that is not strongly goal-directed is influenced by the physical environment in which it occurs.

This chapter considers the possibility that some of the recommended environmental strategies may overstimulate wanderers to the detriment of their health. Several types of studies are reviewed that have not previously been linked. First is the literature on corridor behavior in humans and animals, then the animal literature on treadmill activity, and finally, some findings from observational studies of wandering in dementia. The argument is advanced that, as yet, too little is known about the impetus to wander to advocate either the construction of pathways to specific size and shape (e.g. oval paths) or the use of such equipment as treadmills or walking machines.

WANDERING PATHS AND CORRIDOR BEHAVIOUR

Indoor wandering paths typically evolve from corridors, Yet studies in mental health facilities have suggested, for many years, that corridors are problematic. This section reviews previous research on human behaviour in institutional corridors as well as some animal research on corridor configurations used to stimulate movement.

INSTITUTIONAL CORRIDORS

Among the few positive comments about institutional corridors to be found in the literature are those of Curtis (1974) who argues that *some* of these thoroughfares, for *some* time periods during the day, "drop through the institutional net" and allow both patients and staff to escape from constant supervision. Because the free space they offer maximizes freedom of choice, he contends that corridors "are the *only* part

of the institution which simulates the environment found in the lives of ordinary people" (p. 24).

Certainly, studies with elderly institutionalized people (Cluff & Campbell, 1975; Snyder, 1980) have found that considerable social interaction occurs in corridors. However, no evidence indicates nursing home residents use corridors to avoid authority. It would be speculative to suggest that wanderers spend time in corridors to escape supervision.

CORRIDOR ANXIETY

Many writers (cf. Izumi, 1968; Lawton, 1975; Spivack, 1967; Zimring, 1981) dwell on the negative perceptions and emotions engendered by corridors. For example, Spivack (1967) after noting that the typical straight corridor in U.S. institutions was 436 feet in length (although he found one of 1160 feet), argued that such corridors produce sensory distortions and visual illusions. Examples included patient reports that "floors rippled and turned into water and walls moved" (p. 25) and his own observation that:

The sunlight so blindingly contrasted with the dim artificial illumination within that people appeared as blurred silhouettes. Apparently they had no ankles, feet, wrists, or necks; all had been pinched off, literally squeezed out of visual existence. . . they also appeared to float over the floor because of the light contrast (p. 26).

He also noted that slopes, in some cases like the Ames room often copied in amusement parks, played havoc with the viewer's equilibrium so that "Patients were seen to traverse the whole length of the long narrow corridor with one shoulder rubbing the wall . . . never venturing out into the free unobstructed space of the corridor" (p. 27).

Beattie (1974) suggested physiological optics provide a framework for identifying visual hazards for disturbed patients. His model encompasses Spivack's ideas and some architectural hypotheses, such as one suggesting that "a corridor becomes unpleasant when it has five or more equally spaced doors down one side, and when it is more than five times as long as its width" (p. 46). Corridors, in other words, were seen to have certain inherent features that could lead to visual stress. Among visual hazards Beattie (1974) identified were:

- **excessive length**, which he suggested was anything beyond the distance limits for perceiving facial identity and facial expression;
- **illusions of endless space**, analogous to the outlandishly false perspectives of "*trompe l'oeil*" that can produce giddiness and panic in some who attempt to walk the apparent length of a false perspective;
- **way-finding difficulties**, based on direction-finding problems at multiple choice points (he cited a method for calculating the "uncertainty values" of a route to estimate probabilities of becoming lost);
- **distorted space effects**, such as the visual illusions found by Spivack (1967); and
- **disturbing surface patterns**, such as repetitive patterns of lines or checkerboard effects.

Other features he considered might also contribute to dysfunctional corridors included windowlessness, lighting and colour.

Because Beattie is not cited in recent articles, it may be assumed that his "corridor theory" is receiving little attention at present. However, current institutional designers have drawn attention to the fact that stress caused by disorientation may result in feelings of helplessness, raised blood pressure, headaches, increased physical exertion, and fatigue. Patients, staff, and visitors have been affected (Shumaker & Reizenstein, 1982). Carpman, Grant, and Simmons (1986) provide many strategies for avoiding disorientation and making corridors more functional.

Other landmark research on institutional corridors that seems to be ignored includes a study by Trites et al., (1970) conducted in an acute care facility. These researchers evaluated the utility and aesthetics of three different corridor designs in a carefully designed study using multiple measures, including systematic observation. The three designs evaluated were: radial (or round); single-corridor; and double-corridor nursing units. Results favoured the radial nursing-unit design. Nursing personnel on radial units travelled significantly less than on single- and double- corridor units. Additionally, the majority of the nursing staff preferred to work on radial units and felt the

design enhanced the quality of patient care. Patients and physicians also preferred radial units. Double-corridor units were the second most preferred environment with single-corridor units being ranked third.

Interestingly, a single corridor system received favourable reactions from residents in an Ontario long term care facility even though the corridors were as long as 175 feet. The design, however, made the corridors appear to be residential in length (Cluff & Campbell, 1975). Each corridor was marked by three offsets (or jogs) and each offset had a cluster of four resident rooms and a small sitting room. As well as assessing residents' satisfaction with the design, the study assessed activity in the corridors. On all three floors of the facility, the frequency and density of resident activity along the corridors was highest within 65 feet of the nursing station (the first section) and dropped off significantly after 105 feet (i.e., after the first cluster of bedrooms with their sitting rooms). The largest sitting room, midway along the corridor, and the one furthest from the nursing station were used most (even though there was very little corridor activity in the farthest section).

FROM CORRIDORS TO WANDERING PATHS

Configurations of corridors in long term care facilities, and how they have been adapted for wandering paths, have recently come under the scrutiny of Cohen and his associates (Cohen et al., 1988 a,b; Rand et al., 1987). They found three general types of path configurations: *linear* (including the traditional single, double, and multi-segment corridors), *interrupted*, and *continuous loop* corridors. The interrupted corridor was found in the new butterfly floor plan (Cohen et al., 1988b, p. 49) that attempts to eliminate corridors. As well, the interrupted corridor was found in renovations where central bedrooms, along traditional double-loaded corridors, had been turned into living areas. Examples of continuous loops were found in two facilities specially designed for Alzheimer's patients. One was at the Philadelphia Geriatric Centre, where an 8 foot wide area of darker linoleum wraps around a ballroom-sized activity area. The other, was at the Corinne Dolan Centre designed by Calkins, where the path is triangular in shape. In both of these facilities the path has no wall on one side, giving an open appearance and allowing the wanderer to leave at any point. The design incorporates an important precept from the literature on wayfinding. It has been shown the ability of persons to see their goal or desired location from their present position significantly increases their ability to move

independently and, therefore, their self-sufficiency (Weisman, in press).

This precept appears to have been ignored in an Ontario plan reviewed by Cohen et al. (1988a) which has a continuous loop walled on both sides. In their review, Cohen et al. comment that "the path has no obvious beginning point or gathering space. The pentagonal, less familiar plan, along with the repetitive 'building blocks' (of the household units) create the potential for spatial disorganization" (p. 56). Another negative feature of this plan is its circular configuration. As discussed below, the circularity introduces a problem that has been explored in animal studies.

Outdoor wandering paths found in many facilities, also deserve comment. Such paths are typically walled, or fenced, and have grassed and landscaped areas. Descriptions indicate some such areas are less than ideal. One facility used a "maze effect" to create visual boundaries and discourage activity. This was enhanced by a decorative, see-through fence that would seem to enhance confusion (Maas, 1988). One outdoor space on an upper balcony prompted Cohen et al. (1988a) to ask whether distant views might not "tempt' and 'lure' the residents to 'jump the wall'" (p. 71). Here, as with interior wandering paths, there are no answers as yet to some important questions and no reliable design guidelines (Lovering, 1980).

STRATEGIES TO STIMULATE MOVEMENT: THE ANIMAL LITERATURE ON CORRIDOR BEHAVIOR

Although research on corridor, or runway, behaviour in animals has a long history the most relevant studies are recent ones by Grandin (1980, 1984a,b, 1987). His research, with various commercial animals such as cattle, has been directed toward strategies that stimulate movement. This has led to the design of a curved-wall chute that is particularly effective in keeping animals moving forward without evidence of physiological stress.

Physiological measurements have shown that unfamiliar situations cause stress, but stress is alleviated if animals are allowed to move at their own pace. Research has also shown that cattle, like humans, are highly dependent on their vision. High solid fences are preferable because they prevent distractions from outside the runway. Sharp contrasts of light and dark are avoided because animals often balk and refuse to cross a

shadow or change in floor texture. Animals bunch up in square corners. When a gate or doorway is viewed they tend to balk. Loud noises are also distracting. The same reactions can be expected from humans.

Earlier it was noted that Cohen et al. (1988b) were concerned about whether stopping points contribute to wandering or not. A better question is whether turning points or choice points contribute to wandering or not. More importantly, what effects can be expected from continuous paths, especially if they approach the curved shape Grandin recommends for cattle? Because there is no obvious end, some wandering paths may drive persons with dementia to continue walking beyond what they normally would.

Is the animal research relevant? Animal behaviour is considered relevant in research on heart disease. Almost all human drugs have been tested on animals to see their behavioural reactions. Animal models have been used to study a host of human conditions, such as diabetes, the effects of smoking, as well as those of weight gain and reduction. Similarly, it is argued, the animal literature on corridor behavior is relevant to human wandering and the design of paths.

In making this argument it is *not being suggested* that persons with dementia are equivalent to animals. In fact, it is being suggested that persons on wandering paths should not be treated in any way like commercial animals. As Cohen et al., (1988), Coons (1988) and others have pointed out, too many articles refer to wandering paths as "racetracks".

A humane walkway should have solid walls and should not inhibit views of other activities. The walls should not be curved. The path should not be circular or truly continuous. Whereas square corners and gates cause bunching, both curves and corners appear to compel forward movement. There is much anecdotal evidence that humans, like some animals, have an urge to explore that keeps them climbing hills as long as another hill is in view and keeps them rounding bends until there seems to be an end. Moreover, anecdotal accounts from at least two long term care facilities with open plans suggest that a lack of corners and corridors inhibits wandering (Lawton, 1989; Williams & Wilson, 1974).

TREADMILLS: ANOTHER STRATEGY TO STIMULATE MOVEMENT

As noted earlier, Gnaedinger (1989) recommends that community-dwelling persons with Alzheimer's disease use a walking machine. This recommendation is also contained in a recent federal document based on her report (Canada Mortgage and Housing, 1990, p.11). Some facilities have considered purchasing such a device. However, there are several problems with this recommendation. First, it should be noted that treadmills may stimulate movement, especially if food intake is not adequate. Weight-maintaining diets are considered necessary for 'normal' elderly people who use treadmills (Tonino & Driscoll, 1988). Consequently, persons with dementia who have access to such devices must be very carefully monitored to ensure that nutritional intake is sufficient to sustain the energy expended. Secondly, learning effects tend to occur with treadmills that may lead to increased use over time. Increased use may also result from the release of body endorphins, natural narcotics, associated with running. If persons with dementia have access to treadmills, careful monitoring is necessary to ensure that the devices are not overused.

A substantial body of literature on running wheels, the type of treadmills used in animal laboratories, reinforces the need for monitoring. This literature shows that laboratory animals will run until they are exhausted, and if not carefully monitored, will run themselves to death, especially if their food intake is low (Hall & Hanford, 1954; Milke, 1982). Animals of several species, various ages, and both genders, typically will increase their time on the treadmill, day after day, ignoring food and other pleasures for the opportunity to run.

Taken together these findings suggest that treadmills may incite overactivity and thus may be hazardous to health. Caution is urged in adopting them or any other untested equipment for use by persons with dementia.

OBSERVATIONAL STUDIES

Little is known about the impetus that persons suffering from dementia have to walk. Most published reports are anecdotal and do not address the central features of the behaviour. A small number of empirical studies have, however,

been conducted. Several of these, reviewed below, suggest that wandering is influenced by features of the environment.

EXITING BEHAVIOUR

Hussian (1982), in an observational study, provided strong evidence that wandering behaviour was not a random activity. In mapping routes of three wanderers, he found 59% of stops were within one foot of another person or persons; 29% were at windows with exterior views; 5% at isolated chairs; 3% at water fountains; and 4% in miscellaneous locations. Routes were fairly direct, although hesitations were frequent and there was "unnecessary adjunctive motor activity" (p. 34). Hypothesizing that wandering might be controlled by environmental stimuli, Hussian then trained three other residents, who typically were restrained continuously (except for 15-minute periods every two hours), to associate an aversive stimulus (hand clap) with a large blue circle. When these residents were freed before training, they averaged nine exit attempts per half-hour. After training, when blue circles were placed at areas where trespass was not encouraged, exit attempts dropped to 1.67 per half-hour. The stimulus could be faded for those with less deterioration and the effect remained for many months. However, the blue circles had to remain continuously at the exit location for a resident in the late phase of a dementing disease.

Hussian thus demonstrated that, with relative ease, ward exiting behaviour could be brought under environmental control, even in residents who had a high frequency of exit-taking attempts.

FOUR TYPES OF WANDERERS

Hussian and Davis (1985) cite an unpublished study in which they monitored the locomotion of 13 wanderers on a locked ward. They tallied behaviours such as doorknob touching, asking to leave, and stereotypic movements. Subsequent analysis suggested there were four types of wanderers. One type was termed *self-stimulatory* walkers. This group (consisting of five residents) repetitively touched door knobs and doors as though receiving auditory and tactile stimulation from their actions. They also rubbed objects and clapped their hands. A second type (two individuals) were termed *akathisiac* (having a compulsion to walk). They paced frequently but were uninterested in leaving and did not exhibit stereotypic behaviors. Drug records showed they were on

substantially higher doses of neuroleptics (neuroleptics may precipitate akathisia). A third type (two individuals) were termed *exit-seekers* because that was their focal interest. The fourth type (four individuals) were called *modelers* because they walked only in the presence of another's locomotion.

STRATEGIES TO MANAGE WANDERING

Concluding from the above data that wanderers are not a homogeneous group, Hussian and Davis (1985) argue that strategies to manage wandering will be more successful if they are relevant to the type of wandering behaviour an individual exhibits. For example, ambulation that appears to serve as self-stimulation could be treated with sensory extinction (e.g. by removing sources of stimulation such as door knobs that rattle) and by providing other outlets for stimulation (e.g. items that can be shaken, rubbed, squeezed, and otherwise manipulated). Robb (1985) suggests that akathisiac residents might benefit from a medication change and by scheduled walks. Hussian (1982) suggests that exit-seekers whom he found were often new residents, should be prevented from entering unauthorized areas for a period of time until their attempts extinguish. Snyder et al. (1978) on the other hand, suggest an opposite strategy to manage those who wish to leave. They recommend that wanderers be allowed to leave in the company of staff and not return until they wish. These researchers report that if initial episodes are handled in this way there are seldom repeat incidents. A regular regime of going outside was also found to be helpful. Hussian and Davis (1985) believe instructions on where to go and not go are sufficient for wanderers who model the behaviour of others. This recommendation is supported by recent pilot research on a door monitoring device that uses video-transponders with voiced personalized instructions telling wanderers who approach an exit to "go back" (Martino-Saltzman, 1989). This device was most successful with residents with mild or moderate dementia and those who were not determined to leave.

QUANTITY AND QUALITY OF LOCOMOTION

A very detailed behavioural analysis of wandering was undertaken by the present author in a prospective study conducted with Drs. Dobbs and Rule of the University of Alberta, funded by the Alberta Heritage Foundation for Medical Research and NSERC. Subjects were 10 Alzheimer's residents living, with others having similar disorders, in a special unit in

an unlocked nursing home. One of the objectives of the study was to examine the pattern or quality of their locomotion and determine whether there were differences in the Alzheimer's residents such as those observed by other researchers. Another objective was to determine how the residents interacted with their environment.

Quantitative differences in locomotion were evident: two of the 10 were excessive wanderers, engaging in restless locomotion 23% of the time, six were moderate wanderers who spent 14% of their time in that activity, and two were termed non-wanderers because they spent only 2% of their time in restless locomotion. It is important to realize that restless locomotion was not the dominant activity of these 10 residents, even though it was salient. Most of their time was spent sitting in their lounge without any concurrent behaviour (non-wanderers 59%, moderate wanderers 44%, and excessive wanderers 42%). Although all meals were served in their lounge and most programs occurred there, these took comparatively little time; the dominant activity was what Calkins (1988) and others have called "null behaviour" (i.e. lack of any observable behaviour or activity).

The 10 residents did not fit neatly into the four classifications described by Hussian and Davis (1985). That is, *people* did not match the classifications although their *behaviours* often did. A number of the residents exhibited, at times, self-stimulatory locomotion, exit-seeking locomotion, and modelling locomotion. Because medication levels were not high, akathisia was not evident. While the two residents considered non-wanderers sometimes wandered with others but rarely wandered alone, they could be labeled "modelers". However, none of those studied exhibited wandering that was *primarily* exit-seeking or self-stimulatory (doors were unlocked, therefore door-knob rattling and door touching was not seen). Typically, residents did not attempt to leave, but because doors were not locked, unauthorized exits were possible, and occasionally a resident appeared to be in an "exit-seeking mode".

The restless locomotion of both excessive and moderate wanderers was interleaved with "group walking" as well as the "frequent hesitations and unnecessary adjunctive motor activity" noticed by Hussian (1982, p.39). The frequent hesitations could be a reflection of the navigational difficulty that is often attributed to persons with dementia (Burnside, 1980).

THE INFLUENCE OF CORRIDORS ON WANDERING

The corridors may have precipitated some of the wandering. The nursing home's corridors could not easily be distinguished from each other and may have contributed to both frequent trips down them and the frequent hesitations in those trips. A resident with considerable verbal skills said that she was fearful of leaving her "home corridor" and becoming lost. Other observations suggested these residents were not lost in their home corridors. They appeared to be very accurate regarding bedrooms, rarely entering one that was not their own. If the corridors had been colour-coded and this had been accompanied by training (cf. Hanley, 1981), wayfinding abilities of residents would likely have been enhanced.¹

These same corridors also had some good features for wanderers. There were lounges at the end of each corridor providing a resting area, different view, and often the opportunity for social interaction. Wanderers frequently sat when they came to the lounges. Food wagons and laundry carts often were interspersed along the corridors, offering opportunities for handling a number of different objects of different textures. The nursing station, which was almost constantly staffed during the day shift, was at the center of the corridor system. Wanderers frequently hovered there to watch others and some wanderers participated in interactions. Certainly, the corridors provided more entertainment than the lounge where the residents usually sat.

