PSYCHOGERIATRIC CLIENT IDENTIFICATION PROJECT

Phase 1–Final Report

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INTRODUCTION

The Psychogeriatric Client Identification Project, contracted by the Continuing Care Division and conducted by the Gerontology Research Centre at Simon Fraser University, provides a comprehensive description of the diverse client groups that are typically included under the umbrella term, "psychogeriatric." Traditionally, psychogeriatric clients have been categorized according to medical diagnoses. The current research project adopted a different approach to identifying client needs by using an inclusive definition of the psychogeriatric population and by describing clients in relation to both behavioural characteristics and diagnosis. The focus of the project was on identifying the unique characteristics, behaviours and corresponding needs of client subgroups for the purpose of planning and delivering appropriate services. The specific project objectives were to:

1. describe the characteristics of the various psychogeriatric subgroups, with particular emphasis on behaviours that pose significant care and management challenges within facility and community settings;

2. summarize statistical information on prevalence and projected numbers for British Columbia for the various subgroups; and

3. identify the availability of a model of psychogeriatric care and services that could be applied to policy development and resource planning.

A general overview of the epidemiological, medical, scientific and clinical management research was completed in the first part of the project (key findings are included in Chapter II). In the second part of the project, data describing the characteristics, behaviours and needs of defined psychogeriatric client groups were obtained through interviews with 50 health care professionals and frontline caregivers drawn from both community and facility settings. In addition, the two focus groups were held, one with eight family caregivers and one with five frontline/direct care nursing staff to provide more in-depth insights concerning client needs (research methods and findings are included in Chapters III and IV). The final chapter of the report (Chapter V) synthesizes all of the information collected, producing a set of conclusions and recommendations that are designed to assist the Continuing Care Division in meeting current and projected psychogeriatric client needs.

LITERATURE REVIEW & EPIDEMIOLOGIC/STATISTICAL DATA

A comprehensive literature review was conducted to identify: relevant problem behaviours and psychiatric diagnoses; behaviour prevalence and risk factors; and caregiver coping strategies and management issues. Where possible, this information was reported separately for community and facility-based clients. A review of selected studies reporting both community and facility-based data suggested the following prevalence rates and corresponding care and management issues:

Behaviour/Psychiatric Disorder Prevalence	**Care & Management Issues**
Community-Based Studies	
• 30-61% Agitation • 36-50% Hallucinations/Delusions • 30-65% Losing/Hiding Things • .03-6% Socially Unacceptable • 21-55% Physical Aggression • 4.2%-6.1% Dementia Syndromes • 10%-15% Depressive Symptoms • 0.1%-0.5% Schizophrenia/Paranoia	• family have the most difficulty with unpredictable behaviours, which were some of the major predictors of institutionalization
Facility-Based Studies	
• 22-95% Verbally Disturbing/Aggressive • 23-60% Non-Compliant/Resistive to Care • 12-68% Physically Aggressive • 7-38% Pacing/Wandering • 30-36% Delusions/Paranoia • <5-34% Socially Objectionable/Aberrant • 56.9%-67% Dementia Syndromes • 20%-50% Depressive Symptoms • 2%-3% Schizophrenia/Paranoia	• The vast majority have a diagnosis of dementia • There was a low rate of psychiatric diagnosis, even though there was a high use of psychoactive medications and restraints • Assault and agitated/aggressive behaviour were linked to staff burnout, absenteeism, turnover, low morale, stress, and to client's decreased quality of care/life, social isolation, higher restraint use, stress and transfer • Increased social contact and structured activities during critical hours for clients, and caregiver training were recommended for dealing with the most difficult behaviours • The importance of recognizing and treating depression was highlighted, as well the need for staff training and physician involvement

A more detailed account of the prevalence of behaviour problems and psychiatric conditions in the elderly population, by community and nursing home/facility residence, is contained in Tables 6, 7 and 8.

MAJOR RESEARCH FINDINGS

Survey Respondents & Agency Characteristics

Of the 50 key informants, the most common professional background consisted of registered nurse/registered psychiatric nurse. The majority of these health care professionals, both community and facility-based, had worked with psychogeriatric clients and their families for six years or more in direct contact with clients *always* or *most of the time*. They cared for a primarily female, middle-old (75-84 years) population with high percentages of intermediate care clients in community-based settings, attributed to increasing client acuity levels and the shift to community-based service delivery.

Description of Client Characteristics/Behavioural Disturbances and Service Response

The most notable survey findings, in response to open-ended questions, related to reported behavioural disturbances and needed services for the psychogeriatric client group as follows:

- 40% estimated that more than half of total clients exhibited behavioural disturbances that frontline caregivers find challenging;
- aggressive/combative behaviour and wandering/elopement were the most frequently reported types of problematic behaviours;
- 51% reported that the most problematic psychogeriatric client behaviours were related to dementia/Alzheimer's disease;
- 88% of respondents had encountered problematic behaviours that are either drug-induced or exacerbated by medications;
- The proportions of respondents indicating that they were not able to address certain behaviours were: 41% for very physically aggressive behaviour that is not responsive to available treatment, 31% for clients needing specialized treatment/psychiatric care, 31% for clients with other mental health conditions (e.g. schizophrenia, anxiety/personality disorders), and 31% for those considered to have inappropriate levels of care (including clients not accepted/eligible for service);
- the most commonly recommended accommodation arrangements and/or environmental modifications were smaller, less institutionalized environments and special design features;
- Overall, respondents reported a need for the following additional resources: more specialized geriatric/psychiatry services; better trained direct care staff; and more flexible/available respite and/or adult day care.

Behavioural Disturbance Frequency and Difficulty Ratings

Using the prepared *Behavioural Disturbance Classification Scheme* as a basis for client ratings (see Appendix C), the following were reported:

- Almost all, 98%, rated behaviours in the Problematic ADL's/Coping Strategies category as occurring frequently with many clients affected;
- The Agitated/Aggressive - Physical category stood out as creating the most difficulty for frontline caregivers and the main reason cited was that caregivers are at-risk physically and afraid for their own safety;
- With respect to the three most difficult discrete behaviours across all behavioural categories, 60% of respondents selected assaultive/violent outbursts, followed by elopement (36%) and equal proportions selecting hitting/slapping/punching (18%) and inappropriate sexual advances (18%);
- Very difficult ratings were received for the following behavioural categories: Agitated/Aggressive - Physical (78%), Agitated/Aggressive - Verbal (48%), Socially Unacceptable (49%), and Agitated/Non-Aggressive - Physical (36%);
- 74% reported that, on a frequent basis with many clients affected, frontline caregivers had to deal with the behaviours in the following categories: Agitated/Non-Aggressive - Verbal, Agitated/Non-Aggressive - Physical and Emotional/Affective;
- 51% reported that caregivers were frequently dealing with Agitated/Aggressive - Verbal behaviours with only a few clients were affected;
- The most commonly stated reason why frontline caregivers experience difficulty with the above behaviours is their lack of understanding and education.

Suggested Program Improvements

The following suggested programs and approaches for improving the care and management of psychogeriatric clients were brought forward by both survey respondents and focus group participants:

- 67% indicated that they were not satisfied with the types of care and management strategies used by frontline caregivers and the majority of these stated that trained staff and appropriate approaches for managing difficult behaviours would create significant improvements;
- The most frequently expressed concerns related to the need for appropriate staff training and education, the need for more registered nurses and registered psychiatric nurses, and increases in staffing levels;
- Strong opinions were raised about the need for additional and/or more appropriate services, including: an urgent need for specialized units to care for mentally ill elderly; the need for a centrally-located, acute, longer-term geriatric psychiatric facility; and the need for a wider range of flexible respite, adult day care and home support services;
- The widespread opinion was that physically frail seniors should not be mixed with clients experiencing acute or chronic mental health problems;

- Communication concerns were raised, with repeated mention of the tensions between Continuing Care and Mental Health and the need to allow time for professionals to foster team work and to promote consistent care approaches;
- The main concerns of the 13 focus group participants focused on the lack of available information and access to needed services, as well as the need for physicians and nurses to be specially trained to handle psychiatric cases and to appreciate the importance of proper diagnosis and assessment to rule out treatable conditions.

CONCLUSIONS & RECOMMENDATIONS

Twelve (12) recommendations were proposed related to client subgroups, resource needs and areas for future study. Of these, the five most important recommendations are, in order of priority:

Recommendation #1

Provide more and better access to specialized psychiatric resources to ensure that psychiatric disorders and medical conditions are not undiagnosed, misdiagnosed and untreated. Such specialized services are frequently needed to detect underlying causes of problem behaviours (physical and/or psychiatric) and to design appropriate treatments. There are four distinct specialized psychiatric services that require attention, namely:

1) emergency services for clients experiencing acute psychotic episodes and/or requiring immediate medical stabilization;

2) short-term assessment and treatment services (e.g. STAT Units), including follow-up and re-assessment for psychogeriatric clients and for mentally ill clients who are under/approaching 65 years;

3) intermediate-term treatment and stabilization programs for clients exhibiting very difficult to manage behaviours (e.g. agitated/aggression-physical) who may require 6-10 months of intensive treatment and monitoring; and

4) long-term, tertiary care facilities that are centrally located for persons with severe and intractable behaviour problems that cannot be appropriately cared for in either community or intermediate care settings (e.g. those with severe clinical depression/bipolar disorders or other psychiatric disorders, such as schizophrenia).

Recommendation #8

Provide retraining and continuing education for all direct care staff (including physicians, respite workers, case managers, home support staff, mental health staff and facility/nursing staff). Training of frontline staff should address the importance of behavioural symptoms, the identification of underlying disorders and the effective modes of treatment to relieve distress. Training in appropriate approaches for managing difficult behaviours should also address staff's difficulties in dealing with intractable behaviour problems and associated family support needs.

Recommendation #10

Findings support the advisability of segregating the frail elderly with dementia (and no behaviour problems) from mentally-ill clients who manifest moderate to severe behavioural disturbances (most notably physical and verbal aggression). It is recommended that specialized units have clear specifications regarding purpose, environmental specifications, types of clients accepted and the disciplines providing care. In addition, small, less institutionalized settings are proposed for subgroups of psychogeriatric clients with mental illnesses and behavioural disturbances. Special attention should be given to the following design features: private rooms, isolation/quiet areas, separate dining rooms and lounges, small group areas, gardens and special lighting.

Recommendation #4

Foster more effective communication and collaboration between Continuing Care and Mental Health Services, as well as working partnerships between facility and community-based services. This would enhance care coordination, streamline assessment, treatment and placement services and reduce duplication of effort. It would also facilitate the movement of clients in an appropriate, timely manner and provide effective back-up resources and a sharing of expertise.

Recommendation #11

Identify a range of *best practice sites*, within facility and community-based sectors, that provide exemplary care and conduct a comprehensive review of client mix, staffing and environmental factors. Documentation of the array of available facility and community-based services (transfer, referral and consultation resources) would also be necessary. Such an integrated analysis would extend Phase I findings by identifying and weighting the most important determinants of "best care" for specific client subgroups. This descriptive information could form the basis for program design and resource allocation decisions on a regional basis.

Psychogeriatric Client Identification Project: Phase I - Final Report

I INTRODUCTION

A. Background and Project Objectives

In January, 1995, as Phase I of a projected three-phase research initiative, the Gerontology Research Centre at Simon Fraser University was contracted by the Continuing Care Division to develop a comprehensive description of the diverse client groups that come under the umbrella term "psychogeriatric." The project will assist the Continuing Care Division to plan appropriate services, to allocate and manage resources and to develop policy for this population consistent with the "Closer to Home" initiative.

The specific objectives of the project were to:

- describe the characteristics of the various psychogeriatric subgroups, with particular emphasis on behaviours that pose significant care and management challenges within facility and community settings;
- summarize statistical information on prevalence and current and projected numbers for British Columbia for the various sub-groups; and
- identify the availability of a model of psychogeriatric care and services that could be applied to policy development and resource planning.

The following research activities were undertaken:

1. **Comprehensive literature review** incorporating epidemiological, medical, scientific, and clinical management research, as well as community resources literature;

2. **Construction/compilation of epidemiologic summary tables** including information on prevalence of problem behaviours cross-tabulated by diagnostic sub-group; and

3. **Consultations** which included interviews with 50 health care professionals drawn from both community and facility settings and two focus group discussions, one with paid and the other with unpaid frontline caregivers.

B. Definition of Terms and Behavioural Classification Scheme

An inclusive definition of the psychogeriatric population was adopted for the purposes of this project. The definition included older adults with dementia (e.g. Alzheimer's Disease, vascular dementia); affective/mood disorders (e.g. clinical depression, bipolar disorders); and those with other mental health conditions (e.g. schizophrenia, anxiety disorders). It also included persons suffering from brain disorders related to alcohol and drug abuse, AIDS, brain injury and medication-induced illness (e.g. delirium). While the primary focus was on persons aged 65 and over, where appropriate, younger adults (e.g. those with pre-senile dementia) were included.

Current service models and the preponderance of the literature categorize psychogeriatric clients according to medical diagnosis. This study was designed to describe the diverse client groups in relation to both diagnosis and behavioural characteristics, in particular those which pose management problems. It was believed that a detailed description of problem behaviours (including prevalence, risk factors and suggested management strategies) would provide a sound basis for the design and delivery of client-centred, appropriate services. To complete the *Psychogeriatric Client Identification Project: Phase I*, data were collected from various sources to supplement traditional epidemiologic studies. The perspectives of practitioners, policy-makers, and frontline caregivers were sought to identify the characteristics, behaviours, and needs of defined psychogeriatric client groups.

An eight (8) category list of problem behaviours was constructed based on a preliminary literature review and consultation with key informants (see Appendix A). This categorization scheme provided the framework for a detailed review of epidemiological and statistical data and other literature, as well as for the research component of the project.

C. Report Organization

Chapter II highlights key findings in the literature concerning problem behaviours and client identification by psychiatric diagnosis. The research method and findings from interviews with 50 key informants and two focus group discussions are presented in Chapters III and IV. Chapter V, the concluding chapter, contains a set of recommendations for ways in which the Continuing Care Division can meet current and projected psychogeriatric client needs.

II LITERATURE REVIEW & EPIDEMIOLOGIC/STATISTICAL DATA

A. Introduction

Current service models and the preponderance of the literature categorize psychogeriatric clients according to medical diagnoses. However, those responsible for the care of these clients are primarily concerned with managing behaviour and meeting client needs. A key question is whether the various diagnoses identify unique characteristics, behaviours, and corresponding needs that argue for specialized staff training and segregated or semi-segregated living arrangements; or, whether the diverse client groups can and should be grouped and managed according to functional abilities or problem behaviours. Related questions have been raised about the amount of staff time and effort required to care for persons with different types of psychogeriatric impairment, as compared with mainly physical disabilities. For example, Hall and Buckwalter (1990) argue that:

> Current long-term care patient classification systems, such as resource utilization groups (RUG-II), separate persons with severe behavioural problems from those with primarily physical problems. Such classification systems assume that emotional problems *do not* complicate care of the elderly's physical problems in a way that adds appreciably to their care requirements or consumption of nursing resources (Rohrer, Buckwalter & Russell, 1989). This assumption is not in keeping with recent data (Hu, Haung, & Cartwright, 1986) which found, for example, that based on time records, nursing home staff spent 36% more time caring for residents with AD (p.8).

To provide a basis for evaluating the RUG-II[1] and other models and addressing the specialized staffing and segregation-integration issues, this literature review is organized in two ways: material is grouped by problem behaviours (see Part I) and by psychiatric diagnosis (see Part II). Within each part, sections begin with a brief description of the behaviour or disorder. This is followed by a summary of information concerning prevalence, risk factors, management strategies and issues. Wherever possible, the "how many," "how often" and "by whom" questions are addressed separately for community and facility-based clients.

B. PART 1 - Problem Behaviours

A wide range of behaviours are termed "disturbing" or "problem behaviours" in the literature. For purposes of this study, these have been grouped into eight categories. The categories are: [2]

Agitated/Aggressive-Physical	Ideational
Agitated/Aggressive-Verbal	Emotional/Affective
Agitated/Non-Aggressive-Physical	Socially Unacceptable
Agitated/Non-Aggressive-Verbal	Problematic ADL's/Coping Strategies

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[1] The RUG-II (Resource Utilization Group) is a case-mix reimbursement system which has been used in New York State since 1986 and has become a paradigm for the reform of long-term care financing in the United States. It is based on a Patient Review Instrument designed to capture the intensity of needed nursing resources. Calculations are based on nursing intensity for selected ADL's and special nursing and medical needs. No tests of cognitive status are included, and dementia is not considered a special nursing or medical care need (Aronson, Cox, Guastadisegni et al., 1992)

[2] See Appendix A for a listing of the specific behaviours included in each category.

Some of the studies reported in the literature deal with only one of these categories; others span several categories. The literature review begins with the multi-category studies, and within these, with behaviours considered problematic by community-based family caregivers.

MULTI-CATEGORY STUDIES: COMMUNITY

NATURE AND PREVALENCE OF PROBLEM BEHAVIOUR

Haley, Brown and Levine (1987) interviewed 44 family members providing daily care to patients with dementia. Respondents were also administered Katz et al.'s (1963) Activities of Daily Living Scale, Lawton and Brody's (1969) Instrumental Activities of Daily Living Scale and 17 items from Zarit and Zarit's (1982) Memory and Behaviour Problems Checklist.[3] For each scale item, the caregivers were instructed to report if the behaviour had been exhibited by the care receiver in the last month, and if so, how stressful the behaviour was for the caregiver and how equipped he/she felt to handle it. More than one-third of care receivers were reported to exhibit: agitation (61%), embarrassing behaviour (39%), behaviour dangerous to him/herself (32%), hallucinations (36%) and to hide things (30%). All of these behaviours were reported by the caregivers to be stressful to them and to be behaviours they felt ill-equipped to handle.

RISK FACTORS

Haley, Brown and Levine (1987) suggest that problem behaviours are probably the result of a complicated interaction of brain damage, the environment and the care receiver's effort to cope with declining function. They and other researchers (e.g. Swearer, Drachman, O'Donnell & Mitchell, 1988) emphasize that problem behaviours are not linearly related to the severity of dementia. Such behaviours may occur in persons with only mild dementia. As will be shown, however, the research literature clearly shows that the prevalence of problem behaviours increases dramatically when dementia is present.

COPING STRATEGIES AND MANAGEMENT ISSUES

Haley, Brown and Levine (1987) contend that although families experience the development of ADL and IADL problems as distressing, they typically take over daily care functions and eventually accept that the patient's skills in these areas are gone. Disorientation is rarely a major problem because families learn strategies such as not arguing with the patient's mistakes. Even incontinence is often managed well by families who learn to use toileting schedules, regulate fluid intake or use adult diapers. However, they have difficulty with behaviours such as agitation or hallucinations which can occur unpredictably and with those which require constant vigilance (e.g. dangerous behaviour).

A British study, by Argyle, Jestice and Brook (1985), of caregivers whose relatives had been admitted to a psychogeriatric ward because the caregiver could no longer cope, generally supports the finding that requirements for ADL assistance are well tolerated. They also report good tolerance of the relatives' own problems of anxiety, depression, embarrassment, a reduced social life and conflicting family demands. The behaviours that were most problematic for these caregivers were physical aggression, verbal abuse, wandering, inappropriate urination and fecal smearing, the latter the researchers term "the problems nobody likes to talk about." Deimling and Bass (1986) and Silver and Yudofsky (1987) report similar findings. Stephens, Kinney and Ogrocki (1991) found that stresses associated with asocial or problem behaviours of Alzheimer's patients were the most potent predictors of well-being among in-home caregivers. In a prospective, longitudinal

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[3] See Appendix B for a description of scales measuring problem behaviours in older people.

study, Steele, Rovner, Chase and Folstein (1990) report that such behaviours were among the most important predictors of nursing home placement for Alzheimer's patients.

MULTI-CATEGORY STUDIES: INSTITUTION

NATURE AND PREVALENCE OF PROBLEM BEHAVIOURS

As shown in Table 1, estimates of the proportion of residents exhibiting problem behaviours in institutional settings range from 28% in Saskatchewan Long Term Care facilities (Rockwood, Stolee & Robertson, 1989) to 64% in a sample of 42 nursing homes in upstate New York (Zimmer, Watson & Treat 1984) to 72% and 76%, respectively, in single-facility studies (Cohen-Mansfield, 1986; Rovner, Kafonek, Filipp, Lucas & Folstein, 1986).

Zimmer, Watson and Treat (1984) report that 64% of their random sample of 1,139 elderly residents of 42 skilled nursing homes in the U.S. had "significant" behaviour problems. Behaviours were classified as "significant" if they occurred more than once per week or required constant or active consideration in the patient care plan. Residents with significant problems were further subdivided into "moderate" and "serious" groups. Those classified as having "moderate" problems (41.6%) included persons with impaired judgment and/or physical restraint orders, but "without more serious behavioural problems affecting themselves and others (e.g., aggressive behaviour, physical resistance to care, uncontrolled wandering, etc.)." The five most common problem behaviours exhibited by the 22.6% (n=257) classified as having "serious" problems are shown in Table 2.

Table 2: Percent of Clients in Zimmer, Watson & Treat (1984) Study Exhibiting Selected Problem Behaviours

	% of those with "serious" prob.	% of 1139
Verbally disturbing to others (noisy, abusive, etc.)	55.6	12.6
Physically resistive to care (spitting out medications, refusing to eat, etc.)	50.1	11.4
Physically aggressive (deliberate striking, biting etc.)	36.6	8.3
Reclusive (refusing to leave room, socialize)	22.2	5.0
Dangerous ambulation (into unsafe areas; escaping restraints, etc.)	24.1	5.4

Two-thirds of this group had a diagnosis suggestive of dementia, 5.1% had a diagnosis of psychosis (half with and half without dementia), "depression" was mentioned in 9%, alcoholism in 1.6%, and mental retardation in 0.4% of cases.

In commenting on this study, Hall and Buckwalter (1990) note that despite the fact that 58% of these patients were receiving psychoactive medications, psychiatric referrals had been made in only 14.8% of cases.

Table 1: Prevalence of Problem Behaviours in the Elderly, by Place of Residence (Community, Institution): Summary of Research

RESEARCHER	TARGET SUBJECTS & LOCATION	% WITH BEHAVIOUR PROBLEMS	MOST FREQUENT PROBLEM BEHAVIOURS	MEASURE[1]
COMMUNITY				
Argyle, Jestice & Brook (1985)	62 patients admitted to a UK psychiatric ward because their relatives could no longer cope	Mean no. prob. per patient = 12.3; 4.3 were coped with well, 4.8 presented difficulty and 2.6 were not coped with or tolerated.	Prob. beh. exhibited by 30% - 69%+ of patients included: Unable to dress, restless by day, urinary incont., sleep disturbance, help with washing, communication impairment, uncoop., falling, fecal incont., wandering. Beh. 30%+ of caregivers reported they tolerated poorly: inapprop. micturation, verbal abuse, fecal smearing, feeding difficulties, aggression, wandering, sleep disturb., poor vision, communication prob., restless by day, fecal incont.	Interviews with primary caregivers
Baumgarten, Becker & Gauthier (1990)	50 dementia patients seen at a univ. geriatric clinic in Montreal; 46 Alz. patients participating in a drug trial (baseline data).		Most common prob. beh. in wk. before interview: repetitious questions 72%; lost/hid things 65%; lack of interest in daily activities 51%; night awakening 34%; unwarranted accusations 33%; excessive daytime sleeping 29%; pacing 27; repet. gestures 26%; verbal abusiveness. Note: socially unacceptable & violent beh. much less freq. physical attacks (hits, bites, scratches, kicks)7%; screaming 6%; sexual advances 5%; indecent exposure 3%; destruction of property or clothing 3%, food throwing 1%.	Primary caregiver administered Dementia Behaviour Disturbance Scale. Greene's BMD Scale Mini-Mental State OARS
Baumgarten, Wolfson, & Tarasuk (in preparation)	208 CSHA community based Ss - all with a diagnosis of probable or possible DAT		61-75% were reported to ask repetitive questions, lose or hide things, and exhibit lack of interest in daily activities. 31-53% sleep excessively during the day, make unwarranted accusations, have nocturnal awakening and are incontinent of urine. Socially unacceptable and more violent behaviours less common. In descending order, from 11% to .03% exhibited: screaming, physical attacks, destruction of property or clothing, exposed private body parts, threw food and made inappropriate sexual advances.	Primary caregiver rated freq. of beh. in preceding week on Dementia Behavior Disturbance Scale

Table 1 Cont'd: Prevalence of Problem Behaviours in the Elderly, by Place of Residence (Community, Institution): Summary of Research

RESEARCHER	TARGET SUBJECTS & LOCATION	% WITH BEHAVIOUR PROBLEMS	MOST FREQUENT PROBLEM BEHAVIOURS	MEASURE[1]
COMMUNITY				
Burns, Folstein, Brandt & Folstein (1990)	31 Alz. & 26 Huntington's patients attending AD Research Centre, Dementia Research or Huntington's Clinic at Johns Hopkins Hospital	Irritability - 58% both groups, apathy 48% both groups, aggressive 59% Huntington's group compared with 32% in Alz. group		Interviews with caregivers (usually a spouse); Yudoksky Aggression Scale.
Drachman, Swearer, O'Donnell, Mitchell & Maloon (1992)	31 demented outpatients of Univ. of Mass. Alz. clinic		55% showed aggressive & assaultive beh. verbal attacks most prev. in this category. 77% had disordered ideas & personality most freq. paranoid ideas & delusions; 90% had mech./motor disturb. most freq. repetitive sorting of objects (59%) & shadowing of caretaker (52%); 84% showed vegetative disorders most commonly change in food pref. (77%) and sleep dist. (43%).	COBRA scale
Fisher, Fink & Loomis (1993)	Dementia patients in 84 nursing facilities in Maine		Disorientation, urinary incont., inability to feed/groom. Most diff. to manage: Physical & verbal aggress, agitation, depression.	Questionnaire answered by 248 nursing staff from 84 facilities re: frequency and management diff. of 15 problem behaviours.
Haley, Brown & Levine (1987)	Dementia patients living in the community		Beh. reported to be exhibited by 30% or more of the care receivers during last month included: agitation (61%); embarrassing beh. (39%); beh. dangerous to oneself (32%); hallucinations (36%); hiding things (30%). Care givers felt stressed and ill-equipped to handle all of these.	Katz (1963) ADL Scale. Lawton & Brody (1969) IADL Scale; Zarit & Zarit: Memory and Beh. Problems Checklist Interviews with 44 family caregivers
Lachs, Becker, Siegal, Miller & Tinetti (1992)	114 Alzheimer's outpatients of a geriatric assessment centre	66% had at least 3 beh. probs.	Withdrawal (44%), agitation (30%), incontinence (16%), insomnia (11%), angry or hostile outbursts (11%). Behav. problems reported to be more common in the 25.5% of patients with delusions.	Retrospective record view.

Table 1 Cont'd: Prevalence of Problem Behaviours in the Elderly, by Place of Residence (Community, Institution): Summary of Research

RESEARCHER	TARGET SUBJECTS & LOCATION	% WITH BEHAVIOUR PROBLEMS	MOST FREQUENT PROBLEM BEHAVIOURS	MEASURE[1]
COMMUNITY				
Rabins, Mace & Lucas (1982)	Persons with Alz.		Hallucinations/delusions reported for 50% and disruptive behs (physical violence, hiding things, wandering, demanding, critical behaviour) in up to 70%	Interviews with primary caregivers
Reisberg, Borenstein, Salob, Ferris, Franssen & Georgotas (1987)	57 Alz. outpatients with Global Deterioration Scale scores of 4 or more	58% had sig. beh. symptoms	delusions 48%; agitation 48%; day-night disturb. 42%; restlessness 36%; violence 30%; verbal outbursts 24%	chart review
Ryden (1988)	183 demented persons living in the community	Aggressive beh. weekly or more often in 31% and daily in 16%. Aggression sig. related to degree of cog. impairment and prior history of aggressive beh.		Ryden Aggression Scale
Swearer, Drachman, O'Donnell & Mitchell (1988)	126 demented patients (57 with AD) who attended Univ. of Massachusetts Medical Ctr. ADRDR Clinic	83% were reported to exhibit one or more of 9 prob. behs.; 74% 2+ and 55% 3+.	Angry outbursts (51%); dietary change (46%); sleep disturbance (45%); paranoia (32%); phobia (25; hallucinations/delusions (22%); bizarre beh. (21%); assaultive/viol. (21%); incontinence (17%). Note: severity of dementia correlated sig. with severity of assaultiveness, biz. behs., paranoia and incontinence.	Telephone interviews with caregivers
Teri, Larson & Reifler (1988)	127 Alz. outpatients of a U. of Washington geriatric clinic		Restlessness 45%; falling 28%; poor hygiene 28%; wandering 26%; agitation 24%; suspiciousness 24%; hallucinations 21%; incontinence 16%. Note: wandering, agitation, poor hygiene and incontinence increased sig. with cog. impairment.	Blessed Dementia Rating Scale, checklist of problem behs.

