A Profile of Ontario's Home Care Clients with Alzheimer's Disease or Other Dementias

Drawn from RAI-HC Assessments, 2005

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Preface

The following report was prepared at the request of the Alzheimer Society of Ontario, by ideas for Health at the University of Waterloo. We wish to acknowledge the work of Jeff, Poss, Research Assistant Professor, Department of Health Studies and Gerontology and his associate, John Hirdes, PhD and the support of Paul Stolee, Associate Professor & Graham Trust Research Chair in Health Informatics School of Optometry University of Waterloo.

Our Society is committed to persons with Alzheimer's disease and related dementias, to our partners who provide support and who plan for improved services. This report enables the reader to understand more about people with dementia who live in our communities and the challenges of their natural helpers. It helps us understand what supports they receive and what more they need.

Our Society welcomes the trend toward evidence-based practice and policy-making. We are pleased to be able to contribute this new information to further improve practice and policy for persons affected by dementia in Ontario.

Additional copies of this report are available from;

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Or at our website: www.alzheimerontario.org

About the Data

Case managers in home care in Ontario complete an assessment on all adult (age 18 and over) home care clients who are on service for longer than two months. The information is collected using a standard form called the Resident Assessment Instrument for Home Care (RAI-HC). This assessment uses information from all available sources, such as the client themselves, family and other informal caregivers, paid caregivers and other health care professionals.

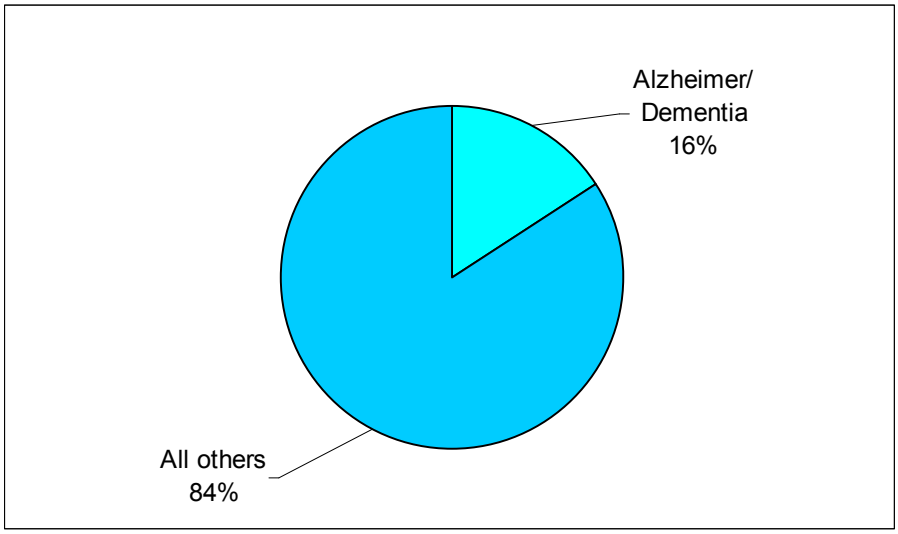
There were over 177,000 RAI-HC assessments completed in 2005, but some home care clients had two or more assessments, so the last assessment for each individual was used, for a total of 127,151.

Only included are individuals residing in private home/apartment or retirement/congregate care settings; home care clients assessed in hospital for placement purposes, and those in long term care homes were excluded from these analyses.

This report acknowledges the work of Ontario case managers working in the Community Care Access Centres who conduct these assessments, as well as the home care clients and their caregivers. The assessment data are provided with individual identifiers removed under license agreement with interRAI, a collaborative international group of health researchers.

These analyses were completed by ideas for Health, University of Waterloo.

Figure 1 Assessed Home Care Clients, 2005



Demographic Characteristics

Among home care clients, those with Alzheimer's disease or other dementia tend to be older and are more likely to be married. Age is consistent with their being diseases of older age.