The corridors however, presented a number of hazards. Carts with cleaning supplies were sometimes left unattended. Altercations sometimes resulted when wanderers encountered higher-functioning residents who resented the presence of the special unit. In addition, five of the six exits from the floor opened off the corridors. These included three exits to fire stairs, a central staircase, and an elevator that descended two floors to the main activity areas. The fire exit doors were painted the same colour as the walls and handles were abnormally high, but the camouflage was only moderately successful. Demented residents occasionally opened the doors and looked down. Only once however, did a resident abscond

¹ Few evaluations have been conducted in long-term care facilities. However, two experimental studies of nursing homes (Herman & Bruce, 1981 and Weber, Brown & Weldon, 1978) suggest that areas in such facilities are so poorly differentiated from one another that even non-demented residents have poor cognitive maps and cannot distinguish photographs of major areas.

through the fire exit on the special care unit. The main stairwell had a glass wall and door, but did not generate much interest unless a family member was leaving through it. Informal observation suggested that only two exits presented much in the way of risks. Several residents absconded through the fire door that opened directly off a lounge. This lounge, used by higher-functioning residents, closely resembled a family living room and possibly the door was seen as a normal household exit. The second risk was the elevator. Residents could abscond when large numbers of residents from the other three wards on their floor used the elevator to reach the dining room and activity areas on the ground floor. With the slow rate at which the doors closed, they also could step into the open, empty elevator to effect an exit. Alarmed fire doors, and a device to detect when wanderers entered the elevator would likely have stopped all unauthorized exits from the floor. Implementation of other environmental manipulations might have reduced other types of wandering. For example the undifferentiated sections of the X-shaped corridors probably contributed to wandering. Colour-coding, accompanied by training, would likely have assisted residents in finding their familiar ward.

CONCLUSION

There are, at present, no clear directives about what is a good wandering path. The notion that loops or continuous corridors should be planned into every unit that houses persons with dementia has gained wide acceptance. Certainly, wanderers require a place to walk safely. However, there has not been enough research on the configuration of pathways to make any definitive recommendations. Ovals and continuous pathways can be disorienting, and may lure wanderers onward and lead to their exhaustion. Therefore, great care is therefore needed to ensure that these pathways do not augment wandering. The notion that paths are "racetracks" on which persons with dementia are "placed" is a dehumanizing concept. A place to walk need not be a racetrack. Cohen et al. (1988b, p. 17) have said, "people should not be forced to wander as the result of disorientation brought on by a confusing, illegible, unpredictable environment". They also should not be forced to keep walking because of poor path design or because they have access to equipment that incites walking. As has been argued in this chapter some of the strategies currently being implemented or recommended may serve the wanderer too well and lead him or her to walk beyond the point where it is beneficial to health.

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8

DESIGNING FACILITIES FOR PEOPLE WITH DEMENTIA: A NEW RESOURCE FOR PLANNERS AND CAREGIVERS

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INTRODUCTION

The Institutional and Professional Services Division of Health and Welfare Canada has recently published a document entitled *Designing Facilities for People with Dementia*. This document is intended to assist people who are involved in the planning and design of dementia care units, by bringing together information about:

- care delivery issues;
- the capabilities, needs and limitations of people with dementia; and
- features of the physical environment which can help dementia care programs to achieve their goals.

An understanding of these three dimensions and the ways in which they interrelate is necessary in order to create environments that can meet the needs of the resident and facilitate caregiving by staff and family. The document focuses on long-term residential care settings and, in particular, on the design of units or areas specifically intended for residents with primary degenerative dementia. However, the ideas it presents should also be of interest to those who serve this population in other settings.

The document is not merely a set of prescriptions. While it does make recommendations, it also seeks to outline the reasoning behind them, and where appropriate, to present alternative points of view about design options. The authors highlight:

- the progressive nature of the illness;

- the variation of symptoms, functional capacities and characteristics within this group;
- the trade-offs implicit in virtually every design decision; and
- the need for creativity and flexibility in adapting the environment to changing needs.

The intent is not to usurp the role of the planning committee or the architect, but to facilitate and enrich the process of consultation and planning that leads to the design and creation of a dementia care unit. A second objective is to promote effective *use* of the environment in the ongoing care of people with dementia. The book is 152 pages in length, with one table and 13 figures. It consists of an introduction, six chapters, a bibliography and a subject index.

TARGET AUDIENCE

The primary audience includes administrators of long-term care facilities, architects, design consultants and planning committees, which may (and should) include care delivery staff and family caregivers. Although it contains more material related to care delivery than most design documents, it is not intended to serve as a manual for direct care staff. However, it should be a useful resource for continuing education of staff and volunteers about maintaining and using a supportive, "prosthetic" environment for people with dementia.

The plan is to distribute the document to:

- a) provincial and territorial government officials who have a mandate in this area, including members of the Federal - Provincial - Territorial Advisory Committees and sub-committees that have been involved to date, and the persons they identify within their respective governments;
- b) professional and other nongovernmental associations and agencies with interest in this area; and
- c) consultants, administrators and service providers in the private sector.

Direct-mail distribution to long-term care facilities, architectural firms and other interested parties will be

considered if resources permit; otherwise the document will be distributed on request, following announcements in various targeted media. In the short term the intention is to get the document into the hands of those who are or will shortly be undertaking renovation or new construction of facilities to serve people with dementia. This would include, among others, architects and design consultants, administrators, boards, and program planners. In the longer term it is hoped that the document can be made available as an educational resource for various groups.

BACKGROUND AND DEVELOPMENT OF THE DOCUMENT

The three-volume reference *Living Accommodations for Seniors: Facility Planning and Design Guidelines* was published in 1988 by what was then the Design for Health Division of the Health Services Directorate. The preparation of this document involved the participation of 24 working group members, 19 steering group members, and a large number of expert reviewers, consultants, writers and editors over a period of four years. There was representation from every region of the country, from federal and provincial levels of government, and from virtually all relevant professional disciplines; there was also input from seniors themselves. The three volumes address accommodation for persons living *independently*, *semi-independently* and those requiring *continuing care*. In the course of preparing the document, the authors decided that addressing the particular design needs of the cognitively impaired elderly warranted a separate working group and a separate document. This recommendation was accepted by the Design for Health Division, which assigned environmental psychologist Dr. Paul Munson to chair a working group that would develop a companion document focusing on this issue. This seven-member working group,¹ which included

¹ Members of the Working Group on Facilities for the Cognitively Impaired Elderly were: Paul Munson, Ph.D., (Chairperson), Institutional and Professional Services Division, Health and Welfare Canada; Ronald Awde, B.E.S., B.Arch., Philip H. Carter, Architect-Planner, Toronto; Donna Badiou, Nursing Consultant, Continuing Care, Saskatchewan Health; Elaine Bourke, Assistant Administrator, Baycrest Centre for Geriatric Care, Toronto; Moyra J.D. Jones, Moyra Jones Resources, Burnaby, British Columbia; Thomas J. Lips, Consultant, Mental Health Division, Health and Welfare Canada; and Myra Schiff, Ph.D., Myra Schiff Consultants Limited, Toronto.

representatives of several regions and disciplines, and two key members of the earlier working groups, met for the first time in the fall of 1988. The objectives and basic structure of the document were agreed upon, and information-gathering, writing and review activities were assigned.

There is a growing literature on physical and program design to accommodate people with dementia. However, as Keen (1989), Gutman (1989) and others have pointed out, few of the recommendations emerging from this literature have been subjected to rigorous scientific evaluation. Recommendations made in this new document are derived, for the most part, from the following sources:

- **empirical studies** conducted with the target population, where available;
- **published design guidelines** addressing related issues, and published program descriptions with formal or informal evaluations;
- **extrapolation from related research**, conducted with populations sharing some characteristics with the target population;
- **extrapolation from basic principles**, goals, concepts and values (e. g. the goal of a homelike atmosphere; the principle of balancing the demands of the environment with the capabilities of the individual; the principle of multiple cueing; the principle of reducing meaningless stimuli); and
- **the knowledge and accumulated practice** experience of various resource people, including working group members, who have worked extensively with this population.

In the opinion of the working group, these five sources, while not sufficient for imposing iron-clad guidelines or standards, could confidently be used to generate recommendations and design ideas, and to guide planners in an examination of key issues of environmental design for this population.

From the outset, linkage was maintained with the Federal - Provincial - Territorial Steering group on Psychogeriatric

Services, which was beginning its activities at about the same period. The draft document was reviewed by two members of the Steering Group and also by several members of the concurrent working group on Services to Elderly Residents with Mental Health Problems in Long-Term Care Facilities. Additionally the document was reviewed by the Federal - Provincial - Territorial Sub-Committee on Institutional Program Guidelines and the Federal - Provincial - Territorial Advisory Committee on Health Facilities Planning and Construction. Final substantive revisions in response to reviewers' concerns were completed in September, 1990 by design consultant Dr. Myra Schiff, in consultation with other members of the Working Group.

KEY DECISIONS

Several decisions were crucial in determining the ultimate form and content of *Designing Facilities for People with Dementia*:

- a) **This was to be a companion document**; it would avoid repeating material from the parent document except when necessary for clarity. For example, there would be no extensive discussion of wheelchair access; it is taken as given, and is not specific to the target population. The document would concentrate on environmental design issues that were particular to (or of particular importance for) people with dementia.
- b) In keeping with the client - centered approach of the parent document, it was decided that **addressing the needs of the target population would be the overriding concern**. Working group members acknowledged that facilities and jurisdictions may differ in their readiness to develop optimal environments for this population; however, they felt it was important not to limit their recommendations to what was easily achievable in all jurisdictions (i.e. the lowest common denominator). Instead, they chose to describe a range of possible features and adaptations, and discuss some of the trade-offs and compromises involved in various design choices. The document encourages planners to do as much as their current resources permit to provide safe, humane, supportive and pleasant

living conditions for residents with dementia. It even goes so far as to propose a few "luxuries" whose main purpose is to make life a little less drab and institutional in facilities that can afford them.

- c) The members affirmed that **the design of environments** (and by extension, the development of design guidelines) **must be built around an understanding of the needs, characteristics and activities of the users.** Thus, instead of making spaces, systems or services the basic unit of organization for the document, they decided to organize it according to the daily life experience of the residents. In this way, members hoped, no component of the environment would be considered (or planned) in isolation from its potential uses.

The structure that emerged is based on activities: each section in the last four chapters begins with an activity that forms an important part of the resident's life (for example, "walking" or "eating"). First, it briefly suggests the philosophical stance that should govern planners as they seek to accommodate and support the activity. Next, it explores the impact that dementia has on this activity. Each section then offers specific suggestions regarding environmental design features or adaptations that would best accommodate the activity in various areas of the facility.

This approach may initially frustrate readers who only want to know about doors and hallways, and not about the people who walk through them. It also leads inevitably to a certain amount of repetition within the document. However, the working group felt that the advantages, in terms of sensitizing planners to the issues involved, outweighed the disadvantages of this unorthodox format. The inclusion of a detailed table of contents, a subject index, a section on "General Design Considerations," and cross-referencing within the text, should also help to satisfy readers who prefer a more conventional format.

d) The working group insisted on a **broad definition of the term "environment"** one that included the human and organizational features of the residents' world as well as the physical features. The document identifies four interrelated components within "the environment":

- **the users**, these are all the different individuals who use the facility: residents; staff, such as nurses aides, doctors, activity workers, occupational therapists, housekeeping staff, and maintenance staff; volunteers; families and friends of residents; other visitors; and people in the community who may use the facility.
- **the use**, different areas within the unit have different functions and support different activities.
- **the physical features** these range from the micro-scale, such as furniture, to the macro-scale, such as the general lay-out of the unit as a whole. In between, this component includes lighting, finishes, furnishings and equipment, decoration, air quality and all the other features commonly accepted as constituting the physical environment.
- **the organizational milieu** this refers to the philosophy of care, the approach to care delivery, and the set of rules, policies and procedures which directly or indirectly affect the way space is used.

The design goal should be to develop a facility in which there is a fit between and among these four components in order to accommodate the needs and abilities of users most effectively.

Maintaining this integrated view of "environment" is essential. There is "an important limitation on the contribution that the [physical] design of a building may make to the lives of those who live in it: **the way that it is used is crucial, and many of the potential benefits**

of good design can be negated through misuse" (Keen, 1989; italics added). Activity areas may be commandeered for storage. Access to outdoor wandering paths and gardens may be cut off. Intercoms or portable radios may blare loud music through an environment that was carefully designed to reduce meaningless stimuli. Or, most seriously, admission practices may reflect a process of "dumping" so-called "problem residents" rather than an assessment-based selection of residents who can benefit most from the designed environment. Such misuses of the environment (or failures to use it effectively) can only be prevented through a process of priority setting, on-going education, and attention to the human and organizational components of the environment.

- e) **The concept of the "prosthetic environment" guided the development of the document.** The term was coined by Lindley (1964) to describe a range of elements in the environment that provide continuous support for the individual; it has been used by later authors (e.g. Calkins, 1988) to refer both to particular physical design features and to an overall approach to design and programming. Just as a prosthetic device can help to compensate for loss of function in a limb, an appropriate prosthetic environment can help to compensate for the loss of mental and physical abilities caused by dementia, while reinforcing and making optimal use of the abilities that remain. For residents with a progressive dementing illness, the goal is not to cure, but neither is it simply to warehouse. An appropriate environment can help residents to *function* better, in that it will meet their needs, help them to enjoy and maintain the skills and capacities they still have, support rather than undermine their accurate perception of reality, and spare them many of the frustrations and confusing stimuli that can lead to distress and disturbing behaviour. The net result can be an actual improvement in functioning - not because the inexorable deterioration of the brain has been reversed, but because "excess disability" has been reduced.

f) As in the case of the parent document, an important goal was to **make the environment as residential (homelike) as possible** in design, scale, appearance and furnishings. The principle of seeking the most homelike option consistent with the other objectives of the unit affected not only physical design recommendations but also the language in which they were couched. For example, the document speaks of "living rooms" rather than "day rooms"; "halls" rather than "corridors". It encourages planners and caregivers to think in residential terms, and to use their sense of home and home life as a touchstone or ideal when considering design and program options. In general, the document favours:

- **smaller, more intimate group-ings of residents**, i.e. both smaller-scale group activities (Calkins, 1988; Shroyer et al., 1987) and smaller units or resident clusters (Coons, 1985; Weaverdyck and Coons, 1988);
- **personalization of residents' rooms**, not only to make the rooms more recognizable and less threatening but also to enhance the resident's sense of control over personal space (Calkins, 1988);
- **more flexible and less "insti-tutional" routines and procedures** (Gutman, 1989);
- **furnishings and decor suggesting an individual's home** rather than a nursing home;
- **active support for residents' participation in simple housework tasks** and other normalizing home-related activities;
- **reducing the visibility and intrusiveness of "institutional" program or design features** that must be retained for reasons of health and safety (e.g. by

"camouflaging" doors that must remain locked);

- allowing as much **personal choice, privacy and liberty** as the demented individual can cope with comfortably and safely; and
- fostering **the ideal of a homelike environment** among planners and direct-care staff.

g) The working group emphasized **the importance of defining the client population clearly, and not too broadly**. With prosthetic environments, as with prosthetic devices, "one size does *not* fit all". The group chose to restrict its attention and its recommendations to addressing the needs of long-term care residents with primary degenerative dementia. It stressed the importance of clearly defined admission criteria for so-called "special care units", based on thorough medical, psychosocial and functional assessment, and it warned specifically against misusing such units as "dumping grounds" for troublesome residents with acute or chronic psychiatric disorders or other behavioural problems unrelated to dementia. It is difficult enough to maintain a prosthetic environment addressing the range of needs, behaviours and functional capacities within a population diagnosed as having progressive dementia; other populations have different needs and require different approaches.

FUTURE DIRECTIONS

Three issues must be highlighted for the future:

- research and evaluation
- education, and
- identification of resources.

RESEARCH AND EVALUATION

The members of the working group are very conscious that this document will not be the last word on designing environments for people with dementia. The need for research and evaluation in the field is increasingly apparent, and the facility planners of the future should be able to call upon a larger body of empirical research in weighing the available design and program options.

Evaluation is the key to future improvements in design for dementia. When new construction or renovation is undertaken, evaluation processes should be provided for in advance (Gutman, 1989). Both new construction and renovation offer valuable opportunities for evaluation of particular design features and approaches. For example, when two dementia care units or wings are being built in a single facility, they should differ in some limited but significant respect so as to provide the basis for a controlled study of a particular environmental variable (Munson, personal communication).

Key research issues that require attention relate to the need for **better methodologies for comparing environments** in terms of their impact on life satisfaction and functioning of demented residents. For example, Keen (1989) notes that:

- a) At present there appears to be "no systematic means of representing information about the physical environment in a way that allows comparison across different buildings" (Keen, p.259). This is partly because of the exceedingly large number of variables involved, but also because of a lack of consistency and conceptual precision in the language we use to describe and compare built environments. Without a common operational language, it is hard to be confident that any comparisons we make are sound.
- b) "[It] is not clear which are the important physical dimensions which should be studied and how these various dimensions might be related to observed behaviour and subjective responses" (Keen, p. 259; see also Gutman, 1989, p. 70).
- c) Since "there is no obvious way of controlling for effects of the physical environment," research designs fail to distinguish between the possible

effects of physical design and those of other variables in the regime of care (Keen, p. 260). Is the resident wandering because she's lost, or because there's nothing else to do? How much of the success (or failure) of a special unit is due to physical design, and how much to staff training and attitudes?

- d) There is a need to develop methods that can distinguish more clearly between two kinds of effects of physical design features: direct "ergonomic" or "functional" effects (Can I see the red door more clearly than the green? Can I turn the doorknob?) and indirect "aesthetic" or "subjective" effects (What associations or meanings does red have for me? What feelings does the red door trigger, if any? Do I like the door open or closed?).