Table 1 Cont'd: Prevalence of Problem Behaviours in the Elderly, by Place of Residence (Community, Institution): Summary of Research

RESEARCHER	TARGET SUBJECTS & LOCATION	% WITH BEHAVIOUR PROBLEMS	MOST FREQUENT PROBLEM BEHAVIOURS	MEASURE
INSTITUTION				
Beck, Baldwin, Modlin & Lewis (1990)	SNF & VA hospital patients	68% of residents reported to be physically aggressive and 95% verbally aggressive	Aggressive beh. reported to take place at various times of the day with highest % in morning while residents were being changed or dressed.	21 nurses and 20 nursing assistants from one SNF and a VA hospital
Beck, Robinson & Baldwin (1992)	38 residents of a VA hospital identified by staff as aggressive.	51 aggressive incidents cited in 29 charts. 49% of incidents occurred in the bathroom, 22% in bedroom, 19% in dayroom, 1% in dining room. 86% reported between 5 am and noon. 22 disruptive but not aggressive incidents were also documented in 10 charts.	26 incidents of physical aggression cited in 15 charts; 24 of verbal aggression in 13 charts; and 1 of sexual aggression.	Chart review - incidents classified in terms of categories in Ryden Aggression Scale.
Bernier & Small (1988)	living environment of nursing home residents		Residents: only 1 beh. received score of 2.5 or over: entering the wrong room. Nursing staff identified 15. Most common: "troublemakers" (res. perceived as lucid & purposely irritating); verbal assault; physical assault; destruction of property; threatening beh. where there was a perception of possible physical harm.	44 nursing home residents and 66 nursing rated 22 prob. behs. on 5 pt. scale of disruption to their working/living environment
Burgio, Jones, Butler & Engel (1988)	136 IC and 24 SNF patients of one urban nursing home		75%+ had mobility prob. were incontinent and had dressing probs.; 39% had aberrantly low activity levels; 33% language probs.; 23% were non-compliant ; 22% were verbally abusive; 20% were physically aggressive; 10-19% exhibited 5 other aberrant behs.	32 day shift geriatric assistants rated Ss on Behaviour Problems Survey, a modified screening tool originally developed to assess beh. probs. in developmentally delayed children. Respondent indicates if S exhibits each of 22 beh. and if it was a prob. Note: higher rates reported by LPNs than RNs (charge nurses)

Table 1 Cont'd: Prevalence of Problem Behaviours in the Elderly, by Place of Residence (Community, Institution): Summary of Research

RESEARCHER	TARGET SUBJECTS & LOCATION	% WITH BEHAVIOUR PROBLEMS	MOST FREQUENT PROBLEM BEHAVIOURS	MEASURE
INSTITUTION				
Cohen-Mansfield (1986)	66 residents of 2 units of a suburban SNF. Units selected because they were known to include a high prop. of agitated individuals.	73% exhibited at least one agitated beh. at least several times a day.	General restlessness (48% once a day or more); constant unwarranted requests for attention (53%); complaining and negativism (33%);and pacing or wandering (38%)	
Cohen-Mansfield, Marx & Rosenthal (1989)	408 nursing home residents	93% manifested one/or more agitated beh. Mean no. exhibited per resident at least once per week = 9.3 (s.d. 8.6)	General restlessness, pacing, repetitious sentences or questions, requests for attention, complaining, negativism and cursing or verbal aggression.	Ss rated by charge nurse from each shift using Cohen-Mansfield Agitation Instrument (CMAI).
Cohen-Mansfield, Werner & Marx (1989)	24 highly agitated, cognitively impaired nursing home residents (8 in each of 3 units). Unit 1 was a Special Care Unit.	At least 1 agitated beh. observed during 83.7% of observation periods on Unit 1 and during 76.6% and 58.3% of observation periods in Units 2 & 3.	Making strange noises, requests for attention, repetitious mannerisms, picking at or inappropriate handling of things, strange movements and pacing (i.e. verbally agitated and physically non-aggressive beh. predominated). Authors note that many agitated behaviours were manifested constantly. They also note that patterns of agitation appear to be specific to the patient (i.e. major individual differences).	RA observed each S for 3 mins. Observation intervals selected by a stratified random time-sampling method covering the 24 hr day. Data recorded on Agitation Behaviour Mapping Instrument.
Drachman, Swearer, O'Donnell, Mitchell & Maloon (1992)	36 nursing home residents with diag. of Alz. disease		64% exhibited aggressive & assaultive beh. (most prev.= verbal attacks 33%; screaming 32%); 67% disordered thoughts & personality (most prev.=delusions 36%; paranoid ideas 30%) 67% mech./motor prob. (most prev.=hyperkinesia 32%); 75% vegetative disorders (most prev.=incontinence 58%, changes in food preferences 47%).	COBRA Scale

Table 1 Cont'd: Prevalence of Problem Behaviours in the Elderly, by Place of Residence (Community, Institution): Summary of Research

RESEARCHER	TARGET SUBJECTS & LOCATION	% WITH BEHAVIOUR PROBLEMS	MOST FREQUENT PROBLEM BEHAVIOURS	MEASURE
INSTITUTION				
Malone, Thompson & Goodwin (1993)	350 bed skilled nursing home .	Of 1592 incident reports in 1 yr. 94 (about 2/ wk) were for aggressive beh. 48% of aggressive incidents occurred in SCU; 44% were accounted for by 6 residents with 3+ each; 12 had 2 and 29 had 1. The incidence was 0.27 per res. per yr. for total facility. Rate on Alz. Unit of 0.75.	62% of victims of aggressive beh. were other nursing home residents, 37% staff and 1% visitors.	Exam. of all incident reports of aggressive beh. for 1 yr.
Miller, Snowdon & Vaughan (1995)	2445 residents of 46 nursing homes in Sydney, Australia	29% identified by senior nurses as beh. disturbed.	Factor pattern for CMAI similar to that reported by Cohen Mansfield et al (1989) Items exhibited by <5% -= intentional falling, hurt self or others, verbal sexual advances, physical sexual advances	CMAI, RAGE; in a sub-study where all Ss were rated, 59% were said to exhibit at least one CMAI behaviour by primary care nurses vs 30% identified by senior nurses as beh. disturbed.
Patel & Hope (1992a)	90 elderly psychiatric inpatients. Diagnoses: dementia (71%); chronic schizophrenia (13%). Remainder included affective disorders, mental handicaps, and other diag.	Over 3 days, 15% moderately or severely aggressive; 45% at least mildly aggressive. 15 of 17 types of aggressive behaviour were observed at least once in over 10% of Ss.	Verbally aggressive behaviour was far more common than physically aggressive behaviour. The most frequently observed behaviour was being uncooperative or resisting help (nearly 60% of sample); sexually offensive behaviour was least frequently seen.	Nursing staff used the Rating Scale for Aggressive Behaviour in the Elderly (RAGE) to report beh. observed over a 3 day period.
Ray, Taylor, Lichtenstein & Meador (1992)	2 samples of nursing home residents: 431 in Tennessee, 122 in Texas.		Gets upset or loses temper easily (62%, 66%); awakens during night (65%, 40%); talks/mutters to self (57%, 50%); resists care (50%, 42%); refuses care (48%, 46%); uncooperative (50%, 43%); says things that don't make sense (49%, 42%); fidgets/restless (44%, 42%).	Using Nursing Home Behavior Problem Scale nurses reported residents exhibiting 29 prob. behaviour at least once in past 3 days.

Table 1 Cont'd: Prevalence of Problem Behaviours in the Elderly, by Place of Residence (Community, Institution): Summary of Research

RESEARCHER	TARGET SUBJECTS & LOCATION	% WITH BEHAVIOUR PROBLEMS	MOST FREQUENT PROBLEM BEHAVIOURS	MEASURE
INSTITUTION				
Rockwood, Stolee & Robertson (1989)	Stratified random sample of 990 residents of 29 LTC institutions in Saskatchewan	21% reported to exhibit problem behaviours daily; a further 8% at least weekly.	% exhibiting at least weekly: disorientation - 15%; aggression 12%; wandering 7%; noisiness 11%; other 14%. Beh. causing most prob. arose from, disorientation - e.g. getting lost within the inst.; unable to cooperate with care.	MSQ Staff asked if resident's beh. posed a prob. to staff/other res. If yes, LTC head nurse asked if res. exhibited selected prob. beh. and if these posed problems.
Rovner, Kafonik, Filipp Lucas & Folstein (1986)	Random sample of 50 residents of 180 bed ICF in Maryland	76% at least one behaviour prob,; 40% had 5 or more	35-40% rated as having communication difficulty, delusions, hallucination, restlessness, to be passive-aggressive, or demand interaction; 25-34% as showing socially objectionable, disruptive beh., or to be active and verbally aggressive; 20-24% wandering, noisy, manipulative, incoherent speech; 14% self-destructive; 2% elation; 0% destroy property	Ss examined by a research psychiatrist & geriatrician; scales used included Geriatric Mental State Schedule, Mini-Mental State Exam. Nursing staff were interviewed to determine Ss functional status and to complete the Psychogeriatric Dependency Rating Scale
Ryan, Tainsh, Kolodny, Lendrum & Fisher (1988)	2 samples of nursing home residents (n=400 and 636)	In Fac.A 29% and in Fac.B. 31% of res. identified as noisemakers by at least 2 nurses	Purposeless & perseverative noise making (moaning, screaming, banging) 10% & 9%; noisemak. related to known cause (eg. care routines, pain, incontin.) 9% & 7%; noisemak., eliciting response (eg. calls for attention, complaints, demands) 4% & 7%; "chatterbox" 2% & 3%; loud speech/externaliz. related to deafness 1%; other noisemak. 3%-4%.	Nurses' reports using Patient Identification Checklist
Ryden, Bossenmaier & McLachlan (1991)	124 residents of special care units in 4 nursing homes.	86.3% of residents showed 1 or more aggressive beh. in the 7 day study period. Mean=6.3 aggressive beh.	Physical aggression seen in 50.8%; verbal aggression in 47.6%; sexually aggressive beh. in 4%.	Incidents of aggression recorded on Ryden Aggression Scale by nursing assistants over a 7 day period

Table 1 Cont'd: Prevalence of Problem Behaviours in the Elderly, by Place of Residence (Community, Institution): Summary of Research

RESEARCHER	TARGET SUBJECTS & LOCATION	% WITH BEHAVIOUR PROBLEMS	MOST FREQUENT PROBLEM BEHAVIOURS	MEASURE
INSTITUTION				
Sorrentino (1992)	173 LTC fac. res. (56% mainly physical symptoms; 44% psychiatric symptoms)	8% aggressive; 35% irritable		Charge nurses on 2 shifts rated Ss on Overt Aggression Scale & Irritability/Apathy Scale
Whall, Gillis, Yankou, Booth & Beel-Bates (1992)	14 nursing homes in Southeast Michigan	36% of residents were reported as disruptive/aggressive in last 6 mo.;of these 85% perceived to have some degree of memory impairment.	Hitting/slapping 70%; verbal aggression 60%; screaming 50%; pacing/wandering 45%; repetitive verbal 35%; requests for attention 20%; noisy 20%; handles things 20%; refuses care 20%. Self injurious beh. property destruction and hiding things not mentioned by any staff as problematic.	147 nurses (58 RNs 75 LPNs) asked to list the 5 most problematic behs. shown by residents and & coping strategies they used. The behs. were classified into CMAI categories.
Winger, Schirm & Stewart (1987)	43 nursing home and 58 IC residents of a VA hospital identified as exhibiting beh. in previous 2 weeks, endangering to others, endangering to self or disturbing.	91% of nursing home & 66% of IC patients exhibited one or more aggressive beh. Mean no. aggressive beh.: nursing home = 5.5; IC = 4.1 If dist. beh. elim. 84% of n.h. and 56% of IC patients had beh. that endangered self or others.	8% showed beh. that was disturbing only; 4% endangering self only; 30% endangering self & disturbing; 33% endangering others, endangering self and disturbing. Endangering self included: refuses treatment, refuses to eat, resists/refuses to follow directions, refuses/spits out meds. Note: aggressive patients described as "doing less well" on MSQ".	MSQ Katz ADL Index 23 Item Beh. Inventory
Zimmer, Watson & Treat (1984)	Random sample of 1,139 residents of 42 SNFs in upstate New York	64% identified as having "significant" problems (i.e. occurring more than once a week). Of these, 42% were labeled as having "moderate" problems (mainly impaired judgment and/or physical restraint order but no serious behav. prob. affecting self or others); 23% had "serious" probs.	Among those with "serious" beh. probs. a) the 3 most common were: - verbally disturbing to others (noisy, abusive); - resistive of care (e.g. spitting out meds, refusing to eat); and - physically aggressive (deliberately striking, biting). b) 66.5% had a diagnosis of OBS, 5% Psychosis (half with OBS half without); 9% Depression; 2% alcoholism, 0.4 % mental retardation.	Record review

[1]See Appendix B for a description of Problem Behaviour Scales.

High use of psychoactive drugs is seen in other studies of nursing home populations showing a high prevalence of problem behaviours. For example, Ray, Taylor, Lichtenstein and Meador (1992), using the 29-item Nursing Home Behaviour Problem Scale (NHBPS), report data from samples of nursing home residents in Tennessee (n=431) and Texas (n=122). The most frequent types of behaviour problems were: becoming upset or losing temper easily (62.2%, 65.6%); awakening during the night (64.5%, 40.2%); talking, muttering or mumbling to self (56.8%, 50.0%); resisting (50.1%, 41.8%) or refusing care (48.3%, 45.9%); uncooperativeness (49.9%, 43.4%); saying things that don't make sense (49.4%, 41.8%); difficulty falling asleep (45.7%, 28.8%); and fidgeting or restlessness (44.3%, 42.6%). As indicated by the bracketed figures, each of these behaviours was reported to have occurred at least once in the 3 days preceding the study for from 42%-66% of the residents. The least frequently reported problems were: inappropriate sexual behaviour (4.9%, 4.1%); inappropriate toileting (10.0%, 9.8%); and attempts to hurt oneself (4.9%, 3.7%) or do dangerous things (12.1%, 2.5%).

In the Tennessee sample, the NHBPS scores were higher in residents who were: 1) receiving sedative drugs (mean scores: no sedatives=10.3; benzodiazipine and antipsychotic=21.7); 2) sedated and physically restrained (21.2); or 3) who had mental impairments noted on their chart (no mental impairments=8.2; severe mental impairments=17.1).

MANAGEMENT ISSUES

Fisher, Fink and Loomis (1993) analyzed reports of 248 nursing staff from 84 nursing facilities in Maine regarding 15 problem behaviours exhibited by dementia patients. The most frequently occurring were disorientation, urinary incontinence, inability to self-feed and self-groom, and agitation. However, similar to family caregivers, facility staff reported that the most difficult behaviours to manage were physical and verbal aggression, agitation and depression.

Single-facility studies

Rovner, Kafonek, Filipp et al. (1986) report that 76% of a random sample of 50 residents of an intermediate care facility showed at least one behaviour problem. Among the 40% with five or more behaviour problems, the most frequent were: disruptive, restless, noisy, and verbally and passively aggressive. Maladaptive behaviours were measured using the Psychogeriatric Dependency Rating Scale (Wilkinson & Graham-White, 1980).

UNI-CATEGORY STUDIES

1. AGITATED/AGGRESSIVE BEHAVIOUR

DEFINITION

Cohen-Mansfield and Billig (1986) operationally define agitation as: inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to result directly from the needs or confusion of the agitated individual. Cohen-Mansfield, Marx and Rosenthal (1989) note that agitated behaviour is always socially inappropriate, and that it can be manifested in three ways: (1) It may be abusive or aggressive toward self or others; (2) It may be appropriate behaviour performed with inappropriate frequency, such as

constantly asking questions; or (3) It may be inappropriate according to social standards for the specific situation, as in putting on too many layers of clothes [see Cohen-Mansfield & Billig (1986) for a detailed discussion of the concept of agitation].

PREVALENCE: INSTITUTIONS

Cohen-Mansfield, Marx and Rosenthal (1989) report that 93% of 408 nursing home residents manifested one or more agitated behaviours at least once a week (mean no. behaviours at least once a week = 9.3; s.d.=8.6). In their study, residents were independently rated by the charge nurse from each of the day (7am-3pm), evening (3pm-11pm) and night shift (11pm-7am). They used the 29-item Cohen-Mansfield Agitation Inventory (CMAI) to rate the frequency of agitated behaviour. The most frequently exhibited agitated behaviours were: general restlessness, pacing, repetitious sentences or questions, requests for attention, complaining, negativism and cursing or verbal aggression. Factor analysis yielded three clusters or syndromes of agitation: aggressive behaviour, physically non-aggressive behaviour, and verbally agitated behaviour.

AGITATED/ AGGRESSIVE - PHYSICAL

PREVALENCE

Argyle, Jestice and Brook (1985) found that 35% of family caregivers who subsequently institutionalized their relative reported aggression as a problem; 50% reported that it was a behaviour they found very difficult to cope with.

Meddaugh (1987) reviewed charts and incident reports and found that 27 of 97 nursing home staff (27.8%) were assaulted by residents 1-2 times during a three-month period. Burgio, Jones, Burier and Engel (1988) interviewed nursing assistants concerning 160 mostly intermediate care clients in one nursing home. The nursing assistants reported 20% of the residents to be physically aggressive. Kirk, Donnelly and Compton (1991) found that 10% of residential home residents were physically aggressive atleast once a week. Winger, Schirm and Stewart (1987) reported that 66% of intermediate care clients living in a metropolitan VA hospital and 91% of nursing home clients exhibited one or more aggressive behaviours.

RISK FACTORS

- Cognitive impairment which includes deficits of perception, memory and thinking (Beck, Baldwin, Modlin & Lewis 1990; Cospito & Gift, 1982; Gurland, Wilder & Toner, 1987; Meddaugh, 1987; Winger, Schirm & Stewart, 1987).

- Organic brain damage due to dementia, neurological disease, stroke, pseudodementia, delirium or mental retardation (Silver and Yudofsky, 1987; Spector, 1991).

- Delusions and hallucinations (Rovner, Kafonek, Filipp et al., 1986, Ancill & Mason, 1988).

- Acute and chronic pain (Ancill & Mason, 1988; Lucas, Steele & Bognanni, 1986)

- Insulin-dependent diabetes (Ancill & Mason, 1988)

- In the case of assault of staff, Beck, Baldwin, Modlin and Lewis (1990) report that aggression occurred most frequently while the caregiver was dressing the patient. Table 3

shows proportions in their study reporting aggression while engaged in this and other activities:

Table 3: Activity During Aggressive Behavior - Beck et al (1990) Study

	%
- Changing or dressing residents	24
- Feeding	17
- Giving medications	12
- Putting residents to bed	7
- Turning down TV	5
- Changing chairs	5
- Taking resident to therapy	2
- Helping make long distance call	2
- Shaving	2
- Taking clothes to be washed	2

- Cohen-Mansfield, Marx, and Werner (1992) report more agitation when two ADL's - eating and bathing/toileting were initiated by others, compared with when these activities were self-initiated. The opposite was true when residents were getting up or transferring.

- Reports are mixed with respect to the influence of time of day. For example, Bowie and Mountain (1993) report that inappropriate behaviour increases steadily as the day progresses from 8am to 9pm. On the other hand, when Beck, Baldwin, Modlin and Lewis (1990) asked nurses and nursing assistants from a nursing home and VA hospital whether cognitively impaired residents exhibited problem behaviours at a specific time, as shown in Table 4, a majority said "no particular time."

Table 4 - Time Aggressive Behaviour Was Reported to Most Commonly Occur (Beck et al. 1990)

	%
No particular time	37
Morning	20
Bedtime	10
Mealtime	5
After meals	2
Before meals	2
At snack time	2
Bath time	2

Rather than relying on perceptions of behaviour, Cohen-Mansfield, Marx, Werner and Freedman (1992) conducted an observational study of 24 nursing home residents selected because of their high level of agitation. Temporal patterns of agitation were found to be specific to the person, but there was some consistency across residents. For example, strange noises, aggressive behaviours, and picking were manifested significantly more often in the evening than during the day supporting the idea of "sundowning." Constant requests for attention occurred most often during lunch. The researchers suggest that there are more requests for attention during lunch because that is when staff are available to help. Residents may scream more at night because they are alone in their rooms but not yet asleep. They propose that agitated behaviour may be "time-locked" to daily schedule as a reaction to the regimentation that is characteristic of care facilities.

They acknowledge, however, that temporal patterns of agitation may have a neurochemical basis or be linked to a physiological mechanism, such as circadian rhythm.

Other data suggest that "sundowning" may occur only in some individuals. For example, Evans (1987) found that both restlessness and verbal behaviour increased in the late afternoon in 12.3% of nursing home residents. Sundowners had more severe cognitive impairment with organic involvement than non-sundowners. Cohen-Mansfield, Marx and Rosenthal (1989) found that 14% of residents were more agitated in the evening and 17% more agitated during the day shift. Cohen-Mansfield, Watson, Meade et al., (1989) found that of eight agitated residents of an Alzheimer's Unit, only two exhibited a sundown syndrome.

Burns, Jacoby and Levy (1990) report that among persons with Alzheimer's disease, aggression is associated with CT evidence of temporal lobe atrophy.

MANAGEMENT ISSUES

Assaultive and generally, agitated/aggressive behaviour, is reported to have a number of negative consequences for caregivers. These include:

- Burnout, absenteeism and staff turnover (Drummond, Sparr & Gordon, 1989; Gurland, Wilder & Toner, 1987; Martin & Kirkpatrick, 1987; Ryden, 1988).

- Lower morale (Gurland, Wilder & Toner, 1987; Rovner, Kafonek, Filipp et al., 1986).

- Stress (Everitt, Fields, Soumersai & Avorn, 1991; Mentes & Ferrario, 1989; Meddaugh, 1987).

These and other "disturbing" behaviours also have negative consequences for the person exhibiting the behaviour, including:

- Decreased quality of care (Mentes & Ferrario, 1989; Meddaugh, 1987).

- Decreased quality of life (Rovner, Kafonek, Filipp et al. 1986).

- Verbal and physical abuse/retaliation by staff and other residents (Beattie, 1987; Beck & Shue, 1994).

- Social isolation of aggressive residents (Beck & Shue, 1994; Drummond, Sparr & Gordon, 1989; Martin & Kirkpatrick, 1987; Ryden, 1988; Winger, Schirm & Stewart, 1987).

- Application of physical or chemical restraints (Everitt, Fields, Soumersai & Avorn, 1991; Jackson, Drugovich, Fretwell et al. 1989; Rader, 1991, Werner, Cohen-Mansfield, Braun et al. 1989).

- Stress (Mentes & Ferrario, 1989; Meddaugh, 1987).

- Transfer to another facility (Jackson, Drugovich, Fretwell et al. 1989).

Jackson, Drugovich, Fretwell et al. (1989) note that "use of restraints and accompanying dependence also increase the financial costs of care by requiring increased custodial care. Moreover, restraints and psychoactive drugs may complicate existing medical conditions, leading in some cases to hospital admission."

Novak and Chappell (1994) note that "a nursing assistant who feels distressed by specific patient behaviours, even if those behaviours happen infrequently, will tend to feel chronic distress or burnout. As this feeling grows, the nursing assistant will feel more distressed by patient behaviours which, together with negative appraisal and Emotional Exhaustion may lead to a downward spiral in the quality of the nursing assistant's work life" (p.115). On the other hand, and in contrast to what Haley, Brown and Levine (1987) report for family caregivers, Novak and Chappell (1994) state that "the data found that nursing assistants who reported *more* frequent potentially disturbing behaviours felt a greater sense of Personal Accomplishment. It appears that frequent potentially disruptive behaviours do not automatically lead nursing assistants to feel burned out."

Among strategies suggested for coping with agitated/ physically aggressive behaviour are:

- Activity diversion such as engaging residents in exercise, household chores, or other activities incompatible with the problem behaviour (Gugel, 1988).

- "Time-out" such as by segregating, isolating or taking the resident away from the area where the problem behaviour is occurring (Casciani, 1988).

- Explanation of limits (Casciani, 1988).

- Assertiveness training for residents who cannot assertively express their needs (Casciani, 1988; Cox, 1993).

- Identification of feelings behind aggressive behaviour and helping residents express their feelings (Cox, 1993).

- Operant conditioning and other behavioural strategies (Burgio & Burgio, 1986; Cox, 1993; Ebersole, 1989; Gugel, 1988).

- Increasing structured activities during critical hours and providing other ways for clients to express frustration and anger (Ebersole, 1989).

- Reduction or increase in the amount of stimulation in the environment (Chrisman, Tabar, Whall & Booth, 1991).

- Caregiver training. For example, Mentes and Ferrario (1989) have developed a staff training program called Calming Aggressive Reactions in the Elderly (CARE). Beck, Baldwin, Modlin and Lewis (1990) describe the program as focusing on early identification of risk factors, knowing the resident, implementing preventive approaches and using protective intervention as a last resort. They report a decline in aggressive episodes for a three-month period following implementation of the program. Feldt and Ryden (1992) describe a training program for nursing assistants. Content areas and objectives include: understanding cognitive impairment; understanding precipitants/idiology of aggressive behaviour; communication techniques; preventing aggressive behaviour; preventing escalation of aggressive behaviour; managing personal feelings; and individualizing the care plan.

2. AGITATED/AGGRESSIVE - VERBAL

PREVALENCE

Nurses' responses to the screaming item from the Cohen-Mansfield Agitation Inventory show that 25% of 408 residents of a nursing home assessed by Cohen-Mansfield, Werner and Marx (1990a) screamed at least four times a week; 15% screamed once or more per day. Cariaga, Burgio, Flynn and Martin. (1988) report disruptive

vocalizations (screaming, abusive language, moaning and repetitious verbalization) in 11% of residents in two 350-bed nursing homes. Ryan, Tainsh, Kolodny et al. (1988), using a broad definition of noisemaking (from a constant plaintive whisper of one resident to abusive screaming of another), report a prevalence rate of 30% for a sample of residents of two long-term care facilities.

RISK FACTORS

- Cariaga, Burgio, Flynn and Martin (1988) report that verbal disruptive behaviours occur most frequently during patient care activities. Cohen-Mansfield, Werner and Marx (1990a) report that screaming was associated with toileting and bathing. They note that "future studies are needed to determine whether this finding is because they are embarrassed at being unclothed in front of others, frustrated at their inability to perform these activities independently, or some other reason". Consistent with the latter explanation, Cohen-Mansfield, Werner and Marx (1990b) found that verbally agitated and aggressive behaviour occurred at locations in which residents might need help (e.g. the toilet).

- Cariaga, Burgio, Flynn and Martin (1989) found that disruptive vocalizations decreased in the early afternoon when staff-patient was at its lowest. Cohen-Mansfield, Marx, Werner and Freedman (1992) on the other hand report more strange noises on weekends, perhaps, they suggest, because residents had no structured activities and there were fewer staff.

- Cohen-Mansfield, Werner and Marx (1990a) found that residents screamed more often when they were alone in their rooms during the evening hours. Werner, Marx and Cohen-Mansfield (1989) report the same finding for a subset of this sample who frequently scream. This suggests, they argue, that screaming is a response to social isolation.

Werner, Marx and Cohen-Mansfield (1989) found that residents screamed more when they were physically restrained than when they were not.

- Teri, Borson, Kiyak and Yamagishi (1991) report that male Alzheimer's patients are more prone to verbal aggression.

MANAGEMENT ISSUES

Cohen-Mansfield, Marx and Rosenthal (1989) point out that:

> Despite the fact that the majority of these behaviours were non-aggressive and verbal, their sheer number is disconcerting, especially when one considers the effects that these behaviours have on other nursing home residents and personnel. For instance, screaming by one nursing home resident may cause another resident to curse at the resident who created the initial disturbance, making it necessary for staff to intervene in an effort to calm both residents (p. M82).

Among suggested management strategies are operant techniques. For example Baltes and Lascomb (1975) used social contact reinforcement (regularly scheduled times devoted to the patient by staff members) as well as tangible reinforcers (e.g. extra privileges) to reduce screaming. Thomson, Turner and Wiebe (1993/94) used a Differential Reinforcement of Other Behaviours procedure.

3. AGITATED/NON-AGGRESSIVE - PHYSICAL

Pacing/Wandering

PREVALENCE

Cohen-Mansfield, Werner, Marx and Freedman (1991) report that 39% of their sample of nursing home residents were rated by staff as pacers; of these, 76% paced on a daily basis. Study 2, of 6 residents who paced, showed that the average time spent pacing was 55%. Dawson and Reid (1987) report that 14.8% of 400 residents of one nursing home were classified by staff as pacers.

Types of Pacers/Wanderers

Hussian and Davis (1985) identify four types of institutional wanderers: 1) akathisiacs (neuroleptic induced pacing and restlessness); 2) exit seekers (newly admitted residents who try to open locked exit doors); 3) self-stimulators (persons who perform other self-stimulating activities, such as turning door knobs in addition to pacing); and 4) modelers (persons who tag onto or "shadow" other pacers).

Cohen-Mansfield, Werner, Marx and Freedman (1991) failed to find a significant relationship between pacing and consumption of neuroleptic drugs, but they did not examine pacing before, during and after administration of neuroleptics. As they note, controlled double-blind studies are needed, as well as studies that evaluate other reasons for pacing.

Algase (1992) reports that 81% of travel among wanderers was direct travel. The remainder may represent inefficient travel patterns resulting form spatial deficits and lowered capacity for way-finding. Using a rhythm approach to record wandering, she also noted that the locomotive phase of most cycles started and stopped when the wanderer was alone. Only a small proportion of cycles (5%) started or stopped when wanderers were with others. This finding suggests to her that wandering may replace social interaction for some people.

RISK FACTORS

- Cohen-Mansfield, Werner, Marx and Freedman (1991) report that pacers had fewer medical diagnoses, better appetites and had resided in the facility for fewer years than non-pacers. They suggest that residents need to have relatively good health in order to expend the energy necessary for pacing. They note that residents who pace have a tendency to fall Also, rates are higher for people who have not previously relocated other than when they entered the nursing home.

- Cohen-Mansfield, Werner, Marx and Freedman (1991) report that in their observational study of 6 pacers, pacing occurred when there was no noise or a low level of noise (mean frequency of pacing was 5.62, 5.55, 3.53 and 2.67 for no noise, low noise, normal noise, and high/unpleasant noise). Pacing was not affected by exposure to either music or television, different environmental temperatures or type of person in the social environment.

- Cohen-Mansfield, Werner, Marx and Freedman (1991) also report that pacing occurred significantly less when it was dark (mean frequency of pacing was 1.09 for darkness, 5.43 for normal light and 5.70 for bright light). Residents paced more often in non-mealtime hours (i.e. when not confined to the dining room).

- Cohen-Mansfield, Marx and Werner (1992) report that pacing was manifested most often when residents were relocating from one room to another. This result, the researchers suggest, may be due to similarities between pacing and relocating.

- Burns, Jacoby and Levy (1990) report that among persons with Alzheimer's disease, wandering is associated with CT scan evidence of increased size of the Sylvan fissure.

MANAGEMENT

Cohen-Mansfield, Werner, Marx and Freedman (1991) suggest that rather than restricting wanderers physically or chemically, staff should divert cognitively impaired residents from wandering into a potentially dangerous situation (e.g. leaving the facility). As they note, a variety of techniques for residents who pace have been described in the literature. For instance:

- Rader (1987) describes a program in which nursing home residents were given special bracelets that identified them as pacers and had their photos, names and room numbers posted in designated places for all staff to see. For a period of time until staff were familiar with them (3-4 weeks), these residents also wore a red dot between their shoulder blades. Other care facilities provided high risk wanderers with special shirts and sweaters (Dawson & Reid, 1987; Hall, 1988).

- McGrowger-Lin and Bhatt (1988) describe a Wanderer's Lounge program for nursing home residents with Alzheimers' Disease. Taking place from 3-5pm, the program included music, exercise, sensory stimulation, nourishment and dancing.

- Robb (1985) has shown that daytime exercise significantly decreases nighttime pacing.

- Dobbs and colleagues (Andiel & Dobbs, 1995; Dobbs & McKinsey, 1993; Dobbs & French, 1994; Maisey & Dobbs, 1994) are testing the hypothesis that wandering in dementia may be an aspect of stimulus seeking and, as such, may be reduced through increased environmental stimulation and/or by administration of a psychoactive stimulant (ritalin).

Milke (1992) argues strongly against the use of treadmills and points out dangers associated with wandering tracks.

Absconding

PREVALENCE

Hiatt (1985) found that on average, nursing homes reported that 2.4 residents absconded over a three month period. In an observational study, Milke (1989) found that over a similar time period, 5 of 20 residents of a Special Care unit absconded. Not all however, were wanderers. Restless locomotion was not antecedent to absconding. Rather, lag-sequential analysis showed that a repetitive three-component sequence predicted absconding: restless locomotion interspersed with navigational difficulties and group walking.

MANAGEMENT

- Hussian and Brown (1987) have demonstrated that placement of two-dimensional grid patterns at the base of exit doors can contain some elderly men suffering from dementia.

- Hussian (1988) found that grids along with verbal prompts to attend to these can reduce exiting.

Trespassing

PREVALENCE

Bernier and Small (1988) found that of 22 problem behaviours, residents identified other residents entering the wrong room as the most disruptive to their quality of life.

4. AGITATED/NON-AGGRESSIVE - VERBAL

PREVALENCE

Halberg, Norberg and Erickson (1990) report that 15% of residents of psychogeriatric wards in Sweden were vocally disruptive (i.e. noisy for long periods, repeating words, sentences or sounds).

RISK FACTORS

Halberg, Norberg and Erickson (1990) found that among severely demented institutionalized residents, those who were vocally disruptive were more likely than controls to have fluctuations in mental state and emotional disturbance, delusions and hallucinations, and more preserved speech. They suggest that vocal disturbance may be more characteristic of frontal lobe dementia than Alzheimer's disease. They also suggest that it could be a result of stress, or be a self-stimulating behaviour (i.e. a reaction to sensory deprivation).

Cohen-Mansfield, Marx and Werner (1992) report that strange noises were manifest most often when residents were unoccupied. Constant requests for attention were exhibited most often when residents were involved in social activities.