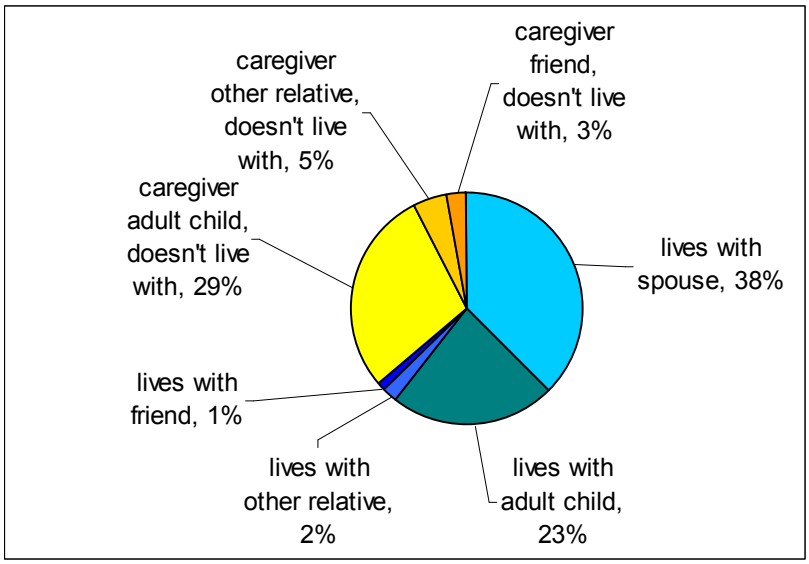
Table 1 Demographic Characteristics

	Alzheimer's disease/other dementia	All other home care clients
Average age	82.3	75.4
Median age (half older/half younger)	83.1	79.2
90% between the ages of	68.6 -- 93.5	46.0 -- 92.8
Sex: Women	64%, age 83.1	68%, age 76.5
Men	36%, age 80.9	32%, age 73.1
Married	44%	37%

Caregiver

Nearly two-thirds of home care clients with Alzheimer's disease or other dementia live with their primary caregiver, almost always a spouse or adult child. In the majority of cases where the primary caregiver does not live with the individual, the caregiver is an adult child. All identified persons with Alzheimer's disease or other dementia in this home care dataset identified a primary caregiver.

Figure 2 Residential Status and Caregiver Relationship



Formal and Informal Home Care Services

As part of the RAI-HC assessment, clients and their families are asked to name the number of hours of care received in the last 7 days, and this can include services provided by CCAC provider agencies as well as other sources such as non-profit community services, insurance or private-pay.

In addition, clients and families are asked to estimate the total number of unpaid care hours provided to the client from all unpaid individuals for needs of instrumental and activities of daily living.

When comparing the Alzheimer's disease and other dementia clients to other home care clients, there is much higher proportional difference for the informal care component, relative to the paid (mostly CCAC) services.

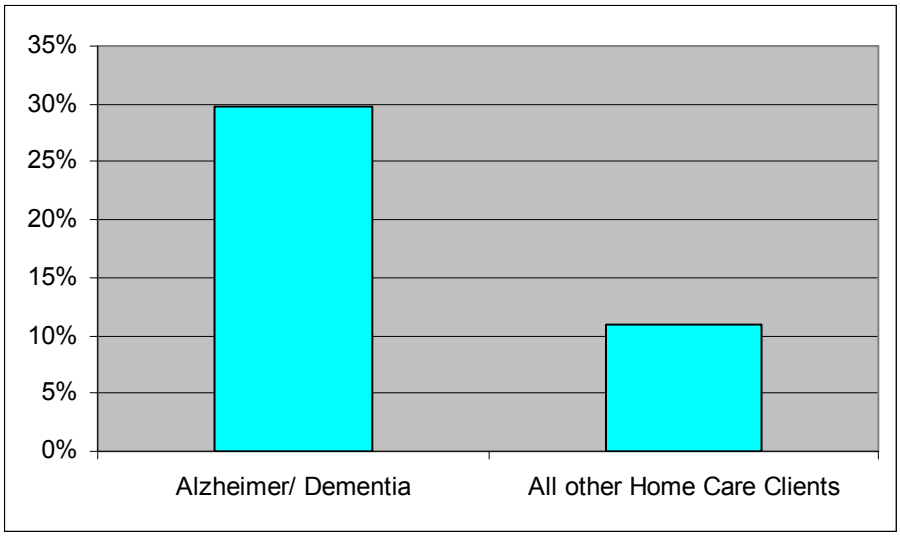
Table 2 Informal and Formal Care Time

Hours of service per week	Alzheimer's disease/other dementia	All other home care clients	% higher for A/D clients
Informal (unpaid) service	30.4	17.4	75%
Formal care	6.8	4.7	45%
Components of formal care:			
Personal care	*4.2*	*2.4*	*76%*
Homemaking	*1.7*	*1.2*	*46%*
Nursing	*0.7*	*0.9*	*-18%*
Therapies	*0.1*	*0.2*	*-39%*

Caregiver Stress

The RAI-HC tool asks each case manager to record if: "a caregiver is unable to continue in caring activities – e.g. decline in the health of the caregiver makes it difficult", and "primary caregiver expresses feelings of distress, anger or depression". One or both of these items was true in about 30% of clients with Alzheimer's disease or other dementia, compared to about 11% among other home care clients.

Figure 3 Caregiver Stress



Responsive Behaviour

For persons with Alzheimer's disease or other dementia, as well as other conditions found among home care clients, a number of behaviours may occur as a result of the person's response to the disease process.