The indirect effects of many environmental features tend to be more numerous, more complex, more variable among individuals and across cultures, and more difficult to identify and study than the direct effects; but they may be equally important. People with different backgrounds derive different meanings and different aesthetic responses to the same design feature. When can we confidently generalize about what is most appropriate for people with dementia?

- e) People with dementia may be able to express their general feeling about an environment but not always about particular elements (Keen, p. 262). We need ways of measuring or confidently inferring the subjective responses of a population with seriously impaired skills of communication and concentration.
- f) Growing interest in environmental design is predicated, in part, on the assumption that there is a strong link between environment and behaviour. However, some work to date apparently involves unwarranted assumptions about causality. There are dangers in adopting a stance of "architectural determinism" (Keen, p.258), as though the resident were simply the passive recipient of continuous environmental

"influences". We may overlook the ways in which people even people with dementia *interact with* the environment. We may develop an exaggerated faith in the power of certain environmental features to "manage" behaviour. We may even become preoccupied with the technical challenge of directing bodies from point A to point B, and forget that these are people who are subjects in their own life stories, not objects requiring safe storage.

On the other end of the spectrum, we risk underestimating the extent to which environmental features (physical, psychosocial and organizational) can condition or even determine residents' behaviours and choices. When they "vote with their feet", seeming to choose one space over another, what forces are at work, besides the individual's personal preferences and functional capacity?

It is clear that some fundamental tasks remain to be accomplished in the realm of research and evaluation. Important steps have been made, however, and there is a growing body of knowledge and experience in both the research community and the service delivery community that can be drawn upon.

EDUCATION

Lawton has said that "the physical environment is not an 'agent'. It is ... there to be used by those who know how to use it" (in Calkins, 1988, p. xiii). It is essential that staff be trained to understand the role of the environment in their work, and to make optimal use of the particular design features of a dementia unit. This training must be an ongoing process, "not only because staff members forget, but because of staff turnover," and because the environment and its uses will need to evolve in response to changing needs (in Calkins, p. xiii). Staff who understand the principles underlying the choice of "prosthetic" design features can be creative participants in this evolution and can be first-hand evaluators of the effectiveness of environmental features.

The skills, actions, inaction, attitudes and moods of staff are crucial elements of the resident's environment -- far more crucial than the colour of the wallpaper or the length of the hallway. Careful selection, insightful supervision and continuing education of staff are essential steps in developing a prosthetic

environment. This has implications for the formal education and in-service training of staff in all disciplines and functions.

IDENTIFYING RESOURCES

In an age of budgetary constraints, how can we afford to do more than warehouse the growing number of frail elderly people with dementia? How can we find staff to provide more than basic physical care? How can we justify devoting resources to the creation of environments that comfort and support them? What is the return on the investment we would have to make to help them enjoy and maintain their skills as long as possible? If we need to ask these questions (and it seems that we do), there are several possible approaches.

We can point out that spending money on appropriate environments should lead to reduced costs in other areas (Calkins, 1988). There is some encouragement in the relatively few empirical studies of the impact of specially designed units on the health and behaviour of people with dementia. Studies surveyed by the U.S. Office of Technology Assessment (cited in Gutman, 1989, p.10) suggest that specialized programs can achieve significant decreases in behaviours that cost money, such as wandering, agitation, and incontinence. There is some evidence of weight gains and other signs of improved health, and frequent reports that residents are calmer, seem more content, and are less likely to require medication or restraint for behavioural reasons. Increased satisfaction among staff and family members is also reported. Such improvements have direct and indirect cost implications.

We can also point out that, in the case of new construction or structurally necessary renovation, many of the choices that make for a prosthetic environment do not cost significantly more than inappropriate choices; some may actually cost less. Many appropriate features can be phased in over time as old materials or fixtures wear out and need to be replaced.

In the final analysis, however, the decision to develop prosthetic environments must rest on the conviction that doing so will reduce the distress and improve the quality of life of people with dementia, and that this is worth spending money on. More and better research can guide us in designing more effective prosthetic environments; but the question of where the comfort and well-being of elderly people with dementia should rank on our scale of social priorities lies within the realms of politics and ethics. Since we all face a significant risk

of dementing illness as we age, it is a question of more than academic interest.

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**PART III: INSTITUTION-COMMUNITY
COOPERATION AND COLLABORATION**

9

THE ORGANIZATION AND COORDINATION OF PSYCHIATRIC SERVICES FOR THE ELDERLY IN AN URBAN SETTING

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INTRODUCTION

The psychiatrically ill elderly and their caregivers are often entangled in an intricate and complex network of services. These services are poorly utilized by this population because of problems with availability and accessibility. It behooves us to understand how to better organize and coordinate these services to rationalize care to this vulnerable population. This chapter begins by focusing on what we consider to be some of the fundamental principles that underlie the provision of specialized psychiatric and mental health services for this target population. The role and function of community-based mental health services and hospital-based geriatric psychiatric services is then discussed. Attention turns next to regional geriatric programs. The chapter concludes with discussion of some planning issues and the need for evaluation.

EMERGING PRINCIPLES

Guidelines and directions for the development of psychiatric services for the elderly, and specifically those suffering from dementia, come mainly from widespread clinical experience in the United Kingdom (Shulman & Arie, 1991). Since the 1960s, many new and innovative services have been developed there. They have had significant influence on the recently formed Section of Old Age Psychiatry within the British Royal College of Psychiatrists. This body has produced a series of documents providing guidelines for the many facets of service delivery to the mentally ill elderly. The combined report of the Royal College of Physicians of London and the Royal College of Psychiatrists (1989) provides a useful summary of the relevant issues involved in the provision of specialist services for the mentally ill elderly.

In addition to this formal series of reports, descriptive papers have emerged documenting the experiences and ideas of

individual services (Arie, 1970; Baker, 1977; Blessed, 1975; Godber, 1975). The cumulative experience and writings of these pioneers has resulted in a consensus regarding health care services to a vulnerable cognitively impaired population and their caregivers. Emerging principles include:

- a) **Comprehensiveness** - One of the greatest challenges in provision of psychiatric services to the elderly is the ability to overcome fragmentation and discontinuity. This is an inevitable phenomenon given the complex and multi-faceted nature of the problems faced by elderly dementing individuals and their caregivers. Dementia patients with an inexorably progressive degenerative disorder often need to be navigated through a complex maze of health and social services. Their caregivers may also require support services and counselling in their own right. Elderly patients with other psychiatric disorders may be as compromised because of concurrent medical problems and functional disabilities. Hence an effective psychogeriatric program must not only offer a comprehensive range of services but also take responsibility for a wide range of disorders and problems. The challenge of service delivery is to be very broad in approach. Admission criteria which are overly restrictive are unhelpful and counter-productive as they will exclude too many patients who are in need of care. In order to be comprehensive in the provision of services to this population it is often necessary to design Regional Geriatric Programs which attempt to oversee a very broad range of services including medical and psychiatric services.

- b) **Accountability** - Too often in North America, service development has proceeded from the principle of resource-based planning rather than population-based planning. This is often more problematic in urban settings which tend to be resource intensive. In these settings services often look for patients who fit neatly into the structure and priorities they have defined for themselves. This approach will inevitably exclude many difficult and vulnerable patients especially

those suffering from dementia. In a purely free market approach to health care delivery, dementing patients and their families are particularly vulnerable as they are seen as draining valuable resources or are viewed cynically as "bed blockers" (Shulman & Arie, 1978). Indeed, there is evidence that many in-patient units tend to avoid admitting dementia patients for these reasons (Rodenberg, 1985).

An important way to protect the rights of the psychiatrically ill elderly (including the dementia patient) and ensure they receive adequate health care is to have health services formally identify a *specific target population*. In this way there are clear lines of responsibility and accountability when a major psychiatric problem develops in an individual suffering from dementia. Essentially, this means that a service is responsible and accountable for all elderly individuals with psychiatric problems who live within the catchment area, unless their psychiatric needs are being adequately met by another resource. In this situation it will be clear who is responsible for the most vulnerable patient - the frail dementing elderly individual living alone. Such patients will be less likely to get caught between the stools of different services anxious to avoid a potentially difficult and resource draining client.

- c) **Defining the target population** - How to appropriately and reasonably define such a target population in a Canadian health care system is a difficult challenge. In many jurisdictions there is a lack of incentive to coordinate even the most limited of services let alone define a population to be served. A simple geographic catchment area design is not always realistic given the complexity of most Canadian urban health care networks. Nonetheless, it is probably best to begin with a preliminary geographic catchment area in defining a target population.

Another factor in the determination of a target population should be the patient's formal affiliation with a specific primary care physician or community health centre. Hopefully, most

patients will live in reasonable proximity to both a general practitioner and a psychiatric service. The importance of the primary care physician in the provision of service is emphasized by a formal linkage between the two. Certainly, it makes sense to ensure that an elderly person who experiences a change in mental state is first assessed by his general practitioner who continues to be closely connected with the patient even after a psychiatric assessment.

Most institutional settings, including homes for the aged and nursing homes, have a very high prevalence of dementia and psychiatric disorders. Yet, the provision of psychiatric services in these settings remains infrequent (Borson et al., 1987). As a result, patients are often needlessly shuttled between the long-term care sector and acute-care hospitals for assessment and treatment. Formal linkages of specific long-term care institutions and specialty psychiatric services should help to improve the quality of care provided to residents.

Ethnic, cultural and religious affiliations should also be accommodated whenever possible in defining catchment areas and target populations. Even if dementing individuals have lost the appreciation of this aspect of their life, their caregivers may benefit. However, individual preference should be taken into consideration only if a service is able to meet all of the "statutory obligations" for its target population.

- d) **Community focus** - With some justification health planning bodies have become suspect of many hospitals' commitments to "community work". Yet in the care of elderly psychiatric patients, especially those suffering from dementia, it is essential to have the capacity to assess them in their own familiar environment. No one should be admitted to a hospital in-patient unit without a careful preliminary assessment in the community. The initial home assessment ("domiciliary visit" as it is known in the U.K.) is often conducted by a psychiatrist with another member of the multidisciplinary team (Arie & Jolley, 1982). Members of the

patient's family, other important social supports and service providers can be invited to contribute to information gathering and treatment planning. Follow-up may be coordinated by a mental health professional who involves the psychiatrist on an "as needed basis" (Shulman & Arie, 1991).

Many patients can be well managed in the community without an in-patient admission. Community follow-up must also be available post-discharge for the frail elderly who cannot or will not frequent traditional outpatient clinics. "Community focus" should be a guiding principle for all specialty psychiatric services, whether community-based or hospital-based.

- e) **Availability and flexibility** - All too often "comprehensive services" for the elderly are established that are so cumbersome and rigid in their approach that they become inaccessible to those very patients who need them the most. Services must be organized so that they can respond to the often rapidly changing status of the frail elderly psychiatric patient.

This is especially a concern for individuals suffering from dementia, who may decompensate quickly leaving a caregiver overwhelmed. In an ideal service network, dementia patients and their families should not have to resort to the emergency room where overworked staff are understandably frustrated at the prospect of dealing with an "emergency" occurring in the context of a chronic illness. Yet this is often the scenario that results in unnecessary and turbulent hospital admissions.

Long waiting lists are problematic and usually reflect an inefficient and ineffective service rather than a lack of resources. In order to be responsive, the initial visit may have to be made by a non-medical member of the team in order to defuse the tension or crisis situation and screen for the nature of the problem. Appropriate follow-up can then be arranged in the community or in hospital.

COMMUNITY-BASED MENTAL HEALTH SERVICES

It is of some value to attempt to separate the roles and functions of community-based services compared to hospital-based services even though the "focus" of both remains "the community". In the urban setting there are often multiple community-based agencies and services. These may have a specific mental health focus or provide a broad range of services. They often operate independently with little coordination. This is a major challenge and ultimately, requires an administrative structure that can bring together the varied health and social services that are relevant to the needs of the elderly. Ideally, there should be a centralized intake for services in the community, including mental health services, where appropriately qualified individuals can screen calls and perform an effective triage function so that the individual or their caregiver can be directed to the appropriate sector of the community service network. The public should have direct and ready access so that any individual, family member or health professional can call the central intake and make the referral.

An important function for community-based services is that of screening. The operative principle should be that the community-based mental health service deals with all cases unless they feel the situation is serious enough to merit a referral to the hospital-based psychiatric service (see below). Indeed, it may be possible to discharge patients from these hospital-based services back to community agencies for on-going monitoring and follow-up with the understanding that specialized services can be called upon should the need arise.

Case management is another key function for community-based services because of the complex and multifaceted nature of psychiatric problems in the elderly, especially dementia. A key worker or case manager is essential to help the individual and their families navigate through the appropriate services, to individualize treatment and to monitor clients and their families.

A wide range of services is required in the community to meet the needs of this vulnerable population. These include nursing, primary medical care (family physician), occupational

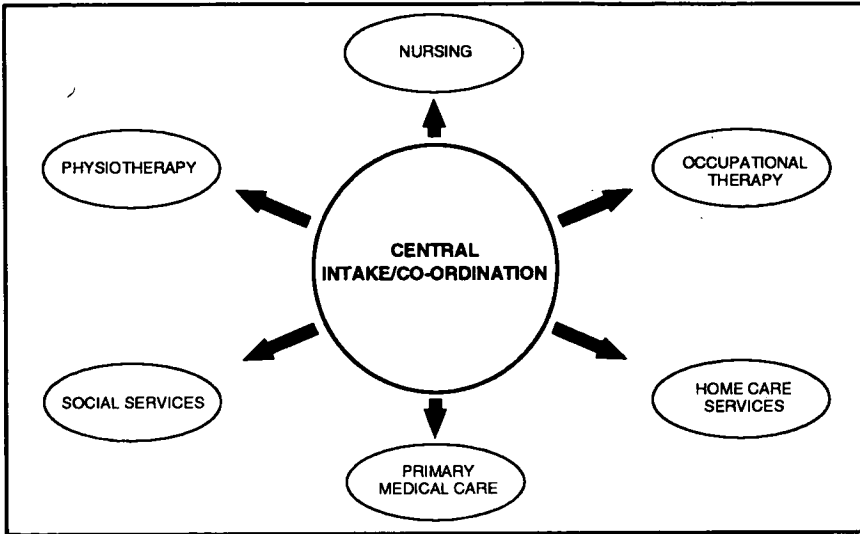


Figure 1: Community-based mental health services for the elderly.*

therapy, physiotherapy, pharmacy, social services, in-home help, meals-on-wheels as well as police services (see Figure 1). Day care and respite care are also fundamental components of community-based services. These interventions are often designed specifically for dementing individuals. However, they may also serve the socially isolated client and the physically frail individual. Most patients do not need to be referred to hospitals for respite or for day care. Many social service centres, religious institutions and other community centers can provide effective day care for those dementing individuals who do not suffer from serious behavioural or psychiatric problems. It may be more appropriate for those with these additional problems to be referred to a hospital-based service for in-patient assessment or day-hospital treatment. Alternatively, it may be appropriate to have these individuals assessed in the community day care setting by specialized psychiatric services.

Finally, another important function of a community-based service is health promotion and public education. By ensuring that the public are aware of the availability of services and promoting early referral and early identification of high risk cases we may prevent a great deal of unnecessary disability.

* Figures 1-3 originally appeared in the Canadian Journal of Psychiatry, 1991, 36(1) and are reprinted with the permission of the journal.

HOSPITAL-BASED GERIATRIC PSYCHIATRIC SERVICE

It is appropriate to refer here to a 'psychiatric' as opposed to a 'mental health' service. The focus here is on significant psychiatric and medical morbidity. Geriatric psychiatrists need to be available for both initial assessment and on-going treatment. Individuals should be referred to the hospital-based service when there is evidence of high psychiatric risk. It is also appropriate to refer when there is clearly a need for hospital resources such as radiological and laboratory investigations or where there is a significant medical component as part of the clinical presentation.

Ideally, the hospital-based service should combine several components including in-patient beds, out-patient clinics and consultation to other medical in-patient services. Community outreach services, which can assess individuals in their own homes or in long-term care institutions, may be located in hospital or in the community. Reasonable access to in-patient services is vital to these psychiatric services. Community outreach personnel need to know how to arrange admission if necessary.

Figure 2 shows how the components and referral patterns of an effective hospital-based psychiatric service can be integrated and blended into a cohesive comprehensive service for the high risk elderly psychiatric patient.

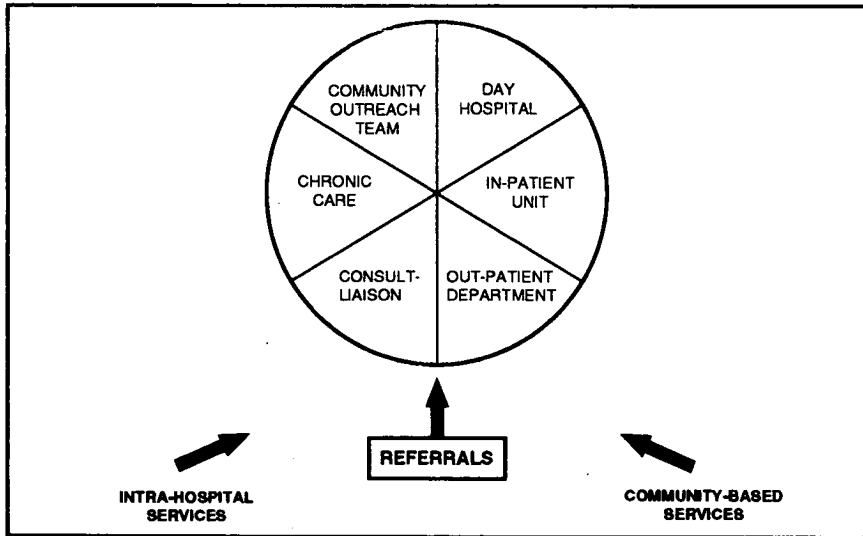


Figure 2: Hospital-based psychiatric services.