MANAGEMENT

Robb(1985) found that wanderers were significantly more silent at night when given daytime exercise.

5. IDEATIONAL

PREVALENCE

Community Studies

Lachs, Becker, Siegal, Miller and Tinetti (1992) reviewed clinical records of 114 patients of an outpatient geriatric assessment centre. All had a diagnosis of probable dementia. Delusions were described in 25.5% of patients. Of the 29 patients with delusions, 34% had a single delusional belief while 66% had two or more. The majority of delusions were paranoid in nature (41%).

A variety of behavioural disturbances were more common in delusional than non-delusional dementia patients including agitation, angry or hostile outbursts, urinary incontinence, wandering or pacing and insomnia. This is an important clinical observation, the authors note, because disruptive behaviours are especially likely to result in caregiver stress (Rabins, Mace & Lucas, 1982).

Institutional Studies

Rovner, Kafonik, Filipp et al. (1986) found that 15 of 50 facility patients (30%) had delusions or hallucinations. Of these, 11 had a diagnosis of primary degenerative dementia, 1 of vascular dementia, 2 of delirium and 1 of late onset schizophrenia. As in the Lachs, Becker, Siegal, Miller and Tinetti (1992) study, such problem behaviours as wandering, noisiness and active aggression were reported to occur more frequently among patients with delusions and hallucinations.

RISK FACTORS

Wragg and Jeste (1989) reviewed 22 studies of community and facility based dementia patients. They estimate that 30%-38% (median=33.5%) of Alzheimer's patients experience delusions, most often of a persecutory type.

Teuth (1995) reports that hallucinations occur in approximately 25% of Alzheimer's patients and are equally distributed between visual and auditory types. Wragg and Jeste (1989) report a range of 21%-49% (median=28%) for dementia patients, with hallucinations more common in vascular than in Alzheimer's type dementia.

While MMSE scores were similar in delusional and non-delusional patients in the Lachs, Becker, Siegal, Miller and Tinetti (1992) study, there was a tendency for delusions to occur more often in patients with mid-range cognitive impairment (17-23 MMSE score).

MANAGEMENT

Delusions are among the "non-cognitive" impairments of dementia amenable to pharmacological intervention (Reisberg, 1990). However, Teuth (1995) recommends a cautious approach to pharmacotherapy because persons with dementia are highly susceptible to the side effects of psychotropic medication. Other interventions he suggests include reminding the person that he/she is not being plotted against and redirecting attention to something else.

NULL BEHAVIOUR

In discussing the prevalence of problem behaviours, it is important not just to ask "how many do it?" and " how frequently?" but also to ask "how often do they do it relative to other types of behaviour?"

Cohen-Mansfield, Marx and Werner (1992) conducted a three month observational study of 24 agitated and severely cognitively impaired nursing home residents. Residents were engaged in no activity during 63% of the observations, were relocating from one place to another in 23% and engaged in ADLs during 16%. They spent little time in structured activities (music therapy) or social activities (receiving visitors). Four agitated behaviours - repetitious mannerisms, strange movements, picking at things and making strange noises - were manifest most often when residents were unoccupied. Constant requests for attention were exhibited most often when residents were involved in social activities.

Dobbs and Rule (1992) tracked both cognitively impaired and non-cognitively impaired nursing home residents. Although the demented residents were ambulatory more often than the non-cognitively impaired, they were inactive most (68%) of the time.

Bowie and Mountain (1993) report similar findings. They observed 110 residents of 7 long-stay wards in British hospitals (8am -9pm) over a 3-month period. All had a

diagnosis of dementia. As shown in Table 5, during 56.5% of their waking time the residents were doing nothing.

Table 5: Proportion of Waking Time Spent in Selected Activities (Bowie & Mountain, 1993)

	%
Self-care	8.6
Social interaction	5.5
Reception of care	5.3
Motor activity	18.7
Antisocial	0.2
Inappropriate	11.3
Neutral	56.5

Bowie and Mountain (1993) note with some dismay that social interaction was mainly patient-patient:

> This lack of engagement cannot be excused on the basis of staffing levels, as not infrequently three or more staff would be present in patient areas, but conversing among themselves or completing care plans rather than engaging the patients. At its worst, this process went on for over three hours on one ward, during which time the four staff on duty completely ignored the patients in terms of socialization, and to say that they were supervising the patients would at times have been difficult to justify (p.863).

6. EMOTIONAL/ AFFECTIVE DISTURBANCE

See Mood Disorders, Anxiety Disorders, Schizophrenia and Paranoia in Part II..

7. SOCIALLY UNACCEPTABLE BEHAVIOUR

PREVALENCE

Dobbs and Rule (1992) report that demented nursing home residents when active, showed far more appropriate behaviour (25% of the time) than problem behaviour (7%). In the Bowie and Mountain (1993) study, anti-social and inappropriate behaviour was observed only 11.5% of the time.

Although disruptive in a nursing home, data from the Canadian Study of Health and Aging (Gutman & Beattie, in preparation) show that such socially unacceptable behaviour as taking off clothes, making inappropriate sexual advances, and throwing food tend generally, to be low frequency behaviour (see Table 6).[4] Miller, Snowdon & Vaughan (1995) also report low frequencies for verbal and physical sexual advances (and for intentional falling and for hurting self and others). Gurland, Wilder and Toner (1987) report that incontinence of urine and feces are the most common "disturbing" behaviours in both dementia and other psychogeriatric conditions. Both their data and data from the CSHA (see Table 6) show rates for incontinence to be higher in institutional settings.

RISK FACTORS

- Among persons with Alzheimer's Disease, Burns, Jacoby and Levy (1990) found no difference on CT measures of those with and without sexual disinhibitions.

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[4] See Appendix C for details concerning the CSHA

MANAGEMENT

The Wanderer's Lounge program described by McGrowder-Lin and Bhatt (1988) is reported to have been effective with a resident who constantly banged on the table and frequently removed her clothes and with another described as "grossly incontinent of bowel and bladder in the absence of pathology".

Sloane (1993) recommends removal to a private area if sexual self-stimulation occurs in public. If self-stimulation occurs frequently, he recommends distraction, redirection or more appropriate sensory stimulation, such as massage therapy. For unwarranted verbal and/or physical sexual advances, redirection, reorientation, diversion/distraction, active ignoring, staying calm and non-response are recommended.

8. PROBLEMATIC ADL'S/COPING STRATEGIES

PREVALENCE AND RISK FACTORS

Sloane and Mathew (1991) note that virtually all nursing home residents with dementia need help with dressing, grooming and bathing. Three sub-groups can be distinguished however, on the basis of transfer, ambulation and continence:

1) **The ambulatory confused** (21% of a national sample). These persons can ambulate, transfer from bed to chair, eat and use the bathroom independently or with reminders;

2)A middle group (55%) who are **failing in one or more of ambulation, transfer and continence**; and

3) **Late-stage residents** (23%) who have lost control over most bodily functions and need to be fed (initially, some can still feed themselves), are incontinent of urine (and often faeces) and are largely confined to a bed or chair.

Wandering is most prevalent in the ambulatory confused, noisiness among the late-stage demented while abusive behaviours are found at all ADL levels.

Approximately half (46%) of their national sample of nursing home residents with dementia had severe communication problems, 24% moderate impairment and 29% mild or no impairment. The most impaired residents communicate through facial expressions, moans, screams and other utterances or via body movement. Sloane and Mathew (1991) note that often they are unable to effectively communicate the fact that they are in pain, nauseated or need to urinate.

Kirk, Donnelly and Compton (1991) found that 37% of residents of residential homes in Ireland had some degree of incontinence of urine and/or faeces. This figure is highly similar to that reported by other British researchers.

MANAGEMENT

In care planning for the ambulatory confused, Sloane and Mathew (1991) emphasize an approach that maximizes residents' independence and involvement and includes an intense, appropriate therapeutic activity program. Mobility maintenance is the recommended goal for those who are failing in ADLs, with close coordination between activities and nursing. Goals for late-stage dementia patients are to provide comfort and contact, preserve dignity and "maintain basic body integrity."

Table 6: % of Subjects Reported by Caregivers as Exhibiting Selected "Problem Behaviors" Frequently or All the Time, by Final Diagnosis and Place of Residence, CSHA, Canada, Wave I.*

	No cognitive loss		Probable AD		Possible AD		Vascular Dementia		Other Dementias		Unclassified Dementia		Total All Dementias	
	Home	Inst. n=86	Home n=133	Inst. n=218	Home n=82	Inst. n=137	Home n=69	Inst. n=101	Home n=17	Inst. n=36	Home n=24	Inst. n=46	Home n=325	Inst. n=538
Lack of interest in daily activity	N/A	10.6	33.1	66.5	26.8	67.9	37.7	55.4	47.1	58.3	33.3	47.8	33.2	62.6
Unwarranted accusations	N/A	2.3	21.1	8.7	15.9	10.9	8.8	9.9	5.9	5.6	12.5	15.2	15.7	9.9
Verbally abusive, curses	N/A	1.2	10.5	3.2	3.7	5.1	4.4	6.9	0	8.3	13.0	10.9	7.1	5.4
Empties drawers or closets	N/A	0	13.5	9.1	2.4	4.4	4.4	5.0	5.9	2.9	8.7	6.5	8.0	6.5
Dresses inappropriately	N/A	2.3	11.3	6.0	4.9	3.6	4.4	4.0	5.9	5.6	8.7	4.3	7.7	4.8
Exposes himself indecently	N/A	0	0	0.5	1.2	2.2	1.5	0	0	0	0	0	0.9	0.7
Screams for no reason	N/A	2.3	4.5	1.8	1.2	1.5	2.9	0	0	0	4.3	2.2	3.1	1.3
Physical attacks	N/A	0	1.5	0.5	0	4.4	0	0	0	0	0	4.3	0.6	1.7
Inappropriate sexual advances	N/A	0	0.8	0	0	0	1.5	0	0	0	0	0	0.6	0
Paces up and down	N/A	1.2	6.7	6.4	7.3	8.1	5.9	4.0	0	2.8	4.3	4.3	6.2	5.9
Moves arms in restless way	N/A	0	11.3	6.4	3.7	13.9	7.3	7.9	0	13.9	4.3	13.0	7.4	11.5
Lost outside	N/A	1.2	13.5	11.5	6.1	12.4	13.2	5.9	17.6	8.3	0	19.6	11.1	11.2

* Gutman and Beattie (1995)

Table 6 continued

	No cognitive loss		Probable AD		Possible AD		Vascular Dementia		Other Dementias		Unclassified Dementia		Total All Dementias	
Incontinent of stool	N/A	4.7	7.5	39.2	1.2	34.3	8.8	39.6	0	50.0	13.0	28.3	6.2	38.5
Wakes up at night for no reason	N/A	7.0	23.3	11.0	7.3	7.3	16.2	9.9	5.9	13.9	26.1	15.2	17.0	10.4
Wanders in the house at night	N/A	1.2	9.8	4.1	6.1	5.1	4.4	2.0	0	0	8.7	13.0	7.1	4.5
Sleeps excessively during the day	N/A	12.8	26.3	30.7	20.7	33.6	36.8	37.6	29.4	47.2	26.1	26.1	27.2	33.5
Overeats	N/A	2.3	6.1	3.7	3.7	3.6	4.4	3.0	5.9	2.8	4.3	6.5	5.0	3.7
Refuses to eat	N/A	3.5	5.3	6.0	2.4	9.5	4.4	8.9	0	11.1	0	2.2	3.7	7.4
Cries or laughs inappropriately	N/A	0	3.8	5.0	3.7	7.2	1.5	11.9	5.9	8.3	4.3	8.7	3.4	7.4
Refuses to be helped	N/A	4.7	15.9	6.9	8.5	6.6	7.3	3.0	5.9	5.6	17.4	10.9	11.8	6.5
Throws food	N/A	0	1.5	0.5	0	1.5	0	0	0	0	0	0	0.6	0.6
Wanders aimlessly outside	N/A	1.2	6.7	6.9	2.4	8.0	1.5	3.0	0	0	0	10.9	4.0	6.3
Hoards things for no reason	N/A	8.1	20.3	15.7	6.1	12.4	5.9	6.9	5.9	11.4	13.0	10.9	12.4	12.5
Destroys property, breaks things	N/A	1.2	3.8	1.8	0	0	0	0	0	0	0	2.2	1.2	0.9
Loses, misplaces or hides things	N/A	5.8	39.1	20.6	26.8	21.1	19.1	10.0	23.5	14.3	17.4	17.4	29.4	18.0
Asks same question again	N/A	8.1	51.9	35.9	42.7	29.9	32.3	25.7	35.3	22.2	43.5	23.9	44.0	30.5
Repeats the same action	N/A	4.7	14.3	23.9	12.2	17.5	4.4	15.8	23.5	8.3	8.7	23.9	11.8	19.7

C. PART 2 - Client Identification By Psychiatric Diagnosis

This part of the literature review describes the prevalence, risk factors and client management issues associated with the main diagnostic groups that are usually included under the umbrella term "psychogeriatrics" (i.e., dementia, mood disorders), as well as for such conditions as schizophrenia and paranoia, anxiety disorders, AIDS related dementia, and dementia associated with Parkinson's disease. The information comes from a variety of sources including: large community psychiatric screening studies; multiple and single facility screening studies; and studies targeting persons with specific psychiatric conditions. The screening studies will be reviewed first, both because they present an overview of the psychogeriatric population and because some (see Rovner, Kafonik, Filipp et al. 1986) raise key care, management, and staffing issues.

PREVALENCE OF PSYCHIATRIC DISORDERS

Community Studies

It is generally estimated that 18-25% of older persons have significant mental health symptoms (Harper, 1990). Rates are considerably lower among community-dwelling older persons than among those in institutions. Still, they are higher than most people realize. For example, Kramer, German, Anthony, Von Korff and Skinner (1985) report that 17.3% of participants aged 65+ in the East Baltimore Mental Health survey had one or more Diagnostic Interview Schedule/DSM-III disorders (American Psychiatric Association, 1987). In the age group 65-74, five conditions had prevalence rates of 1% or more:

* Phobic disorders (12.1%)
* Severe cognitive impairment (3%)
* Alcohol use disorder (2.1%)
* Obsessive-compulsive disorders (1.3%)
* Dysthymia (1.0%).

In the age group 75+, four conditions had prevalence rates of 1% or more:

* Phobic disorders (10.1%)
* Severe cognitive impairment (9.3%)
* Major depression (1.3%)
* Dysthymia (1.1%).

(see Appendix C for a description of the study methodology)

Institutional Studies

Rovner, Kafonek, Filipp, Lucas and Folstein (1986) found that 94% of a random sample (n=50) of residents of a large American proprietary intermediate care home had mental disorders according to DSM-III criteria. Primary degenerative dementia (56%) and multi-infarct dementia (18%) were the most common diagnoses. Other diagnoses included Parkinson's with dementia (4%), delirium due to drug intoxication (6%), major depression (active 6%, in remission 2%) and paraphrenia (2%). The majority of the sample are described as severely demented with additional non-cognitive psychiatric symptoms, such as delusions, hallucinations, or depression (see Table 7).

Table 7: Prevalence of Non-Cognitive Psychiatric Symptoms in Demented Persons (Rovner, Kafonek, Filipp, et al., 1986).

	%
Primary degenerative dementia	56
With delusions &/or hallucinations	22
With depression	10
With mania	2
Uncomplicated	22
Multi-infarct dementia	18
With delusions &/or hallucinations	2
With depression	8
Uncomplicated	8

The researchers note that only one of the 50 residents had a history of psychiatric hospitalization. Therefore, the high prevalence of mental disorders could not be attributed to transinstitutionalization from state hospitals. They worry that this particular nursing home, and perhaps many others, function as long-term psychiatric facilities, but without the trained personnel and treatment approaches usually found in psychiatric hospitals.

In support of their concern, there is evidence in the literature that psychiatric disorders in nursing homes frequently are undiagnosed (Sabin, Vitug & Mark ,1982), misdiagnosed (Barnes & Raskind ,1980), or diagnosed in a way that obscures treatable disorders (Ernst, Badash , Beran et al. 1977).

PREVALENCE RATES, RISK FACTORS AND MANAGEMENT ISSUES ASSOCIATED WITH SPECIFIC DIAGNOSES

1. DEMENTIA

DEFINITION

According to DSM-III, dementia is a disease in which there is loss of intellectual abilities severe enough to interfere with social or occupational function, memory impairment and at least one of the following:

a) Impairment of abstract thinking;
b)Impaired judgment;
c) Personality change; or
d) Aphasia (disorder of language due to brain dysfunction), apraxia (inability to carry out motor activities despite intact comprehension and motor function), agnosia (failure to recognize or identify objects despite intact sensory function), or "construction difficulty" (e.g. inability to copy 3-dimensional figures, assemble blocks or arrange sticks in specific designs).

The two most common sub-types are primary degenerative dementia of the Alzheimer's type and vascular dementia (also known as multi-infarct dementia). Primary degenerative dementia is characterized by an insidious onset and progressive deterioration. In vascular dementia, there tends to be a stepwise deterioration with "patchy" distribution of deficits (i.e. affecting some functions but not others) early in the course of the disease; focal neurological signs and symptoms (e.g. exaggeration of deep tendon reflexes, pseudobulbar palsy, gait abnormalities, weakness of extremities, etc.); and evidence of cerebrovascular disease.

Other sub-types (Barnes & Raskind, 1990) include: alcohol dementia, dementia post head-trauma, dementia post-anoxia, dementia associated with specific neurological disease such as Huntington's or Parkinson's, dementia associated with AIDS and dementia of unknown origin.

PREVALENCE

As Anthony and Aboraya (1992) note, the world literature on the epidemiology of dementia now includes more that 50 prevalence surveys, among them the recently completed Canadian Study of Health and Aging (CSHA). Table 8 shows clinically determined cases of possible and probable dementia to range from 4.2% among community dwelling older Canadians to 56.9% in the institutional population. Approximately half the cases in the community sample and two-thirds of the institutional sample have diagnoses of Alzheimer's disease. The prevalence of dementia increases dramatically with age, particularly in the institutional sample.

Data from the UK also show high proportions of persons with dementia in institutional settings. For example, Mann, Graham and Ashby (1984) report that 36% of their sample of residents of Part III British residential homes obtained scores of 3-7 on the Organic Brain Syndrome sub-scale of the CARE. Scores in this range are indicative of mild to moderate dementia. A further 31% were too confused to be interviewed and were classified as severely demented.

RISK FACTORS

A population based case-control study of risk factors for Alzheimer's disease was conducted as part of the CSHA (Canadian Study of Health and Aging, 1994; Canadian Study of Health and Aging Working Group, 1994). Subjects consisted of 258 cases diagnosed with probable Alzheimer's disease, with onset of symptoms within three years of diagnosis and 535 age-matched controls. The data showed increased risk of Alzheimer's disease with increasing numbers of affected first-degree relatives. Those with less education seemed to be at higher risk. Although the results are not conclusive, they suggest that risk is higher among persons that had a head injury and among persons who had worked in jobs that exposed them to glues, pesticides and fertilizers. There was little evidence that Alzheimer's disease is associated with the use of antiperspirants containing aluminum or the use of antacids. There was no link between Alzheimer's disease and alcohol consumption. There was no evidence that smoking reduced the risk of Alzheimer's disease, as has been suggested in some prior studies. Persons with arthritis had roughly half the likelihood of developing Alzheimer's disease. This was also true for people who take non-steroidal anti-inflammatory drugs for arthritis.

Nelson (1990a) points out that vascular dementia is more common in men than women, which is the opposite of the degenerative dementias. Other factors she lists as contributing to the disease include: obesity; smoking; peripheral vascular disease; diabetes mellitus; arrhythmias; myocardial infarction and transient ischemic attacks.

No prevalence rates could be found for AIDS caused dementia or for AIDS in older persons. Riley (1989) reports that 10% of AIDS cases diagnosed in the USA in 1988 were persons aged 50 or over, including 1% aged 65 and over (n=1,000 people). Manton and Singer (1989) worry, however, that since the latent period of AIDS for some people may be as much as 10-15 years, or even longer, in future there may be an increased incidence of relatively early onset dementia.

To date, demand for nursing home care by AIDS victims has not been strong. HIV positive persons more commonly live in board and care than in nursing homes. Birkett (1991) notes that one reason is because the life expectancy of AIDS dementia victims is short. A second reason is that most "AIDS victims, however depressed or

demoralized, are cognitively intact and not psychotic. They are also young. The young who are not demented or psychotic do not wish to be in a nursing home with the old and demented." Further, AIDS is a disease with long periods that are relatively asymptomatic, interspersed with severe acute illness, which is most appropriately treated in an acute care hospital.

2. DELIRIUM

DEFINITION

Delirium is a brain impairment in which memory, thinking and perception are simultaneously impaired. It may be differentiated from dementia by its acute onset and reversible causes (Nelson, 1990). The DSM-IIIR criteria include: reduced ability to maintain attention or to shift attention; disorganized thinking; and two or more of the following: reduced level of consciousness, perceptual disturbances, sleep-wake cycle disturbance, increased or decreased psychomotor activity, disorientation to time, place or person and memory impairment. Other key characteristics are the development of clinical features over a short time period (hours, days) and a tendency for symptoms to fluctuate over the course of the day.

PREVALENCE

Rovner, Kafonek, Fillip et al. (1986) report a rate of 6.0% in the intermediate care facility they studied. Nelson (1990) estimates that one-third to one-half of hospitalized older persons become delirious at some time during their hospitalization.

RISK FACTORS

The most common causes of delirium are drugs, especially cholinergics, and infections (Ancill, 1994; Winograd & Jarvik, 1986). Older demented patients are especially vulnerable to delirium (Teuth & Cheong, 1993). Ancill (1994) notes that in the demented patient, any acute disease will precipitate a delirium and, in many cases, there may be several aetiological factors that need to be identified and treated.

3. MOOD DISORDERS

Depression

According to DSM-IIIR, a diagnosis of a "Major Depressive Episode" may be made if during the same two-week period, in the absence of organic factors or bereavement, there is dysphoric mood (feeling sad) and five or more symptoms from a list that includes: decreased appetite; weight loss; decreased energy; decreased concentration ability; feelings of guilt; psychomotor retardation or agitation; sleep disturbance; and suicidal ideation. Other common symptoms (Buckwalter, 1989) include feelings of worthlessness and low self-esteem, flat affect, diminished interest in people and activities and an inability to enjoy life.

PREVALENCE

Community Studies

Buckwalter (1989) estimates that over 10% of community-dwelling elderly suffer from depressive symptoms. Gurland (1991) estimates depressions conforming to DSM-III criteria (major depression, dysthymia, cyclothymic disorder and atypical depression) at 2%-4% (Myers et al. 1984) with major depression accounting for less than 1% (Blazer, Hughes & George, 1987). However, if all persons with depressive symptomatology are included, he agrees that the rate rises to between 10% and 15%. Copeland, Dewey,

Wood et al. (1987) estimate 10.7% of older people to be at the diagnostic syndrome sub-case level and 11.3% at the case level for a total of 22.0%. They estimate diagnostic syndrome at 3.0% which is close to the 3.7% figure found by Blazer and William (1980) using DSM-III criteria.

Institutional Studies

Short-stay Psychiatric Inpatients

Wattis (1990) notes that while diagnoses of depression (DSM-III) appear to level off or even decrease in old age, hospital use by depressed patients increases dramatically with age. For example, Murphy and Grundy (1984) found that older depressed patients stayed in hospital, on average, 1.5 times longer than younger depressed patients. Over four years, old people with depression used 25% of all available acute bed days for all ages in a large psychiatric hospital.

Gurland (1991) reports that older persons meeting DSM-IIIR criteria account for 50% of all admissions to short-stay psychiatric hospitals.

Long-Term Care Institutions

Buckwalter (1989) estimates a rate of depression from 20-50% in persons residing in long term care settings. Mann, Graham and Ashby (1984) studied 438 residents of 12 Part III Residential Homes in one London Burrough. One third were found to be suffering from severe dementia, one third mild to moderate dementia and one third were free of dementia. Of the latter two groups, 38% exhibited depressive symptomatology. Rovner, Kafonek, Filipp et al. (1986) report that 6% of the residents of the nursing home they studied had an active major depression, another 2% were in remission.

Common Issues of Differential Diagnosis

Buckwalter (1989), Birkett (1991), George (1993), Wattis (1990), Winograd and Jarvik (1986) and others note that depression is often underestimated in older people. George (1993) suggests one reason may be because older people are more prone to mild depression than younger adults. Other reasons include masking of symptoms by concomitant physical illness and older persons' tendency to somaticize, that is, complain of physical (appetite or sleep disturbance) rather then mental disturbance (depression or anxiety). Further, most experts concur that frequently depressive symptoms are ignored because they are "expected behaviours" of old age, a myth shared both by health care professionals and the elderly themselves (Buckwalter, 1989). Additionally, concentration and memory can be affected which may make distinguishing depression from dementia difficult (see Nelson, 1990 or Teuth, 1995 for a list of major distinguishing features). Finally, George (1993) suggests that older adults may present significant depressive syndromes that do not fit DSM-III or DSM-IIIR guidelines. As evidence, she cites a study by Blazer, Hughes and George (1987) of 1,304 community-dwelling older adults of whom 27% exhibited significant depressive symptoms; however, only 0.8% qualified for a diagnosis of major depression.

Wattis (1990) also notes that it is sometimes difficult to distinguish between paraphrenia with depression and intermediate psychotic depression, as well as between depressive illness and bereavement reactions. To make it even more complicated, male-female differences in presentation of depression in old age have been suggested, with men over-represented in those with anxious, irritable, attention-seeking behaviour, somatic complaints, physical illness and predisposing anxious personalities (Wattis, 1990).

Various authors underscore the importance of recognizing depression since, in most cases, it is treatable. Mithani (1994), for example, estimates a success rate of approximately 80% in treatment of major depressions in the elderly.

RISK FACTORS

- Depression plateaus after age 65 and then decreases further with aging (Gurland, 1991; Wattis, 1990).

- The correlation of frailty, physical illness and disability with depression is striking (Buckwalter, 1989; Gurland, 1991).

- Depression in late life is strongly associated with cerebrovascular disease, which is found in 12-15% of depressed patients. Up to 60% of post-stroke patients show evidence of depressed mood (Wattis, 1990).

- An estimated 40-50% of Alzheimer's patients show depressed mood (Wragg & Jeste, 1989) and 10%-20% major depression, the latter usually early in their illness (Cooper, Mungas & Weiler, 1990; Teuth, 1995).

- Both depressed mood and major depression is more common in persons with Alzheimer's disease than with other types of dementia (Wragg & Jeste, 1989).

- Up to two-thirds of depressed elderly have hypochondriacal symptoms. Hypochondriasis occurring for the first time in old age should alert health care practitioners to possible underlying physical illness or to major depression (Wattis, 1990).

- More than one-third of major depressions found in one community study were associated with medication use (Gurland, 1991).

Bipolar Disorders

Concepts of unipolar and bipolar affective disorder have been challenged by research on hypomania in old age. For example, Shulman and Post (1980) report that of 67 elderly with bipolar disorders, half had their first hypomanic attack in old age after a long unipolar illness . In half of these individuals, there was a latency of more than 15 years between first affective episode and first attack of hypomania; in a quarter, the latency was more than 25 years. Many had more than two episodes before their first hypomanic attack. Criteria for identifying younger "unipolar" patients may be invalid when hypomania develops in old age (Wattis, 1990).

Manic states occur less commonly with advancing age and are often found - even in first episodes - to be associated with central nervous system lesions in older persons (Gurland, 1993). Wragg and Jeste (1989) note that in contrast to depression, elevated mood is seldom seem in Alzheimer's patients (rates range from 3%-17%) and that exclusively manic episodes have not been reported. Ancil (1994) notes that mania in the elderly presents with aggression and psychosis and is often undiagnosed.

MANAGEMENT

When there are paranoid delusions and depressed mood, ECT and/or combinations of neuroleptics and antidepressants are recommended (Wattis, 1990). Lithium is the treatment of choice for mania (Ancill, 1994).

Various non-biomedical management strategies are also suggested for depression. These include:
- Increase choice and perception of control (Buckwalter, 1989).
- Reminiscence/life review (Buckwalter, 1989).
- Sensory stimulation (Buckwalter, 1989).
- Structured remotivation groups (Buckwalter, 1989).
- Psychodrama (Buckwalter, 1989).

Table 8: Prevalence of Psychiatric Conditions in the Elderly Population, by Place of Residence

DIAGNOSIS	COMMUNITY	NURSING HOME/FACILITY	OVERALL	
Dementia Syndromes	**CSHA 1994*** **4.2%** 65-74 1.6% 75-84 6.9% 85+ 17.8% **Copeland et al 1989** **5.2%** **Folstein et al 1985** **6.1%** 65-74 2.1% 75+ 11.7%	**CSHA 1994** **56.9%** 65-74 41.9% 75-84 53.3% 85+ 66.0% **Mann et al 1984** **67.0%** Mild-moderate 31% Severe 36%	**Anthony & Aboraya 1992** - based on review of 50+ studies estimate world-wide prev. of moderate & severe dementia at 2%- 14.0% **CSHA 1994** 65-74 2.4% 75-84 11.1% 85+ 34.5% **Gurland 1991** 65+ 7.5% 80+ 20.0%+ **Skoog et al 1993** 85+ 29.8%	**8.0%**
Alzheimer type (primary degenerative)	**CSHA 1994** **2.7%** 65-74 0.8% 75-84 4.3% 85+ 13.8% **Evans et al 1987** **12.3%** **Folstein et al 1985** **2.0%** 65-74 0.3% 75+ 4.6%	**CSHA 1994** **36.7%** 65-74 13.1% 75-84 33.1% 85+ 49.0% **Rovner et al 1986** **56.0%**	**CSHA 1994** 65-74 1.0% 75-84 6.9% 85+ 26.0%	**5.1%**
Vascular (Multi-infarct)	**Folstein et al 1985** **2.8%** 65-74 0.7% 75+ 6.0% **CSHA 1994** **0.7%** 65-74 0.3% 75-84 1.3% 85+ 2.4%	**CSHA 1994** **11.5%** 65-74 13.7% 75-84 12.9% 85+ 93.0% **Rovner et al 1986** **18.0%**	**CSHA 1994** 65-74 0.6% 75-84 2.4% 85+ 4.8%	**1.5%**

* All CSHA findings reported in this table are national data.