In contrast to community-based mental health services, the public should not have direct access to hospital-based geriatric psychiatric services. Screening should be done by the community-based mental health services. This makes for more efficient use of the expensive and resource intensive hospital-based service. For example, day *hospital* care is an appropriate function for a hospital-based service which takes patients who cannot be managed by the community-based day care programs.

The educational function of a hospital-based service should be directed primarily at other health professionals. However, important educational opportunities also exist in providing information to community support personnel and staff of long-term care facilities. Finally, education of the public is an often overlooked but important activity which can be a joint function of both hospital and community-based personnel.

REGIONAL GERIATRIC PROGRAMS

In recent years there has been an attempt to develop regionalized networks of health care services that oversee the enormous range and complexity of health care services for the elderly (Shulman, 1991). These are still in their initial phases of development but should have a community focus.

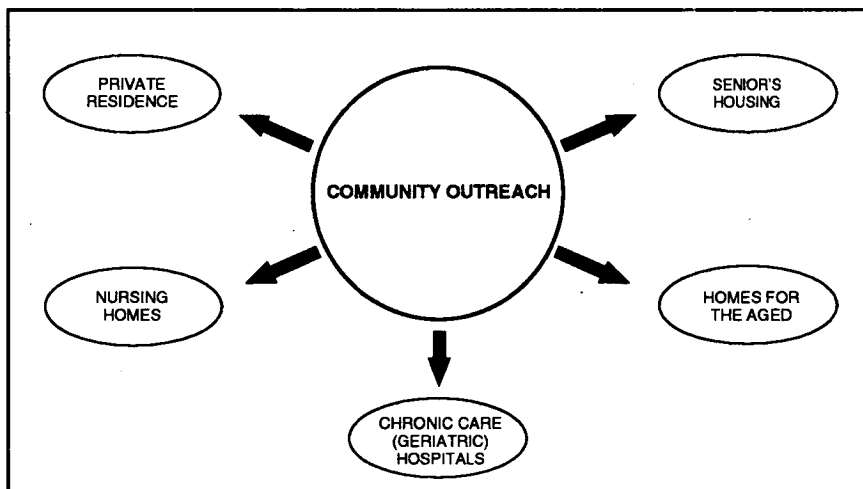


Figure 3: Community outreach

Figure 3 shows the various settings which both community-based and hospital-based services need to reach. Long-term care takes place not just in chronic care hospitals but more often in individuals' homes, supported by devoted caregivers. Indeed, the evidence is strong that the vast majority of long-term care for dementia takes place in the community rather than in the institutional sector (Doty, 1986). There is a clear challenge for services to bridge the so-called "acute" and "chronic" sectors. Some Regional Geriatric Programs attempt to do this by establishing a single administrative overseer. Moreover, formal linkages can often be established between specific geriatric services and institutional settings so that there is no question of accountability or responsibility for difficult cases. Here the principle of inter-dependence or "quid pro quo" facilitates effective functioning. That is, institutional settings need to be responsive to the needs of the acute care sector when appropriate assessment indicates the need for placement. At the same time, the community and hospital-based sector needs to be responsive to institutional settings that are having difficulty coping with behaviourally or psychiatrically ill dementing elderly.

Finally, another important challenge for the health care system in Canada is to ensure that the private and public sectors are also well connected. Often the private sector finds itself isolated and frustrated with difficult behavioural problems to which the public sector is not responding. However, on-going concerns prevail about the quality of psychiatric care in private care settings.

PLANNING ISSUES AND THE NEED FOR EVALUATION

Governments are increasingly concerned with the drain being placed on limited resources by the growing elderly population and especially, the psychogeriatric population. Even with the establishment of regionalized networks of services that are coordinated and efficient, there is still a need to answer important questions regarding the planning of future services and the reorganization of existing services. For example, what size of target population is manageable and appropriate for most services within an urban setting? A recent survey (Shulman & Arie, 1991) suggests that a target population of 20-30,000 elderly is one in which resources can be used most efficiently. However, this needs to be formally evaluated. What is an

appropriate number of in-patient beds to serve the psychiatric needs of a defined elderly population? What types and numbers of personnel do these services require? What are the best facilities necessary to meet their needs and what specific program initiatives provide high quality care with efficient use of limited resources? Community services need to develop standards of care for dementia patients and other vulnerable populations they routinely serve. The same questions regarding personnel, facilities and programming need to be answered for the relatively new community services providing respite care and day care. All of these important questions need to be addressed by developing services that report their clinical experiences and are formally evaluated.

In order to evaluate services adequately, it is important that we establish a common framework such as the comprehensive model outlined above. Services that screen for highly selected cases will have biased samples that are not generalizable to other settings. Randomized controlled trials should evaluate specific interventions and services that may delay institutionalization and/or prevent hospitalization. However, it is essential that these investigations also focus on the quality of life of the individual and the caregiver. For some dementing elderly individuals and their caregivers, institutionalization may indeed be the most desirable and necessary outcome especially when one looks at the quality of life issue. We need effective means of measuring quality of life (Mohide et al., 1988) and we need to develop standards for high quality care.

Because of the tremendous challenge to the health and social system it is important that developing programs and services also pay attention to their cost-effectiveness. Even though we assume that the services are necessary and fulfill an important function in society, we must find ways of providing the most efficient use of limited resources. Cost-effectiveness analysis should be applied to measure the incremental costs of different interventions or services for the same unit of outcome (Drummond et al., 1991).

A potentially efficient method for utilizing limited resources for this target population is to define global budgets for comprehensive services. Here a service is given a global budget and is responsible for the distribution and organization of services for its specific target population. However, it must be assumed that there is a system of clearly defined responsibility and accountability. Otherwise, as long as a service can avoid the most difficult and economically draining patients, it will be

easier to stay within budget and any evaluations will have little meaning.

In summary, the organization and coordination of the vast range of services for dementia represents one of the great public health and economic challenges of our generation. It is important that we facilitate the evaluation of such services and promote the development of innovative, creative, cost-effective and high quality services for this vulnerable population.

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10

ORGANIZATION AND COORDINATION OF SERVICES TO INDIVIDUALS WITH DEMENTIA LIVING IN RURAL SETTINGS

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INTRODUCTION

This chapter describes, from the perspective of the Long Term Care Programs Division of the Manitoba Health Services Commission, Manitoba's experience in providing services to individuals with dementia living in rural areas.

The Division is responsible for the funding and standards of care for 8,388 Personal Care Home beds throughout the province.¹ Of these beds, 3,797 (45.3 %) are located in rural areas, many in very small facilities, some as small as 14 beds.

Approximately 30% of residents in Manitoba's Personal Care Homes have diagnoses indicating a psychiatric condition and this does not include persons without such a diagnosis but with behaviour problems. The most commonly represented psychiatric conditions are 1) senile and presenile organic psychoses and 2) affective psychoses and depressive disorders. Of the 30%, 1140 live in rural Manitoba.

Clearly, the mentally impaired elderly present Personal Care Homes with a challenge in terms of providing appropriate care for them while at the same time maintaining a high quality

¹ In Manitoba, Personal Care Homes provide care for persons requiring long-term supervision and assistance with activities of daily living, basic nursing care under the supervision of a registered nurse and usually with a medical component to their care; and/or for persons requiring continual supportive and/or restorative care under medical direction and professional nursing supervision, with professional nursing staff required to perform direct, skilled nursing care.

of life for all residents. Increasingly, it is becoming apparent that although segregation of mentally impaired residents into specialized areas is an option, the larger reality is that all Personal Care Homes must be prepared to care for these residents within the current framework of their facility.

PROBLEMS IN PROVIDING DEMENTIA CARE IN RURAL SETTINGS

One of the primary problems in providing care for persons with dementia in the Personal Care Home setting is that many staff do not have specialized training or expertise in dementia care. This problem is exacerbated in rural areas. Where populations are small, specialized personnel are less likely to be available. For example, not every rural community in Manitoba has access to a psychiatrist.

In addition to the shortage of trained staff, which is experienced by most facilities, rural communities differ from urban centres in their geography, population density, economics and lifestyle. Staff often feel "psychologically distanced" from the urban centres where the available expertise seems to be centred. Professional isolation is an ever present concern. Additionally, the small size of many rural facilities (72.3% have under 50 beds; 27.7% have fewer than 20 beds) precludes the implementation of specialized units for cognitively disturbed residents, either because the numbers are not available to create a group environment or because of space and/or staffing constraints.

Staffing is also a problem for home care. In rural areas, as well as in cities, the Manitoba Home Care system provides supports such as personal care, nursing and therapy service, respite care and adult day care programs that enable elderly people to be maintained at home to the point where safety is jeopardized or where the cost of care becomes equivalent to that of institutional care (when 8 hours per day, 5 days per week of service is required this point is usually reached). Home care supports are also contingent on the availability of staff. In rural areas it is often difficult to recruit appropriate home care staff. When they are not available, when safety becomes an issue and/or where cost limits are exceeded, for many individuals the only option is institutionalization in a Personal Care Home.

THE MANITOBA RESPONSE

As our Personal Care Homes have been faced with caring for increasing numbers of residents with dementing illness, the provision of staff education and training has become a priority. In responding to the need, the Manitoba government has developed the following initiatives:

- a) **Educational Inservice Program for Staff in Long Term Care Facilities** - In conjunction with the Registered Psychiatric Nurses Association of Manitoba, a specialized training workshop program has been developed that is geared to staff in rural facilities.
- b) **Special Care Units as a Regional Resource to Personal Care Homes** - In the Manitoba context, the Special Care Unit model is a three-dimensional program including: an inpatient/resident unit; an outreach/consultation component; and an educational and research focus. Rather than being used for permanent admissions, two of these units have been purpose-built to serve as resources to surrounding Personal Care Homes. One, the Salem Home Special Care Unit, described below, is in a rural setting while the other is in an urban setting (the city of Winnipeg). When evaluated after two years, this pilot project indicated that there were different needs and different populations in rural as compared to urban areas.
- c) **Special Care Resource Teams** - Teams with psychogeriatric expertise have been designated to provide consultation and education to groups of Personal Care Homes. This model, described in detail in the next chapter of this volume, has been implemented in the city of Winnipeg and it is hoped that it will be extended to rural areas when funding is available.

THE SALEM HOME SPECIAL CARE UNIT A REGIONAL RESOURCE IN RURAL MANITOBA

In October, 1987 a Special Care Unit was opened at the Salem Home for the Aged in Winkler, Manitoba. Winkler is located in the South Central Region in Manitoba, a geographically discrete portion of one of the province's seven health regions. Covering 185 kilometers, the population of this area is 55,678, with 8,052 (14.5%) aged 65 and over. In this catchment area there are 13 Personal Care Homes (representing 585 beds), 10 hospitals and one psychiatric facility.

The Salem Home is a 125 bed Personal Care Home with a history of community involvement and leadership in the long term care field. At the time it was selected as the location for the unit, it was undergoing a renovation program. The 10 bed unit built as part of that renovation was opened as a two-year pilot project and is now a permanently established program.

PHILOSOPHY AND OBJECTIVES

The philosophy of the Salem Home's Special Care Unit is that each client is an individual and therefore requires individualized care planning.

The objectives of the unit are:

- 1) To provide care for individuals with behaviour management problems whose care needs cannot be met appropriately in their existing environment.
- 2) To provide therapy and a milieu that are conducive to behaviour change.
- 3) To provide compassion and human dignity to those who enter the Special Care Unit.
- 4) To provide a holistic approach to care including physical, emotional and spiritual care.
- 5) To provide support to the families whose loved one are admitted to the Special Care Unit.
- 6) To utilize staff who have expertise in the multi-disciplinary approach regarding management of individuals with behaviour problems in a specially designed environment.

- 7) To participate in research and education related to behaviour management.
- 8) To provide consultation services to staff within the Salem Personal Care Home and in other Personal Care Homes concerning the management of individuals with behaviour problems.
- 9) To participate in ongoing evaluation of the Special Care Unit program with the Manitoba Health Services Commission and the Office of Continuing Care.

The management of disruptive behaviour was chosen as the target for the unit because such behaviours were perceived to be on the increase in Personal Care Homes in the Region. One reason for the increase may be the limited social support available. Limited social support has been identified as a risk indicator for disruptive behaviour (c.f. Mentès and Ferrario, 1989). The demise of family farms and the resulting increase in younger people being employed in urban settings has greatly increased social isolation for the elderly population in rural settings. Traditionally, rural settings were synonymous with close knit families and grandma's apple pie. Today, the son no longer takes over the farm and the pie is baked by Duncan Hines.

ADMISSION CRITERIA

Admission and treatment in the Special Care Unit is available only to persons currently living in a Personal Care Home or on the waiting list to be admitted.

REFERRAL SOURCES

At the time of this writing, 43 persons have been admitted to the Special Care Unit. Of these, 60% came from Personal Care Homes, 28% from hospitals, 7% from psychiatric hospitals and 5% from the community.

CLIENT CHARACTERISTICS

Age and Sex

The average age of these clients was 80 but they ranged from as young as 54 to as old as 92. A majority (56%) were male.

Types of behaviour problems

Table 1 shows the behaviour problems exhibited by these 43 clients. As can be seen, the most common categories (41% to 53% of clients) were: physical aggression, disruptively noisy, and verbally abusive. Most displayed more than one behaviour problem.

-	53%	physical aggression
-	41%	disruptively noisy
-	41%	verbally abusive
-	18%	dangerous wandering
-	9%	sexually inappropriate
-	7%	demanding excessive attention
-	7%	psychosomatic complaints
-	5%	threatening
-	5%	resistive to care
-	5%	self abusive
-	5%	agitated
-	2%	bulimia
-	2%	feces smearing
-	2%	poking other residents

DIAGNOSES

Of the 43 clients, 55% had a diagnosis of dementia, 13% a history of depression, 12% had suffered a right hemisphere stroke and 9% a transient ischemic attack, 9% were mentally retarded and 9% had Parkinson's Disease.

TREATMENT AND TREATMENT GOAL

Medications are usually decreased and are used only as a last resort. The primary method of treatment is behaviour modification. Our treatment goal is to devise a plan that will

treat the problem behaviours and be transferrable to the referring facility. The following case studies illustrate our approach.

CASE #1 -Mrs. S

Mrs. S, an 85 year old client was referred to us because of her dangerous wandering. The referring facility treated this problem with both physical and chemical restraints, resulting in increased agitation and a tendency to fall. In the Special Care Unit a two-fold approach was implemented. Firstly, all exit doors were marked with a red stop sign. Any time Mrs. S approached the door the sign would be pointed out to her and she would be directed away. At this time she received social and tangible reinforcers. The second approach was to establish a distraction program using her old abilities in craftwork to occupy her time. In a 10 week period her exit-seeking decreased 100% and psychotropic medications were discontinued.

CASE #2 - Mrs. J

Mrs. J, an 89 year old client, severely demented with Alzheimer's Disease, was admitted due to her agitation and loud calling behaviour. The calling out episodes were too frequent to be measured on a continual basis. A daily half-hour monitoring session was carried out and a baseline frequency was established. A positive reinforcement program was implemented. Staff provided social reinforcement, holding her hand and speaking softly to her during quiet times. This client stayed in the Special Care Unit for 27 weeks during which time her calling decreased to an acceptable level. (Frequency at baseline was 3.29 per 1/2 hour and at discharge was 0.29). She has been discharged for 23 months and is assessed as doing much better by the nurses at the referring facility.

SUCSESSES AND DIFFICULTIES

The problem behaviour we have treated most successfully is physical aggression. The solution to dangerous wandering is difficult to achieve in most instances.

Client follow-up is a problem. While originally, the referring facilities were asked to keep an hour-by-hour record of clients' behaviour for the first week of every month, up to six months subsequent to their discharge from the Special Care Unit, this proved unfeasible. We now ask staff to use a more qualitative approach, which consists of filling out a form, once a month, for the first six months post-discharge, in which they indicate whether the client shows: substantial improvement, fair improvement, is the same as prior to admission to the Special Care Unit or is worse.

Table 2 shows nurses' ratings for 22 clients followed-up from 4 to 86 weeks post-discharge (mean time since discharge = 41 weeks). The primary behaviour problems shown by these 22 at admission to the Special Care Unit were: 50% aggression; 28% repetitive noise; 18% loud yelling and 4% poking other residents; 81% had a diagnosis of dementia. The high proportion showing at least some improvement is encouraging.

Table 2
POST-DISCHARGE STATUS OF SCU CLIENTS
SALEM HOME, WINKLER MANITOBA

-	27%	substantial improvement
-	9%	substantial to fair improvement
-	14%	fair improvement
-	4%	the same to fair
-	18%	the same
-	0%	worse
-	27%	deceased.

Also encouraging is clients' reaction to the physical design of the Special Care Unit. As can be seen in Figure 1, it is a self-contained unit for ten residents with individual rooms grouped around an open central activity area. A dedicated dining area overlooks an exterior, secured patio which opens off the unit. We have found that with a configuration of this type, even the most territorial of clients feels free to leave his/her room. This is because they can see their room from all the common areas. This shape also facilitates staff supervision and monitoring of clients.

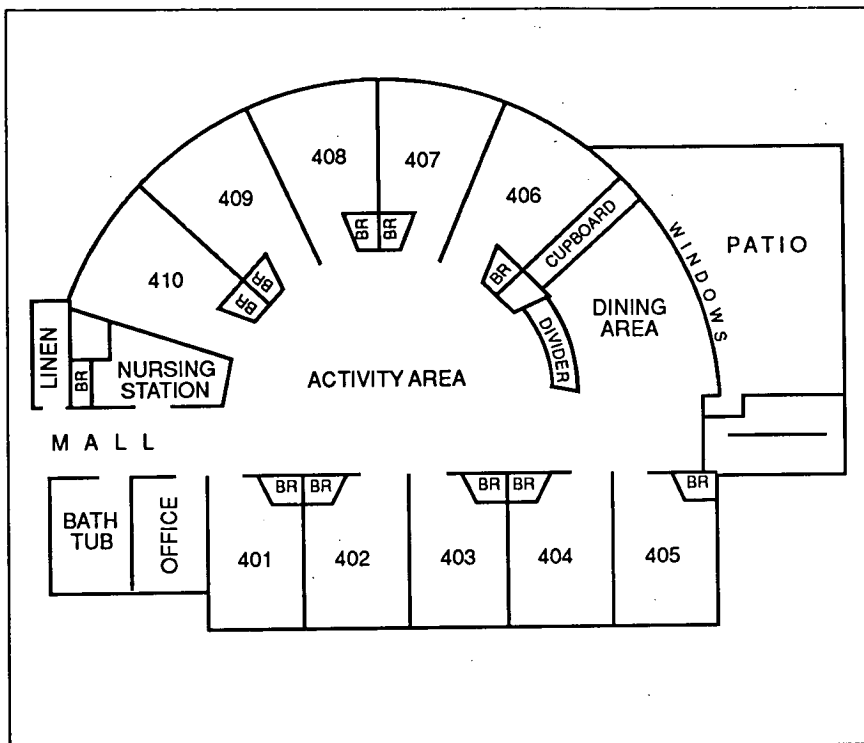


Figure 1: Floor Plan of Special Care Unit, Salem Home For the Aged, Winkler, Manitoba

A final comment relates to the difficulty of assembling a multidisciplinary team of health care providers in a community of farmers and factory workers. The way this was accomplished was to hire R.N's, R.P.N's and support workers. Other staff come to the unit on a consulting basis: a geriatrician, a psychologist, a music therapist and an occupational therapist, once per week. The unit also has access to a psychiatrist on a consultative basis. It should be noted, however, that some of these consultants are shared with the local psychiatric hospital. This limits their ability to provide consultation to referring facilities outside the Special Care Unit, a task that has fallen largely on the shoulders of the Unit Coordinator. Given the large catchment area, the amount of time spent travelling (up to 1 1/2 hours) has posed problems. Despite this, the consulting service has been maintained with some regularity. The concept of a Special Care Unit as a regional resource shows much promise and is seen as a valuable asset by all referring facilities.

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11

THE BETHANIA SPECIAL CARE RESOURCE TEAM

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INTRODUCTION

As Sarchuk and Wiebe (1992) have indicated (see chapter 10 this volume) one response of the Manitoba government to meeting the needs of the increasing numbers of elderly with mental impairments has been to establish Special Care Resource Teams. In 1989, three such teams were established in the city of Winnipeg. Each consisted of two full-time staff. Their mandate was to provide consistent and ongoing consultative services to the 33 Personal Care Homes in the city to help them manage their behaviourally disordered elderly residents. This chapter describes the staff, clients and services provided by one of these teams, the team based at the Bethania Mennonite Personal Care Home.

STAFFING OF THE SPECIAL CARE RESOURCE TEAM

The Bethania Special Care Resource Team (SCRT) is currently staffed by a full-time social worker and a full-time psychiatric nurse. The SCRT is one-half of the Bethania Special Care Program. The other half of the program consists of a 10 bed in-patient Special Care Unit analogous to the unit at the Salem Home described by Sarchuk and Weibe. Staff of the SCRT complement the staff of the in-patient unit and work closely with them.

SERVICES PROVIDED

The SCRT provides weekly or biweekly consultative services to 11 Personal Care Homes in the Winnipeg area (combined resident population = 1502). The frequency of the consultative visits depends on the size of the home.

The services provided range from informal advice concerning the behaviour of a particular resident to the

development of formal, intensive behaviour management programs. Any of the suggestions or programs provided by the team are then instituted by the Home's staff with the SCRT's guidance.

In addition to these direct resident services, the team also provides staff inservices across a wide range of topics. In the first 15 months of operation, 56 inservice sessions were conducted, reaching approximately 450 staff. Among topics covered were: staff stress management, client behaviour management, sexuality and aging and transference/counter-transference issues.

CLIENTS SERVED

In the 20 month period from July 1, 1989 when the SCRT commenced operation to March 30, 1990, 48 referrals were received. The average time from referral to first contact was six days (range 0-20 days); 31% of clients were seen the same day the referral was received. On average, each month there were 26 Personal Care Home visits, 47 client contacts and 81 hours spent in direct client contact.

Among the 48 clients seen during this period the primary diagnoses were: Alzheimer's (26%), Other Dementias (22%), right C.V.A.(17%) and Organic Brain Syndrome (9%). The main types of behaviour problems exhibited by these clients were: physical aggression (33%), calling out (17%), verbal abuse (11%) and excessive attention seeking (9%).

In the six months of operation April - September, 1990 an additional 40 referrals were received. Again, the average time from referral to first contact was six days (range 0-25 days); 28% were seen the same day the referral was received. On average, each month there were 28 Personal Care Home visits, 48 client contacts and 106 hours of direct client contact.

In similarity to the previous period, the two primary diagnostic categories represented were Alzheimer's (12%) and Other Dementias (25%), but as can be seen the proportions were reversed. Depression came third (10%) followed by Organic Brain Syndrome (7%). The two most common behaviour problems were again physical aggression (30%) and calling out (17%). The next two most common problems were wandering (10%) and verbal abuse (9%).

It should be noted that the proportions exhibiting physical aggression were higher and the proportion exhibiting verbal abuse were lower than those reported by Burgio et al. (1988). In their study, geriatric assistants in an urban nursing home estimated physical aggression at 20% and verbal abuse at 22%. Some possible explanations for the difference include the use of different definitions in our study. Also, we are only reporting clients' primary behaviour problem.

NATURE OF THE INTERVENTION

In general, when a referral is made, the normal practice of the SCRT is to undertake a complete review of the client's file; administer a mental status test (usually the Mini-Mental State Exam developed by Folstein, Folstein & McHugh, 1975); meet with the Personal Care Home staff (and with the family if necessary and possible) and make our own observations of the client. Behavioural approaches are then applied. The general practice is to start with approaches which are the simplest, least disruptive and invasive to the client and which can be managed by the Personal Care Home staff. More detailed and complicated approaches are only used if the initial approaches are unsuccessful. The following three case studies illustrate the way in which we work with clients.

CASE #1 - MISS S

Miss S was a 78 year old female with primary diagnoses of: 1) Depression/paranoid tendency 2) hypoxia post cardio-respiratory arrest (two years before our involvement and in which some brain damage had occurred) 3) hypertension and 4) mild cognitive impairment.

Miss S had been admitted to the Personal Care Home 11 months earlier, having come from a psychiatric unit in a general hospital. The staff of the Personal Care Home consulted the SCRT to assist with the management of her physically aggressive behaviour and screaming.

The baseline data, completed by the Personal Care Home staff, showed a relationship between the time of day and the occurrence of these problem behaviours (see Figure 1). Over 26 days there were 36 notations of mild aggression, 9 (25%) of which took place on day shifts, 27 (75%) on evening shifts and none on night shifts. The average number of incidents was 1.4

per day with the behaviour occurring most commonly between 1700 and 2100 hours.

Figure 1 also shows a relationship between screaming behaviour and time of day. Over a 26 day period there were 30 episodes of screaming lasting one minute to two hours. The duration of a screaming episode was measured by considering the end of one episode to be silence or appropriate verbal interaction for one full minute. The day shift noted four episodes (13%), the evening shift noted 25 (83%) and the night shift noted one episode (3%). The average was 1.3 per day with a small peak between 1100 and 1300 hours and a large peak between 1500 and 1900 hours. The facility staff felt the behaviour was far more frequent than they were able to record.

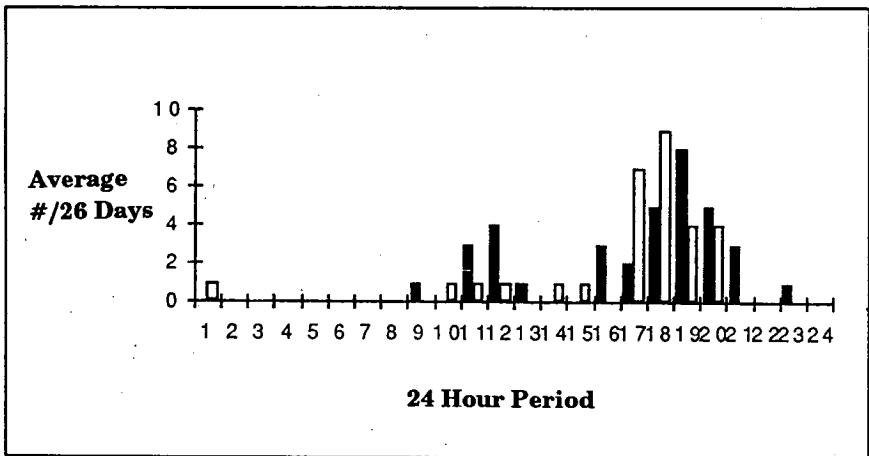


Figure 1: Miss S. Aggression/Screaming Episodes.

The behaviours requiring change were defined as:

- a) **Combatative/aggressive behaviours:** scratching; hair pulling; biting; grabbing; pinching; throwing objects; and pushing.

It is important to note that all the aggressive incidents were directed at staff and were always related to times when care was being given.

- b) **Screaming Behaviour:** loud moaning; screaming; crying.

INTERVENTIONS

In treating the aggressive behaviour the SCRT decided to focus on an approach that used Differential Reinforcement of Other Behaviours (D.R.O.) and Extinction (see Martin & Pear, 1988). More specifically, if Miss S attempted or succeeded at being aggressive, after telling her that the behaviour was inappropriate, the staff would walk away for five minutes. The same staff would then return at the end of five minutes and continue care. Initially, this procedure was repeated as often as necessary. She was also given social and edible reinforcers when she was not being aggressive. The D.R.O. schedule was hourly but initially, she was only required to be free of aggressive incidents for the last 15 minutes of the hour in order to receive the reward. The required time to be free of aggression was increased as the overall incidents of aggression decreased.

Miss S's screaming behaviour was also managed with D.R.O., Extinction, and isolation. The plan was to completely ignore the first five minutes of screaming. This behaviour, however, could not be entirely ignored because it was very upsetting and disruptive to fellow residents. Therefore, if she persisted in screaming beyond five minutes, a staff member gave her a matter of fact warning. The warning consisted of one direct statement that if she continued to scream for a further five minutes, she would be placed in the "time out" area. For a next five minutes she was again ignored, after which, if still screaming, she was placed in the library or kitchenette alone. At the end of a further five minutes, if she was quiet, she was removed and reinforced. If she was still noisy, the staff waited until she had been quiet for one full minute and then they brought her out and reinforced her. When she was not screaming, she was reinforced on an intermittent schedule (e.g. she was given compliments, praise and pats on the arm whenever staff passed by her).

During the course of the treatment program the staff noted that their attention was not as reinforcing to Miss S as it was initially understood to be. Social reinforcement was therefore diminished and edible reinforcers, which had greater value to Miss S, were increased.

Unfortunately, due to an increasing patient load, the facility staff were unable to continue data collection during the

treatment phase. However, the staff verified verbally that there was major improvement. It should be noted that, on two occasions, when the formal program was stopped because staff felt they no longer needed to apply it, the problem behaviours increased. Both times, when staff subsequently reapplied the approaches consistently, Miss S's behaviour improved. What the staff eventually realized was that they needed to include the treatment intervention as part of their daily routine with Miss S. An additional benefit of the treatment program for Miss S was that subsequent to its introduction, she increased her participation in activities which, prior to treatment had been at the zero level, to a rate of three times per week.

Approximately seven months after the file was closed (the staff requested closure as they felt the client had progressed very significantly) the SCRT conducted some brief observations of Miss S's behaviour. During a 30 minute period two incidents of mild aggression (e.g. pushing staff's hands away) and two incidents of screaming, which lasted less than one second each, were observed. Both behaviours occurred while the staff were providing care. The staff indicated that while aggression and screaming behaviours were still present, they were much less severe and they no longer had trouble managing Miss S.

CASE #2 - MRS. A

Mrs. A is a 69 year old female with primary diagnoses of: 1) right C.V.A. with left hemiparesis and 2) hypertension.

She had been admitted to her Personal Care Home six months prior to the SCRT's involvement. The team was consulted for assistance in managing her excessive attention seeking behaviour.

The specific behaviours the Personal Care Home wished to extinguish included:

- a) **Requests for cigarettes outside her scheduled time.** Mrs. A. was an unsafe smoker and required constant supervision while smoking.
- b) **Attention seeking:** any calling out, requests for unnecessary boosts in her chair, for a repeat of the time of activities or events which she was already aware of, refusing medication and using the call bell for routine or excessive requests.

- c) **Other requests:** any unnecessary requests outside the regularly scheduled time for bathroom, bedpan or physical care (e.g. turns during the night).
- d) **Lifting her foot:** requests outside her regular routine to have her foot repositioned. (Mrs. A had been seen on several occasions manually moving her foot out of position within seconds of having it adjusted and then again requesting repositioning. This was typical of much of her attention seeking behaviour.)

INTERVENTION

The intervention designed by the SCRT was again a D.R.O. approach. We assisted the staff in building trust with Mrs. A largely through establishing a daily routine that included times for all her care, cigarettes, boosts in her chair and her foot repositioning. Staff were encouraged to assign one caregiver to perform all of her care each shift thereby decreasing the opportunities she had to manipulate staff. The caregiver was instructed, when completing one task, to tell Mrs. A what the next task would be and what time it would be completed. Mrs. A was also given a written schedule she could keep with her and refer to. She was placed on a regular interval schedule (Q 30 minutes) of positive reinforcement for zero attention seeking behaviours. She also received one unconditional 10 minute period of staff time each shift. The staff took care to offer this time when she was being quiet not when she was being demanding. They also attempted to keep it as close as possible to the time they had arranged with her at the beginning of the shift that day.

As can be seen in Figure 2, over the eight weeks of the treatment (weeks 3-10), the following changes were noted:

- a) Cigarette requests decreased from an average of approximately 7 per day at baseline (weeks 1 and 2) to 2 per day.
- b) Attention seeking decreased from approximately 13 per day to 4 per day.
- c) Other requests decreased from an average of approximately 5 per day to 1 per day.

- d) Lifting her foot: decreased from an average of approximately 6 per day to 1 per day.

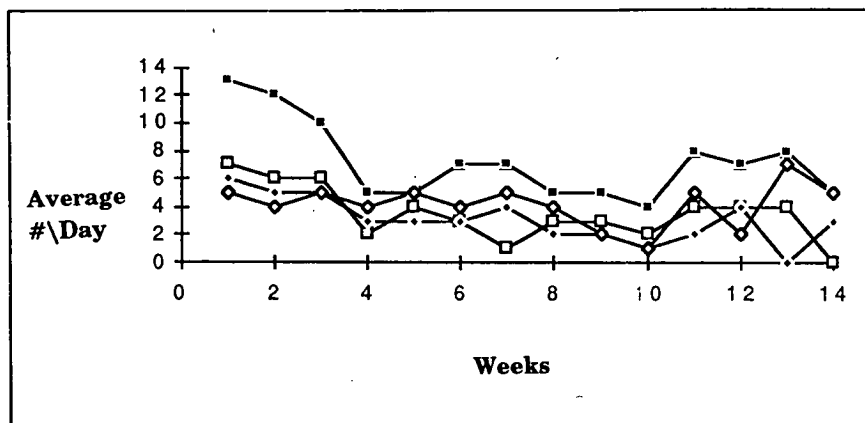


Figure 2: Mrs. A. Four Problem Behaviours

At the conclusion of the 8th week of treatment (week 10 of the program) the staff were very satisfied with Mrs. A's progress and decided to discontinue the program. In an attempt to determine the effects of discontinuation, the SCRT conducted four probes of Mrs. A's behaviour, each one week apart. As can be seen in Figure 2, there was an increase in all four problem behaviours during these four weeks. When these findings were discussed with the staff they agreed to reintroduce the program.

Mrs. A's health deteriorated and she passed away before a 12 month follow-up visit could be conducted by the SCRT. The staff reported however, that following reintroduction of the program, they remained pleased with her diminished behaviour problems and the increased positive contact they enjoyed with her.

CASE #3 - MRS. S

Mrs. S is a 77 year old woman with primary diagnoses of: 1) organic brain syndrome with severe dementia and 2) glaucoma with left eye blindness.

Mrs. S had been admitted to her Personal Care Home approximately three years prior to the SCRT receiving a

referral. The reason for the referral was Mrs. S's stereotypical picking and wiping which was destroying personal and facility property. This behaviour was a constant occurrence throughout her stay at the home.

The picking behaviour was chosen as the initial target for intervention because the wiping behaviour was less destructive and was managed by staff moving her along to a new spot.

Picking was defined as: pulling at clothes, skin, hair or threads with thumb and forefinger.

Since this referral was very recent and the intervention had begun just two weeks prior to this writing, only baseline data and some anecdotal comments of staff are presented.

Figure 3 documents Mrs. S's picking behaviour over a 17 day baseline period. As can be seen, the frequency of this behaviour ranged from a low of zero occurrences per day to a high of 10 hours of picking per day.

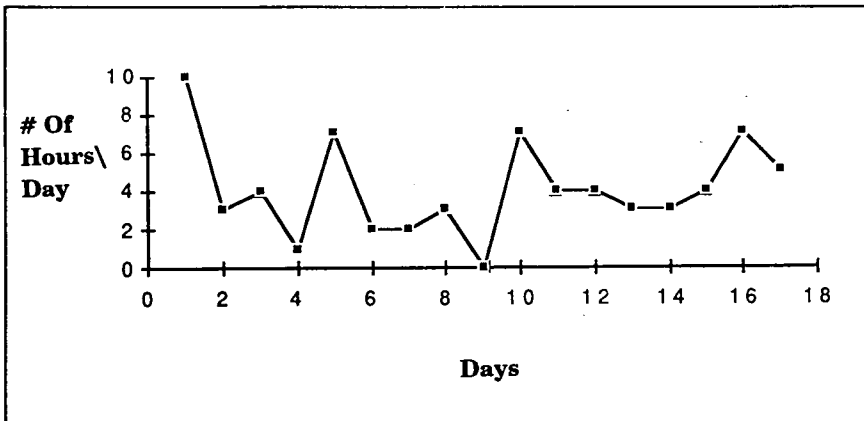


Figure 3: Mrs. S. Picking Behaviour

INTERVENTION

The intervention devised by the SCRT consisted of having Mrs. S wear a pair of white cotton evening gloves. The gloves prevented Mrs. S from picking at things but she still could manipulate her fingers and function appropriately. The idea was that the gloves would break up the behavioural chain

of picking by not allowing her the reinforcement of successfully picking something apart.