Table 8 Cont'd: Prevalence of Psychiatric Conditions in the Elderly Population, by Place of Residence

DIAGNOSIS	COMMUNITY		NURSING HOME/FACILITY		OVERALL	
Mixed	**Folstein et al 1985** 65-74 1.0% 75+ 1.2%	**1.3%**				
Dementia due to Parkinson's disease	**CSHA**	**0.1%**	**CSHA** **Rovner et al 1986**	**1.6%** **4.0%**		
Dementia due to AIDS					**No estimate available other than Riley 1989 who states that 10% of AIDS victims are 50 yrs+, 1% are 65+**	
Delirium	**CSHA**	**0.1%**	**CSHA** **Rovner et al 1986**	**0.4%** **6.0%**		
Anxiety Disorders	**Gurland 1991** **Copeland 1987** **Bland et al 1988**	**4%+** **2.4%** **3.5%**			**Skoog et al 1993** 85+ 10.5%	
Panic Disorders	**Copeland et al 1987** **Kramer et al 1985** 65-74 0.2% 75+ 0	**1.1%** **0.1%**			**Skoog et al 1993** 85+ 5.5%	
Phobic Disorders	**Copeland et al 1987** **Kramer et al 1985** 65-74 12.1% 75+ 10.1%	**0.7%** **11.5%**			**Skoog et al 1993** 85+ 3.4%	
Hypochondriasis	**Copeland et al 1987**	**0.5%**			**Skoog et al 1993** 85+ 1.0%	
Obsessive/Comp. Disorders	**Copeland et al** **Kramer et al 1985** 65-74 1.3% 75+ 0.6%	**0.1%** **1.1%**			**Skoog et al 1993** 85+ 3.2%	

Table 8 Cont'd: Prevalence of Psychiatric Conditions in the Elderly Population, by Place of Residence

DIAGNOSIS	COMMUNITY		NURSING HOME/FACILITY		OVERALL	
Depressive Symptomatology	**Blazer 1989** 65-74 8.8% 75-84 10.5% 85+ 12.6% **Blazer, Hughes & George 1987** **Buckwalter 1989** **Copeland et al 1987** **Gurland 1991**	 8% 10+% 11.3% 10-15%	**Buckwalter 1989** **Mann et al 1984** of residents who could be clinically assessed **Parmelee, Katz & Lawton et al 1988**	20-50% 38% 40%	**Wattis (1990)** **Skoog et al 1993** 85+ 12.6%	15.0%
DSMIII Criteria	**Myers et al. 1984** **Meyers and Alexopolous 1988**	2-4% 2.0%	**Blazer et al 1980** **Bland et al 1988**	3.7% 10.0%		
Major Depression	**Kramer et al 1985** **Blazer et al ,1987** **CSHA**	1.3% < 1% 1.3%	**Rovner et al 1986** **(+2% in remission)** **CSHA**	6% 1.9%		2-4%
Schizophrenia/ Paranoia	**Copeland et al 1985** **Gurland 1991** **Kramer et al 1985** 65-74 0.2% 75+ 0	0.1% 0.5% 0.1%	**Gurland 1991** **Rovner et al 1986**	3.0% 2.0%	**Skoog et al 1993** 85+ 0.6%	
Alcohol Dependence/Abuse	**Bland et al 1988** **Gurland 1991** **Kramer et al 1985** 65-74 2.1% 75+ 0.1%	1.7% 1-2% 1.5%				
Proportion with Diagnosable Disorders	**Regier et al. 1988** **Rapp et al 1988 40-50% of older persons hospitalized for medical conditions**	12%+	**Rovner et al 1986 nursing home residents with DSM-III mental disorders**	94%	**McEwan et al 1991**	25%

4. ANXIETY DISORDERS

According to DSM-IIIR, anxiety disorders (also known as anxiety and phobic neuroses) include panic disorders, phobias, obsessive-compulsive disorders and generalized anxiety disorders. General anxiety disorders are characterized by tension, inability to relax, trembling, hyperactivity, frequent urination, upset stomach, diarrhea, anticipation of misfortune, vigilance, difficulty concentrating, impatience and insomnia

Riley (1990) reports that the anxiety disorders most commonly found in older people are obsessive-compulsive disorders, generalized anxiety disorders and phobias. She notes that an obsessive-compulsive disorder in an older person may be associated with or predispose to depression. Obsessive-compulsive disorders are also sometimes seen in people with dementia.

The most common form of phobias in older persons are agoraphobias, especially in older women (Turnbull & Turnbull, 1985).

PREVALENCE

Copeland, Dewey, Wood et al. (1987) interviewed a sample of 1070 community dwelling elderly in Liverpool, using a community version of the Geriatric Mental State Exam. Findings were processed to give a computerized diagnosis by AGECAT. The overall rate for neurotic disorders among persons aged 65+ was 2.4%. Rates for sub-types were: anxiety 1.1%; phobia 0.7%, hypochondriasis 0.5%; and obsessive 0.1%. Gurland (1991) reports a rate of 4%+ for panic, phobia, obsessional and somatization disorders.

RISK FACTORS

Skoog, Nilsson, Landahl and Steen (1993) report that anxiety rates were significantly higher for women aged 85+ than for similarly aged men in the Gothenburg study.

5. SCHIZOPHRENIA & PARANOIA

Schizophrenia is a functional psychosis that involves a thought disorder characterized by altered concepts of reality, such as persistent bizarre delusions and prominent hallucinations. Other symptoms include illogical thinking and speech, loose associations, flat or grossly inappropriate affect, disorganized psychomotor behaviour, decreased ability to function in work and social activities and poor hygiene (Hogstel, 1990).

There are 5 main diagnostic categories of schizophrenia used in the diagnosis of older adults as well as other age groups:
1) Disorganized type;
2) Catatonic type;
3) Paranoid type;
4) Undifferentiated type; and
5) Residual type.

Onset is usually in adolescence or early adulthood, but it is now widely accepted that schizophrenia and conditions related to schizophrenia such as paranoid disorders (sometimes diagnosed as paraphrenia in Europe) may occur for the first time in late adulthood (45-64 years) or old age (Gurland, 1991; Rabins, 1992; Rabins et al. 1984).

PREVALENCE

Gurland (1991) reports that active symptoms among schizophrenic individuals grown old and among those with late onset schizophrenia or persistent paranoid states are rare (less than 0.5% of the elderly population) although the noticeable nature of their bizarre behaviour may make it seem like there are more. Skoog, Nilsson, Landahl and Steen (1993) report a similar rate (0.6%) among 85 year old participants in the Gothenburg study follow-up.

Rates are higher when only institutionalized elderly are considered. For example, Rovner, Kafonek, Filipp et al. (1986) report a rate of 2% with paraphrenia in their random sample of a large intermediate care facility. Gurland (1991) states that on average about 3% of elderly nursing home patients have a primary paranoid state. He also notes that about 10% of short-stay psychiatric in-patient first admissions after age 60 have late-onset symptoms closely related to schizophrenia.

Several authors draw attention to differences between early and late onset schizophrenics. For example, Gurland (1991) reports that in late-onset patients delusions are more florid, but there is less thought disorder and affect flattening; hallucinations are more likely to be visual, tactile, gustatory or olfactory rather than auditory; and that paranoia tends to predominate among late-onset patients.

Hogstel (1990) reminds us that older schizophrenics have long-standing problems and have been taking antipsychotic medication for years.

RISK FACTORS

Late onset schizophrenia is more common in women than men. Rabins (1992) states that this difference is not fully explained by the longer life span of women. Late onset schizophrenics are frequently described as having had unusual or abnormal premorbid personalities (Rabins, 1992).

Teuth (1995) reports that approximately 30% of early stage Alzheimer's patients show paranoia and about 50% of late stage are psychotic -- that is, exhibit delusions, hallucinations and paranoia.

Ancill (1994), Gurland (1991) and Rabins (1992) note that hearing impairment is common in older people with paranoid disorders. Ancill (1994) suggests that their disability may best be understood as a delusional interpretation of impaired sensory information. Rabins (1992) suggests that sensory deprivation could be a risk factor. He also notes that because non-auditory hallucinations are common in organic disorders, it is important to rule out identifiable focal CNS lesions or systemic disorders such as brain tumor, peripheral neuropathy, etc.

MANAGEMENT

Neuroleptic medications are the treatment of choice. However, these drugs have serious side-effects (Jencks & Clauser, 1991), the most common of which is tardive dyskinesia, an involuntary movement disorder than occurs months or years after neuroleptics have begun. Tardive dyskines consists of abnormal movements of the lips, tongue, mouth, limbs or trunk. Old age is a risk factor for developing tardive dyskinesia as are being female and having cognitive dysfunction. The elderly are also prone to develop the parkinsonian or extrapyrmidal side-effects of neuroleptic therapy (e.g. Pisa-syndrome).

6. SUBSTANCE DEPENDENCE/ABUSE

Causative factors within the DSM-IIIR category Psychoactive Substance Disorder include alcohol, therapeutic agents, industrial compounds, illicit drugs and any other chemicals having an important effect on the central nervous system.

PREVALENCE

Atkinson, Ganzini and Bernstein (1992) note that the elderly show increased sensitivity to the effects of most psychoactive substances. They point out that early studies of alcohol and opioid dependency perpetuated the myth that, because of early death and spontaneous recovery, alcohol and substance abuse disorders were rare after middle age. It is now widely recognized, however, that alcoholism may continue into old age and, that some people become alcoholics for the first time after age 60.

All reports comparing the prevalence of heavy use or abuse agree that in the elderly, alcohol problems are more common than drug problems, and that legally available drugs are far more commonly a problem than illicit drugs.

There is no information available on the rate of spontaneous remission in older alcoholics. Atkinson, Ganzini and Bernstein (1992) review 16 studies of heavy or problem drinking in community-dwelling elderly. For studies including both men and women, they report rates ranging from 4% to 17% for heavy or problem drinking. The B.C. Alcohol and Drug Services (1994) report a range of from 2% - 10%. Gurland (1991) places the rate for alcoholism (both early and late onset) at 1-2% of older persons.

Among prescription drugs, older people primarily develop drug-use disorders from sedative-hypnotic agents, especially benzodiazepines. Opiod analgesics are a distant second, the abuse potential of anti-depressants and neuroleptics is inconsequential and psychostimulant abuse is virtually unknown (Atkinson, Ganzini and Bernstein, 1992). Myers et al (1984) place the community prevalence rate for drug dependence of all types at less than 1% in persons aged 65+.

RISK FACTORS

Risk factors vary depending on the substance. For example, males are two to six times more likely to have documented alcohol problems than females. Females are more likely than males to abuse sedatives and hypnotics. Persons suffering from depression or dementia or chronic physical illness are at risk. Atkinson, Ganzini and Bernstein (1992) also note a variety of psychosocial and iatrogenic factors (see Table 9) and predict higher rates of alcohol consumption and problems in future cohorts of elderly given today's' greater acceptance of alcohol consumption.

Kashka and Tweed (1990) are concerned that rates of alcoholism and drug dependence in older women, often described as negligible, underestimate the problem. Reasons for this are that alcoholic women die at a younger age than alcoholic men and are more stigmatized.

Table 9: Risk Factors for Substance Abuse in the Elderly (Atkinson, Ganzini & Bernstein, 1992)

Demographic Factors
- Male gender (alcohol, illicit substances)
- Female gender (sedative-hypnotics)

Substance-related Factors
- Prior substance abuse
- Family history (alcohol)

Increased Biological Sensitivity
- Drug sensitivity
- Pharmacokinetic factors
- Pharmacodynamic factors
- Medical illnesses associated with aging
- Cognitive loss
- Cardiovascular disease
- Metabolic disorders

Iatrogenic Factors
- Prescription drug dependence
- Drug-drug and alcohol-drug interaction
- Caregiver over use of PRN medication
- Physician advice/permission to use alcohol

Psychosocial Factors
- Loss and other major life stress
- Discretionary time and money
- Social isolation
- Family collusion

Psychiatric Factors
- Depression
- Dementia
- Subjective symptoms of chronic illness

Cohort and Period Effects

D. Summary and Conclusions

Several themes emerge from the literature review. One is that long term care facilities are home to many persons exhibiting a wide variety of problem behaviours. A second, is that more and more, these facilities are becoming custodians of persons with psychiatric illness (Smith, Buckwalter & Albanese, 1990; Spore, Smyer & Cohen, 1991; Zimmer, Watson & Treat, 1984). As Benedict (1983) notes, this is a consequence both of under utilization of outpatient services by older persons and of the trend in many jurisdictions to reduce their admission to state mental hospitals. A third theme is that the relationship between problem behaviours and psychiatric illness is not well recognized despite their frequent co-occurrence in the older population and, their direct relation to the burden of care.

A number of authors note that mental health problems are often misdiagnosed or overlooked in the elderly. As Rovner, Kafonek, Filipp et al. (1986) note:

> Behaviours such as agitation, combativeness and wandering interfere with the provision of care in the nursing home, lower the morale of staff, and detract from the quality of life of residents. If these behaviours are symptoms of potentially treatable mental disorders, recognizing them as such is as critical to care as is recognizing any symptom in medicine and requires identification of the underlying disorders, relief of distress, and training of staff to recognize the importance of behaviours as symptoms (p.1446).

Many authors echo their call for increased training of facility staff in psychiatric nursing techniques and, for increased physician training and involvement, especially where psychoactive drugs are prescribed (Hall & Buckwalter, 1989; Maletta, 1988; Rader, 1987; Rovner, Steele, German et al. 1992; Smith, Buckwalter & Albanese, 1990; Zimmer, Watson & Treat, 1984). A need for more community-based programs and access to mental health and psychiatric specialists is also identified (Bernstein & Hensley, 1993), including in rural areas (see Sarchuk & Weibe, 1992 or Smith, Buckwalter & Albanese, 1990 for an example of a rural psychiatric outreach program).

Prescribing practices clearly need to be monitored and modified given some of the findings. For example, 29.1% of 85 year olds in the Gothenberg study using a psychotropic drug had no mental disorder; only one-fifth of those with depressive disorders were receiving antidepressant medication. There is ample evidence in the literature (see Jencks & Clauser, 1991) that this situation is not confined to Sweden but rather, is the norm in many jurisdictions. Inappropriate use of nonpsychotropic medications in care facilities has also been reported (Williams & Betley, 1995).

Rovner, Steele, German, Clark and Folstein (1992) draw attention to the fact that many of those exhibiting problem behaviours in nursing home settings are restrained physically or chemically. Overuse and misuse of both types of restraints are well documented. Also well known are the adverse consequences, which include delirium, increased functional dependency, bed sores, contractures, and even death. Still, often neither the psychiatric diagnosis nor a clear description of the behaviours for which restraints and psychotropic drugs are prescribed appear in care facility records. Rather, residents may be vaguely defined by behaviour (e.g."wanderers") or by terms such as "senility" or organic brain syndrome. A major concern is that in the absence of a psychiatric diagnosis, persons exhibiting problem behaviours may not receive the treatment they need. Rather, they may simply be considered uncooperative and be restrained or isolated. To test this hypothesis, Rovner, Steele, German, Clark and Folstein (1992) compared 454 new nursing home admissions described by staff as cooperative vs. uncooperative in terms of their psychiatric diagnosis and use of restraints and neuroleptics. Being perceived as uncooperative was found to be independently associated with psychotropic drugs and restraints in this study.

Another key theme is that although their behaviour may be similar, persons with different psychogeriatric conditions may have different resource needs. For example, Folstein, Anthony, Parhad, Duffy and Gruenberg (1995) point out that:

> ... patients with multi-infarct dementia often suffer from hypertension and often require cardiac medication. Patients with Alzheimer's disease are often free of other somatic disorders. One would expect, therefore, that these two cognitively impaired groups would require different types of health care (p.231).

Anthony and Aboraya (1992) provide some useful direction for addressing the issue of whether clients should be identified and grouped on the basis of diagnosis or whether some other classification system should be sought. They point out that while there is a continual need to weight the value of diagnostic categories, we need to ask if these categories are useful in testing theories about the conditions under which mental and behavioural disturbances occur or in learning how to prevent their occurrence. They conclude that the answer, at present, is "yes." One major reason for this is that while the psychogeriatric population is heterogeneous "the categories mark off useful etiological classes within which there is a relative homogeneity of causal conditions" (p.31).

There are several studies that indicate that the clients' level of cognitive impairment has a significant impact on staff effort, with the severely cognitively impaired requiring greater effort (Aronson, Cox, Guastadisegni et al., 1992; Aronson, Post & Guastadisegni, 1993).

There are many articles dealing with the segregation-integration issue with respect to the mixing of mentally lucid and confused patients in residential settings. The experience at Maimonides Hospital in Montreal, described by Novick (1988), summarizes the views of many writers. Novick points out that there are three categories of confused persons: 1) those who are confused with no behaviour problems; 2) those who are confused and have behaviour problems; and 3) those totally out of touch with reality. While those in category 1 can be successfully combined with lucid residents, the experience at Maimonides is that the latter two groups cannot. Further, Novick reports that:

> ... on the third floor, confused residents who do not have behaviour problems are affected negatively by those with problems. The former react to the dysfunctional behaviours aggressively either by shouting in anger or by physical attack, or by complaining about these behaviours. This situation tends to lead to the advisability of segregating these two groups from each other as well (p.19).

Levenson (1987) reminds us that rather than "being lumped with the demented," depressed patients must be offered adequate treatment.

III CONSULTATION PROCESS

A. Research Design/Methods

Two data gathering techniques were used to compile the description of psychogeriatric client groups: key informant interviews with health care professionals; and focus group discussions with family caregivers and frontline facility staff. No attempt was made to select a representative sample of health care professionals involved in the care and management of psychogeriatric clients. However, a systematic approach was used to develop a list of key informants for the personal interviews.

Respondents were chosen for the key informants' survey using the following guidelines to construct the sample: equal representation of health care professionals drawn from community and facility settings; broad cross-section of clinicians, administrators, and service coordinators with experience in private practice, specialized service areas and the range of relevant care facilities and community-based services; and diverse geographic representation from the Greater Vancouver Regional District (Lower Mainland), the Victoria Capital Region District and regional health council areas in Northern BC. The limitations imposed by the selected survey sample constrain the ability to make generalizations about disease and behavioural prevalence from the survey results to the BC population. However, survey findings are compared with the compiled epidemiologic information and the medical/scientific literature to strengthen the identification of behavioural characteristics and subgroups for the purposes of this study. The duration of the project was approximately five months from the finalization of the research contract. The key informant interviews began the end of March, 1995 and the focus group sessions ended the first week in May, 1995. Prospective survey participants were contacted by the researchers to enlist their participation during the interview period. It was necessary to replace several of the health care professionals on the consultation list to facilitate scheduling and to ensure that a balance of perspectives and a range of settings were included.

The list of consultation sources was developed collaboratively with Continuing Care Division representatives. In addition, informal discussions were held with selected field contacts and consultants, on the advice of the Ministry Project Coordinator, to validate the key informants' list, to suggest other potential survey participants and to determine if an appropriate model exists to guide the provision of care and services for psychogeriatric clients in BC. An existing model of psychogeriatric care and services was not identified in the process.

B. The Sample

Key Informant Survey Participants

There were 50 health care professionals interviewed (see Appendix D for the finalized list of participants and Appendix E for the Ministry's Letter of Introduction that was circulated to all survey respondents). Service sector representation was almost equally split between facility-based (n=26) and community-based participants (n=24). The sample included 27 frontline/direct care staff (primarily staff nurses, long term care case managers, social workers, physicians, adult day program staff, mental health/outreach workers and rehabilitation therapists), and 23 administrators/coordinators representing a range of community and facility-based settings. The original intent was to compare the perspectives and experiences of frontline/direct care staff with those of the administrator/coordinator group. However, a comparison between community and facility-based participants proved more insightful with respect to the behavioural disturbance classification and the corresponding description of client subgroups. In this way, more could be learned about the actual caregiver experiences with specific client subgroups, the care and management approaches used, and the related issues and problems encountered in the respective settings.

Focus Group Participants

Two focus groups were held, one involving family caregivers and the other, frontline/direct care nursing staff. The focus groups were designed to extend survey results providing specific insights and in-depth descriptions of direct caregiver experiences at-home and in facility settings, as well as to create specific profiles of the psychogeriatric client subgroups. In addition, focus groups were intended to further identify and categorize those behaviours most difficult to manage and to describe the caregiver strategies used and needed resources.

The recruiting procedure and the composition of the focus groups were as follows:

1) Family Caregivers - Following the Key Informant Interview with the Regional Representative from the Caregivers' Association of BC, the facilitator for the BC Caregiver' Support Group in Port Coquitlam was approached to request a session with support group members. All 14 group members were invited to participate in the focus group session held at the Dogwood Pavilion, Port Coquitlam, on April 21, 1995. Eight members, including the facilitator, attended the session. All session participants were female and their ages ranged from 40 to 71 years, with the majority of caregivers (six) in the 55-64 year age group. Participants were primarily caring for/had very recently cared for their husbands in their own homes (one had recently admitted her husband to an intermediate care facility), and two had cared for their mothers at home. The age range of care recipients was 72 to 95 years and the types of impairments/conditions of care recipients included: dementia/transient ischemic attacks; dementia/amyotrophic lateral sclerosis; confusion/heart disease/impaired vision; confusion/colon cancer; Alzheimer's disease; Parkinson's disease/leukemia; and Parkinson's disease/multiple strokes.

2) Frontline/Direct Care Nursing Staff - Following the Key Informant Interview with a nurse clinician in the Geriatric Division of Riverview Hospital, the Hospital's Coordinator of Planning and subsequently the Downsizing Project Planner were contacted to constitute a sample of Transitional Assistance Program (TAP) nurses. As part of TAP, these nurses had all accompanied patients into their "downsized" community locations for up to five days to assist with placement and care planning. One of the sites receiving Riverview's "downsized" patients, Hawthorne Care Centre in Port Coquitlam, was also contacted and a senior nurse manager agreed to participate with one of the Centre's staff nurses to contribute insights from a receiving institution's perspective. These five staff attended a focus group session held at Hawthorne Care Centre on May 5, 1995. All session participants were female and their age range was mainly in the 45-54 year category (one each were in the 35-44 and the less than 35 year age categories). Participants had worked directly with psychogeriatric patients/residents for, on average, 10 years (3 to 23 year range). Current work assignments included: RPN on psychotic affective disorders developmental treatment program; RPN on admission, treatment and discharge ward for psychogeriatric patients; RPN on behavioural assessment rehabilitation program (geriatric female aggressive ward); senior nurse manager (RN/BScN/Masters Degree in Counseling Psychology) for intermediate care facility/development of extended care and special care units; and LPN in intermediate care.

C. Data Collection and Analysis

Key Informant Interview

Three experienced interviewers conducted the key informant interviews (L. MacFadgen, J. Killam and a Research Assistant from the School of Nursing, University of Victoria). There were 50, 1 1/4 hour personal interviews (including nine telephone interviews) with health care professionals. All interviews were completed during the period March 16 to April 18, 1995. The first part of the structured interview dealt with respondent characteristics (Part 1), the second section (Part 2) described agency characteristics, and the third and final section (Part 3) collected information about client characteristics and behaviours, using the prepared *Behavioural Disturbance Classification Scheme* in relation to the total client population (See Appendix F for a copy of the survey instrument).

The same individual (L. MacFadgen) served as the session leader for both of the focus group discussions. Each session was approximately 1 1/2 hours long. The focus group protocol was developed, taking into account the results and the major themes arising from the key informant interviews. An overview of the project and personal introductions by all participants opened the sessions. Five open-ended questions were used to lead the focus group discussions. For the BC Caregivers' Support Group session, the major areas of inquiry included:

1. the most stressful aspects of caring for their relatives at-home or in care facilities and corresponding coping strategies;
2. the most difficult behaviours encountered and their effects on caregiver stress levels;
3. the importance of trained facility and home support staff in helping to address the special needs of psychogeriatric clients and their families;
4. the types of resources (e.g. flexible caregiver respite and support services) needed to support families caring for an affected family member at-home for as long as possible;
5. any advice for other families caring for individuals exhibiting difficult behaviours to help them meet their ongoing care and support needs.

For the frontline/direct care nursing staff session, open-ended questions dealt with:

1. the frequency of behaviours placing the most stress on direct care staff and their effects on caregiver stress levels;
2. the types of environmental modifications (e.g. special care units, locked/quiet areas) that would improve care to psychogeriatric patients/residents and why they are important;
3. the specialized resources needed to meet the ongoing care and support needs of specific patient/resident groups (e.g. those with clinical depression, suicidal impulses, psychoses, intractable yelling/screaming, and the very physically aggressive);
4. the importance of having more and better trained facility and home support staff to address the special needs of psychogeriatric clients and their families;
5. the types of resources or program enhancements that would lead to improvements in the care and management of psychogeriatric patients/residents;
6. any advice for designing programs and allocating resources for the psychogeriatric population.

Descriptive data from the key informant interviews were collected on pre-coded questionnaires, with several open-ended items requiring post-coding. Data were run on an SPSS Program (Release 4.0, SPSS Inc.) to compute response frequencies and percentages. A 2x2 cross-tab analysis was performed comparing the community and facility-based respondents for behavioural disturbance descriptions (Part 3). Due to the small sample size and the descriptive nature of the study, the data were not subjected to further statistical analysis. The focus group sessions were audio-taped and a content summary of the major themes and issues was prepared.

IV RESEARCH FINDINGS

Key Informant Survey

The researchers were impressed with the participants' level of knowledge about the care and management strategies and resources required to meet the special needs of psychogeriatric clients and their families. Survey participants repeatedly expressed how important this project is, given the downsizing of Riverview Hospital and the "Closer to Home" policy directions. They were committed to finding better placement and care solutions and appreciated having the opportunity to contribute information that would assist with program design and resource allocation for the psychogeriatric population.

Survey findings are presented in the following order:

- Characteristics of survey respondents;
- Agency characteristics;
- Description of client characteristics /behavioural disturbances and service response;
- Selected client behavioural characteristics;
- Assessment of facility and community-based resources/needs;
- Description of behavioural disturbance categories/groupings;
- Behavioural disturbance frequency ratings (comparing community and facility-based respondents);
- Behavioural disturbance difficulty ratings (comparing community and facility-based respondents);
- Behaviour management difficulty ratings (comparing community and facility-based respondents); and
- Specialized programs/approaches and suggested improvements (comparing community and facility-based respondents).

A descriptive summary of the focus group discussions will be presented giving particular attention to the following themes:

- Appropriate client mix (frontline/direct care nursing staff only);
- Availability of a range of respite/support resources to maintain afflicted individuals in the least restrictive environment (family caregivers only);
- Increased access to specialized psychogeriatric resources/program enhancements;
- Increased staff ratios and educational preparation; and
- Improved service coordination/liaison and communication.

A. Characteristics of Survey Respondents

Table 10 shows the socio-demographic characteristics of the survey participants. The most commonly reported professional background and educational attainment for participants were registered nurse/psychiatric nurse (46%) and BScN/nursing diploma (32%). While the majority of health care professionals interviewed had been working with their current organization for relatively short durations (<1-10 years), they had worked with psychogeriatric clients and their families for six years or more. Of the total work-related experience reported, 70% of respondents indicated that they had direct client contact *always* or *most of the time*. The largest proportion of participants' work-related experience was in long term care facility/hospital settings and the main corresponding levels of care were *all levels* (36%) followed by *intermediate care* (32%).

Table 10: Respondents' Socio-Demographic Characteristics
Psychogeriatric Client ID Project - Key Informants' Survey

Respondent Characteristics	Number (n)	Percentage (%)
Service Sector[1]		
Community-based	24	48
Facility-based	26	52
Professional Status/Position[2]		
Administrator/Coordinator	23	46
Frontline/Direct Care Worker	27	54
Work Tenure with Employer/Organization		
< 1-10 years	32	64
11-20 years	14	28
20+ years	4	8
Work Tenure with Psychogeriatric Client/Caregiver[3]		
< 3 years	3	6
3-5 years	5	10
6-10 years	11	22
> 10 years	31	62
Majority of Work-Related Experience[4]		
Long Term Care Facility/Hospital	19	38
Specialized Facility/Hospital	9	18
Mental Health Outreach Service/Centre/Clinic	8	16
Health Unit/Continuing Care	9	18
Other Settings	5	10

[1]All percentages are calculated based on total respondents (n=50), unless indicated by missing values.

[2]The administrative category includes: clinical service director/assistant director; education/support service coordinator/consultant; executive director/program coordinator; and medical/division director. The frontline/direct care worker category includes: geriatrician; geriatric psychiatrist; long term care case manager/liaison nurse/CHN; nurse clinician/CNS; staff nurse/RN; clinical pharmacist; recreation therapist; social worker; and outreach/community mental health worker. The most commonly reported professional background and educational attainment were registered nurse/registered psychiatric nurse (n=23, 46%) and BScN/nursing diploma (n=16, 32%) respectively.

[3]With respect to this total work-related experience, 70% of respondents (n=35) reported having direct client contact "always or most of the time."

[4]With respect to the settings reported for the majority of work-related experience, the main corresponding levels of care were "all levels" (n=18, 36%) followed by "intermediate care" (n=16, 32%).

B. Agency Characteristics

The profile of services provided in participants' organizations is included in Table 11. The main types of services provided (from intermediate/extended care facility through to home support services) reflects the range of organizations and perspectives sought in constituting the study group. Only 32% of respondents reported providing specialized geriatric/psychiatry services (primarily assessment/diagnosis and treatment and/or outpatient consultation). With respect to reported facility census information, there was an equal split between facilities caring for 100 or less, and 100-300 patients/residents (38% respectively). It is interesting to note that 25% of facility respondents reported having a census of 300 or greater patients/residents. The majority of facility respondents (59%) indicated that the average number of new admissions per year was greater than 30 patients/residents. By comparison, the majority of community-based respondents reported having monthly caseloads of 100 or less clients (61%) and receiving an average of less than 100 new clients per year (57%). With respect to client gender profiles, respondents reported caring for a primarily female population (49% of respondents reporting female census information estimated that greater than 67% of their total client population was female, compared with 64% of respondents who provided male census information estimating that between 0-33% of their population was male). Respondents reported that they were caring for a primarily middle-old (75-84 years) population (81% estimated that 25% or greater of their total client population fell in this age group). An intermediate level of care was reported most commonly for both facility and community-based respondents (48% and 83% respectively). The high percentage of intermediate care clients in community-based settings is indicative of the increasing client acuity levels, and the trend towards community-based service delivery enabling older adults to be maintained at home for longer periods of time.

Table 11: Summarized Agency Characteristics
Psychogeriatric Client ID Project - Key Informants' Survey

Agency Characteristics	Number (n)	Percentage (%)
Main Services Provided[1]		
Intermediate/Extended Care Facility	16	32
Specialized Geriatric/Psychiatric Services	16	32
Assessment/Case Management/Service Liaison	8	16
Adult Day Care/Day Program	8	16
Counseling/Caregiver Support/Advocacy	7	14
Caregiver/Provider Education	5	10
Home Support Services	5	10
Other	12	24
Facility Census/Total Numbers (n=24)[2]		
< 100 residents	9	38
100-300 residents	9	38
> 300 residents	6	25
Facility Levels of Care (n=25)		
Intermediate	12	48
Extended	11	44
Other Levels/Combinations	2	8
Average Facility Admissions/ Year (n=22)		
≤ 30	9	41
> 30	13	59

[1]Multiple responses are reported.

[2]If total n does not equal 24 for community-based respondents and 26 for facility-based respondents, the remainder represent missing values .

Table 11 Cont'd: Summarized Agency Characteristics

Agency Characteristics	Number (n)	Percentage (%)
Community Monthly Caseload (n=23)[3]		
≤ 100	14	61
100-300	3	13
> 300	6	26
Average n of Clients Accepted/Year (n=23)		
≤ 100	13	57
> 100	10	43
Community Levels of Care (n=23)		
Personal	1	4
Intermediate	19	83
Other Levels/Combinations	3	13
Resident/Client Gender Profile (n=47)[4]		
Males: 0-33%	30	64
34-67%	16	34
> 67%	1	2
Females: 0-33%	1	2
34-67%	23	49
> 67%	23	49

[3]If total n does not equal 24 for community-based respondents and 26 for facility-based respondents, the remainder represent missing values.

[4]If n does not equal 50 for each gender profile, the remainder represent missing values.

Table 11 Cont'd: Summarized Agency Characteristics

Agency Characteristics		Number (n)	Percentage (%)
Resident/Client Age Profile (n=48)[5]			
Young (< 65 years):	< 25%	44	92
	25-50%	1	6
	> 50%	3	6
Young-Old (65-74 years):	< 25%	34	71
	25-50%	14	29
	> 50%	0	0
Middle-Old (75-84 years):	< 25%	9	19
	25-50%	24	50
	> 50%	15	31
Old-Old (85+ Years):	< 25%	27	56
	25-50%	15	31
	> 50%	6	13

[5]If n does not equal 50 for each age group, the remainder represent missing values.

C. Description of Client Characteristics/Behavioural Disturbances and Service Response

As shown in Table 12, a high percentage of survey respondents (40%) estimated that they had greater than 50% of total clients exhibiting significant behavioural disturbances that frontline caregivers find challenging. Overall, **aggressive/combative behaviour** and **wandering/elopement** (74% and 45% respectively) were the most frequently reported types of presenting behaviours followed by equal percentages (30%) for ADL difficulties, anxiety/agitation/repetitive behaviour, and confusion/impaired judgment/incompetence.

Most participants (80%) reported that they were not able to provide care/supportive services for all types of psychogeriatric clients. In fact, 41% indicated that they were not able to address **very physically aggressive behaviour** that was not responsive to available treatment. Equal percentages of respondents (31%) reported that they were not able to address the following:

- Clients needing specialized treatment/psychiatric care (mainly those with clinical depression and bipolar disorders);
- Clients with other mental health conditions (e.g. schizophrenia, anxiety/personality disorders); and
- Inappropriate levels of care/conditions (including those clients not accepted/eligible for service and those receiving "inappropriate care").

It is important to note that responses related to inappropriate levels of care/conditions include a mix of those behavioural disturbances that are not accepted on a service and those that are cared for, but considered to be beyond the scope of current service capabilities. Clients who could no longer be cared for within existing services were typically transferred or referred to specialized psychiatric facilities; 44% of respondents cited such services (e.g. Riverview Hospital, St. Vincent's' Hospital, STAT Centres, and hospital-based behavioural assessment units/consultation).

Almost all participants (92%) indicated that they offer specialized services for the psychogeriatric client group, with 41% reporting that they provide specialized geriatric/psychiatry services (as previously described). The most commonly cited special accommodation arrangements or environmental modifications provided included: locked units/wanderguard system (68% of respondents); and separate areas, adequate space/reduced stimuli (45% of respondents). Of those respondents recommending accommodation arrangements and/or environmental modifications that would improve care and service for psychogeriatric clients, 81% cited a **less institutionalized environment/special design features** (e.g. private rooms, separate dining and lounge areas, small group areas, gardens, special lighting). It is interesting to note that respondents also mentioned permanent staff assignments and a balanced patient/resident mix as modifications that would lead to improvements. With respect to staff inservice training programs provided, the majority of respondents indicated that the following topics were offered to a primarily direct care staff audience: management of difficult behaviours and related behaviour management strategies (67% of respondents); and overviews of relevant diseases/underlying conditions (54% of respondents).

Table 12: Description of Behavioural Disturbances & Service Response
Psychogeriatric Client ID Project - Key Informants' Survey

Descriptive Profile	Number (n)	Percentage (%)
% Clients with Significant Behavioural Disturbances[1]		
< 25%	14	28
25-50%	16	32
51-75%	6	12
> 75%	14	28
Types of Presenting Behaviours[2]		
Aggressive/Combative Behaviour	37	74
Wandering/Elopement	24	48
ADL Difficulties	15	30
Agitation/Anxiety/Repetitive Behaviour	15	30
Confusion/Impaired Judgment/Incompetence	15	30
Behavioural Disturbances Not Addressed (n=42)[3]		
Very Physically Aggressive/Non-Responsive to Treatment	17	41
Patients Needing Specialized Treatment/Psychiatric Care	13	31
Other Mental Health Conditions	13	31
Inappropriate Levels of Care/Conditions	13	31
Transfer/Referral Sources Used (n=39)[4]		
Specialized Psychiatric Facilities	17	44
Appropriate Resources/ General	16	41
Hospital/Emergency Services/Psychiatric Units	12	31
No Available Transfer Resources/Carried on Service	11	28

[1] All percentages are calculated based on total respondents (n=50), unless otherwise indicated.

[2] Multiple responses are reported. ADL difficulties include: incontinence; falls; dietary changes; and communication difficulties.

[3] A total of 40 respondents (80%) reported that they are not able to provide care/supportive services for all types of psychogeriatric clients. Patients requiring specialized treatment/psychiatric care refers mainly to those with clinical depression and bipolar disorders. Other mental health conditions reported include: schizophrenia; anxiety and personality disorders. Inappropriate levels of care/conditions captures those beyond the scope of current service capabilities (those not accepted/eligible for service and those receiving "inappropriate care").

Table 12 Cont'd: Description of Behavioural Disturbances & Service Response

Descriptive Profile	Number (n)	Percentage (%)
Specialized Psychogeriatric Services Provided (n=46)[5]		
Specialized Geriatric/Psychiatry Services	19	41
Special Therapeutic Services/Teams	15	33
Special Care/Dementia Units	11	24
Accommodation /Environmental Modifications (n=31)[6]		
Locked Unit/Wanderguard System	21	68
Separate Areas/Adequate Space/Reduced Stimuli	14	45
Special Equipment/Design Features	13	42
Identified Environmental Improvements (n=26)[7]		
Less Institutionalized Environment/Special Design Features	21	81
Secured Environment (Dutch Doors/Alarms)	5	19
Inservice Topics Offered (n=48)[8]		
Management of Difficult Behaviours/Approaches	32	67
Overview of Diseases/Underlying Conditions	26	54
General Care Issues/Medication	18	38

[4]The most commonly cited specialized psychiatric facilities were: Riverview Hospital; St. Vincent's Hospital; and hospital-based behavioural assessment units. Appropriate resources/general includes: intermediate/extended care facilities; clinics; continuing care; family physicians; and detox/substance abuse resources.

[5]A total of 46 respondents (92%) reported offering specialized services for the psychogeriatric client group. The main groups served by these services were psychogeriatric clients and seniors with dementia/mental health disorders. Specialized geriatric/psychiatry services include: assessment, diagnostic, and treatment services through tertiary inpatient care and outpatient consultation.

[6]Multiple responses are reported.

[7]Multiple responses are reported. Items identified under less institutionalized environment/special design features include: private rooms; separate dining and lounge areas; small group areas; garden area; special lighting; permanent staff assignments; and balanced resident mix.

[8]Multiple responses are reported. With respect to the inservice topics reported, 52% of training was geared to a direct care staff audience.

D. Most Problematic Client Behaviours

In response to an open-ended question, respondents identified the three most problematic psychogeriatric client behaviours that pose the most significant care and management challenges for frontline caregivers. As shown in Table 13, the two most frequently cited problematic behaviours were **aggressive/combative behaviour** and **wandering/elopement** (80% and 41% of respondents respectively). Consistent with previous studies (see Table 4), almost half (46%) of all identified problematic client behaviours were associated with no specific times/situations, and 16% and 12% respectively, were associated with personal care and evening hours/sundowning. The relationship between the most problematic psychogeriatric client behaviours and specific diagnoses/disorders shows that of all identified behaviours, 51% were reported to be related to **dementia/Alzheimer's disease**. Given the prevalence rates for dementia/AD and the over-representation of afflicted patients/residents in care facilities, this is not a surprising finding. Almost all participants (88% of persons responding) reported that they encounter problematic behaviours that are drug-induced or exacerbated by medications. The most common drug-related behaviour problems cited included drowsiness/listlessness/ withdrawal, hyperactivity/agitation/anxiety, and aggression/resistive behaviour (50%, 43% and 41% of respondents respectively).

E. Assessment of Facility and Community-Based Resources/Needs

Respondents were asked to indicate on a four-point scale (1 = completely and 4 = not at all) the extent that current, direct care staffing levels throughout their organization meet the needs of psychogeriatric clients (Table 14). Almost three quarters of respondents (74%) gave the assessment *to some extent* or *not at all*. The main reason cited as to why staffing levels do not meet needs was the need for **more and better trained staff**; 84% of persons responding reported that there was a lack of trained staff available and/or that they simply require more staff. Respondents referred to there being a focus on physical care only, given current staffing levels and increased client acuity.

With respect to the reported facility-based resources used frequently by organizations in the care of psychogeriatric clients and their families, the majority of respondents (59%) cited use of specialized geriatric/psychiatry services (as previously described) and 54% indicated use of hospital/emergency services and psychiatric units. Of respondents who commented on the extent that facility-based resources meet needs, 71% gave the assessment *to some extent* or *not at all* and the main reasons given by 67% of respondents were a general lack of staff/resources and a lack of trained staff.

Table 13: Most Problematic Client Behaviours
Psychogeriatric Client ID Project - Key Informants' Survey

Client Behavioural Characteristics	Number (n)	Percentage (%)
Most Problematic Behaviours Identified (n=49)[1]		
Aggressive/Combative Behaviour	39	80
Wandering/Elopement	20	41
Non-Compliant/Resistive to Treatment	14	29
Agitation/Anxiety/Repetitive Behaviour	13	27
Specific Times/Situations for Behaviours (n=44)[2]		
During Personal Care Activity	20	16
Evening Hours/Sundowning	15	12
Diagnoses Associated with Behaviours (n=42)[3]		
Dementia/Alzheimer's Disease	58	51
Combination of Disorders/Conditions	29	25
Drug-Related Behaviour Problems (n=44)[4]		
Drowsiness/Listlessness/Withdrawal	22	50
Hyperactivity/Agitation/Anxiety	19	43
Aggression/Resistive Behaviour	18	41

[1]All percentages are calculated based on total respondents (n=50), unless otherwise indicated by missing values. When selecting the three most problematic psychogeriatric client behaviours, respondents were asked to focus on those that pose the most significant care and management challenges for frontline caregivers. Frontline caregivers were defined as persons providing direct care on an ongoing basis (for community respondents, reference was made to: program workers, home support workers, homemakers, and unpaid family caregivers; for facility respondents, reference was made to: personal care workers, LPN's, care aides, and staff nurses).

[2]Multiple responses are reported. Almost half (46%) of all identified problematic client behaviours were associated with no specific times/situations, and 16% and 12%, respectively, were associated with personal care and evening hours/sundowning.

[3]Multiple responses are reported. Of persons responding (n=45), 87% identified a relationship between the three most problematic client behaviours and specific diagnoses/disorders. Of all the identified problematic client behaviours, 51% were reported to be related to dementia/Alzheimer's Disease.

[4]Multiple responses are reported. Of total persons responding, 88% (n=44) reported that they encounter problematic behaviours that are either drug-induced or exacerbated by medications.

Table 14: Assessment of Facility and Community-Based Resources/Needs
Psychogeriatric Client ID Project - Key Informants' Survey

Resource Description	Number (n)	Percentage (%)
Extent that Staffing Levels Meet Needs[1]		
Completely	1	2
To a Great Extent	12	24
To Some Extent	34	68
Not At all	3	6
Reasons Staffing Levels Do Not Meet Needs (n=38)[2]		
Require More Staff/Lack of Trained Staff Given Acuity	32	84
Need More Community Assessment/Consultation/Support	5	13
Facility-Based Resources Used Frequently (n=46)[3]		
Specialized Geriatric/Psychiatry Services	27	59
Hospital/Emergency Services/Psychiatric Units	25	54
Long Term Care Facility/Hospital	21	46
Extent that Facility Resources Meet Needs (n=45)		
Completely	1	2
To a Great Extent	12	27
To Some Extent	31	69
Not At all	1	2
Reasons Facility Resources Don't Meet Needs (n=33)[4]		
General Lack of Staff/Resources	12	36
General Lack of Trained Staff	10	30
Inability to Provide Amount/Type of Treatment/Service	9	27

[1]All percentages are calculated based on total respondents (n=50), unless otherwise indicated.

[2]Multiple responses are reported. Respondents stated that there was a focus on physical care, not client-centred care due to staffing levels and increased resident/client acuity. Current caseloads were reported to be too heavy in long term care and mental health.

[3]Multiple responses are reported. The most commonly cited specialized geriatric/psychiatry services were: Riverview Hospital; St. Vincent's Hospital; STAT Centre; psychiatric assessment unit/consultation.

[4]Multiple responses are reported. The most commonly identified types of treatment/service that could not be provided were financial/competency assessment services and individual counseling.

Table 14 Cont'd: Assessment of Facility and Community-Based Resources/Needs

Resource Description	Number (n)	Percentage (%)
Community-Based Resources Used Frequently (n=44)[5]		
Adult Day Care/Day Program/Centre	24	55
Mental Health Team/Services/Centre	23	52
Home Support Services	15	34
Continuing Care/Case Managers	11	25
Extent that Community Resources Meet Needs (n=43)		
Completely	0	0
To a Great Extent	17	40
To Some Extent	25	58
Not At all	1	2
Reasons Community Resources Don't Meet Needs (n=33)[6]		
Inability to Provide Amount/Type of Treatment/Service	12	46
Lack of Specialized Resources for Behaviour Problems	4	15
More Direct Care/Mental Health Staff	4	15
Additional Resources to Meet Special Needs (n=48)[7]		
More Specialized Geriatric/Psychiatry Services	20	42
Better Trained Direct Care Staff	18	38
More Flexible/Available Respite Services/Adult Day Care	17	35
Most Needed Additional Resource (n=46)[8]		
More Specialized Geriatric/Psychiatry Services	12	26
Better Trained Direct Care Staff	7	15

[5]Multiple responses are reported.

[6]Multiple responses are reported. The most commonly identified types of service that could not be provided were financial/competency assessment services and individual counseling.

[7]Multiple responses are reported. The most commonly identified specialized geriatric/psychiatry services were assessment, treatment and support resources (including more available beds for intractable behaviours). With respect to direct care staff training needs, respondents targeted respite workers, case managers, home support staff, mental health staff, physicians and facility/nursing staff.

[8]Multiple responses are reported (See note #7 for identified services and targeted staff groups for training).

The community-based resources used frequently by organizations caring for the psychogeriatric population were: adult day care/day programs and seniors' centres; and mental health teams/services/centres (55% and 52% of respondents respectively). For those respondents commenting on the extent to which community-based resources meet the needs of psychogeriatric clients and their families, 60% indicated *to some extent* or *not at all* and the main reason given by 46% of respondents was their inability to provide the appropriate amount and/or type of treatment or service.

In general, respondents stated that the following types of additional resources are required to address the special needs of psychogeriatric clients and their families:

1) More **specialized geriatric/psychiatry services** (including more assessment, treatment and support resources and more available beds for intractable behaviours);
2) Better **trained direct care staff** (including respite workers, case managers, home support staff, mental health staff, physicians and facility/nursing staff); and
3) More **flexible/available respite and/or adult day care**.

The first two resources were ranked as the most needed (26% and 15% respectively).

F. Description of Behavioural Disturbance Categories/Groupings

Participants were asked to apply the *Behavioural Disturbance Classification Scheme* to their total client population (refer to Appendix A for the eight behavioural categories). For each category, respondents estimated the percentage of residents/clients who exhibit any combination of the specific behaviours listed (Table 15). It is important to note that the percentages cited are crude estimates only and cannot be used to determine behaviour prevalence rates. However, the clustering of responses in the collapsed percentage groupings give some indication of the extent of behavioural disturbances for each category. For each behavioural category, except Problematic ADL's/Coping Strategies, the most commonly used frequency categories were: *less than 10%* or *10-25%.*

Estimates in the *less than 10%* frequency category were most commonly given for the following behavioural categories: **Agitated/Aggressive-Physical**; **Socially Unacceptable**; and **Ideational**. For each of the following four categories, the largest number of respondents estimated behavioural disturbances in the *10-25%* range: Agitated/Aggressive-Verbal; Agitated/Non-Aggressive-Physical; Emotional/Affective; and Agitated/Non-Aggressive-Verbal. Respondents most commonly estimated that the following behaviours were exhibited by 26-50% of clients: **Emotional/Affective**, the **Agitated/Non-Aggressive-Verbal** and the **Agitated/Non-Aggressive-Physical**. In marked contrast, the majority of respondents (58%) reported that *over 75%* of their total client population exhibited behaviours contained in the **Problematic ADL's/Coping Strategies** category. This is indicative of the high client acuity levels in the facility and community settings generally, and the behaviours typically found in intermediate and extended care facilities (e.g. incontinence of bladder/bowel, inability to feed/groom self, immobility, etc.).

Table 15: Description of Behavioural Disturbance Categories/Groupings
Psychogeriatric Client ID Project - Key Informants' Survey

Behavioural Disturbance Category	Number (n)	Percentage (%)
1. Agitated/Aggressive-Physical (n=48)[1]		
Total Clients: < 10 %	23	**48**
10-25%	18	38
26-50%	6	12
51-75%	0	0
> 75%	1	2
2. Agitated/Aggressive-Verbal		
Total Clients: < 10 %	16	33
10-25%	25	**52**
26-50%	5	10
51-75%	2	4
> 75%	0	0
3. Agitated/Non-Aggressive-Physical		
Total Clients: < 10 %	9	19
10-25%	23	**48**
26-50%	10	21
51-75%	5	10
> 75%	1	2
4. Agitated/Non-Aggressive-Verbal		
Total Clients: < 10 %	8	17
10-25%	18	**38**
26-50%	14	29
51-75%	5	10
> 75%	2	4

[1]All percentages are calculated based on total persons responding (n=48). When calculating the percentages of total clients exhibiting behavioural disturbances, respondents applied the complete behavioural categories against their total population (using the eight major behavioural disturbance groupings, as opposed to discrete behaviours). No attempt was made to validate respondents' reported behavioural disturbance percentages, therefore, they are crude estimates only. Because there was considerable variability in the percentages reported, responses were ranked for each respondent to indicate relative proportions of behavioural disturbances. Aggregate data for the behavioural categories ranking *first to third* showed the highest responses for the following behavioural disturbance categories: Problematic ADL's/Coping Strategies; Emotional/Affective; and Agitated/Non-Aggressive-Verbal.

Table 15 Cont'd: Description of Behavioural Disturbance Categories/Groupings

Behavioural Disturbance Category	Number (n)	Percentage (%)
5. Ideational		
Total Clients: < 10 %	19	**40**
10-25%	15	31
26-50%	12	25
51-75%	2	4
> 75%	0	0
6. Emotional/Affective		
Total Clients: < 10 %	2	4
10-25%	21	**44**
26-50%	18	38
51-75%	5	10
> 75%	2	4
7. Socially Unacceptable		
Total Clients: < 10 %	23	**48**
10-25%	19	40
26-50%	4	8
51-75%	0	0
> 75%	2	4
8. Problematic ADL's/Coping Strategies		
Total Clients: < 10 %	1	2
10-25%	2	4
26-50%	11	23
51-75%	6	13
> 75%	28	**58**

In addition to the reported percentages, responses were rank ordered for each respondent to show relative relationships among the eight behavioural categories. Aggregate data for the behavioural categories ranking *first* to *third* showed the highest responses for the following behavioural disturbance categories: **Problematic ADL's/Coping Strategies**; **Emotional/Affective**; and **Agitated/Non-Aggressive-Verbal**. This lends further support to the conclusion that these three behavioural categories have the highest percentages of clients exhibiting behavioural disturbances.

G. Behavioural Disturbance Frequency Ratings

For the three remaining questions using the *Behavioural Disturbance Classification Scheme*, data are reported as a comparison of community and facility-based respondents. Respondents were asked to determine which behavioural groupings pose the most significant problems for frontline caregivers. Frontline caregivers were defined as persons providing direct care on an ongoing basis including program workers, home support workers and homemakers for community-based respondents, and personal care workers, LPN's, care aides, and/or staff nurses for facility-based respondents.

Table 16 depicts the frequency ratings for respondents who were asked how often frontline caregivers have to deal with the behavioural disturbances for each behavioural category. For any categories rated *frequently*, they were asked if *many* or only a *few* clients exhibit these behaviours, on average. This table gives important information on the scope of behavioural problems encountered. Consistent with previous findings, high frequencies were reported for the **Agitated/Non-Aggressive-Physical, Agitated/Non-Aggressive-Verbal** and **Emotional/Affective** categories. Almost three quarters of respondents (73.5%) stated that frontline caregivers had to deal with these behavioural disturbances on a frequent basis and for all three categories, many clients were reported to exhibit these behaviours. While approximately half of the respondents reported that frontline caregivers were frequently dealing with Agitated/Aggressive - Verbal behaviours and Agitated/Aggressive-Physical behaviours (51% and 48.9% respectively), their ratings indicated that only a few clients were affected. As in previous assessments, **Problematic ADL's/Coping Strategies** were common occurrences; almost all participants (97.9%) rated these behaviours as occurring frequently and they were unanimous that many clients were affected. For the remaining behavioural categories (Ideational and Socially Unacceptable), the modal response was that frontline caregivers *occasionally* deal with the behaviours with only a few clients being affected.

With respect to the community-facility comparisons, no surprising patterns emerged. Facility respondents gave consistently more *frequently* ratings for **all** behavioural categories than their community counterparts, with one exception; slightly higher proportions of community respondents indicated that frontline caregivers were dealing with Ideational behaviours with only a few clients being affected. For behaviours dealt with *frequently*, the largest percentage differences (24% greater for facility respondents) were reported for Agitated/Non-Aggressive-Physical and Agitated/Non-Aggressive-Verbal categories.

Table 16: Behavioural Disturbance Frequency Ratings: A Comparison of Community and Facility-Based Respondents
Psychogeriatric Client ID Project - Key Informants' Survey

Frequency Rating of Behavioural Disturbances Encountered by Frontline Staff	Community Based N=24 n	(%)	Facility-Based N=26 n	(%)	Totals N=50 n	(%)
1. Agitated/Aggressive-Physical (n=49)[1]						
Dealt with: Frequently	10	(43.5)	14	(53.8)	24	(48.9)
Occasionally	10	(43.5)	11	(42.3)	21	(42.8)
Seldom	2	(8.7)	1	(3.8)	3	(6.1)
Never	1	(4.3)	0	(0.0)	1	(2.0)
# Clients Affected: Many	1	(10.0)	5	(35.7)	6	(25.0)
Few	9	(90.0)	9	(64.2)	18	(75.0)
2. Agitated/Aggressive-Verbal						
Dealt with: Frequently	11	(47.8)	14	(53.8)	25	(51.0)
Occasionally	10	(43.5)	11	(42.3)	21	(42.8)
Seldom	1	(4.3)	1	(3.8)	2	(4.0)
Never	1	(4.3)	0	(0.0)	1	(2.0)
# Clients Affected: Many	2	(18.2)	5	(35.7)	7	(28.0)
Few	9	(81.8)	9	(64.3)	18	(72.0)
3. Agitated/Non-Aggressive-Physical						
Dealt with: Frequently	14	(60.9)	22	(84.6)	36	(73.5)
Occasionally	8	(34.8)	3	(11.5)	11	(22.4)
Seldom	1	(4.3)	1	(3.8)	2	(4.0)
Never	0	(0.0)	0	(0.0)	0	(0.0)
# Clients Affected: Many	9	(64.3)	13	(59.1)	22	(61.1)
Few	5	(35.7)	9	(40.9)	14	(38.9)
4. Agitated/Non-Aggressive-Verbal						
Dealt with: Frequently	14	(60.9)	22	(84.6)	36	(73.5)
Occasionally	8	(34.8)	4	(15.4)	12	(24.5)
Seldom	1	(4.3)	0	(0.0)	1	(2.0)
Never	0	(0.0)	0	(0.0)	0	(0.0)
# Clients Affected:[2] Many	7	(53.8)	14	(63.6)	21	(60.0)
Few	6	(46.2)	8	(36.4)	14	(40.0)

[1]Totals do not equal 50, due to missing data in the community-based sample.
[2]When respondents reported that frontline caregivers had to deal with the behavioural disturbance groupings "frequently," they were asked to indicate if it affected "many" or only a "few" clients. Many/few totals do not equal totals for "frequently" rating, due to missing data for the community-based sample.

Table 16 Cont'd: Behavioural Disturbance Frequency Ratings: A Comparison of Community and Facility-Based Respondents

Frequency Rating of Behavioural Disturbances Encountered by Frontline Staff	Community Based N=24 n	(%)	Facility-Based N=26 n	(%)	Totals N=50 n	(%)
5. Ideational (n=48)[1]						
Dealt with: Frequently	9	(40.9)	9	(34.6)	18	(37.5)
Occasionally	11	(50.0)	12	(46.2)	23	(47.9)
Seldom	2	(9.1)	5	(19.2)	7	(14.6)
Never	0	(0.0)	0	(0.0)	0	(0.0)
# Clients Affected: Many	3	(33.3)	4	(44.4)	7	(38.9)
Few	6	(66.7)	5	(55.6)	11	(61.1)
6. Emotional/Affective						
Dealt with: Frequently	16	(69.6)	20	(76.9)	36	(73.5)
Occasionally	6	(26.1)	5	(19.2)	11	(22.4)
Seldom	1	(4.3)	1	(3.8)	2	(4.0)
Never	0	(0.0)	0	(0.0)	0	(0.0)
# Clients Affected:[2] Many	8	(53.3)	16	(80.0)	24	(68.6)
Few	7	(46.7)	4	(20.0)	11	(31.4)
7. Socially Unacceptable						
Dealt with: Frequently	5	(21.7)	10	(38.5)	15	(30.6)
Occasionally	10	(43.5)	14	(53.8)	24	(49.0)
Seldom	8	(34.8)	1	(3.8)	9	(18.3)
Never	0	(0.0)	1	(3.8)	1	(2.0)
# Clients Affected: Many	2	(40.0)	4	(40.0)	6	(40.0)
Few	3	(60.0)	6	(60.0)	9	(60.0)
8. Problematic ADL's/Coping Strategies (n=48)[1]						
Dealt with: Frequently	21	(95.5)	26	(100.0)	47	(97.9)
Occasionally	1	(4.5)	0	(0.0)	1	(2.1)
Seldom	0	(0.0)	0	(0.0)	0	(0.0)
Never	0	(0.0)	0	(0.0)	0	(0.0)
# Clients Affected:[2] Many	20	(100.0)	26	(100.0)	46	(100.0)
Few	0	(0.0)	0	(0.0)	0	(0.0)

H. Behavioural Disturbance Difficulty Ratings

To determine which behavioural groupings are the most difficult for frontline caregivers to deal with on an ongoing basis, respondents were asked to give a difficulty rating for each behavioural category. Table 17 depicts this information along with the reasons why items were rated as *moderately* or *very difficult*. In order of magnitude, the following behavioural categories were rated as being *moderately* and *very difficult* for the greatest majority of respondents:

- Agitated/Aggressive-Physical (96%);
- Agitated/Aggressive-Verbal (78%);
- Socially Unacceptable (71.4%); and
- Agitated/Non-Aggressive-Physical (70%).

It is interesting to note that the most commonly stated reason why frontline caregivers experience such difficulty is their **lack of understanding and education**. In addition, 70.8% of respondents indicated that the main reason caregivers experience difficulty with Agitated/Aggressive-Physical behaviours is because they are at-risk physically and afraid for their own safety. The main reason given for the difficulties with behaviours in the Socially Unacceptable category (60.6% of respondents) was the stigma associated with the behaviours (eg. inappropriate dressing/undressing) and the fact that they are generally unpleasant/distressing. Half of the respondents stated that frontline caregivers find it *moderately* or *very difficult* to deal with the Agitated/Non-Aggressive-Physical behaviours because they are time consuming and require constant supervision; this may be most pronounced for the wandering/pacing aimlessly and elopement behaviours listed in this category. Of the respondents indicating that frontline caregivers find it *moderately* or *very difficult* to deal with Problematic ADL's/Coping Strategies (55.1%), most also stated that it is largely due to the fact that such care is physically and emotionally taxing or stressful (73.1% of respondents).

With respect to the community-facility comparisons, community respondents gave higher *very difficult* ratings for the following behavioural categories: Agitated/Aggressive-Physical; Agitated/Aggressive-Verbal; Ideational; and Emotional/Affective. Respondents reported that one behavioural disturbance category, **Agitated/Aggressive-Physical**, stood out as creating the most difficulty for frontline caregivers (60.9% of community and 65.4% of facility respondents) and the main reason given was that caregivers are at-risk physically and afraid for their own safety. Almost equal proportions of community and facility respondents gave a *very difficult* rating for behaviours found in the **Agitated/Non-Aggressive-Physical** and **Socially Unacceptable** categories. It may be that these behaviours are the most difficult and distressing to not only the frontline caregivers, but also to other patients/residents.

Table 17: Behavioural Disturbance Difficulty Ratings: A Comparison of Community and Facility-Based Respondents
Psychogeriatric Client ID Project - Key Informants' Survey

Difficulty Rating of Behavioural Disturbances Encountered by Frontline Staff		Community Based N=24 n	(%)	Facility-Based N=26 n	(%)	Totals N=50 n	(%)
1. Agitated/Aggressive-Physical							
Experienced as:	Not Difficult	1	(4.2)	0	(0.0)	1	(2.0)
	Somewhat Difficult	0	(0.0)	1	(3.8)	1	(2.0)
	Moderately Difficult	2	(8.3)	7	(26.9)	9	(18.0)
	Very Difficult	21	(87.5)	18	(69.2)	39	(78.0)
Why:[2]	Caregiver Afraid/ At-Risk Physically	17	(73.9)	17	(68.0)	34	(70.8)
	Lack of Understanding/ Education	7	(30.4)	10	(40.0)	17	(35.4)
2. Agitated/Aggressive-Verbal							
Experienced as:	Not Difficult	1	(4.2)	0	(0.0)	1	(2.0)
	Somewhat Difficult	7	(29.2)	3	(11.5)	10	(20.0)
	Moderately Difficult	3	(12.5)	12	(46.2)	15	(30.0)
	Very Difficult	13	(54.2)	11	(42.3)	24	(48.0)
Why:	Lack of Understanding/ Education	6	(37.5)	11	(47.8)	17	(44.7)
	Physically/Emotionally Taxing/Stressful	4	(25.0)	6	(26.1)	10	(26.3)
3. Agitated/Non-Aggressive-Physical							
Experienced as:	Not Difficult	1	(4.2)	0	(0.0)	1	(2.0)
	Somewhat Difficult	6	(25.0)	8	(30.8)	14	(28.0)
	Moderately Difficult	8	(33.3)	9	(34.6)	17	(34.0)
	Very Difficult	9	(37.5)	9	(34.6)	18	(36.0)
Why:	Time Consuming/ Constant Supervision	9	(52.9)	8	(44.4)	17	(50.0)
	Lack of Understanding/ Education	1	(5.9)	5	(27.8)	6	(17.6)
	Distressing to Others	1	(2.9)	5	(14.7)	6	(17.6)
4. Agitated/Non-Aggressive-Verbal (n=48)[1]							
Experienced as:	Not Difficult	1	(4.5)	2	(7.7)	3	(6.3)
	Somewhat Difficult	11	(50.0)	12	(46.2)	23	(47.9)
	Moderately Difficult	8	(36.4)	8	(30.8)	16	(33.3)
	Very Difficult	2	(9.1)	4	(15.4)	6	(12.5)
Why:	Physically/Emotionally Taxing/Stressful	7	(70.0)	7	(58.3)	14	(60.8)
	Lack of Understanding/ Education	3	(30.0)	3	(25.0)	6	(26.0)

Table 17 Cont'd: Behavioural Disturbance Difficulty Ratings: A Comparison of Community and Facility-Based Respondents

Difficulty Rating of Behavioural Disturbances Encountered by Frontline Staff[3]		Community Based N=24 n	(%)	Facility-Based N=26 n	(%)	Totals N=50 n	(%)
5. Ideational (n=49)[1]							
Experienced as:	Not Difficult	3	(13.0)	3	(11.5)	6	(12.2)
	Somewhat Difficult	6	(26.1)	10	(38.5)	16	(32.6)
	Moderately Difficult	7	(30.4)	9	(34.6)	16	(32.7)
	Very Difficult	7	(30.4)	4	(15.4)	11	(22.4)
Why:	No Solution/Difficult to Handle	7	(50.0)	6	(46.2)	13	(48.1)
	Lack of Understanding/ Education	9	(64.3)	2	(15.4)	11	(40.7)
6. Emotional/Affective (n=49)[1]							
Experienced as:	Not Difficult	5	(21.8)	3	(11.5)	8	(16.3)
	Somewhat Difficult	9	(39.1)	13	(50.0)	22	(44.9)
	Moderately Difficult	5	(21.8)	7	(26.9)	12	(24.5)
	Very Difficult	4	(17.4)	3	(11.5)	7	(14.3)
Why:	Physically/Emotionally Taxing/Stressful	4	(44.4)	5	(50.0)	9	(47.4)
	Lack of Understanding/ Education	5	(55.6)	3	(30.0)	8	(42.1)
7. Socially Unacceptable (n=49)[1]							
Experienced as:	Not Difficult	2	(8.7)	1	(3.8)	3	(6.1)
	Somewhat Difficult	5	(21.7)	6	(23.1)	11	(22.4)
	Moderately Difficult	4	(17.4)	7	(26.9)	11	(22.4)
	Very Difficult	12	(52.2)	12	(46.2)	24	(49.0)
Why:	Stigma/Unpleasant/ Distressing	9	(56.3)	11	(57.9)	20	(60.6)
	Lack of Understanding/ Education	6	(37.5)	6	(31.6)	12	(36.4)

Table 17 Cont'd: Behavioural Disturbance Difficulty Ratings: A Comparison of Community and Facility-Based Respondents

Difficulty Rating of Behavioural Disturbances Encountered by Frontline Staff[3]		Community Based N=24 n	(%)	Facility-Based N=26 n	(%)	Totals N=50 n	(%)
8. Problematic ADL's/Coping Strategies (n=49)[1]							
Experienced as:	Not Difficult	3	(13.0)	6	(23.1)	9	(18.4)
	Somewhat Difficult	8	(34.8)	5	(19.2)	13	(26.5)
	Moderately Difficult	5	(21.7)	7	(26.9)	12	(24.5)
	Very Difficult	7	(30.4)	8	(30.8)	15	(30.6)
Why:	Physically/Emotionally Taxing/Stressful	11	(91.7)	8	(53.3)	19	(73.1)
	Lack of Understanding/ Education	2	(16.7)	2	(13.3)	4	(15.4)

[1]Totals do not equal 50, due to missing data in the community-based sample.