The program consists of a D.R.O. procedure with random reinforcement and application of the gloves for a total of four hours per day, in one and two hour time blocks. The gloves were removed when she was taken to meals and activities and when engaged in personal care. All picking behaviour was placed on an extinction schedule. Reinforcement was given for not picking, whether or not she had on the gloves.

At this time the gloves have been applied for two weeks. The staff have noted that when the gloves are on Mrs. S usually sits with her hands in her lap and does not pick. They also report that the frequency of picking behaviour has decreased at times when the gloves are off. However, it is still too soon to see if this approach is successful.

OVERALL PROGRAM EFFECTIVENESS

One of the latest independent measurements conducted to ascertain the effectiveness of the SCRT was in the Summer of 1990. At this time, the Manitoba Health Services Commission contracted with a registered nurse who had several years of geriatric experience to randomly select 1-2 clients from each of the Personal Care Homes served by the team. Her task was to review their charts, care plans and files to determine if the SCRT's involvement had resulted in any improvement in their behaviour, as identified by the Personal Care Home's staff. In total, 31 (45%) of the team's active or recently closed files were reviewed. Of the 31, 10 (32.2%) of the clients had been identified by the Personal Care Home staff as having shown marked improvement; 8 (25.8%) as having shown slight improvement; and 9 (29.0%) as unchanged. Of the remainder, 1(3.2%) was admitted to the Special Care Unit, 2 (6.4%) were awaiting further medical assessment and 1(3.2%) had died. It is noteworthy that 58.0% showed at least some degree of improvement and none were rated as worse.

CONCLUSION

Well over 20 years ago, Cautela (1966) extolled the virtues of using behavioural approaches with geriatric patients. Eleven years later, Gentry (1977) stated that in his opinion, a behavioural approach learnt itself nicely to dealing with problems of the aged or aging. One advantage to this approach,

he stated, was that "...time is not unnecessarily spent on determining the relevance of long past experiences as underlying causes of the recent behaviour..." (p. 22). However, despite data suggesting that behavioural problems are quite prevalent among both community dwelling and institutionalized older persons (Burgio, Butler and Engel, 1988) it is only recently that behavioural methods have begun to be applied with much frequency with this client population. Articles concerning the application of this treatment modality to older adults are still underrepresented in the professional literature (see review articles by Baltes & Barton, 1977; Burgio & Burgio, 1986; Hussian, 1984; Paterson & Jackson, 1980; Williamson & Ascione, 1985; and Wisocki, 1984).

Based on our experience, we feel that behavioural assessments and approaches are very helpful in getting staff to look at behaviour from a more analytical perspective; in getting them to look for positive attributes in their clients; in encouraging them to apply individualized approaches to care; and in helping them to change their outlook regarding difficult clients. We have also seen a fair bit of generalization, especially in regard to their application of positive reinforcement both to those clients with whom we have been involved and with other residents who display appropriate behaviours. Behavioural approaches help residents unlearn the institutionalized behaviours they have acquired since admission.

We have, however, encountered a number of problems in attempting to implement behavioural programs in Personal Care Homes. Among them are that:

- a) **Data collection by facility staff is typically unreliable.** Overall, they have difficulty understanding its importance. They also have rigorous work schedules which make data collection an onerous task.
- b) **As yet, we have not been able to complete our inservice series regarding the cause and maintenance of problem behaviours and approaches to changing them.** As a result, there is little understanding of the methodologies we attempt to use. Lack of time for inservice is a major factor. Staff are not released from ward duty very readily or very often.
- c) **There is a general belief that one cannot change the elderly and that institutionalized**

behaviours cannot be unlearned by persons with dementia.

- d) **Some staff are very resistant to changing their approaches.** They may feel threatened or incapable or that they have failed in not having been able to come up with "the answer" themselves. Some are simply not willing to try approaches they don't believe will work.
- e) **Finding solutions that are both effective and that can be carried out with present staffing levels is often difficult.** The most effective approaches are usually significantly watered down. We have found that programs that are complicated and which require extra work on the part of floor staff are usually poorly or inconsistently run. The result is less dramatic change than would otherwise occur, longer periods before success is seen, greater disillusionment for staff because of the delayed reward for their work and, longer program time frames.

However, we have no doubt that the concept of an SCRT is a valid one. As one nursing assistant stated "...we know you can't solve all our problems but it sure helps to know that someone is out there who cares and is trying to help..."

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**PART IV: FACILITATING SHELTER AND
CARE AT HOME**

12

ADAPTING THE HOME TO MEET THE NEEDS OF PERSONS WITH DEMENTIA AND THEIR FAMILY CAREGIVERS*

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INTRODUCTION

Approximately 80% of persons with Alzheimer's disease and other dementias live at home with their caregiver, usually a spouse (Robertson & Reisner, 1982). With increasing numbers of family caregivers looking after relatives with dementia at home, it is helpful to know how people adapt their homes to accommodate the characteristic behaviours of persons with dementia and the needs of primary caregivers.

Who needs this information? At least three groups can benefit from some knowledge about "what goes on behind closed doors" in the care of persons with dementia:

- current and future caregivers, so that they can take advantage of other caregivers' creativity and solutions;
- architects and designers of retrofitted or purpose-built housing for the cognitively impaired, so that they may learn about the spatial, safety and other needs of this special user group; and
- policy makers, so that they might become more aware of what goes on in non-institutional environments, where the majority of people with dementia are living.

* This paper is based on the findings from a research project carried out by the author during 1988, funded by a grant from The Canada Mortgage and Housing Corporation's External Research Program. Findings are reported fully in *Housing Alzheimer's Disease at Home* (Gnaedinger, 1989) and summarized in an illustrated booklet *At Home with Alzheimer's Disease: Useful Adaptations to the Home Environment*, available free from the Canadian Housing Information Centre, Canada Mortgage and Housing Corporation National Office, 682 Montreal Road, Ottawa ON K1A 0P7

A preliminary literature search revealed that there are two main bodies of work on the shelter and care of people with dementia:

- one concentrates on management techniques and psycho-social factors (Coons & Weaverdyck, 1986; Gilleard, Boyd & Watt, 1982; Kirkland, 1986; Paul, 1988; Reisberg, 1984; Robertson & Reisner, 1982);
- the other on designing for dementia in *institutional* settings (Brotherhood Foundation, n.d.; Calkins, 1987a,b; Calkins, 1988; Cohen et al., 1988a,b; Hall, Kirschling & Todd, 1986; Hanley, 1981; Hiatt, 1980a,b; Lawton, 1979; Lawton, Fulcomer & Kleban, 1984; Peppard, 1986; Rodenberg, 1986; Shroyer, Hutton & Anderson, 1987; Summers, 1986).

There is very little material on the physical, practical aspects of housing persons with Alzheimer's disease and other dementias at home (Burke Rehabilitation Centre, 1985; Crystal, 1987; Hiatt, 1983; Mace & Rabins, 1981; Pynoos, Cohen & Lucas, 1988; Winston, 1988; Woerner & Casper, 1987). The study described below was carried out to help fill that gap in our knowledge.

RESEARCH METHODS AND SAMPLE CHARACTERISTICS

The scope of the research was national and four research methods were used. First, the literature review was expanded, covering academic articles, how-to books, newsletters, and newspapers. Most references provided no more than a few sentences or paragraphs on the topic.

Next, telephone interviews were conducted with key informants. These consisted of ten members of the executive of the Alzheimer Society from across Canada as well as three individuals living in the Ottawa-Carleton area who worked with persons with Alzheimer's disease. Of the 13 informants, 11 claimed to be "very familiar" with Alzheimer's households and 6 had personal experience as a caregiver.

Based on the information gathered from these two sources, a survey questionnaire for caregivers was designed,

pretested, and mailed to a stratified random sample of 1,000 members of the Alzheimer Society of Canada. The sample was stratified by province and by language (200 French and 800 English questionnaires were sent). The choice of the membership of the Alzheimer Society as the sample was based on the expectation that a significant proportion - possibly half - of these members are, or have been, caregivers of people with Alzheimer's disease. In total 162 questionnaires were returned, of which 138 were usable - 104 English and 34 French.

Of the 138 respondents, almost three quarters (74%) identified themselves as current or former *full-time* caregivers. Over two-thirds (68%) were female. The majority (79%) lived in a house; 14% lived in a market apartment, 4% in a seniors' apartment and 3% in other types of dwellings such as a mobile home or retirement home. Just under half (46%) were 64 years of age and under; approximately one third (31%) were between 65 and 74; and a quarter (23%) were 75 years of age and over. It should be noted that the ages given did not necessarily represent the age of people while they were actively caregiving. Many of those who answered the questionnaire did so after their relatives had been institutionalized or had died.

In the final stage of research, in-depth, in-home interviews were conducted with 25 current and former caregivers from across Canada (6 in British Columbia, 2 in Alberta, 4 in Manitoba, 6 in Ontario, 3 in Quebec and 4 in Prince Edward Island).

The interviews lasted up to two hours. Most (68%) of the caregivers interviewed were spouses (9 wives, 8 husbands); 4 were daughters; 1 was a son; and 3 were couples. Most of the interviews took place in the caregiver's home, typically a single-family detached house. Most of those interviewed were older people, the spouses ranging in age from 60 to 82 years; the adult children caregivers in their sixties and seventies.

Although the caregivers interviewed varied in age, income, educational level, and ability to cope, they had several characteristics in common: they appeared to be highly organized individuals; their devotion to the family member they were or had been caring for was profound; the stress and exhaustion they experienced was palpable, even in those people whose relatives had been placed in a facility or had died years before; and, they clearly needed to tell about their years of anxiety and their grief.

SYMPTOMS AND BEHAVIOURS TYPICAL OF PERSONS WITH ALZHEIMER'S DISEASE

Because general information on dementia is provided elsewhere in this volume, only the typical behaviours of persons with Alzheimer's disease and related dementias *that specifically relate to adaptations in the home* are listed here.

It must be pointed out that not all persons with Alzheimer's disease and related dementias have the same symptoms or exhibit the same behaviours. They vary by individual and with the stage of the disease. However, there are some changes and behavioural characteristics recognized as "typical" that are particularly relevant to adapting the living environment.

The relevant *cognitive* changes are: loss of memory, especially recent memory; marred visual perception, especially depth perception; and disorientation.

Typical *behavioural* characteristics are: agitated, persistent behaviour that appears to be purposeless, such as wandering and rummaging; changes in sleep patterns, typically getting up in the night; quickness to anger, often directed at the primary caregiver; and a demonstrated fear of darkness and fear of being alone.

The main *physical* change seems to be the tendency to stumble, related perhaps to the loss in depth perception. Many persons with Alzheimer's disease though remain very fit into advanced stages of the disease.

SUMMARY OF RESEARCH FINDINGS

The research questions were clustered around five types of adaptations to the home. Those made in order to:

- increase safety and security in all parts of the home and in the area immediately surrounding it;
- enhance orientation;
- accommodate wandering/pacing;
- prevent or reduce agitation; and
- meet caregivers' needs.

The questions asked in the survey and during the personal interviews covered the same topics, but were not always asked in the same order, because very often the respondents had their own agendas and a very apparent need to tell their stories. In presenting the findings data from the survey and interviews have been integrated. The following themes emerge.

SAFETY/SECURITY

The most outstanding theme was the need for constant surveillance or supervision of persons with Alzheimer's disease. A number of respondents reported that neighbours are part of an extended surveillance system.

In addition to general vigilance, a number of specific safety and security precautions are taken in many Alzheimer's households. These include:

- **installing extra locks on exit doors** - for example, adding a lock requiring two or more steps, which will usually thwart a person in the later stages of dementia; adding a simple hook and eye lock well above the normal line of vision; or simply using a dead bolt that locks from the inside and pocketing the key;
- **removing the lock from the bathroom door** (several of those who had not done so explained that they were married couples who had never locked the bathroom door during all their married life);
- **removing dangerous objects or substances** - for example, pills, cleaning solvents, sharp knives, power tools, scissors, lighters and matches, even car keys - anything the patient could no longer use safely in the judgment of the caregiver;
- **regulating appliances with the potential to cause burns or fire** - for example, by removing fuses or knobs or turning off the circuit breaker for the stove; lowering the hot water temperature to prevent scalding; and placing furniture in front of hot radiators;

- **adding assistive devices in bathrooms**, such as grab bars, bath seats, long hoses for bathing a seated person and non-slip mats;
- **removing stoppers from all sinks**, to avoid accidental overflows;
- **installing rubber treads** on inside and outside stairs to improve traction; and
- **adding a safety railing** on inside and outside stairs and along a veranda.

Several respondents mentioned safety/security measures that they had tried and found *unsuccessful*. These included: a locked gate without a padlock, which could be opened too easily and placing heavy pieces of furniture in front of exit doors, which made the patient angry.

ENHANCING ORIENTATION

Caregivers reported making a number of practical changes to enhance the orientation of the person with dementia, such as:

- **adding night lights** near or in the bathroom;
- **keeping lights on in the house all day and night**;
- **removing, consciously closing or marking doors** to reduce confusion and decision-making about where to go; and
- **posting signs, symbols or notes** (the latter with apparently limited effectiveness).

It was pointed out that making too many modifications may increase *disorientation*. For example, one gentleman redecorated his wife's bedroom to try to relieve her depression, but she refused to enter it - saying it was not "her room".

WANDERING/PACING

The main adaptations to accommodate wandering or pacing, were pushing furniture back against walls and removing coffee tables, other small tables, lamp cords and other objects so as to clear a path for wandering or pacing.

AGITATION

The more common changes made to prevent or reduce agitation were keeping curtains closed and removing or covering mirrors so as to eliminate reflections, which are typically not recognized by persons in the later stages of Alzheimer's disease and which can be very frightening to them.

Other strategies involved changes in lifestyle rather than physical modifications such as keeping the television off, removing it to the caregiver's private room, or watching only non-violent programs.

CAREGIVERS' NEEDS

The only needs expressed by respondents that related to physical aspects of their dwellings were for:

- **"a room of one's own"** - a place to lock oneself away and rest or read or cry when frustrated and exhausted. This could be a locked bedroom, basement den, or refurbished attic space. Almost half of the respondents agreed that this was *very* important; and
- **assistance with tasks** such as installing a grab bar or a lock.

Other needs expressed by caregivers were for help in carrying out their onerous task and for reliable support from *and confidence in*: home support workers, the medical profession, neighbours, family members and other Alzheimer's caregivers. These needs were expressed over and over again, despite the fact that the research questions, in both the survey and the personal interviews, belaboured the theme of "practical, physical modifications" to the dwelling.

CONCLUSIONS AND RECOMMENDATIONS

The research revealed that the main caregiving strategy is surveillance, and the most frequently expressed need was for assistance to family caregivers.

These findings lead to four recommendations all related to supporting caregiving in the family home. Two recommendations relate to social policy; two relate to housing policy.

- a) **The financial costs of modifying the home should be made reimbursable.**

This recommendation is based on the observation that the financial costs of adapting the home are high for pensioners who were the majority of respondents in this study. For example, the average amount spent on the purchase and installation of locks was \$195.00 - a lot of money for pensioners. Other evidence of cost being a deterrent was the finding that only nine of the twenty-five caregivers had installed electronic security systems - costing up to \$2400. One of the reported reasons for not doing so was cost.

- b) **There is a need to provide instrumental support to caregivers wishing to make home adaptations.**

For example, caregivers may need help installing a grab bar or a lock or putting up a railing. Even for caregivers who have the money and time to purchase these items, some may not be capable of installing them. In other cases just the idea of attempting any project beyond the activities of daily living may be overwhelming. The establishment of a program that would provide assistance of this type is something service clubs might consider.

- c) **Separate suites, or space that could easily be made self-contained, should become a more common feature in the design of single family dwellings.**

The caregivers' declared need to have "a refuge" within the home, a space that is aurally and visually private, is in keeping with the increasingly accepted notion of including space in the design of single family dwellings that could easily be converted to a self-contained apartment. Such an apartment could serve several different functions over the various life stages of a family. One of these functions could be private space for a family or hired caregiver. Or, in the case of a frail but mentally competent elderly person living alone in a detached dwelling, the space could be rented out to a homesharer or a student. This would serve to provide the homeowner with both a source of income and a sense of security.

- d) **All bathrooms should be built with enough room for two people to maneuver in them, reinforced walls that could support grab bars mounted in any number of places, and non-skid flooring.**

These features would not only make it easier for caregivers of persons with dementia, but would also help assistants to disabled people, handicapped people themselves, mothers of young children, and small children to function safely in the bathroom.

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13

THE ALZHEIMER'S FAMILY CARE CENTRE -- DAY CARE WITH A DIFFERENCE

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INTRODUCTION

There is growing recognition that dementia places significant stress and strain on family caregivers and may have a devastating impact on a family's social, psychological and economic resources (Quayhagen & Quayhagen, 1988). Psychiatric symptoms associated with caregiving for a person with dementia include: depression, anxiety, anger, fatigue and social isolation (Toseland & Rossiter, 1989; Zarit, Reever & Bach-Peterson, 1980). Home remains, however, the residence and caregiving setting of choice for most dementia patients, for as long as possible given the individual's needs for care (Sands & Suzuki, 1983). Consequently, the need for more respite and home/community-based services for dementia patients and their informal care providers is apparent (Mace, 1984).

Adult day care has become increasingly popular since its inception in the 1970s and is now considered to be an integral part of the long term care system. Most adult day care centres, however, have been designed for physically disabled or socially isolated older adults who require either rehabilitation or social and recreational activities not for the cognitively impaired (Weissert et al., 1989). Nevertheless, more and more adult day care centres, 45% in one recent U.S. survey (Mace, 1984), report accepting clients with dementia or cognitive impairments. While the potential value of adult day care for dementia patients is unquestionable, involving cognitively impaired persons in programs geared to physically frail elders poses a

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number of practical and administrative problems. These include: staff unfamiliarity with or misconceptions about dementing illness; lack of knowledge/experience in management of the functional and behavioural problems associated with dementia; staff reluctance to work with agitated or confused patients; insufficient staff/client ratios; inappropriate physical environment for this type of client; and difficulties integrating participants with markedly different cognitive abilities (Cherry & Rafkin, 1988). In response to these concerns, special adult day care centres for cognitively-impaired adults increasingly are emerging.

This chapter describes one such centre: The Alzheimer's Family Care Centre (AFCC). The AFCC is a specialized adult day care centre located in Victoria B.C., designed to assess and stabilize dementia patients living in the community. Funded by the Victoria Health Project, the AFCC is one of several programs designed and directed by the Elderly Outreach Service (EOS), a community geriatric psychiatry team. AFCC activities are shared amongst a number of local service providers, as indicated in Table 1.

GOALS AND OBJECTIVES OF THE AFCC

The goals of the AFCC (Stebbins, Coady & Scaletta, 1989) are as follows:

- 1) To help individuals mildly to moderately impaired by Alzheimer's disease or other dementias to live as independently as possible through structured day care interventions.
- 2) To maintain them at optimal levels of health.
- 3) To relieve family caregivers of some of the burdens associated with their care.
- 4) To provide consistent and on-going care for the patients in collaboration with their caregivers.
- 5) To enhance self-help/mutual aid opportunities for caregivers.
- 6) To work with the B.C. Continuing Care Program, home support agencies, and the patient's primary caregiver to ensure appropriate placement following day care enrollment.

Table 1

AFCC ACTIVITIES AND RELATIONSHIP TO PARTICIPATING AGENCIES

<u>Activity</u>	<u>Performed by</u>
1. Referral	Made by any agency or individual and received by EOS
2. Intake assessment	Conducted by EOS Occupational Therapist and EOS colleague; referred to AFCC if appropriate
3. Further assessment and /or treatment (if indicated by initial assessment)	Conducted by EOS colleagues; referred then to AFCC or other agencies, as appropriate
4. Day care staff training	Provided and organized by EOS
5. Daycare programming and assessment of client functioning at day care setting	Conducted by Capital Mental Health Association (CMHA) staff appointed to the AFCC program
6. Family caregiver education and support	Provided primarily by the EOS staff, especially the team's Social Worker(s). Environmental adaptations and training to support the patient's functional abilities are provided by the team's Occupational Therapist. Referrals also are made to Continuing Care and to the Family Caregivers' Network, as appropriate
7. Ongoing monitoring of the care plan	Conducted by EOS staff, AFCC staff, and a Continuing Care representative
8. Planning for care upon discharge	Conducted primarily by Continuing Care in conjunction with the family and with input from AFCC and EOS staff. A joint discharge report is prepared by EOS and AFCC and provided to care providers. EOS and AFCC are available to meet with care facility and day care staff for "case conferencing" to ease the transition at discharge.
9. Administrative activities	Shared by EOS and CMHA

- 7) To provide on-going health monitoring via nursing staff.
- 8) To support patient's functional abilities through a varied, individualized and flexible program of activities.
- 9) To maintain a consistent and safe environment for the patient during day care hours of operation.
- 10) To evaluate the program and the attainment of its goals and objectives.
- 6) To assist caregivers with training and implementation of behavioural techniques for the management of problem behaviours in their demented charges.
- 7) To assess the patient's functioning level throughout a *six month treatment period*, develop specific interventions for that patient, and train the patient's primary caregiver and other health care workers caring for the patient in these interventions.
- 8) To assist in the placement of the patient in community or long term care facilities following their day care involvement.

The objectives in developing the AFCC were:

- 1) To establish a day care program for dementia patients living in the Greater Victoria area.
- 2) To train an interdisciplinary team in the operation of day care programs for dementia patients.
- 3) To conduct a detailed intake procedure that includes identification of level of impairment in the patient; targeting of specific behavioural disturbances for case management; assessment of level of caregiver burden and daily disruption of activities; and, a one-month "trial period" to assess the program's suitability to the patient.
- 4) To develop a written treatment plan for each patient in collaboration with the caregiver and

the program staff, and to review this treatment plan at regular intervals.

- 5) To insure continuity of care through individual case management, with a primary case manager identified for each patient. The case manager is responsible for care plans, re-assessments, collaboration with families, and discharge planning.

PROGRAM DESCRIPTION

CLIENTS SERVED

The AFCC will consider for service any community-dwelling individual in the Capital Regional District aged 65 or over who is mildly to moderately cognitively and functionally impaired secondary to an untreatable progressive dementia.¹

Exclusion criteria include persons who:

- a) are non-ambulatory and unable to transfer independently;
- b) are medically unstable;
- c) exhibit behaviours which endanger themselves or others; and/or
- d) are severely demented and thus unable to derive significant benefit from the program's activities.

REFERRALS

All AFCC referrals are accepted through the EOS's open referral system, meaning that referrals will be accepted from anyone in the community. Most referrals are made by Continuing Care staff, local physicians, and dementia patients' immediate family. Health care professionals make referrals by completing the EOS's referral form (predominantly demographic data and the reason for referral), and attaching any other relevant information. All referrals must be approved

¹ Several dementia patients under age 65 have also been accepted by the program.

by the patient's family physician before the individual is considered for service.

INTAKE

Intake is usually completed by the EOS's Occupational Therapist, often in conjunction with another member of the EOS's interdisciplinary team. ² Intake usually consists of one or two interviews with the prospective patient and his/her primary caregiver(s). The following data are usually gathered:

- a) **Medical profile** - Medical information is requested from the patient's family physician on the usual EOS medical form, which asks for a problem list, past medical history, recent lab work, current medications and dosages, and the physician's knowledge of any recent events which might affect the patient's health status or the caregiver's ability to provide care. This information is reviewed by the EOS's general practitioner in order to ensure that all potentially remediable causes of cognitive impairment have been addressed.
- b) **Cognitive functioning** - The patient's cognitive functioning is assessed using the Modified Mini-Mental State (3MS) Exam (Teng & Chui, 1987). Where patients refuse or are too agitated to complete this (or the shorter Mini-Mental State Exam by Folstein, Folstein & McHugh, 1975 which is imbedded within the 3MS), an attempt is made to gain a sense of their orientation, language abilities, attention span, short and long term memory, through informal conversation.
- c) **Activities of Daily Living and Instrumental Activities of Daily Living** - The patient's level of performance of Activities of Daily Living (toileting, feeding, dressing, grooming,

² The mandate of the EOS is to provide short-term assessment, treatment and follow-up of community-dwelling elderly persons with psychiatric disorders. EOS also provides consultations and education to local health care providers. The team's clinical complement includes: geriatric psychiatrists, clinical psychologists, nurses, an occupational therapist, a general practitioner and a social worker.

ambulation and bathing) and Instrumental Activities of Daily Living (ability to use the telephone, shop, prepare food, do housekeeping and laundry, get places, take responsibility for his/her own medications, handle finances) are assessed using the Self-Maintaining and Instrumental Activities of Daily Living Scale (Lawton & Brody, 1969). This instrument gives a good picture not only of the patient's deficits, but also of the tasks the caregiver must now perform. Further, it provides the opportunity to find out who has usually performed certain tasks and filled particular roles within the couple or family. This is particularly helpful in making appropriate recommendations with respect to other community support systems and services which may benefit the family.

- d) **Problem Behaviours** - Behavioural disturbances related to dementia are assessed using the Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) (Reisberg et al, 1987). The BEHAVE-AD assesses characteristic behavioural changes such as: agitation, tearful episodes, fearfulness, motor restlessness, verbal outbursts, violence, day-night disturbance, flattened affect/withdrawn, suspiciousness, "people are stealing things" delusion, etc. The assessment measures are said to be largely independent of the cognitive changes in Alzheimer's Disease (Reisberg et al., 1987) and certainly, in our experience, address behaviours which are distressing to careproviders.
- e) **Demographic Data** - Demographic data, gathered from the primary caregiver, include: primary language; level of education of the caregiver and care-recipient; duration of caregiving; employment status of caregiver; sufficiency of income to meet caregiving needs; family history of emotional problems; and legal/financial provisions to protect the patient.
- f) **Caregiver's Status** - A well-being inventory and a coping checklist are often left with the caregiver for mailing back to EOS. These give the caregiver an opportunity to reflect on the types of coping strategies used and on his/her overall

well-being. Information from these tools can later be used to begin interventions with the caregiver.

- g) **Other Data** - Other data obtained include information concerning: the sleep pattern of the caregiver and care recipient; alcohol, tobacco and prescription drug use by the family; and other services currently/recently received (e.g. homemakers, caregiver support group, home- or facility- based respite, other adult day care). As well, brief family, occupational and leisure activities histories are obtained. A second interview is usually required to gather this information.

These data, which are discussed with the EOS's Clinical Director (a geriatric psychiatrist), are used to consider the patient's/family's suitability and priority for services and to provide baseline data for program evaluation purposes.

If the patient/family are deemed appropriate for services, we request at this time that they visit the centre to meet the staff and other patients. Prior to the patient actually starting the program, intake information is shared with the day care staff. Program participation does not commence until we receive complete and up-to-date medical information from the family physician.

If the patient/family are considered unsuitable for services, attempts are made to provide referral to other more appropriate agencies. Consultations, where appropriate, are often provided to these agencies by the clinical staff.

PROGRAM PHILOSOPHY

All staff involved with the AFCC share an approach to care of the dementing person. We believe it is our responsibility and our challenge to identify not only the participant's limitations but also to find, even in the most impaired individual, the remaining strengths and challenges that the person can still use and enjoy.

PHYSICAL SPACE

The day care, held at the Pathways Centre, is located in a small former fire hall. It offers areas where one or several of the participants may be separated from other participants when quiet time is needed, and it has a large fenced back yard which includes a garden. The building's exit doors have been equipped with alarms.

DAYS/HOURS OF OPERATION

The program operates Mondays and Wednesdays between the hours of 9:30 and 3:30, and accommodates a maximum of nine patients at any one time. In order to maximize service to the community, participants may remain in the program for a maximum of six months.

DAILY PROGRAM

A sample of the daily program is provided below. It is modified frequently to accommodate the needs of our patients, yet maintains the consistency and routine which is important for persons with dementia.

- 9:30 - 10:00 Orientation to staff and day's activities.
- 10:00 - 10:30 Nutrition break, current events, reminiscence, reality orientation.
- 10:30 - 11:00 Contenance routine, and grooming/personal care.
- 11:00 - 12:00 Music, sing-song and occasionally dancing.
- 12:00 - 1:00 Lunch.
- 1:00 - 1:30 Contenance routine and rest time.
- 11:00 - 12:00 Group activities (e.g. arts and crafts, games) or individual projects.
- 2:00 - 2:30 Exercise and movement (e.g. a walk to the lake).
- 2:30 - 3:00 Nutrition and socialization.
- 3:00 - 3:30 Contenance routine, review of day's activities; plans for going home.

ACTIVITY PROGRAM

The activity program includes regular visits from the Society for the Prevention of Cruelty to Animals and until recently, an art therapist worked with patients one morning per week. Whenever possible an attempt is made to accommodate patients previous or current interests.

COST

The patient's family is charged a nominal fee of \$2 per day; families are also responsible for any transportation costs. Many patients are transported to the program by HandyDART, a specialized bus. A home support worker was hired soon after the program started to assist patients on the HandyDART. This proved useful to manage the seemingly inevitable behavioural disturbances that occur on the bus. The home support worker has ensured that clients arrive safely at their destination and has preserved our important relationship with HandyDART.

STAFFING

The CMHA provides a team of health care workers who are responsible for the day to day program activities. These include one on-site program coordinator, two activity workers and one nursing staff. These staff may consult with the EOS team as needed.

Prior to commencement of the program, the three day care staff were provided with education regarding dementing illness, training in specific interventions for problem behaviours and information regarding approaches with caregivers. Both initial and on-going education of the day care staff is provided by members of the EOS team.

BEHAVIOURAL MONITORING

The patient's behaviour is monitored throughout normal day care activities and is documented daily by the program staff. These observations, along with information provided to staff by the patient's primary caregiver, are discussed at review meetings, which are held every three weeks. These meetings include CMHA daycare staff, one or more representatives from the EOS, a representative from the Continuing Care Program, and any students or volunteers who are currently involved in

the program. A care plan is developed, reviewed or updated, and the efficacy of the treatment strategies is evaluated.

The primary caregiver is informed regularly of the patient's progress in the program and the effectiveness (or lack thereof) of the behavioural management strategies. The way in which this is accomplished depends on the individual care-provider (e.g. for care-providers who transport their loved-one to the program, this is often done informally at the beginning or end of the day). There is a least one face-to-face interview with the caregiver at mid-term and again at the end of the program; this generally involves the patient's EOS case-manager and the on-site coordinator at the day care program.

CAREGIVER SUPPORT

In order to establish the rapport necessary to facilitate caregiver training, education and/or counselling, the EOS Occupational Therapist may make home visits. These are often undertaken with the stated goal of either:

1. gathering additional data about the patient to enhance our staff's ability to provide individualized programming or,
2. to discuss ways to promote safety and improved functioning of the dementia patient at home through simple environmental modifications or through modifications of the caregiver's way of interacting with the patient. It is at this point that family members may be more receptive to counselling or individual psychotherapy. Regrettably, staff shortages have limited the availability of services to the caregivers.

EDUCATION

As stated in our goals and objectives, part of our mandate has been to educate formal and informal caregivers about the care and management of dementia. This has taken the form of a monthly education session -- one month primarily directed at family caregivers; the next month primarily for health care workers. Practical small group work is often a part of these sessions.

PROGRAM HIGHLIGHTS

In summary, key features of the AFCC are:

1. Small staff/client ratio.
2. Safe, suitable environment for the needs of dementia patients.
3. Staff training about dementia and the management of behavioural disturbances.
4. Individualized care plans coordinated with other community services.
5. Education, training and support for family caregivers.
6. Education for formal caregivers.

PATIENT CHARACTERISTICS

Fifty-two patients applied to the AFCC program between its inception on June 5, 1989 and October 1, 1990. Of these, 37 were accepted for the program but five did not enter. They and their caregivers preferred to wait, remain at home or in their current day care, until the AFCC program was "really necessary".³

Of the 32 who entered the program, eight have already completed the full six months. Seven are currently attending and will complete their six months soon. The remaining 17 may be categorized into two groups: those (5 patients) who stayed for three sessions or less and those (12 patients) who stayed for three sessions or more but for less than six months. In both of these groups, patients most often left the program due to institutional placement (12 out of 17 cases).

- a) **Sociodemographic Characteristics** - The mean age of all 52 program applicants was 78.2: 11 were under age 70; 21 were between age 70 and 80; and 20 were aged 80 or older. Fifty-six

³ Of the 15 patients found inappropriate for the AFCC, four were assessed to be too high functioning; six were too low functioning, too agitated, or there was evidence of significant psychopathology in either the patient or the caregiver; three were institutionalized prior to the program start date, and two moved out of town.

percent of the patients entering the AFCC program were female; nearly all were married (90%) and living with their spouse (90%). There was no difference in the marital status and type of living arrangements between those who entered the program and those who did not.

- b) **Mental Status** - Mental status testing was undertaken with 44 of the 52 applicants, 28 of whom entered the AFCC program. The mean MMSE score for the 28 was 12.5 (range 3-22). The mean MMSE for the 16 applicants who did not enter the program was 11.7 (range 0-24). The difference was not statistically significant. In both groups, the variability in subjects' mental status test scores is noteworthy.

INDICATORS OF PROGRAM EFFICACY

A number of indicators of program efficacy are presented in Table 2. These include data relating to caregiver's perceptions of, and satisfaction with, the AFCC and the Pathways day care program. Observational data on changes in patients' behaviour in the day care program and at home, as noted by program staff and family caregivers, are also presented.

REFERRAL SOURCES/RATE

The high number of word of mouth referrals to the AFCC is noteworthy -- that is, referrals resulting from satisfied family caregivers telling other caregivers about the program. This is especially noteworthy considering that a high proportion of patients had tried other day care programs, but these either did not work out or the patient was deemed inappropriate for service.

PATIENT "SATISFACTION" /ENJOYMENT

With this population, it is extremely difficult to evaluate patient satisfaction since self-reports may be unreliable. Patient satisfaction/enjoyment may be estimated, however, by documenting attendance and participation in activities. At the AFCC, daily logs are kept, examination of which revealed that there were clear preferences among patients regarding most and least favoured activities. Most preferred activities included:

Table 2
INDICATORS OF PROGRAM EFFICACY

INDICATORS	DATA SOURCE
1. Patients' "satisfaction"/ enjoyment of program	<ul style="list-style-type: none"> a) Attendance in program b) Participation in activities c) Expressed enjoyment of activities d) Differential degrees of enjoyment of various activities, i.e. preferred activities such as eating, singing, dancing, SPCA visits
2. Patient's improved behavioural functioning	<ul style="list-style-type: none"> a) AFCC staff's documentation of behavioural changes via day care's training and interventions b) Caregivers' reports that behavioural changes have been maintained at home c) Reduced agitation; reduced wandering d) Improved sleep e) Maintenance of social skills
3. Caregiver satisfaction with the program	<ul style="list-style-type: none"> a) Unsolicited reports from caregivers to AFCC staff b) Material contributions c) Reports that this daycare "worked" when others did not
4. Caregiver provided with respite	<ul style="list-style-type: none"> a) Reported to AFCC staff b) Caregivers won't schedule activities during respite time
5. Improvements in caregiver health and well-being	<ul style="list-style-type: none"> a) Reported to AFCC staff b) Reports of improved sleep
6. Caregiver support	<ul style="list-style-type: none"> a) Linkage to Caregiver Support Groups
7. Increased likelihood of caregivers' acceptance of community/health care services or resources	<ul style="list-style-type: none"> a) Access to education relating to dementia and caregiving via EOS b) Consultations with EOS professionals, resulting in referrals to services/treatment of mental health problems

anything food related; singing; dancing; SPCA/pet visits and walks/outings. Interestingly, social activities such as these were most popular and served to enhance patients' socialization skills in Mace's (1984) report of a specialized day care. Least preferred activities at the AFCC were those involving, and perhaps taxing, patients' memory and cognitive skills, such as word or board games, ADL skill enhancement activities and arts and crafts.