[2]Respondents reporting "moderately" or "very difficult" ratings were asked to give reasons why; column totals cannot be added for *reasons why* due to multiple responses.

[3]Respondents reported that one behavioural disturbance category, Agitated/Aggressive-Physical, stood out as creating the most difficulty for frontline caregivers (60.9% of community and 65.4% of facility respondents) with the main reason cited as "caregiver afraid/at-risk physically."

I. Behaviour Management Difficulty Ratings

Table 18 includes data pertaining to specific behaviours that present management problems for frontline caregivers. Respondents were asked to indicate up to three of the most difficult behaviours within each of the eight behavioural disturbance categories. The highest percentage responses within each category are reported as follows:

Category #	*Most Difficult Behaviours*
1	Assaultive/violent outbursts, and hitting/slapping/punching (73.5% each);
2	Angry/hostile outbursts (75.5%);
3	Elopement (76%);
4	Demanding/requests for attention (94.0%);
5	Paranoia (83.3%);
6	Irritability (51.0%);
7	Inappropriate sexual advances (77.1%); and
8	Incontinence of bowel (65.5%).

In an attempt to further isolate behaviour management difficulties for frontline caregivers, respondents identified the top three most difficult behaviours across all categories. The majority of respondents (60%) highlighted **assaultive/violent outbursts** within the Agitated/Aggressive-Physical category as one of the most difficult behaviours. Further attesting to the difficulties associated with behaviours in this category, respondents frequently reported one or more of the behaviours within the Agitated/Aggressive-Physical category in combination with behaviours in other categories such as: Agitated/Aggressive-Verbal; Ideational; and Problematic ADL's/Coping Strategies.

With respect to the community-facility comparisons of management difficulties, respondents reported very similar percentages for the following discrete behaviours: hitting/slapping/punching; paranoia; angry hostile outbursts; screaming/yelling; and hallucinations. The most marked differences were in the Problematic ADL's/Coping Strategies category, with community respondents reporting considerably higher percentages for **incontinence problems**. This is not surprising, given that incontinence (bowel and bladder) is very physically taxing for at-home caregivers.

J. Specialized Programs/Approaches and Suggested Improvements

Respondents were asked to report any specialized programs/approaches they were using with success for psychogeriatric client groups. Table 19 shows that special therapeutic programs/resources (such as music therapy) were the most commonly cited (48% of respondents). When asked if they were satisfied with the types of care and management strategies used by frontline caregivers in their organizations, 67% of respondents indicated that they were not satisfied with the situation, or gave qualified yes/no answers. The majority of respondents (64.7% of total respondents and 83.3% in the facility sample) indicated that **trained staff and appropriate approaches** for managing difficult behaviours would create significant improvements. It would be interesting to investigate the specific training and/or staff preparation, in both facility and

community settings, that would lead to such improvements and for which specific groups of psychogeriatric clients.

Table 18 : Behaviour Management Difficulty Ratings: A Comparison of Community and Facility-Based Respondents
Psychogeriatric Client ID Project - Key Informants' Survey

Behaviour Management Difficulty Rating for Individual Behaviours	Community Based N=24 n	(%)	Facility-Based N=26 n	(%)	Totals N=50 n	(%)
1. Agitated/Aggressive-Physical (n=49)[1]						
Assaultive/Violent Outbursts	18	(78.3)	18	(69.2)	36	(73.5)
Hitting/Slapping/Punching	17	(73.9)	19	(73.1)	36	(73.5)
Using/Brandishing a Weapon	6	(26.1)	5	(19.2)	11	(22.4)
2. Agitated/Aggressive-Verbal (n=49)						
Angry Hostile Outbursts	17	(73.9)	20	(76.9)	37	(75.5)
Screaming/Yelling	16	(69.6)	17	(65.4)	33	(67.3)
Verbal Harassment/Accusations	12	(52.2)	15	(57.7)	27	(55.1)
3. Agitated/Non-Aggressive-Physical						
Elopement	19	(79.2)	19	(73.1)	38	(76.0)
Wandering/Pacing Aimlessly	15	(62.5)	11	(42.3)	26	(52.0)
Restlessness	9	(37.5)	13	(50.0)	22	(44.0)
4. Agitated/Non-Aggressive-Verbal						
Demanding/Requests for Attention	21	(87.5)	26	(100.0)	47	(94.0)
Repetitive Sentences/Questions	15	(62.5)	20	(76.9)	35	(70.0)
Complaining/Negativism	17	(70.8)	16	(61.5)	33	(66.0)
5. Ideational (n=48)						
Paranoia	19	(82.6)	21	(84.0)	40	(83.3)
Delusions	16	(69.6)	12	(48.0)	28	(58.3)
Hallucinations	11	(47.8)	13	(52.0)	24	(50.0)
6. Emotional/Affective (n=49)						
Irritability	13	(54.2)	12	(48.0)	25	(51.0)
Prolonged Grief/Depression	8	(33.3)	12	(48.0)	20	(40.8)
Anxiety Disorder	12	(50.0)	7	(28.0)	19	(38.8)

[1]All percentages are calculated based on total respondents (n=50), unless otherwise indicated. Respondents reported up to three of the most difficult behaviours for frontline caregivers to manage.

Table 18 Cont'd: Behaviour Management Difficulty Ratings: Comparison of Community and Facility-Based Respondents

Behaviour Management Difficulty Rating for Individual Behaviours	Community Based N=24		Facility-Based N=26		Totals N=50	
	n	(%)	n	(%)	n	(%)
7. Socially Unacceptable (n=48)						
Inappropriate Sexual Advances	16	(72.7)	21	(80.8)	37	(77.1)
Fecal Smearing	12	(54.5)	9	(34.6)	21	(43.8)
Urinating in Public Places	7	(31.8)	8	(30.8)	15	(31.3)
8. Problematic ADL's/Coping Strategies (n=29)						
Incontinence (Bladder)	9	(52.9)	3	(25.0)	12	(41.4)
Incontinence (Bowel)	13	(76.5)	6	(50.0)	19	(65.5)
Most Difficult Individual Behaviours[2]						
Assaultive/Violent Outbursts	16	(66.7)	14	(53.8)	30	(60.0)
Hitting/Slapping/Punching	3	(12.5)	6	(23.1)	9	(18.0)
Elopement	6	(25.0)	3	(11.5)	18	(36.0)
Inappropriate Sexual Advances	1	(4.2)	8	(30.8)	9	(18.0)

[2]Respondents reported the three most difficult individual behaviours, across all categories, for frontline caregivers to manage. With respect to the typical combinations of behaviours that pose significant care and management challenges for frontline staff, several unique combinations were reported. The behavioural disturbance categories most often reported together included: 1. Agitated/Aggressive-Physical and Agitated Aggressive-Verbal; 2. Agitated/Aggressive-Physical and Ideational; and 3. Agitated/Aggressive-Physical and Problematic ADL's/Coping Strategies.

Table 19 : Specialized Programs/Approaches and Suggested Improvements: A Comparison of Community and Facility-Based Respondents
Psychogeriatric Client ID Project - Key Informants' Survey

	Community Based N=24		Facility-Based N=26		Totals N=50	
	n	(%)	n	(%)	n	(%)
Specialized Programs/Approached Used (n=50)[1]						
Special Therapeutic Programs/Resources	9	(37.5)	15	(57.7)	24	(48.0)
Trained Staff/Appropriate Approaches	7	(29.2)	5	(19.2)	12	(24.0)
Satisfied with Types of Care and Management Strategies						
Yes	8	(33.3)	9	(34.6)	17	(34.0)
No	13	(54.2)	8	(30.8)	21	(42.0)
Yes/No Qualified	3	(12.5)	9	(34.6)	12	(25.0)
Suggested Improvements (n=34)[2]						
Trained Staff/Appropriate Approaches	7	(43.8)	15	(83.3)	22	(64.7)
Higher Staff Ratios/Reorganization	7	(43.8)	7	(38.9)	14	(41.2)

[1]Respondents reported on what was working well/their successes. Special therapeutic programs/resources typically referred to both staff and associated programs (e.g. music therapy).

[2]Overall satisfaction refers to the types of care and management strategies that frontline caregivers were using in the organization. If respondents indicated that they were not satisfied, they were asked to comment on what would improve the ability to care for clients exhibiting challenging behaviours (n=16 and 18 for community and facility-based respondents respectively).

K. Utility of Behavioural Classification Scheme

Respondents were asked for any final comments concerning how appropriate the behavioural categories are for identifying and grouping problematic behaviours. Summarized comments are as follows:

- Many respondents were impressed with the inclusive definition of the psychogeriatric population. However, a small number of respondents (mostly those associated with specialized geriatric/psychiatry facilities) objected to the use of the term stating a preference for the term "geriatric psychiatry" or "geriatric mental health/mental health and aging." They emphasized that proper psychiatric diagnosis and treatment are needed, especially with the more complex mental health conditions (e.g. mood disorders); the current definition does not convey the need for in-depth client assessments that can detect treatable biological illness and underlying medical conditions.

- In keeping with the previous observation, a few respondents expressed their discomfort in discussing behaviours separately from diagnoses and causative/contributing factors. They maintain that the same behaviour can have many root causes and therefore requires specific interventions and treatment approaches (e.g. acute illness is often the causative fact for delusions and must be properly diagnosed for effective treatment). It was also noted that isolated behaviours are less meaningful than behavioural constellations or groupings that are often present for individual clients.

- The Classification Scheme was generally perceived to offer a comprehensive listing and grouping of behaviours occurring in the psychogeriatric population. Some respondents had difficult with the wide range of behaviours contained in some categories, as well as the mix of acuity levels (e.g. in the Emotional/Affective category, anxiety disorders are lumped with suicidal impulses); it was also recommended that slow developing conditions be separated from those requiring a crisis response.

- Problematic ADL's/Coping Strategies (Category 8) prompted several comments and questions from respondents. Attention was drawn to the fact that some items included in the list are not behaviours, but actual causative factors or diagnostic-related descriptors (e.g. disorientation/confusion). Others stated that these diagnostic-related items were the primary reason for referrals, and thus described the majority of clients they served. In addition, reference was made to the fact that listed items are not behaviours per se, but indicators of levels of care or physical care requirements.

(e.g. spitting and throwing food/objects should be moved from the Socially Unacceptable to the Agitated/Aggressive-Physical category; dietary aberrations/changes, such as refusing to eat, should be moved from Problematic ADL's/Coping Strategies to the Emotional/Affective category, as it is one of the signs of depression). Others identified omissions in the Classification Scheme, such as: resistive to care (Agitated/Aggressive-Physical); frequent requests for attention (Emotional/Affective); and smoking dangerously (Problematic ADL's/Coping Strategies).

L. Suggested Program Improvements

At the conclusion of the interview, respondents were invited to add any comments or suggestions and a wide range of responses were received. The majority of comments arose from two central concerns:

i) the failure of the "system" to adapt to the increasing numbers of elderly with psychiatric problems, and the increasing client acuity levels. The need for a more client-centered approach was mentioned repeatedly; and
ii) the ramifications of health care restructuring and the redistribution of services "Closer to Home" without commensurate increases in the numbers and types of required services.

The resultant comments and suggestions are summarized under the following headings: Staffing/Management Approaches; Range of Needed Services/Specialized Resources; Client Mix; and Other Concerns/Issues. It, in no way, reflects all the opinions stated, however common issues and suggestions are captured. Because of the open-ended nature of the question, summarized themes and anecdotal comments are included rather than response frequencies.

Staffing/Management Approaches

Some of the most frequently expressed concerns related to staffing issues, specifically in the areas of **training/education**, **nursing staff ratios**, and **professional mix**.

- Care is being provided for new types of clients in facilities designed for, and with staff trained and experienced in, meeting primarily physical care requirements.

- The increase in the amount of care needed has outstripped the staffing available (in fact, in many instances, staffing levels have been decreased). Shorter inpatient stays translate into the need for more mental health workers and continuing care/home support staff to provide community-based care. "Mental Health provides excellent assessment and treatment planning, but they do not have the mandate nor the resources to provide the necessary ongoing monitoring." Another respondent stated that "clients in the past who would have gone to Riverview may make up a small

proportion of the total caseload (both community and facility), but they require a disproportionate amount of staff time and cause a lot of staff stress." Most facilities report being unable to free workers to meet with consultants for client-specific education, therefore the effectiveness of these professional resources is drastically reduced.

- The need for appropriate training and educational preparation of staff was mentioned by many respondents. Expressed needs were wide ranging but included the following examples:

- "Clients today require more care than in the past but staff skills have not kept pace. Frontline staff positions should be upgraded with commensurate pay and training increases."
- "Staff must be able to detect behaviour changes and underlying causes to properly treat clients."
- "We cope but staff feel inadequate caring for people without proper training. We are having to accept people we aren't equipped for with respect to environment and staffing."
- "We ask family caregivers with minimal training to care for clients who would present a challenge to the most skilled professional, and then we wonder why there are problems. Families are being asked to take on more and more responsibility for care and they are not receiving the required training and support." In addition, it was noted that family caregivers require a lot of staff time that is not accounted for in staffing hours, and that staff also require emotional support to sustain them .

- Suggestions for the appropriate mix of staff included:

i) there should be more registered nurses (RN's) and registered psychiatric nurses (RPN's) providing frontline care;
ii) every facility should have RPN's on staff to provide care and to consult with other staff; and
iii) every facility should be required to have recreation therapist(s). As one respondent succinctly states, "the environment, routine and utilization of non-professionals as frontline workers escalates the mental health problems in facilities. People need to act out in order to get what they want and to control their world."

- Final participant comments in this section related to physician training, for example, "physicians should be more involved and better trained. Selected physicians could be specially trained and government-funded, and they in turn could teach others." There were also concerns raised regarding the number of physicians, case managers and direct care staff who are not well-informed about medications; it was felt that there was an unwillingness to seek current information from available sources.

Range of Needed Services/Specialized Resources

There were strong opinions raised concerning the need for **additional and/or more appropriate services**. Many, but not all, comments related to the increasing demands being made on the system as a result of the downsizing of Riverview.

- A number of respondents indicated that there is a need for an acute, longer-term geriatric psychiatric facility. Practitioners believe that there is a significant group of clients who will not be appropriately served by the existing community-based or inpatient psychiatric services. One centrally located provincial facility was recommended to provide the necessary expertise and technology.

- An urgent need was expressed for specialized units to care for elderly clients with mental illness. It was suggested that each unit have clear specifications regarding purpose, types of clients accepted and the disciplines providing care. Observations were made that placement in existing long term care facilities is not always suitable (these issues are covered in more detail in the Client Mix section).

- A generic staffing model was proposed to enable staff to perform a range of care functions. This was seen as a means to promote continuity of care (minimizing the number of staff interacting with confused residents/clients), as well as increasing staffing flexibility.

- The issue of using current resources more effectively was also raised with a recommendation that more appropriate approaches be adopted within existing services (it was recognized that union contracts may limit consideration of some options).

- Many respondents drew attention to the fact that a wider range of services with the capacity to serve the increasing numbers of psychogeriatric clients is needed. Some of the service needs expressed include:

1) more, as well as more flexible, respite and adult day care programs. One person stated that "adult day programs tend to function as 'dumping grounds' for case managers because more appropriate services are not available;" and
2) home support workers are needed who are able to provide service for shorter periods several times in one day. For example, clients could manage at home with brief visits to assist them get up, get lunch, and settle for the night. It was suggested that workers could do this if they were visiting several clients in close proximity.

- There was a general suggestion emphasizing the importance of establishing effective partnerships among community and facility services (including acute care) to facilitate the movement of clients in an appropriate, timely manner, and to provide effective back up resources and a sharing of expertise.

Client Mix

Many comments reflected the opinion that **mixing** physically frail seniors with clients experiencing acute or chronic mental health problems in long term care facilities is **not working** for either group of clients and their families. The following specific examples and case scenarios were offered:

- Similar behaviours can have different underlying causes and therefore require different client handling. An example given of an inappropriate client mix was the person with mental illness who has a definite idea of their personal space, and the person with dementia who has lost this sense and therefore often encroaches on the space of the other. The mentally ill clients often lash out as a result, and this was contrasted with the lashing out behaviour of demented individuals during such activities as personal care.

- One respondent stated that "the milieu in facilities has changed. Now there are so many extremely cognitively impaired residents, it is no longer a good place for the physically impaired but cognitively intact. This milieu often stops families from visiting and the residents' quality of life is awful."

- The risks inherent in mixing clients inappropriately were also highlighted. One respondent pointed out that Special Care Units were originally designed to care for the frail, demented elderly, that is those who are vulnerable to injury from "the physically strong, aging schizophrenic who is prone to physical acting out." It was suggested that more than one type of SCU is needed to serve different populations (at a minimum, separate those with dementia from those with mental illnesses, such as schizophrenia). There was also mention made of the fact that many facilities are trying to provide specialized services without having access to an appropriate physical environment. A common theme raised dealt with the well-documented need for smaller spaces with sufficient "quiet" areas, safe wandering areas, and access to green space.

- Several respondents emphasized that mental health conditions (or combinations of conditions) are being undiagnosed and/or under-treated. Among those mentioned were: delirium; depression; the mix of delirium and depression; personality disorders; and medication-related conditions/behaviours. It was also mentioned that the "fiercely independent, ex-street person does not adapt to the types of facilities we offer."

Other Concerns/Issues

Some additional concerns and issues were raised by respondents that were mainly related to **communications** among relevant team players.

- Repeated mention was made of the tensions between Continuing Care and Mental Health. This is perceived as a serious issue given the downsizing of Riverview and the continual movement of mentally ill elderly into the community. It may be noteworthy that the only two survey refusals came from Mental Health personnel.

- Perceptions exist that Home Care Agencies and Continuing Care staff do not communicate. The need was expressed for more sharing of information among provider agencies that is both general and client-specific in nature. Additionally, time for communication among professionals to foster team work and to promote a consistent approach for the psychogeriatrc client group was considered essential.

- The final issue raised dealt with competency (financial and personal) with reference to the increased emphasis on human rights. Care providers are seeing substantial increases in financial abuse, aggression, and safety issues (e.g. fire) and are grappling with the issue of "when is the risk significant enough to intervene?"

Focus Group Sessions

M. Summary of Focus Group Results

BC Caregivers' Support Group

By far the greatest concern for family caregivers is having to face caregiving situations that are unpredictable, relentless and uncertain without being able to access the **information**, **services** and **support** needed. The discussion focused on general caregiving stresses, as opposed to isolating specific behaviours that were difficult to manage at-home. A summary of the session results follows, in order of the questions addressed and the major themes raised.

Major Stresses

- Participants talked about the relentless nature of their caregiving tasks (24-hours a day). There is no freedom or spontaneity for socializing, nor any ability to plan ahead. Because caregivers did not know what was going to happen next, they felt very vulnerable and could not plan (this included personal financial planning and one of the younger women said that she was "scared that she would not have enough to live on in her later years").

- Many caregivers experienced financial difficulties stating that "the funds of the family were put at risk." In one situation, the caregiver was spending approximately $500/month for medication related to Parkinson's disease (she was under 65 years). She had to use her charge card, as it was such a significant drain on her monthly income. Another participant said that the government pays so little of the total expenses incurred while caring for a spouse at-home that she was afraid to disclose her finances to case managers because she feared losing her house in the process.

- Watching a loved one deteriorate (predominately a husband) and feeling helpless in the process was mentioned. One women said that the frustration was overwhelming as her husband progressively lost his ability to communicate; she felt she did not know what he was feeling and needing on a daily basis.

Lack of Information/Service Access

- The lack of information and ability to get help was a major concern. Home support workers were not seen to offer much in terms of day-to-day problem-solving and solutions. It was felt that services were not uniformly available; one caregiver said that it really depended on the social worker and "not everyone gives you what you need." One women stated that "she felt like a runner" trying to get all the help that she needed and her case manager was "oblivious to her need for more than four-hours/week of support." Physicians were seen as able to order the care required, but they often did not have the information about services or specific caregiver needs.

- The notion of "taking care of yourself" was seen as impossible. There were no adult sitting services available to have someone come into the home even for short periods of time. Confusion and wandering behaviour frighten others and the caregivers felt that they had no choice but to stay at home themselves. One women recounted an incident where her mother was being cared for in an adult day care and she received an emergency call that she had wandered out of the program. She felt she had no recourse to complain or she faced losing the only respite service that would accept her mother.

- General concerns were raised about the lack of staff training and attentiveness to the care recipient's needs. It was felt that the onus was on the family to know the home support guidelines and to make lists of tasks and care requirements. One women felt hesitant to re-instruct a home support worker because she felt uncomfortable telling her what to do. There was a general sentiment expressed that "you put up with inappropriate care" for fear of losing support (lateness, inability to complete tasks/routines were some of the difficulties mentioned). The type of home support worker needed was described as being: self-motivated, client-oriented, having an understanding of specific diseases/conditions and associated needs, and having the ability to communicate with the care recipient and be a true companion.

Needed Resources/General Recommendations

- Participants indicated that when individuals take on a caregiver role, they should be informed about: what their entitlements are; where they can go/what services and information about diseases/stages of illness are available; and what impact care will have on the family's finances/financial strain. Family caregivers should not have to face the situation of "learning as you go." Written information should be widely available (from family doctors, health units, etc.) to help family members make informed decisions about caregiving. It should not be a struggle to find out what help is available and how to link up to support groups. Currently, there is no compiled information about available services. One caregiver talked about having to go to the library to find out about ALS; she said that she was "struggling all by herself" to cope with overwhelming grief, uncertainty and the burden of care."

- Smaller, more homelike settings (e.g. group homes) were recommended as more humane, and more economical care environments .

- The need for evening and overnight home support was raised. The only way to access after hours care (generally available 8:00 am to 5:00 pm) was in an emergency situation. Many caregivers talked about "burn-out" and the need for respite. There was unanimous agreement that respite beds were very difficult to find and inflexible in the duration of care (the need for shorter, more frequent stays, rather than the typical two-week stay was expressed).

- Final caregiver comments addressed the current cutbacks and bed closures. As one caregiver succinctly stated, "we are the forgotten people in the system and as long as we continue to do the care, they will say let them do it." It was felt that family care probably costs more in the end, because caregivers suffer health breakdowns and become people in need of care themselves. Participants cautioned that before beds are closed, health planners should contact family caregivers to find out what community resources are needed to absorb the increased burden of care.

Frontline Direct Care Nursing Staff

This session gave specific insights into the difficulties associated with the downsizing of Riverview from the perspective of TAP nurses (Riverview's Transitional Assistance Program) and nurses at one intermediate care facility that had received a number of Riverview patients. It proved to be a very dynamic, candid session as participants were eager to share concerns, primarily with respect to staffing, environmental and client mix issues. The summarized results are organized according to the actual session process and reflect generalized concerns.

Behavioural Disturbances/Client Mix Problems

- The following behaviours were mentioned as placing the most stress on frontline caregivers:
- Agitated/aggressive behaviour (particularly in relation to mood swings);
- Noisiness/yelling/screaming (even having two such residents can totally upset and distract other residents);
- Attention-seeking behaviours (they take time to address and can lead to other manifested behaviours, such as noisiness/striking out);
- Elopement (not an issue in locked ward areas); and
- Apathy/withdrawal (the caregiver receives little feedback from these individuals).

A case scenario was shared of an elderly, ex-Riverview patient who has a long-standing psychiatric illness; she is very intimidating to other intermediate care residents because she is extremely territorial and has unpredictable mood swings. She was cited as an example of the kind of resident who does not mix well with the frail, demented elderly.

- Separate units for the following two client groups were recommended:

1) Residents exhibiting interfering behaviours (very confused, those constantly yelling/screaming, and those who are difficult to re-direct because of their advanced stage of dementia); and
2) Residents diagnosed with manic depression and schizophrenia who are prone to agitated behaviour and physical aggression. Such persons totally deplete staff resources; if there are 10 in a facility, then the remaining 150 residents are said to be "neglected."

- Several nurses stated that a number of "special needs units" are required to address the problems associated with distinct client groups. For instance, some special care units caring for residents with advanced Alzheimer's disease (up to and including those needing palliative care) have the following features: reduced noise and stimulation levels, outside/covered walkways, a focus on activities (dedicated music therapist), one-to-one volunteers and consistent staffing patterns that are considered critical to the effective functioning of the unit. There was consensus that residents with mental illnesses are very disruptive to persons with advanced dementia (specific reference was made to: unpredictable/intractable aggression, mania, compulsive/addictive behaviours, and schizophrenia). At a minimum, "special needs units" caring for persons with mental illnesses will need isolation areas for the safety of all residents/staff, a mix of private rooms to reduce the threats associated with territorial behaviour and a range of quiet areas and small group spaces.

Specialized Resources/Program Enhancements

- Focus group participants highlighted the problems encountered in caring for the resident with a long-standing psychiatric illness who is under 65 years of age. Patients cannot be referred back to Riverview for psychiatric treatment if they are under 65 years, nor can they be referred to mental health teams; staff's only recourse is to send the resident to acute care emergency, especially on weekends when no physician support is available. Approximately 10 of the 160 residents currently being cared for at the intermediate care facility could fall into this emergency category at any given time, placing the staff and other residents in very vulnerable situations.

- A generalized need for physicians and nurses who are specially trained to handle psychiatric crises was expressed. Staff need to have an understanding of "why the behaviour escalates" including an awareness of the importance of proper diagnosis, and assessment to rule out treatable conditions that exacerbate behaviours. Staff need to be skilled in working with families "who can become part of the problem;" a humanistic quality and skills in behaviour management were mentioned. Nurses pointed to the need for increased staffing levels for handling the more severe behaviour problems (including unpredictable aggressive behaviours). On one floor in the intermediate care facility having a number of discharged

Riverview patients, the staffing ratio is one care aide to 32 residents, compared with one RPN and one skilled health care worker to seven patients on an inpatient unit at Riverview. An increase in absolute numbers of staff was considered essential to provide the much needed emotional and social support that mentally ill residents need.

- There was a general concern that there is limited access to an inpatient facility for handling severe acting out behaviour for those under 65 years, and for increasing numbers of psychogeriatric clients given current downsizing trends. Respondents emphasized the need for follow-up/re-assessment resources (access to a geriatric psychiatrist on more than a 9:00 am-5:00 pm schedule). In addition, one nurse spoke of the gaps in service between Riverview and the Mental Health Team, where the Team will service only those over 65 years with chronic psychiatric illnesses. It was stated that the Mental Health team conduct multiple assessments without providing back-up or follow-up support.

- Priority resource needs put forward by participants included:

- Emergency/crisis access for acute behaviours that may need medication adjustments;
- Better liaison between Riverview, Continuing Care, Mental Health Services, acute care emergency and intermediate care facilities. A hold on admissions was advised if Continuing Care refuses to disclose the patient's history to ensure that the environment can safely handle the proposed admission;
- Increased staffing levels in facilities that are caring for mentally ill elderly and those under/approaching 65 years. Better placement criteria and resident/family counseling resources were recommended;
- Better staff education. The health care workers at Riverview have all completed the Long Term Care Aide Program and have participated in peer counseling support programs. Basic training incorporating mental health components would be beneficial for intermediate care facility staff;
- More group home settings that can manage 4-12 psychogeriatric residents were recommended; one nurse mentioned that each community will have to determine the ideal settings for specific groups of psychogeriatric clients; she said that "the saturation point has been reached for many communities in absorbing more mentally ill patients than can be cared for at acceptable levels."

V CONCLUSIONS AND RECOMMENDATIONS

A. BC Prevalence Estimates by Diagnoses

For planning purposes, the prevalence estimates outlined in Part II (Table 6) were applied to current (1991) and projected (2011) statistics for the 65+ BC population. Estimates were calculated for the three major diagnostic categories having available community and institutional comparative data. Current CSHA (1994) data were used to compute dementia syndrome statistics and average prevalence estimates were drawn from other research studies for depression (DSMIII Criteria) and schizophrenia/paranoia.

Table 20: BC Prevalence Estimates for Selected Psychogeriatric Diagnoses in 1991 and 2011

Major Diagnostic Category	1991 Community n=391,830 (65+)		1991 Institution n=26,165 (65+)		2011 Community n=649,393 (65+)		2011 Institution n=43,363 (65+)	
Dementia Syndromes	16,457	4.2%	14,888	56.9%	27,275	4.2%	24,647	56.9%
Depression (DSMIII)	11,755	3.0%	1,047	4.0%	19,482	3.0%	1,735	4.0%
Schizophrenia/Paranoia	1,175	0.3%	654	2.5%	1,948	0.3%	1,084	2.5%

The above projections show that we can expect significant increases in the number of clients with dementia syndromes. The diagnosable depressions also constitute sizable increases in number. While the other psychiatric conditions (e.g. schizophrenia) are less prevalent, they will continue to exert pressures on community and facility resources. The literature and key informant survey findings highlight the fact that the behavioural disturbances associated with these conditions are disruptive to others, very taxing to frontline caregivers and represent a significant drain on long term care resources.