PATIENTS' BEHAVIOURAL FUNCTIONING

CMHA day care staff document their clinical observations on a daily basis, focusing on the "problem" behaviours targeted for intervention. Preliminary examination of these data suggest that in a number of cases there has been a reduction in patients' agitation and wandering and improvements in their sleeping. Caregivers have reported that behavioural changes are often maintained at home, especially during the evenings or days immediately following AFCC program days (that is, on week days and evenings more than on weekends).

Decreases in day care patients' agitation and wandering, and improvements in their sleeping patterns, have been reported in previous studies examining the impact of adult day care (Cherry & Rafkin, 1988; Clendaniel & Fleishell, 1989; Panella et al., 1984; Mace, 1984). Specialized day care programs are likely to promote these positive changes in patients' behaviours because patients have the benefit of sufficient structured exercise and a reduction in environmental stimulation (Clendaniel & Fleishell, 1989; Panella et al., 1984). Moreover, adult day care staff are trained to understand the antecedents of, and thus attempt to circumvent, patients' wandering and agitation (Cherry & Rafkin, 1988; Panella et al., 1984).

CAREGIVER SATISFACTION

For those patients who stayed with the program for more than three sessions, caregivers unanimously, albeit informally, expressed high levels of satisfaction to either CMHA or EOS staff. Indeed, many reported that the AFCC program was effective for them, whereas other day programs were not. Caregivers' satisfaction also was evidenced by their contributions to the day care (money, program supplies and small gifts for staff such as chocolates or home-baking) and by the fact that caregivers remain in touch with staff, volunteers and other patients and caregivers for months after their own

family member had completed his/her involvement in the program and/or had been placed in a long term care facility. A high degree of caregiver satisfaction was also reported in Panella et al.'s (1984) and Sands and Suzuki's (1983) examinations of specialized adult day care programs.

CAREGIVER RESPITE

It was evident that caregivers valued the time to themselves that was afforded by the patient's involvement with the AFCC. This was expressed informally but repeatedly by nearly all caregivers. Caregivers treasured this time so much that many were reluctant to attend occasional special activities (such as social events with other AFCC families) during program hours, even though they expressed considerable interest in participating in such activities.

The importance of the respite time provided by adult day care programs has been reported in other studies (Mace, 1984; Panella et al., 1984; Sands & Suzuki, 1983). Indeed, in one study (Panella et al., 1984), family caregivers indicated that the greatest benefit of the day care program was the respite it afforded them.

It should be noted that time away from the care recipient cannot be equated with "respite". This time is respite time only if the caregiver can physically and emotionally disengage him/herself from the situation. Family caregivers can do this only if they have confidence in the quality of the care provided by the substitute caregiver(s). Without this confidence, time and energy may be spent worrying about their family member's well-being or feeling guilty about leaving him/her with someone else. Caregivers of patients at the AFCC indicated that they took advantage of and greatly appreciated their time off. For them, this time truly was "respite".

CAREGIVER HEALTH AND WELL-BEING

At the AFCC, unsolicited reports of improved health and well-being are quite common. Several caregivers reported feeling better despite a pre-existing health problem, such as hypertension. Many reported sleeping better. This can be attributed both to improvements in the dementia victim's sleep pattern (as well as reduced agitation and wandering) and to the respite caregivers were provided during the day. The effects of improved sleep for caregivers are far-reaching in that those who

are better rested will be better able to attend to the care recipient's needs as well as cope with his/her cognitive and behavioural disturbances.

CAREGIVER SUPPORT

One of the special features of the AFCC is its close working relationship with the Greater Victoria Network of Caregiver Support Groups and individual caregiver support groups. Although not obligated to become involved, AFCC caregivers have direct access to support groups if they so desire. Frequently, their involvement continued long after the care recipient completed the AFCC program or was placed in a long term care facility.

The finding that about half of the AFCC family caregivers elected *not* to become involved with support groups is consistent with findings reported elsewhere. For example, Montgomery and Borgatta (1989) report that more than one third of the caregivers in their study did not take advantage of support groups and respite programs despite being repeatedly informed about these interventions. Some caregivers' reluctance stems from denial of their family member's disease, its consequences and its irreversibility; others may not be ready to hear of the concerns and issues facing caregivers of persons in whom the disease is much further advanced.

CAREGIVERS' ACCEPTANCE OF COMMUNITY RESOURCES

As a component of the EOS, AFCC patients and families have access to the services of an interdisciplinary team of mental health workers. Ongoing support and encouragement from the EOS and CMHA staff, as well as access to services and support in crisis situations, resulted in many caregivers seeking and receiving help from formal care providers -- help which they needed and appreciated, but which they had been reluctant or felt unable to access before.

WHAT HAVE WE LEARNED AND WHERE DO WE GO FROM HERE?

After only one year of operation our data are suggestive rather than conclusive. However, we are able to offer several comments with regard to the program's strengths and limitations, and to make several recommendations for future adult day care programs.

PROGRAM STRENGTHS

First, we have demonstrated that the AFCC day care can provide dementia patients with a safe, structured and supportive environment. Given the strong reluctance of most other adult day care centres to admit people with dementia, and the inability of many centres to appropriately manage dementia patients, the provision of such an environment is, in itself, an accomplishment.

A second major strength is its role in providing family caregivers with crucial respite and support. Third, the AFCC program provides a setting in which to assess patients' behavioural and cognitive skills and to identify remaining strengths and functional abilities. The program strives to enhance or maintain these strengths and to design individually tailored interventions to address behavioural disturbances and stabilize behaviour.

A final strength of the AFCC program is its commitment to caregiver education. To complement the ongoing behavioural monitoring of patients in the program, feedback is regularly provided to caregivers on the most effective intervention strategies used during program hours.⁴

⁴ Caregivers' reports suggest varying degrees of success in terms of the ways and extent to which these interventions are implemented at home. This is likely related to caregivers' expectations about their family member's functional abilities and to their own coping skills and techniques. Caregivers whose expectations are more realistic and who accept, and have some understanding of the disease process and its behavioural ramifications, seem better able to benefit from caregiver training.

PROGRAM LIMITATIONS

The AFCC's status as a short-term program of six month's duration must be viewed as its most serious drawback. The question of what happens to patients and caregivers upon their completion of the program may be so daunting that many caregivers and health care professionals who might otherwise make a referral ponder whether involvement is worthwhile. Clearly, this issue must have been of concern to those caregivers who elected to delay their involvement with the program until it, and the respite it afforded them, was *really* necessary.

Second, although the AFCC provides support to caregivers, its resources are insufficient to provide for their needs to the extent necessary. The staff complement of the AFCC program would profit considerably by including a counsellor or therapist to attend to the emotional/psychological needs of family caregivers.

RECOMMENDATIONS

Establishment of the AFCC has revealed many critical gaps in the array of services available for dementia patients and their caregivers. Most importantly, there is a clear need for a number of specialized, accessible day care programs for people with dementia. In view of the difficulties in arranging for and transporting dementia patients to services, specialized day care programs ideally would provide a full range of health and personal care services (e.g. bathing and nail care to diabetics, podiatry etc.) thus helping to ensure that patients received quality, health-related care in a cost-efficient manner. Moreover, programs such as the AFCC, with a focus on behavioural/cognitive assessment and the design of interventions, should be closely affiliated with and augment other day care programs. The cognitive and behavioural monitoring performed on a daily basis at other day care centres would also benefit from regular clinical direction from an interdisciplinary geriatric psychiatry team such as the EOS.

The AFCC program staff and participants have also identified a need for ongoing, individual psychotherapy or counselling for family caregivers of people with dementia. This type of clinical intervention must be viewed as distinct from, but complementary to, existing caregiver support groups. Individual counselling would provide caregivers with the opportunity to

vent and explore their feelings of anxiety, guilt, anger and confusion while, at the same time, they would be able to broaden their repertoire of coping and relaxation techniques.

Additionally, there must be increased opportunities for caregivers and their care recipients to socialize in a supervised environment. As caregivers know only too well, the number of social and recreational activities appropriate for dementia patients dwindles dramatically as the disease progresses, until the care recipient's -- and the caregiver's -- social world may effectively disappear. Holding social events, such as pot luck suppers and dances at the day care centre would enable socialization to occur in a non-threatening setting, bolstered by the presence of professional caregivers trained to work with people with dementia. Note, however, that if social opportunities are to be organized and provided, events should not be held during the caregivers' usual "respite" time, that is, during day care hours. Once caregivers have become accustomed to having respite time, this time becomes of considerable importance in promoting their health and well-being.

Finally, one year's experience at the AFCC reinforces the well known point that any type of specialized day program, for any type of functionally impaired population must have adequate transportation. At the AFCC, transportation problems threatened to be an obstacle for a number of caregivers; caregivers were also sometimes unable to attend formal educational sessions due to inadequate transportation. Clearly, if dementia patients are to remain in the community longer, we cannot overlook the role of services such as transportation in ensuring a program's success.

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14

RESPITE CARE: WHAT ARE THE OPTIONS?

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INTRODUCTION

Scharlach and Frenzel (1986) define respite care as : "a caregiving service that provides a planned, intermittent break from the ongoing responsibility of caring for a chronically disabled individual who is being managed at home. It is seen as a preventive health care measure designed to provide relief to the caregiver and potentially delay or avoid institutionalization of the care recipient"(p. 78).

Respite programs are unique in the health field because they provide services to those who give care as well as to those who receive care (Warren & Cohen, 1985). These programs have often been referred to as the best kept secret in the Canadian health care field. However, in the British health care system, they have been a well established component for many years (Robertson, Griffiths & Cosin, 1977).

In recent years, respite care has gained widespread attention in North America as one of a number of strategies to prolong community residence for disabled aged. It has also emerged, in several studies (Crossman, London & Berry, 1981; Horowitz & Dobrof, 1982; Lawton, Brody & Saperstein, 1989) as the top priority unmet need among caregivers.

Reports of respite programs continue to appear in the literature as providers are learning about and are communicating ways to develop and operate these programs (cf. Looney, 1987). At least two publications are available (Montgomery & Prothero, 1986; Quinn & Crabtree, 1987) to guide their development.

WHAT ARE SOME OF THE RESPITE OPTIONS?

Respite programs may be classified into three broad groups:

- **Institutional Respite** - the client lives independently or with family or friends in the community and is transported to an institutional setting;
- **In-home Respite** - the caregiver looking after the client at home receives relief help which frees him/her for a specified period of time; and
- **Responsibility Respite** - relieves the caregiver from some of the chores of daily living.

INSTITUTIONAL RESPITE

There are a variety of programs which may be included in this category.

Day Care is probably the best known. Offered in many communities, usually on a 1 - 5 days per week basis, day care is frequently an extension of an institutional service although there are now more free-standing programs located in churches, senior centres, and shopping malls. The admission criteria differ from one program to another, but many attempt to serve individuals at risk for institutionalization - i.e. the frail elderly and those with Alzheimer's and related disorders. Some day care programs have been established specifically for the physically disabled. As indicated in chapter 13 of this volume, some are specialized for care of the cognitively impaired elderly.

Although their goal may not be respite, **Day Hospitals and Psychogeriatric Day Hospitals** provide the same type of relief to the family plus more sophisticated services and therapy to the client.

Night Care is another example. Here, the client comes into an institution overnight and returns home during the day, allowing the caregiver to get proper rest.

Some institutions have also implemented **Intermittent Hospitalization** programs (Remnet, 1979; Robertson, Griffiths & Cosin, 1977). A Canadian example is the program established by Dr. Warren Davidson, at the Moncton Hospital, Moncton,

New Brunswick. In this program, six weeks following discharge from the hospital, the client will be re-admitted for one week to a four bed unit that was developed to admit clients who were not in a crisis situation but were considered to be at risk in the community. The client is then placed on a permanent cycle of six weeks at home, one week in the unit. This provides the opportunity for regular reassessment and monitoring of the client as well as regular respite for the caregiver. The program also offers counseling to the caregivers. The program has been so successful two more are planned in the Maritimes. A similar rotating bed program is in operation in England.

Respite Vacation Care is another option that offers relief to families. It can be offered by long-term care facilities, hospitals or in a free-standing location. The program can be established by merely setting aside one bed. Most programs offer accommodation for 1 - 4 weeks although some offer care for shorter periods such as weekends (see Crossman, London & Barry, 1981 for a description of a weekend respite program).

One of the arguments that has been voiced against institutional respite is an economic one relating to loss of bed days. However, a study conducted in New York estimates that one respite care bed may serve as a resource for seven times the number of people that are served by one long term care bed.

In Regional Niagara, throughout our six long term care facilities there are a total of nine respite beds. Additionally, Satellite Home beds can be allocated for respite on request. (Over the past 10 years, occupancy of these beds has increased from 50 - 60% to 80 - 90%).

IN-HOME RESPITE

In the Regional Municipality of Niagara we have established an **Alzheimer Respite Companion Program** to serve individuals caring for the cognitively impaired at home. In this program, well-trained individuals go into the home so as to enable the family to get out for short periods (a minimum of 3 hours to a maximum of 20 hours per week). Services may include family counseling to help them better understand their situation, know what to expect and how to cope.

In an innovative home respite program in England, University students go into the homes of Alzheimer's victims and provide supervision during the night so the family caregiver can sleep.

RESPONSIBILITY RESPITE

Examples of programs that provide responsibility relief to family caregivers include:

Friendly Visiting which offers the care recipient the opportunity for friendship and contact on a one-to-one basis. This service provides security in the knowledge that someone will visit on a regular basis. It alleviates loneliness and boredom and prevents social isolation. Friendly visitors will often notice and get assistance when a person needs medical attention. This program can also relieve the caregiver by having a trained visitor go into the home while the caregiver goes out.

Meals on Wheels which ensures the elderly are receiving nourishing meals and relieves the family of this worry. Sometimes just as important is the contact with the individual delivering the meals.

Home Care which provides nursing and homemaker services that support and relieve the caregiver with medical care, bathing or household chores.

Home Help Services which provide help with chores like lawn care, house maintenance or shopping which many older or disabled persons cannot carry out. They may also arrange medical appointments and provide transportation.

Postal Security Alert Programs which provide an element of security to seniors and their families through knowing that the letter carrier is looking out for the resident and will summon help if necessary.

Personal Emergency Response Systems which provide the subscriber with an electronic device that, when activated, rings at the hospital or agency and summons assistance.

Palliative Care Programs which bring understanding and support to dying persons and their families.

OTHER PROGRAMS

A number of innovative respite programs were described at the International Congress on Gerontology in New York City

in 1985. One of these was a short-term family placement program in which elderly persons were placed in private homes. Usually the homeowners were people who had been caregivers.

In Japan I learned of employers paying for respite care as part of the employee's benefit package so the caregiver will not be absent from work.

In England, pet care is being provided for those elderly persons who would refuse to leave their homes unless their pets were being looked after.

Family support groups are another way to provide emotional support to family caregivers. As offered by the Regional Niagara Senior Citizens Department, these programs are sometimes called "Caring for Elderly Relatives" and usually have six or seven sessions in the hope that caregivers will be motivated to continue meeting and sharing. The sessions may cover the following topics: family relationships and stress on caregivers; emotions and problem behaviour; physical health; living arrangements; legal information and information on services.

THE VALUE OF RESPITE

As much as we are aware of the constant stress, fatigue and overwork that are part of the caregiver's role in the home and of the potential value of respite programs in easing their burden, very little research has been conducted to date evaluating the impact of these programs. To help fill the knowledge gap, the Senior Citizens Department and other agencies in Regional Niagara are presently involved in a study being conducted by a research team from the University of Toronto. The purpose is to determine the value of various types of respite service in the management of Alzheimer's and related disorders. Both clients and caregivers will be interviewed. This is a two year study, to be completed by the end of 1991.

Besides formal studies, there are, however, a number of other ways respite programs can be evaluated. These include popular support for the program and evidence of user satisfaction. Using these measures, it is evident that the Regional Niagara Alzheimer Respite Companion Program is a success. For example, in the past year it has grown by 50%, without any advertising in the community. Secondly, in the first seven months of 1991, it was used for an average of 1,152 hours per month. However, the most revealing evidence of success

comes from the caregivers themselves. In a 1988 survey, very high levels of satisfaction (75 % very satisfied) were reported in the area of confidence in leaving a relative with a respite worker, appreciation for a break for personal time and an improved quality of life. This is further reflected in the spontaneous comments of respondents to the effect that:

"respite relieved the trapped feeling"

"I feel less resentful now"

These data are in line with data reported by Lawton, Brody and Saperstein(1989) in a controlled study of respite services for Alzheimer's caregivers. These authors note: "The evaluation given to respite service by its recipients was a resounding endorsement. Caregivers had received relief and were satisfied with the service" (p.15). The authors add that most of those who wished for respite services used them and most of those who used the services were extremely satisfied with them.

OBSTACLES TO THE DEVELOPMENT OF RESPITE CARE

Some of the obstacles to developing respite programs have been the lack of:

- national or provincial public policy that promotes and supports respite care.
- funding.
- research that demonstrates the value of respite care.
- financial assistance to those in need of respite care.
- a clear mandate as to who should provide the service.
- professional and care provider support for respite programs.
- public awareness and demand for respite care.

- social and health policies that recognize the role, contribution and need of the family.

CONCLUSION

Very often, families caring for an elderly relative are offered too little support too late. As Horejsi (1982) notes:

We seem to be able to offer services once the family has nearly destroyed itself or is in a genuine crisis, but don't do much to prevent the destruction in the first place. In a sense, we ask families to "spend down" their emotional and psychological resources before we can offer a relevant service (p. 63).

On the other hand, from our experience in Niagara it is apparent that some caregivers are reluctant to trust in the respite provider or feel guilty using respite programs. Also, they often wait until late in the caregiving process or until a crisis occurs to seek help. Caregivers often need considerable time, education and encouragement to begin to understand and use respite services.

The responsibility for giving care will continue to fall disproportionately upon elderly spouses who themselves may have health problems and upon daughters and daughters-in-law who often have work commitments outside the home and young children in the home.

There seems little question that respite programs can play a role in supporting the family caregiver. The barriers obstructing the development of respite programs must be broken down. Family caregivers must be made aware of the value of those already in existence.

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