B. Recommendations Related to Client Subgroups and Resource Needs

Based on the literature review, the above epidemiological/statistical data and the results of the consultation process, the following ten (10) recommendations are proposed to develop appropriate, accessible psychogeriatric services for the identified client subgroups (not listed in any priority order):

Recommendation #1

Provide more and better access to specialized psychiatric resources to ensure that psychiatric disorders and medical conditions are not undiagnosed, misdiagnosed and untreated. Such specialized services are frequently needed to detect underlying causes of problem behaviours (physical and/or psychiatric) and to design appropriate treatments.

Recommendation #2

It is recognized that there are some excellent specialized psychiatric resources available to the psychogeriatric population; however, these services tend to be in short supply at present and are insufficient to meet increasing demand. There are four distinct specialized psychiatric services that require attention, namely:

1. Emergency services for clients experiencing acute psychotic episodes and/or requiring immediate medical stabilization;
2. Short-term assessment and treatment services (e.g. STAT Units), including follow-up and re-assessment for psychogeriatric clients and for mentally ill clients who are under/approaching 65 years;
3. Intermediate-term treatment and stabilization programs for clients exhibiting very difficult to manage behaviours (e.g. agitated/aggression-physical) who may require 6-10 months of intensive treatment and monitoring; and
4. Long-term, tertiary care facilities that are centrally located for persons with severe and intractable behaviour problems that cannot be appropriately cared for in either community or intermediate care settings (e.g. those with severe clinical depression/bipolar disorders or other psychiatric disorders, such as schizophrenia).

Recommendation #3

Provide more, and more flexible respite, adult day care and home support services to support both formal and informal caregivers in the shift toward community-based care.

Recommendation #4

Foster more effective communication and collaboration between Continuing Care and Mental Health Services, as well as working partnerships between facility and community-based services. This would enhance care coordination, streamline assessment, treatment and placement services and reduce duplication of effort. It would also facilitate the movement of clients in an appropriate, timely manner and provide effective back-up resources and a sharing of expertise.

Recommendation #5

Promote more appropriate use of drug therapy through the continual upgrading of physicians, facility nursing staff and community nurses. Continuing education sessions should cover the appropriate use of medications, the serious side effects commonly encountered (e.g. tardive dyskinesia, extrapyrmidal side effects), as well as the overuse and misuse of physical restraints and psychotropic drugs. Increased physician involvement and nursing staff training are called for, as well as regular monitoring of drug prescribing practices, especially psychotropic drugs.

Recommendation #6

Increase direct care staffing levels within intermediate and community care settings to address increases in client acuity and the prevalence of behavioural disturbances.

Those behaviours judged to be the most difficult for frontline caregivers to deal with on an ongoing basis include: agitated/aggressive-physical behaviours; agitated/aggressive-verbal behaviours; socially unacceptable behaviours; and agitated/non-aggressive-physical behaviours. Staffing level enhancements should address the following:

i) Facility staff require additional time to meet with consultants for client-specific education, to foster teamwork and consistent care approaches and to provide emotional support to family caregivers;
ii) More community staff are needed to accommodate shorter inpatient stays and more rapid transitions to community-based care; and
iii) More registered nurses and registered psychiatric nurses should be added to both facility and community staff complements to manage the more severe behaviour problems and to better meet the emotional and social support needs of mentally ill clients.

Recommendation #7

Encourage staff to offer structured resident/patient activities and therapeutic programs to reduce social isolation and to occupy individuals exhibiting agitated/aggressive-verbal and ideational behaviours (e.g. wandering, noisiness, screaming, repetitious mannerisms).

Recommendation #8

Provide retraining and continuing education for all direct care staff (including physicians, respite workers, case managers, home support staff, mental health staff and facility/nursing staff). Training of frontline staff should address the importance of behavioural symptoms, the identification of underlying disorders and the effective modes of treatment to relieve distress. Training in appropriate approaches for managing difficult behaviours should also address staff's difficulties in dealing with intractable behaviour problems and associated family support needs.

Recommendation #9

Strong support was received for conducting psychiatric assessment and diagnostic work-ups to detect treatable causative factors for behavioural symptoms. It was generally agreed that the *Behavioural Classification Scheme* could not be used without considering diagnostic criteria to identify and group psychogeriatric clients. However, the Classification Scheme, with the suggested revisions, could prove invaluable for:

i) Describing existing client profiles in behavioural terms, giving particular attention to those behavioural disturbances that pose the most significant care and management challenges for frontline caregivers;
ii) Monitoring case mix and associated workload changes overtime to determine staffing needs; and

iii) Identifying staff training, retraining and continuing education requirements within both facility and community-based settings.
At a minimum, suggested revisions to the Classification Scheme included separating slow developing conditions from those requiring a crisis response and separating causative factors, diagnostic descriptors or indicators of care levels from behavioural descriptors. It should also be adapted to take into account the identification of behavioural constellations or groupings most commonly encountered.

Recommendation #10

Findings support the advisability of segregating the frail elderly with dementia (and no behaviour problems) from mentally-ill clients who manifest moderate to severe behavioural disturbances (most notably physical and verbal aggression). It is recommended that specialized units have clear specifications regarding purpose, environmental specifications, types of clients accepted and the disciplines providing care. In addition, small, less institutionalized settings are proposed for subgroups of psychogeriatric clients with mental illnesses and behavioural disturbances. Special attention should be given to the following design features: private rooms, isolation/quiet areas, separate dining rooms and lounges, small group areas, gardens and special lighting

C. Recommendations for Future Study

Project Phases II and III were originally proposed to compile an inventory of current services/settings for psychogeriatric subgroups, and to develop a psychogeriatric model respectively. The remaining two (2) recommendations are offered in keeping with stated strategic planning objectives:

Recommendation #11

Identify a range of *best practice sites*, within facility and community-based sectors, that provide exemplary care and conduct a comprehensive review of client mix, staffing and environmental factors. Documentation of the array of available facility and community-based services (transfer, referral and consultation resources) would also be necessary. Such an integrated analysis would extend Phase I findings by identifying and weighting the most important determinants of "best care" for specific client subgroups. This descriptive information could form the basis for program design and resource allocation decisions on a regional basis.

Recommendation #12

The development of a comprehensive psychogeriatric care model would be a logical next step following the Phase II analysis. It is recommend that a small advisory group be struck, perhaps involving selected members from the Phase I key informant survey list, to identify the essential functions and care components of a comprehensive service network. Such a model would identify ways to better coordinate, manage and evaluate psychogeriatric care that would be applicable to any jurisdiction within British Columbia.

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APPENDIX A: BEHAVIOURAL DISTURBANCE CLASSIFICATION SCHEME

1. AGITATED/AGGRESSIVE - PHYSICAL
- assaultive/violent outbursts
- tackling
- using/brandishing a weapon
- throwing objects/striking
- temper tantrums
- hitting/slapping/punching
- elbowing
- grabbing
- pushing/shoving
- kicking
- biting
- pinching/squeezing
- pulling hair
- scratching
- tearing things
- damaging property/breaking things
- making threatening gestures
- self-mutilation

2. AGITATED/AGGRESSIVE - VERBAL
- angry/hostile outbursts
- threatens to attack
- verbal harassment/unwarranted accusations
- screaming/yelling
- cursing/obscene, profane language

3. AGITATED/NON-AGGRESSIVE - PHYSICAL
- wandering/pacing aimlessly (day or night)
- elopement
- ambulates in inappropriate places
- following people inappropriately
- hyperactivity
- repetitious mannerisms/actions
- restlessness
- activity disturbances

4. AGITATED/NON-AGGRESSIVE - VERBAL
- repetitive sentences/questions
- strange noises
- muttering
- complaining/negativism
- demanding/requests for attention

5. IDEATIONAL
- hallucinations (sees/hears things)
- delusions (fixed/incorrect ideas)
- paranoia (suspicious/accusatory)
- phobia (fear of objects/events)
- compulsiveness
- confabulation

APPENDIX A: CONT'D

6. EMOTIONAL/AFFECTIVE
- prolonged grief/depression with clinical symptoms
- anxiety disorder
- mood extremes (laughing, crying)
- irritability
- hopelessness
- apathy/withdrawal/decreased activity
- suicidal impulses
- bodily preoccupation
- slow reactions (Bradyphrenia)

7. SOCIALLY UNACCEPTABLE
- inappropriate dressing/undressing
- indecent exposure
- inappropriate sexual advances and/or behaviours
- making obscene gestures
- fecal smearing
- urinating in public places
- spitting
- throwing food/objects
- taking others' possessions/emptying others' cupboards
- pica (i.e. craving for unusual substances, such as dirt or paint)

8. PROBLEMATIC ADL'S/COPING STRATEGIES
- incontinence (bladder)
- incontinence (bowel)
- inability to feed self
- dietary aberrations/changes (overeats, refuses to eat)
- inability to groom self
- immobility
- disorientation/confusion
- memory/judgment loss
- communication difficulties
- cognitive impairment
- impaired concentration/attention span
- danger of harming self/others (leaves stove on)
- sleep disturbances (wakes up at night, sleeps excessively during day)
- alcohol abuse
- falls
- change in pain tolerance

APPENDIX B - PROBLEM BEHAVIOUR SCALES

Agitation Checklist see Aronson, M.K. Cox, D., Guastadisegni, P. et al. (1992). Dementia and the nursing home: Association with care needs. Journal of the American Geriatrics Society, 40(1), 27-33.

Behavior and Mood Disturbance Scale (BMD) `see Greene, J. G., Smith, R., Gardiner, M.and Timbury, G.C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: A factor analytic study. Age and Ageing, 11, 121-126.

Behaviour Observation Scale for Intramural Psychogeriatrics (GIP) see Verstraten, P.F.J. (1988). The GIP: An observational ward behaviour scale. Psychopharmacology Bulletin, 24(4), 717-719.

Developed in the Netherlands, the GIP contains 82 items organized into 14 scales: nonsocial behaviour, apathetic behaviour, distorted consciousness, loss of decorum, rebellious behaviour, incoherent behaviour, distorted memory, disoriented behaviour, senseless repetitive behaviour, restless behaviour, suspicious behaviour, melancholic or sorrowful behaviour, dependent behaviour and anxious behaviour.

Patients are rated by ward personnel for frequency of behaviour in the last 2 weeks (never, seldom, frequently, usually). Inter-rater reliability is reported to range from .53 to .90, with values above .70 for 11 scales. Among the other three scales the lowest value was for anxious behaviour.

Behaviour Problem Checklist (BPC) see Niederehe, G. (1988). TRIMS Behaviour Problem Checklist (BPC). Psychopharmacology Bulletin, 24(4), 771-776.

Behavior Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) see Reisberg, B., Borenstein, J., Salob, S.P., Ferris, S.H., Franssen, E. and Georgotas, A.. (1987). Behavioral symptoms in Alzheimer's disease: phenomenology and treatment. Journal of Clinical Psychiatry, 48(5-Suppl.), 9-15.

This 25-item scale measures behaviour in seven domains: paranoid and delusional ideation, hallucinations, activity disturbance, aggressiveness, diurnal rhythm disturbances, affective disturbance, and anxieties and phobias. An additional single item asks the extent to which symptoms are troubling to the caregiver.

Behavioral and Emotional Activities Manifested in Dementia (BEAM-D) see Sinha, D., Zelman, F.P., Nelson, S. et al. (1992). A new scale for assessing behavioral agitation in dementia, Psychiatry Research, 41, 73-88.

This scale, designed to assess behavioural problems in cognitively impaired older persons, has two sections: a behavioural component subdivided into nine symptom categories and a component assessing hallucinations and delusions. High correlations ($r=.79$ to .92 across three shifts) are reported between the behavioural component and the CMAI (Miller, Snowdon & Vaughan, 1995.)

Brief Agitation Rating Scale (BARS) see Finkel, S. I., Lyons, J.S. and Anderson, R. L. (1993). A brief agitation rating scale (BARS) for nursing home elderly, Journal of the American Geriatrics Society, 41, 50-52.

A 10-item scale developed from the 29-item CMAI. Items measure frequency of: hitting, grabbing, pushing, pacing or aimless wandering, performing repetitive mannerisms, restlessness, screaming, repetitive sentences or questions, strange noises, and complaining. (The authors say these are the most frequently occurring behaviours measured by the CMAI).

Across shifts, the BARS accounted for approximately 90% of the variance of the CMAI. Concurrent validity of the BARS was supported by significant correlations with BEHAVE-AD (r= .44 day, .33 evening and .21 night) and BSSD (r=.53 day, .34 evening and 0 night).

Caretaker Obstreperous Behavior Rating Assessment (COBRA) see Drachman, D.A., Swearer, J.M., O'Donnell, B.F. Mitchell, A.L. and Maloon, A. (1992). The Caretaker Obstreperous-Behavior Rating Assessment (COBRA) Scale, Journal of the American Geriatrics Society, 40, 463-470.

Designed for use by families or professional caretakers, this instrument assesses four categories of problem behaviour: aggressive/assaultive (8 behaviours), mechanical/motor (9 behaviours), ideational/personality (7 behaviours) and vegetative (6 behaviors with subdivisions). An accompanying video illustrates each behaviour to improve reliability of reporting. The significance of each behaviour is estimated via severity (0= no appreciable disruption; 4= presents significant danger) frequency ratings (0=no occurrence past 3 mo. 4=daily or more often). High test-retest (r=.73-.95) and inter-rater reliability (r=.73-.99) scores are reported.

Cohen-Mansfield Agitation Inventory (CMAI) see Cohen-Mansfield, J., Marx, M.S. and Rosenthal. A.S. (1989). A description of agitation in a nursing home, Journal of Gerontology: Medical Sciences, 44, M77-M84.

This is a nurses' rating scale designed to be used at the end of each eight hour shift. It consists of 29 agitated behaviours, each rated on a 7 point scale of frequency (1=never; 7=on average several times an hour). The items cluster into 3 main factors (physically aggressive, physically non-aggressive and verbally agitated behaviours) which were reported to be stable across shifts. According to the authors, this suggests that many of the agitated behaviours studied occur and reoccur in specific people throughout the 24 hour day.

Factor 1 - physically aggressive: (6)
hitting, kicking, pushing, scratching, grabbing, cursing

Factor 2 - physically non-aggressive: (7)
pacing, inappropriate robing or disrobing, repetitious sentences or questions, repetitious mannerisms, trying to get to different places, handling things inappropriately, general restlessness.

Factor 3- verbally agitated behaviour: (4)
constant requests for attention, screaming, complaining, negativism

Factor 4: (2)
hiding/hoarding behaviour: hiding things, hoarding things
(day-shift only)

Note: spitting and making strange noises did not load on any factor and the following rare behaviours (exhibited by fewer than 5% at least once per week) were not included in the factor analysis:

biting
tearing things
eating or drinking inappropriate substances
hurting oneself or others
intentional falling
physical sexual advances
verbal sexual advances
throwing things

Dementia Behavior Disturbance Scale (DBD) see Baumgarten, M., Becker, R. and Gauthier, S. (1990). Validity and reliability of the Dementia Behaviour Disturbance Scale, Journal of the American Geriatrics Society, 38(3), 221-226.

This 28-item scale was designed to be used in an interview format with the dementia patient's primary caregiver as the respondent. Problem behaviours included are: agitation, aggression, diurnal rhythm disturbance, eating disturbance, passivity and inappropriate sexual behaviour. Each listed behaviour is rated for frequency of expression in the preceding week (0=never exhibited; 4=exhibited all the time).

Disruptive Behavior Rating Scale see Mungas, D., Weiler, P., Franzi, C. and Henry, R. (1989). Assessment of disruptive behavior associated with dementia: The Disruptive Behavior Rating Scale, Journal of Geriatric Psychiatry and Neurology, 2, 196-202.

Four dimensions of disruptive behaviour are rated over a seven day period: two concern aggression and two, activity disturbance. Each is rated on a five-point scale measuring severity of response to the behaviour. A 20 item checklist (13 items on aggressive behaviour and 7 on activity disturbance) is used as an aid for the ratings.

Dysfunctional Behaviour Rating Instrument (DBRI) see Molloy, D.W., McIlroy, W.E., Guyatt, G.H. and Lever, J.A. (1991). Validity and reliability of the Dysfunctional Behaviour Rating Scale, Acta Psychiatrica Scandinavica, 84, 103-106.

Memory and Behavior Problems Checklist (MBPC) see Zarit, S.H., Orr, N.K. and Zarit, J.M. (1985). The Hidden Victims of Alzheimer's Disease: Families Under Stress. New York: New York University Press.

Items in this scale assess aggressive behaviour, ADLs, apraxias and spatial disorientation (wandering, getting lost indoors, getting lost in familiar streets and inability to recognize familiar surroundings).

The Revised Memory and Behavior Problem Checklist (Teri & Logsdon (1990) has 64 items in three categories: depressive, disruptive and behaviour related to memory impairment. It also measures how stressful caregivers consider each behaviour.

Nurses' Observation Scale for Geriatric Patients (NOSGER) see Spiegel, R., Brunner, C., Ermini-Funfschilling, D., Monsch, A., Notter, M., Puxty, J. and Tremmel, L. (1991). A new behavioral assessment scale for geriatric out- and in-patients: The NOSGER (Nurses' Observation Scale for Geriatric Patients), Journal of the American Geriatrics Society, 39(4),339-347.

The NOSGER was designed for use with persons with mild to moderate Alzheimer's disease living at home or in an institution. It contains 30 items each rated for frequency of occurrence in the last two weeks (5=all the time; 1=never)on a five-point scale. It measures six dimensions: memory, IADLs, self-care, mood, social behaviour and disturbing behaviour. Items in the latter category include: restless during the night, runs away, when asked questions seems quarrelsome and irritable, verbally or physically aggressive, behaves stubbornly, does not follow instructions or rules. It does not ask about hallucinations and delusions because such items were thought to be threatening to family caregivers of persons in the early stages of dementia. The scale is available in German, English and French.

Nurses' Observation Scale for Inpatient Evaluation (NOSIE) see Honigfeld, G. and Klett, C.J. (1965). The Nurses' Observation Scale for Inpatient Evaluation - A new scale for measuring impairment in chronic schizophrenia, Journal of Clinical Psychology, 65-71. This 69-item nurses' rating scale was developed specifically to assess older schizophrenic patients many of whom are mute or marginally communicative, apathetic and indifferent. It contains seven factors:

1. Social Competence;
2. Social Interest;
3. Personal Neatness;
4. Cooperation;
5. Irritability;
6. Manifest Psychosis; and
7. Psychotic Depression.

Patients are rated on how frequently they exhibited the behaviour in the last three days (0 = never; 4 = always). A 30-item version is also available, see Honigfeld, G. (1974). NOISE-30: History and current status of its use in pharmacopsychiatric research. In P. Pichot (Ed.). Modern Problems in Pharmacopsychiatry, vol. 7, Psychological Measurement in Psychopharmacology. Basel: Karger, p.238.

Nursing Home Behavior Problem Scale see Ray, W.A., Taylor, J.A., Lichtenstein, M.J. and Meador, K. G. (1992). The Nursing Home Behavior Problem Scale, Journal of Gerontology: MEDICAL SCIENCES, 47(1), M9-16.

This 29-item rating scale, completed by nurses or nursing assistants, was designed specifically for use in a nursing home. Its purpose is to measure behaviour so disruptive or stressful as to lead to the use of antipsychotic drugs or restraints. Items are grouped into 6 sub-scales: 1) Uncooperative or aggressive behaviour; 2) Irrational or restless behaviour; 3) Sleep problems; 4) Annoying behaviour; 5) Inappropriate behaviour; and 6) Dangerous behaviour. Scoring is from 0=never to 4=always. Binary scoring (present, absent) increases inter-rated reliability (Correlation -.747 with the NOISIE and .911 with CMAI).

Psychogeriatric Dependency Rating Scale (PGDRS) see Wilkinson, I.M., and Graham-White, J.(1980). Psychogeriatric Dependency Rating Scales (PGDRS): A method of assessment for use by nurses, British Journal of Psychiatry, 137, 558-565.

Rating Scale for Aggressive Behavior in the Elderly (RAGE) see Patel, V. and Hope, R.A. (1992). A rating scale for aggressive behaviour in the elderly - the RAGE, Psychological Medicine, 22, 211-221.

This is a nurses rating scale containing 23 items, of which 19 inquire about observable behaviour (e.g. kicking; shouting), 3 about the consequences of aggressive behaviour and 1 asks for a global judgment of overall aggressiveness. The ratings are made at the end of a 3-day observation period of inpatients.

A 4-point frequency scale is used for the behavioural items: 0= never occurred; 1= at least once in past 3 days; 2= at least once every day; 3= more than once a day in past 3 days. Two of the non-behavioural items were rated on the basis of the severity of the injury inflicted on self or other; the other concerned whether the patient was sedated or restrained as a consequence of aggressive behaviour. Global rating categories are: not at all, mildly, moderately and severely aggressive.

Ryden Aggression Scale (RAS) see Ryden, M.B. (1988). Aggressive behavior in persons with dementia who live in the community. Journal of Alzheimer Disease and Associated Disorders, 2, 342-355.

This 25-item instrument was designed specifically for use in the community. It has three subscales which measure physical aggression (16 items), verbal aggression (4 items) and sexual aggression (5 items). Caregivers rate frequency of behaviour.

DIRECT OBSERVATION TECHNIQUES:

Patel (1993), Beck, Rossby and Baldwin (1991) and others consider direct observation to potentially provide the gold standard for behaviour assessment. Several instruments have been developed to aid the process.

Agitation Behavior Mapping Instrument (ABMI) see Cohen-Mansfield, J., Werner, P., and Marx, M.S. (1989). An observational study of agitation in agitated nursing home residents, International Psychogeriatrics, 1,153-165.

Cohen-Mansfield Agitation Inventory II (CMAI-II) see Chrisman, M., Tabar, D., Whall, A.L. and Booth, D.E. (1991). Agitated behavior in the cognitively impaired elderly. Journal of Gerontological Nursing, 17(12), 9-13.

This scale is an adaptation of the CMAI used for concurrent observation rather than retrospective rating. Chrisman et al (1991) report high inter-rater reliability coefficients.(r= .71 to .81). They also compare the CMAI-II to two other observational tools: the **Ward Behavior Inventory** (Burdock & Hardesty, 1968) a 138-item scale developed to provide information about behaviours of hospitalized adult psychiatric patients and a revised version of the **Confusion Inventory** (Evans, 1987) a 48-item checklist of psychomotor and psychosocial behavioural indicators of confusion, originally developed to study "sundowning."

Patient Behaviour Observation Instrument see Bowie, P. and Mountain, G. (1993). Using direct observation to record the behaviour of long-stay patients with dementia. International Journal of Geriatric Psychiatry, 8, 857-864.

See also:

Madson, J (1991). The study of wandering in persons with senile dementia. American Journal of Alzheimer Care and Related Disorders and Research, 6(1), 21-24 for a review of wandering assessment tools and techniques.

Patel, V. (1993). Assessment of behavioural phenomena in dementia. In: V. Patel (Ed.) (1993). Aging and Dementia: A Methodological Approach. Boston: Research Studies in Gerontology (pp. 221-236) for discussion of steps to be taken in conducting an observational study.

STAFF KNOWLEDGE ASSESSMENT TOOLS:

Penn State Mental Health Caregiving Questionnaire (MHQ) see Spore, D.L., Smyer, M. A. and Cohn, M.D. (1991). Assessing nursing assistants' knowledge of behavioral approaches to mental health problems, The Gerontologist, 31(1), 309-317.

This 20-item multiple choice test is designed to assess nursing assistants' knowledge of depression, agitation, and disorientation and behavioral approaches to dealing with them. Ten items were adapted from the Mennier and Holmes (1987) Behavioral Knowledge Questionnaire and ten are new items based on the researchers' experience with a nursing home intervention project.

APPENDIX C - KEY SCREENING STUDIES

British Residential Homes Study

Mann, Graham and Ashby (1984) interviewed 438 residents of 12 Part III Residential Homes in the UK. The interview included the Depression and the Organic Brain Syndrome (OBS) scales of the Comprehensive Assessment and Referral Evaluation Schedule (CARE - Gurland et al., 1977). Also, the head of the home rated the subject in terms of: 1) Mental State - presence of confusion, depression, suspiciousness; 2) Problem Behaviours - wandering, incontinence, aggressive or abusive behaviour; 3) Dependency in ADL's - degree of assistance needed for mobility, dressing, toileting, eating; 4) Activity - alone or with visitor; and 5) Medications. Frequency ratings were: less than once per week; between once a week and daily; or daily.

Residents too confused to be interviewed were classified as having severe dementia; those with scores of 3-7 on the OBS scale were classified as having mild-moderate dementia, and those scoring below 2 as not having dementia . Classification of depression was on the basis of a score of 7 or more on the Depression Scale.

Canadian Study of Health and Aging

The Canadian Study of Health and Aging (CSHA) was undertaken in 1991-92 in 36 cities and surrounding areas across Canada. It included 10,263 people aged 65 and over: 9,008 living in the community and 1,255 in institutions. The study also interviewed the main caregivers of 1,048 people with dementia who were compared to caregivers of a random sample of 638 elderly persons who did not have cognitive problems. Coordinated by the Department of Epidemiology and Community Medicine at the University of Ottawa and the federal government's Laboratory Centre for Disease Control, and involving 18 study centres from across Canada, the CSHA had four main objectives. These were to:

1) Establish the prevalence of dementia using a common research protocol;
2) Determine risk factors for Alzheimer's disease and other forms of dementia;
3) Describe current patterns of caring for persons with dementia and to assess the burdens on caregivers and their need for support; and
4) Establish a uniform database for subsequent studies examining the natural history of dementia and for planning and evaluating interventions.

Subjects in the initial screening study were an age-stratified random sample aged 65-74, 75-84, and 85+ with deliberate over sampling of the 85+ group. Institutions were stratified by size: small (6-25 residents), medium (26-99) and large (100+) with subjects randomly selected from within the selected institutions.

All members of the community sample received a screening interview. Those who screened positive for cognitive impairment and a randomly selected control group who screened negative went forward for clinical assessment to determine the presence of dementia and to provide a diagnosis. Institutionalized subjects went directly to the clinical assessment.

The screening interview included questions on level of performance of ADLs, general health, and social support. Cognitive impairment was assessed using the Modified Mini-Mental State Exam (3MS)(Teng, 1987). The clinical assessment began with a nurse's assessment of hearing, vision and vital signs; a repeat of the 3MS; and questions about personal and family history (CAMDEX). It also included neuropsychological tests and evaluation (information subtest of WAIS, Buschke's Immediate Cued and Delayed Recall Test and the WAIS-R block design, similarities, comprehension and digit symbol

subtests); physician's assessment and laboratory tests. (Canadian Study of Health and Aging Working Group, 1994)

A risk-factors study was also conducted as part of CSHA-1. Participants included 258 cases clinically diagnosed with probable Alzheimer's disease, with onset of symptoms within 3 years of diagnosis and 535 controls, frequency matched on age group, study centre and residence in community or institution, clinically confirmed to be cognitively normal.

East Baltimore Mental Health Survey

In the first phase of this 3-phase study, interviews were conducted with a probability sample of 3,481 adult households in eastern Baltimore using the Diagnostic Interview Schedule (DIS) of the National Institute of Mental Health (Robins, Helzer, Croughan et al. 1981) and the Mini-Mental State Exam (Folstein et al. 1985). Of the 3,481, 2,558 were aged 18-64, 589 were aged 65-74 and 334 were 75+.

All Phase 1 subjects likely to have a DIS diagnosis and 17% with no DIS diagnosis were invited to participate in Phase 2. Of 1,086 invited, 810 were examined by psychiatrists who used standardized methods to make standardized clinical diagnoses according to DSM-III criteria.

In Phase 3, 36 of 44 subjects with probable or possible dementing illness were examined by a neurologist and given a series of laboratory tests, a CT scan and an EEG.

Folstein, Anthony, Parhad, Duffy and Gruenberg (1985) report the distribution of a variety of mental health disorders cross-tabbed by MMSE scores using 2 cut-off points.

Gothenberg Longitudinal Study

This longitudinal study began as a cross-sectional study of 973 men and women living in Gotherburg, the second largest city in Sweden. All were born between July 1, 1901 and June 30, 1902 and were aged 70 when the study began in 1971-72. The first follow-up was conducted in 1975 simultaneous with the testing of another sample consisting of individuals who became 70 in 1976-77. A third cohort of 70-year-olds was added in 1981-82. The original birth cohort has now been examined at ages 70, 75, 79, 81, 83 and most recently, at age 85.

The study of 85 year olds (Skoog, Nilsson, Landahl & Steen, 1993) was conducted in 3 stages. First, subjects were interviewed in their home by a registered nurse. The interview inquired about their social and living conditions, need for social and medical care and drug consumption. The subjects were then examined in a geriatric university hospital out-patient department. Finally, a psychiatrist examined them in their home. Psychiatric symptoms and signs were rated in accordance with the Comprehensive Psychopathological Rating Scale (CPRS), Asberg et al. 1978. Several other tests were also administered. These included the Mini-Mental State Examination (Folstein et al. 1975), short version of the Blessed Test (Katzman et al. 1983), the Gottfries-Brane-Steen Scale (GBS) and a global rating of mental health were conducted. Subjects also completed several personality inventories, were asked for permission to interview a close friend and were asked to undertake a CT scan and lumbar puncture. A total of 491 completed the psychiatric interviews (143 men and 351 women).

Liverpool Study

Copeland, Dewey, Wood et al. (1987) interviewed a random sample of 1,070 community dwelling persons aged 65+ in Liverpool, using a community version of the Geriatric Mental State Schedule. Findings were processed to give a computerized diagnosis by AGECAT.

Maryland Nursing Home Study

Rovner, Kafonek, Filipp, Lucas and Folstein (1986) studied a random sample of 50 residents of a 180-bed intermediate care facility in Maryland. Demographic information, medical history, diagnosis and medications were obtained from chart review. Subjects were examined by a psychiatrist and a geriatrician to assess functional status, presence of chronic disease, psychiatric diagnosis and degree of cognitive impairment. Geriatric Mental State Schedule and Mini-Mental State Exam were used to assess psychiatric and cognitive status. Diagnosis was made according to DSM-III criteria. Additionally, the psychiatrist or geriatrician interviewed the member of the nursing staff most familiar with the resident and then completed the Psychogeriatric Dependency Rating Scale (Wilkinson & Graham-White, 1980).

National Institute of Mental Health Epidemiologic Catchment Area Study (ECA)

This was a 5-site collaborative study completed between 1980-1985. The ECA sample included probability samples of adult households and institutionalized populations in each community. Participants included 20,000+ who agreed to complete a baseline interview and a follow-up interview one year later. To assess psychiatric disorders, trained lay interviewers administered the Diagnostic Interview Schedule (DIS), which is based on DSM-III criteria (See Regier et al. 1988) for a summary of prevalence rates made using computerized diagnoses from the baseline interviews.

APPENDIX D: FINALIZED LIST OF SURVEY PARTICIPANTS

PSYCHOGERIATRIC CLIENT ID PROJECT: KEY INFORMANT SURVEY PARTICIPANTS (N=50)

1. Caregivers' Associations (n=3 Coordinators/Directors)

- Caregivers' Association of BC: Joyce Crawford, Project Coordinator
- Alzheimer Society of BC: Erin Harris, Education Coordinator/Support Services Coordinator
- Canadian Mental Health Association/Victoria Branch: Gail Simpson, Executive Director

2. Physicians (n=5)

- Geriatric Psychiatrist/Medical Director: Dr. Martha Donnelly, STAT Centre, Vancouver Hospital
- General Practitioner/Director of Geriatric Division: Dr. Akber Mithani, Riverview Hospital
- Geriatrician: Dr. David Wooldridge, Geriatric Assessment and Treatment Centre, St. Mary's Hospital
- General Practitioner/Medical Coordinator: Dr. Peter Bowan-Roberts, Ladysmith Hospital and Duncan Extended Care Unit
- General Practitioner/Medical Director: Dr. Keith Phillips, Prince George Regional Care Society

3. Continuing Care Divisions (n=6 Case Managers, Liaison Workers, Coordinator)

- Carolyn Hammell, Residential Care Coordinator/RN, Central Island/Coast Health District, Nanaimo
- Sheila Bill, Hospital Liaison Nurse/RN, GVHS Capital Region District, Victoria
- Donna Hay, Long Term Care Case Manager/RN, Central Kootenay Health Unit
- Christina Boscovich, Assistant Manager/Long Term Care Case Manager/ Physiotherapist, VHD Burrard Unit
- Lynn Westland, Long Term Care Case Manager/RN, Tri-Cities Health Unit, New Westminster
- Lauren Hogan, Long Term Care Case Manager/Social Worker, VHD Burrard Unit

4. Specialized Services, e.g. STAT Units, Outpatient and Assessment Services (n=12 Coordinators, Clinicians)

- Mary Blake, Social Worker, Geriatric Psychiatry Outreach Team, Vancouver Hospital
- Joe Scaletta, Coordinator, Mental Health Services/Emergency Outreach Service, Victoria
- Irene Barnes, Community Health Nurse/RN, Emergency Outreach Service, Victoria
- Sheila Westberg, Education Coordinator/Social Worker, Geriatric Psychiatry, St. Vincent's Hospital
- Sue Porter, Nurse/Pre-Assessor/RN, STAT Unit, Vancouver Hospital
- Alethea Reith, Nurse Clinician, Mobile Geriatric Assessment and Treatment Team/Long Term Care Team, Burnaby
- Penny McCourt, Social Worker, Mobile Geriatric Assessment and Treatment Team, Nanaimo

APPENDIX D: CONT'D

- Marnelle Roberts, Geriatric Coordinator/Social Worker, Regional Mental Health Centre, Prince George
- Louise Johnson, Consultant/Educator, MOH Psychogeriatric Outreach Service, Victoria
- Dr. Naseem Amarshi, Clinical Pharmacy Specialist, Vancouver Hospital
- Sue McCallum, Nurse Clinician/Educator, Geriatric Division, Riverview Hospital
- Dr. Elizabeth Drance, Geriatric Psychiatrist, STAT Centre and Broadway North Mental Health Team, GVMHSS

5. Community-based Services, e.g. Adult Day Care, Outreach/Mental Health Teams (n=9 Coordinators/Directors and Clinicians)

- Ann Nolte, Coordinator, Chronic Psychiatric Program, Pathways Adult Day Care, Victoria
- Pat McCullagh, Program Coordinator, Pathways Adult Day Care, Victoria
- Carol Kirkwood, Assistant Director/RN, Adult Day Care, ASK Friendship Society
- Elizabeth Tovey, Director of Richmond Mental Health Team, GVMHSS
- Glenda MacPherson, Social Worker, Broadway North Mental Health Team, GVMHSS
- Louise Hollands, Outreach Counselor/Social Worker, Substance Abuse Program, CMHA
- Betsy Lockhart, Regional Coordinator of Elderly Services/Psychologist, Mental Health Division, North Region, Prince George
- Maurene Williams, Registered Nurse, VON Adult Day Centre, Vancouver
- Joan Stewart, Team Leader/RN, VON Adult Day Centre, Vancouver

6. Facility-based Services, e.g. Personal, Intermediate and Extended Care (n=15 Coordinators/Directors, Clinicians)

- Gloria Parker, Director of Resident Care, Tillicum Lodge, Victoria
- Anne Marie Monahan, Clinical Nurse Specialist, Geriatric Mental Health, Juan de Fuca Hospital, Victoria
- Eileen Goudy, Nurse Manager, Geriatric Assessment Inpatient Services, Victoria General Hospital
- Regina Naing, Staff Nurse/LGN, Cooper Place Intermediate Care, Vancouver
- Sue Ball, Director of Care, Malaspina Lodge Intermediate Care, Nanaimo
- Pam Mayhew, Nurse Manager, Gorge Road Hospital, Victoria
- Fern Potter, Team Leader/RN, Gorge Road Hospital, Victoria
- Barb Brandon, Team Leader/RN, Priory Hospital, Victoria
- Kathy Hallinen, Staff Nurse/RN, Dogwood Lodge Intermediate Care, Burnaby
- Lesley Brooks, Director of Therapies, St. Michael's Centre, Burnaby
- Margaret Cluff, Director of Activation/Occupational Therapist, Cedarview Intermediate Care, North Vancouver
- Cathy Kits, Recreation Therapist, Simpson Hospital, Langley
- Yoying Orosa, Social Worker, Yaletown Intermediate Care, Vancouver
- Jan Volker, Head Nurse/RN, Yaletown Intermediate Care, Vancouver
- Lorraine Lyons, Nurse Clinician, Geriatric Psychiatry, St. Vincent's Hospital

N.B. The list of consultation sources was identified collaboratively with Continuing Care Division representatives. In a few instances, it was necessary to locate alternate survey participants (with similar backgrounds). In addition, a number of key informants have multiple affiliations and could be included in more than one category (e.g. physicians and specialized services). For data collection and analysis, a comparison between community and facility-based participants was conducted (n=24 and n=26 respectively).

Province of
British Columbia

Ministry of Health and
Ministry Responsible for Seniors

Continuing Care Division
Parliament Buildings
Victoria
British Columbia
V8V 4V7

APPENDIX E: LETTER OF INTRODUCTION

January 5, 1995

To Whom it May Concern:

This is to advise that the Gerontology Research Centre of Simon Fraser University has been commissioned by the Continuing Care Division to undertake a project to delineate the client sub-groups often referred as being under the umbrella term 'psychogeriatric'.

The contract with the Gerontology Research Centre is funded by the Ministry of Health and is being administered by consultants in the Continuing Care Division.

the purpose of the study is to:

1. Define and identify appropriate descriptors of the characteristics of the various sub-groups of the psychogeriatric population.

2. Determine whether these characteristics have already been defined and whether a model exists.

3. To obtain information from caregivers on the descriptors of the client sub-groups and the appropriateness of the descriptors and model.

4. To identify incidence/prevalence of the sub-groups based on the indicators and model.

The consultants will be conducting personal interviews and focus groups. The research is sponsored by Simon Fraser University and supervised by Dr. Gloria Gutman. The consultant has agreed that those individuals interviewed will be fully informed of the purpose and procedures and may decline to participate should they choose to. Individuals may withdraw if and when they choose and their confidentially will be preserved by the researchers. No information gathered by the researchers will be used to adversely affect the individuals.

. . . 2

We look forward to co-operation of those involved in this study. If there are any questions pertaining to this study, they should be directed to Michael Beseau (952-1131) or Lee Frost (952-1177), Consultants, Residential Services, Continuing Care Division.

Yours Sincerely,

Andrew Butler
Director
Residential Services

MB\vh (Butler\gutman.ltr)

APPENDIX F: KEY INFORMANT SURVEY INSTRUMENT

PSYCHOGERIATRIC CLIENT ID PROJECT
KEY INFORMANT INTERVIEW SCHEDULE

March 10, 1995

Respondent ID: _____
Date of Interview: _____
Interviewer ID: _____

Interviewer's Introductory Comments

Thank you for agreeing to participate in the Psychogeriatric Client Identification Project. I want to emphasize that the information you provide will remain strictly confidential and it will be summarized by geographic location and service affiliation.

This key informant survey is one component of a study aimed at identifying and describing the behavioural characteristics within the psychogeriatric population. Interviews are being conducted with a broad cross-section of key informants including clinicians, continuing care case managers, administrators and service coordinators drawn from private practice, specialized service areas, and a range of community-based and facility settings. We are asking survey participants to identify and categorize those behaviours posing significant care and environmental problems for frontline caregivers. A profile of psychogeriatric client subgroups will be created based on specific behavioural characteristics. The descriptive information compiled from this survey will help the Ministry of Health address program design and development needs. What we learn about psychogeriatric client subgroups and their needs will be helpful to Ministry officials, service providers and frontline caregivers, as we experience the shift towards community-based, client-centered care.

[**INTERVIEWER'S NOTE:** *Ask the participant to read the information card defining the psychogeriatric population (Appendix A). Tell respondents to keep the card in front of them as a reference for the remainder of the interview.*]

DEFINITION
For the purposes of this survey, the psychogeriatric population includes: older adults with dementia (e.g. Alzheimer's Disease, vascular dementia, etc.); those with affective/mood disorders (e.g. clinical depression, bipolar disorders, etc.); and those with other mental health conditions (schizophrenia, anxiety and personality disorders, etc.). It also includes persons suffering from brain disorders related to alcohol and drug use, AIDS, brain injury and medication-induced illness.

The aim is to identify and describe behavioural problems that are on-going and overly disruptive of the individual's ability to function effectively. The focus is on the manifested behaviours, not the specific medical diagnoses or underlying mental conditions/disorders.

Date of Interview (YYMMDD) |___|___|___|___|___|___|___|

Interviewer ID |___|

Respondent ID |___|___|

PART 1: HEALTH CARE PROFESSIONALS' SURVEY

1. How long have you worked for your current employer? Mo |___|___|

   _____ Months/Years Yr |___|___|

2. What is your current position/job title?

   _____

   _____ |___|___|

3. What single category best describes your relevant professional background? [NOTE: *Probe if necessary to identify most relevant category and record only one.*]

   1 Administrator
   2 Dietician
   3 General Practitioner
   4 Geriatric Psychiatrist
   5 Geriatrician
   6 Pharmacist
   7 Psychologist
   8 Rehabilitation Therapist, specify _____
   9 Registered Nurse |___|___|
   10 Registered Psychiatric Nurse
   11 Social Worker
   12 Other, specify _____ Specify |___|___|

4. What is your highest level of education attained?

   1 High school diploma _____
   2 Some university or college, specify _____
   3 Certificate, specify _____
   4 Diploma, specify _____
   5 Bachelor's degree, specify _____
   6 Post-graduate diploma, specify _____
   7 Post-graduate professional degree/specialization, specify _____
   _____
   8 Master's Degree, specify _____ |___|___|
   9 Doctoral Degree, specify _____
   10 Other, specify _____ Specify |___|___|

5. How long, in total, have you worked with psychogeriatric clients and/or their unpaid caregivers? [**NOTE:** *Read list and record selected response.*]

1 Less than 6 months
2 6-11 months
3 1-2 years
4 3-5 years
5 6-10 years
6 More than 10 years |___|

6. With respect to this total work-related experience, how frequently were you in direct contact with psychogeriatric clients? [**NOTE:** *Read list and record selected response.*]

1 Always
2 Most of the time
3 About half the time
4 Not much of the time
5 Never |___|

7. In which setting did you spend the <u>majority</u> of your work-related experience? [**NOTE:** *Probe for: the general type of setting, rather than the name of the organization; and the main level of care, on average, that best describes the experience. Record the type of setting and the corresponding level of care (e.g. hospital, extended care level).*]

___ Facility setting

Type of Setting *Level of Care*

_____ Type |___|___|

_____ Level |___|___|

___ Community-based setting

Type of Setting *Level of Care*

_____ Type |___|___|

_____ Level |___|___|

PART 2: AGENCY CHARACTERISTICS - FACILITIES/COMMUNITY SERVICES

1. Give a brief description of the main types of services provided by your organization (e.g. long term care facility services, outpatient assessment/treatment programs, information and referral services).

_____ |___|
_____ |___|
_____ |___|
_____ |___|

2. Indicate the primary client group(s) served by your organization. [NOTE: *Probe for the type(s) of residents (clients) accepted/not-accepted.*]

_____ |___|
_____ |___|
_____ |___|
_____ |___|

FACILITY RESPONDENTS (Skip to Q #7 for Community Service Respondents):

3. What is the total number of residents at present? _____ |___|___|___|

4. With respect to levels of care, indicate the level that best describes the majority of your current residents [*Check one.*]

1 PC
2 IC1
3 IC2
4 IC3
5 IC2 and IC3 Combination |___|
6 EC
7 Other, Specify _____ Specify |___|

5. What are the average number of facility admissions per year?
_____ per Month OR _____ per Year
per Mo |___|___|
per Yr |___|___|

6. What is the average length of stay?
_____ Months/Years [NOTE: Circle month or year].
per Mo |___|___|
per Yr |___|___|

COMMUNITY SERVICE RESPONDENTS (Skip to Q #11 for Facility Respondents):

[NOTE: *For respondents who carry a caseload, ask them to focus on the organization as a whole, or to extrapolate from their caseload to all clients served by the organization. Use this general focus for the remainder of the interview.*]

7. What is the monthly client caseload at present? _____ |__|__|__|

8. What is the average number of new cases accepted per year?

   _____ per Month OR _____ per Year per Mo |__|__|
   per Yr |__|__|

9. With respect to levels of care, indicate the level that best describes the majority of your current clients [*Check one.*]

   1 PC
   2 IC1
   3 IC2
   4 IC3 |__|
   5 IC2 and IC3 Combination
   6 EC
   7 Other, Specify _____ Specify |__|

10. What is the average duration of client contact?
    _____ Months/Years [NOTE: Circle month or year.] per Mo |__|__|
    per Yr |__|__|

ALL RESPONDENTS:

11. We are interested in your current resident (or client) profile. Please estimate the percentage of your resident (or client) population who are:

    Males: _____ |__|__|__|
    Females: _____ |__|__|__|

    With respect to age groups, please estimate the percentages who are:

    [NOTE: *Make sure that percentages total 100%.*]

    Under 65 years of age: _____ |__|__|__|
    Young-old (65-74 years): _____ |__|__|__|
    Middle-old (75-84 years): _____ |__|__|__|
    Old-old (85+ years) : _____ |__|__|__|

12. Of your total resident population (or monthly caseload), please estimate the percentage of clients exhibiting significant behavioural disturbances. Focus on those behaviours that pose significant care and environment challenges for frontline caregivers.

[NOTE: *Explain that "frontline caregivers" are persons providing direct care on an ongoing basis (for community-based respondents, these include: program workers, home support workers, and homemakers; for facility-based respondents, these include: personal care workers, LPN's, care aides, and/or staff nurses).*]

Percent Exhibiting Significant Behavioural Disturbances: _____ |__|__|__|

Please give an overall description of the types of presenting behaviours within this client group.

_____ |__|

_____ |__|

_____ |__|

_____ |__|

[INTERVIEWER'S NOTE: *Tell respondent that a major focus of the study is creating a descriptive profile of psychogeriatric client groups within facility and community settings. It will include a description of significant behavioural disturbances that frontline caregivers encounter on an ongoing basis. Explain that the remaining questions pertain to ONLY the psychogeriatric client population within the facility/community service.]*

13. Are you able to provide care and/or supportive services for all types of psychogeriatric clients? [NOTE: *Ask respondent to refer back to the definition of psychogeriatric population.*]

1 Yes
2 No |__|

(IF NO), specify those behavioural disturbances and/or disorders that you are not able to address. Please give details.

_____ |__|

_____ |__|

_____ |__|

_____ |__|

(IF NO), describe where you transfer/refer clients when they can no longer be cared for within your facility/community service.

_____ |___|
_____ |___|
_____ |___|
_____ |___|

14. Do you provide specialized services for the psychogeriatric client group?

1 Yes
2 No |___|

(IF YES), please describe the type(s) of services provided and the specific client group(s) served.

Type of Service	Client Group Served	Type	Group
_____		|___|	|___|
_____		|___|	|___|
_____		|___|	|___|
_____		|___|	|___|

15. Do you provide special accommodation arrangements and/or environmental modifications for this client group?

1 Yes
2 No
3 Not applicable |___|

(IF YES), please give details.

_____ |___|
_____ |___|
_____ |___|
_____ |___|

16. **(IF APPLICABLE)**, what accommodation arrangements and/or environmental modifications would improve care and service for psychogeriatric clients?

_____ |___|
_____ |___|
_____ |___|
_____ |___|

17. Are staff inservice training programs offered on care and management strategies for psychogeriatric clients?

[NOTE: *If respondent answers "yes", ask how regularly training is offered.*]

1 yes, on a regular basis
2 yes, on an irregular/sporadic basis
3 no |___|

(IF YES), describe the topic area(s) and target audience(s) covered by such sessions.

Topic Area	Target Audience	Topic	Target
_____		|___| |___|
_____		|___| |___|
_____		|___| |___|
_____		|___| |___|

18. Do you offer counseling and/or support services for the families of psychogeriatric clients?

1 Yes
2 No |___|

(IF YES), describe the type(s) of services offered.

_____ |___|
_____ |___|
_____ |___|
_____ |___|

19. In your opinion, to what extent do current, direct care staffing levels meet the needs of psychogeriatric residents/clients? [NOTE: *Ask respondent to refer to direct care staffing levels throughout the organization, as opposed to limiting response to the individual's own discipline. Read list and code selected response.*]

1 Completely
2 To a great extent
3 To some extent
4 Not at all
5 Not applicable |___|

(IF RESPONDENT INDICATED"), "to some extent" or " not at all" please comment on the reasons why staffing levels do not meet needs.

_____ |___|

_____ |___|

_____ |___|

_____ |___|

[INTERVIEWER'S NOTE: *Tell respondents that we are interested in the types of available facility and community-based resources that their organization uses frequently for psychogeriatric clients and their families. Describe facility-based resources as: inpatient beds, and other resources that are accessed directly through facilities (e.g. STAT Unit, special care unit, outreach team).*]

20. What types of facility-based resources are used frequently by your organization (e.g. STAT Unit, special care unit, outreach team, etc.). [NOTE: *Ask for a brief description of the services outlined. For facility respondents, ask them what other facility-based resources they refer to, and/or that they access frequently.*]

Facility-based Resources:

Type *Brief Description of Service*

_____ |___|

_____ |___|

_____ |___|

_____ |___|

21. For those facility-based resources listed above, indicate the extent to which they collectively meet the needs of psychogeriatric clients and their families. [NOTE: *Read list and code selected response.*]

1 Completely
2 To a great extent
3 To some extent
4 Not at all |___|

(IF RESPONDENT INDICATED to "some extent" or "not at all"), please elaborate on the reasons why facility-based resources are unable to meet psychogeriatric client and family needs.

_____ |___|

_____ |___|

_____ |___|

_____ |___|

22. What types of community-based resources are used frequently by your organization (e.g. adult day program, seniors' centres, etc.). [**NOTE:** *Ask for a brief description of the services outlined. For community respondents, ask them what other community-based resources they refer to, and/or that they access frequently.*]

Community-based Resources:

Type *Brief Description of Service*

_____ |___|
_____ |___|
_____ |___|
_____ |___|

23. For those community-based resources listed above, indicate the extent to which they collectively meet the needs of psychogeriatric clients and their families.
[**NOTE:** *Read list and code selected response.*]

1 Completely
2 To a great extent
3 To some extent
4 Not at all |___|

(IF RESPONDENT INDICATED to "some extent" or "not at all"), please elaborate on the reasons why community-based resources are unable to meet psychogeriatric client and family needs.

_____ |___|
_____ |___|
_____ |___|
_____ |___|

24. In general, what types of additional resources are required to address the special needs of psychogeriatric clients and their families?

1. _____ |___|
2. _____ |___|
3. _____ |___|
4. _____ |___|
5. _____ |___|

25. Of all the items indicated, what are the most needed additional resources in order of priority. [**NOTE:** *Ask respondent to rank order the listed responses from Q #24 and record the rank of the item in the blanks below*].

		Item #	
1	Most needed	___	|___|
2	Second most needed	___	|___|
3	Third most needed	___	|___|

PART 3: CLIENT CHARACTERISTICS/BEHAVIOURS

1. In your opinion, what are the three most problematic psychogeriatric client behaviours? When selecting the behaviours, focus on those that pose the most significant care and management challenges for frontline caregivers. Please consider factors such as how stressful it is for frontline staff and how much time is spent dealing with the problematic behaviours. [NOTE: *Identify and record the three most problematic behaviours, if more are given.*]

   1. _____ |__|
   2. _____ |__|
   3. _____ |__|

2. Are there specific times and/or situations during which these three problematic behaviours are most likely to occur?

   1 Yes
   2 No |__|

   [IF YES, ASK FOR SPECIFICS IN RELATION TO THE THREE BEHAVIOURS CITED; ASK AS AN OPEN ENDED QUESTION AND PROMPT WITH LIST AS NECESSARY], indicate when they are most likely to occur:

   First Cited
   1 no specific times and/or situations
   2 at a specific time of day, specify _____
   3 during personal care activity, specify _____
   4 during therapeutic/recreational activities, specify _____ |__|
   5 at meal times
   6 during visiting times
   7 other factors responsible (e.g. environmental stress, staff shortages, underlying physical conditions, etc.), specify

   Specify
   |__|
   |__|
   _____ |__|
   _____ |__|
   _____ |__|

Second Cited

1 no specific times and/or situations
2 at a specific time of day, specify _____
3 during personal care activity, specify _____
4 during therapeutic/recreational activities, specify _____ |__|
5 at meal times
6 during visiting times
7 other factors responsible (e.g. environmental stress, staff shortages, underlying physical conditions, etc.), specify

Specify
|__|
|__|
_____ |__|
_____ |__|
_____ |__|

Third Cited

1 no specific times and/or situations
2 at a specific time of day, specify _____
3 during personal care activity, specify _____
4 during therapeutic/recreational activities, specify _____ |__|
5 at meal times
6 during visiting times
7 other factors responsible (e.g. environmental stress, staff shortages, underlying physical conditions, etc.), specify

Specify
|__|
|__|
_____ |__|
_____ |__|
_____ |__|

3. In your experience, do you find that these three problematic behaviours are associated with specific diagnoses/disorders?

1 Yes
2 No |__|

(IF YES), please specify the diagnoses/disorders for the three reported problematic behaviours.

Behaviour	*Diagnosis/Disorder*	Behav.	Diag.
1.	_____	|__|	|__|
2.	_____	|__|	|__|
3.	_____	|__|	|__|

4. In your experience, do you encounter problematic behaviours that are either drug-induced or exacerbated by medications?

   1 Yes
   2 No |__|

   (IF YES), please describe the typical drug-related behavioural problems encountered. [**NOTE:** *Ask respondent to focus on the manifested behaviours associated with drugs/medications.*]

   _____ |__|
   _____ |__|
   _____ |__|

5. [**INTERVIEWER'S NOTE:** *Ask the respondent to read the Behavioural Disturbance Classification Scheme Response Card (Appendix B). Tell respondent that while we want him/her to read through and consider all the specific behaviours within each category, we are really interested in behavioural groupings (there is only one item at the end of the section that deals with discrete behaviours). Ask participant to respond using the complete behavioural category with respect to their total client population. Give the respondent time to read and reflect on the behavioural categories.*]

   For each of the behavioural categories, I will ask you what percentage of your total current client population exhibits behavioural disturbances characteristic of the behavioural category.

   Starting with the (first, second ...) category, what percentage of your residents/clients exhibits these behavioural disturbances?
   [**NOTE:** *Record the actual percentage cited in the boxes.*]

Behavioural Category	*Percentage of Population*
1. AGITATED/AGGRESSIVE - PHYSICAL	|__|__|__|
2. AGITATED/AGGRESSIVE - VERBAL	|__|__|__|
3. AGITATED/NON-AGGRESSIVE - PHYSICAL	|__|__|__|
4. AGITATED/NON-AGGRESSIVE - VERBAL	|__|__|__|
5. IDEATIONAL	|__|__|__|
6. EMOTIONAL/AFFECTIVE	|__|__|__|
7. SOCIALLY UNACCEPTABLE	|__|__|__|
8. PROBLEMATIC ADL'S/COPING STRATEGIES	|__|__|__|

6. [INTERVIEWER'S NOTE: *Tell participant that we are trying to determine which behavioural groupings pose the most significant problems for frontline caregivers with respect to frequency.*

Explain that "frontline caregivers" are persons providing direct care on an ongoing basis (for community-based respondents, these include: program workers, home support workers, and homemakers; for facility-based respondents, these include: personal care workers, LPN's, care aides, and/or staff nurses). Ask participant to respond using the Behavioural Disturbance Classification Scheme, making reference to behavioural groupings and applying the broad categories to their total client population.

First ask for each category, how often frontline caregivers have to deal with the behaviours. If respondent answers "frequently", then ask if many or only a few clients exhibit the behavioural disturbances (otherwise skip the number affected). Record the number in the box that corresponds with the frequency and record the number affected for only those with "frequent" ratings.]

For each of the categories, I will ask you how <u>often</u> frontline caregivers have to deal with the behavioural disturbances.

For those you mention as being dealt with "frequently", I will then ask if <u>many</u>, or only a <u>few</u> clients exhibit these behaviours on average.

Starting with the (first, second ...) category, how often do frontline caregivers have to deal with these behaviours? (If answers "frequently") do many or only a few clients exhibit these behaviours?

Behavioural Category	*Frequency Rating* 1=Frequently 2=Occasionally 3=Seldom 4=Never	*#Affected* 1=Many 2=A Few
1. AGITATED/AGGRESSIVE - PHYSICAL	|___|	|___|
2. AGITATED/AGGRESSIVE - VERBAL	|___|	|___|
3. AGITATED/NON-AGGRESSIVE - PHYSICAL	|___|	|___|
4. AGITATED/NON-AGGRESSIVE - VERBAL	|___|	|___|
5. IDEATIONAL	|___|	|___|
6. EMOTIONAL/AFFECTIVE	|___|	|___|
7. SOCIALLY UNACCEPTABLE	|___|	|___|
8. PROBLEMATIC ADL'S/COPING STRATEGIES	|___|	|___|

7. [**INTERVIEWER'S NOTE:** *Tell participant that we are trying to determine which behavioural groupings are the most difficult for frontline caregivers to deal with on an ongoing basis.*

Explain that "frontline caregivers" are persons providing direct care on an ongoing basis (for community-based respondents, these include: program workers, home support workers, and homemakers; for facility-based respondents, these include: personal care workers, LPN's, care aides, and/or staff nurses). Ask participant to respond using the Behavioural Disturbance Classification Scheme, making reference to behavioural groupings and applying the broad categories to their total client population.

Record the number in the blank that corresponds with the difficulty rating.]

For each of the categories, I will ask you how difficult it is for frontline caregivers to deal with the behavioural disturbances. When rating the difficulty of behaviours, please consider factors such as how stressful it is for frontline staff and how much time is spent dealing with the problematic behaviours.

For those you mention as being "moderately or very difficult", I will then ask you to tell me why you think this is so.

Starting with the (first, second ...) category, how difficult is it for frontline caregivers to deal with these behaviours? (If answers "moderately or very difficult") why do you think this is so?

Behavioural Category	Difficulty Rating 1=Not Difficult 2=Somewhat Difficult 3=Moderately Difficult 4=Very Difficult
1. AGITATED/AGGRESSIVE - PHYSICAL	|___|
Reason Why	
_____	|___|
_____	|___|
_____	|___|
2. AGITATED/AGGRESSIVE - VERBAL	|___|
Reason Why	
_____	|___|
_____	|___|
_____	|___|

(1 = Not Difficult, 2 = Somewhat Difficult, 3 = Moderately Difficult, 4 = Very Difficult)

3. AGITATED/NON-AGGRESSIVE - PHYSICAL |___|

Reason Why

_____ |___|

_____ |___|

_____ |___|

4. AGITATED/NON-AGGRESSIVE - VERBAL |___|

Reason Why

_____ |___|

_____ |___|

_____ |___|

5. IDEATIONAL |___|

Reason Why

_____ |___|

_____ |___|

_____ |___|

6. EMOTIONAL/AFFECTIVE |___|

Reason Why

_____ |___|

_____ |___|

_____ |___|

7. SOCIALLY UNACCEPTABLE |___|

Reason Why

_____ |___|

_____ |___|

_____ |___|

8. PROBLEMATIC ADL'S/COPING STRATEGIES |___|

Reason Why

_____ |___|

_____ |___|

_____ |___|

8. With respect to the stresses and time constraints frontline caregivers experience, is there one behavioural category that stands out as creating the most difficulty?

1 Yes
2 No |__|

(IF YES), specify which behavioural category creates the most difficulty and the reasons why.

Behavioural category *Reason why* Behav. |__|

_____ Why |__|

_____ Why |__|

_____ Why |__|

9. [INTERVIEWER'S NOTE: *For this question, make sure participant responds using discrete behaviours contained in each category. Ask respondent to indicate up to three difficult behaviour management problems for frontline caregivers (use relevant definition) within each category.*]

Now we are going to talk about the difficulties frontline caregivers have in managing behaviours. This time we will be focusing on individual behaviours within each category. Again, consider factors such as how stressful and time consuming it is for frontline staff to deal with the problematic behaviours.

Starting with the (first, second ...) category, give me up to three of the most difficult behaviours for frontline caregivers to manage.

Behavioural Category	Difficult Behaviour(s)	
1. AGITATED/AGGRESSIVE - PHYSICAL	_____	|__|__|
	_____	|__|__|
	_____	|__|__|
2. AGITATED/AGGRESSIVE - VERBAL	_____	|__|__|
	_____	|__|__|
	_____	|__|__|
3. AGITATED/NON-AGGRESSIVE - PHYSICAL	_____	|__|__|
	_____	|__|__|
	_____	|__|__|
4. AGITATED/NON-AGGRESSIVE - VERBAL	_____	|__|__|
	_____	|__|__|
	_____	|__|__|

5. IDEATIONAL _____ |__|__|
_____ |__|__|
_____ |__|__|

6. EMOTIONAL/AFFECTIVE _____ |__|__|
_____ |__|__|
_____ |__|__|

7. SOCIALLY UNACCEPTABLE _____ |__|__|
_____ |__|__|
_____ |__|__|

8. PROBLEMATIC ADL'S/COPING STRATEGIES _____ |__|__|
_____ |__|__|
_____ |__|__|

10. Of all of the individual behaviours you have identified, which three are the most difficult for frontline staff? [**NOTE:** *Direct respondent to indicate the three that stand out across all categories.*]

Class. Behav.

1. _____ |__| |__|__|
2. _____ |__| |__|__|
3. _____ |__| |__|__|

11. Are there typical combinations of behaviours that pose significant care and management challenges for frontline staff?

1 Yes
2 No |__|

(IF YES), what are they?

_____ |__|__|
_____ |__|__|
_____ |__|__|
_____ |__|__|

15. Do you have any other comments or suggestions to add?

1 Yes
2 No |__|

(IF YES) Please elaborate. _____ |__|

_____ |__|

_____

_____

_____

_____

Thank you very much for your participation. You have contributed to our understanding of behavioural characteristics for subgroups of psychogeriatric clients. If you have any further thoughts or comments pertaining to this study, please do not hesitate to contact me.

[**NOTE:** *Give telephone number.*]

12. What (if any) specialized programs or approaches are being used by your organization to successfully address challenging behaviour problems? [**NOTE:** *Probe for what is working well/successes.*]

_____ |__|
_____ |__|
_____ |__|
_____ |__|

13. Overall, are you satisfied with the types of care and management strategies used by frontline caregivers in your organization to care for clients exhibiting challenging behaviours?

1 Yes
2 No |__|

(IF NO) what would improve the ability to care for clients exhibiting challenging behaviours?

_____ |__|
_____ |__|
_____ |__|
_____ |__|

Final Comments

14. We are interested in knowing how appropriate the behavioural categories are for identifying and grouping problematic behaviours. Please share any comments or concerns

_____ |__|
_____ |__|
_____
_____