The following table presents the proportion of persons with five assessed behaviours found to be present in the 3 days prior to the assessment. The overall rate of these challenging and stressful behaviours is nearly 10 times higher among home care clients with Alzheimer's disease or other dementia.

Table 3 Rates of Responsive Behaviour

	Alzheimer's disease/other dementia	All other home care clients
Wandering	10.6%	0.4%
Verbally abusive	10.3%	1.4%
Physically abusive	3.3%	0.3%
Socially inappropriate	5.9%	0.6%
Resists care	16.6%	1.7%
Any of the above	***28.7%***	***3.2%***

Client Behaviour and its Relationship with Caregiver Stress and Informal Time

For all home care clients, but notably for those with Alzheimer's disease or other dementia, these behaviours are associated with higher levels in two related outcomes for informal caregivers: stress and caregiving time.

Figure 4 Caregiver Stress and Responsive Behaviour

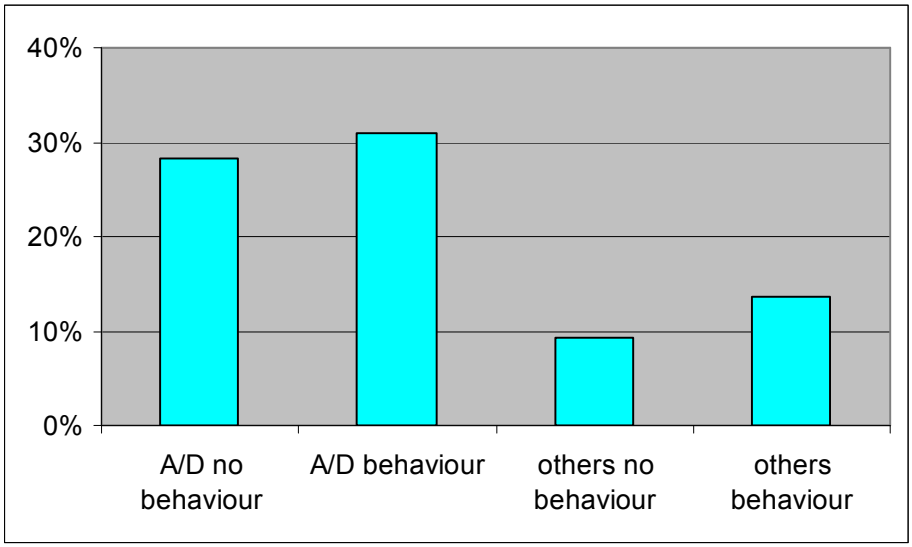
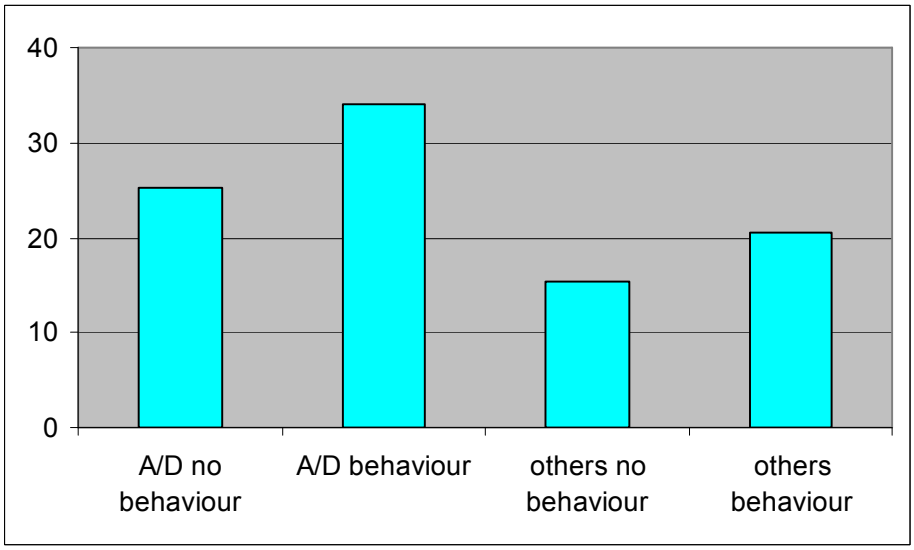


Figure 5 Informal Care Hours and Responsive Behaviour



Mood

Mood items are important indicators of emotional well being. Several mood items are collected in the RAI-HC, and two are reported here. Both persistent anger with oneself or others as well as expressions of unrealistic fears are notably higher among home care clients with Alzheimer's disease or other dementia.

Figure 6 Persistent Anger with Self or Others

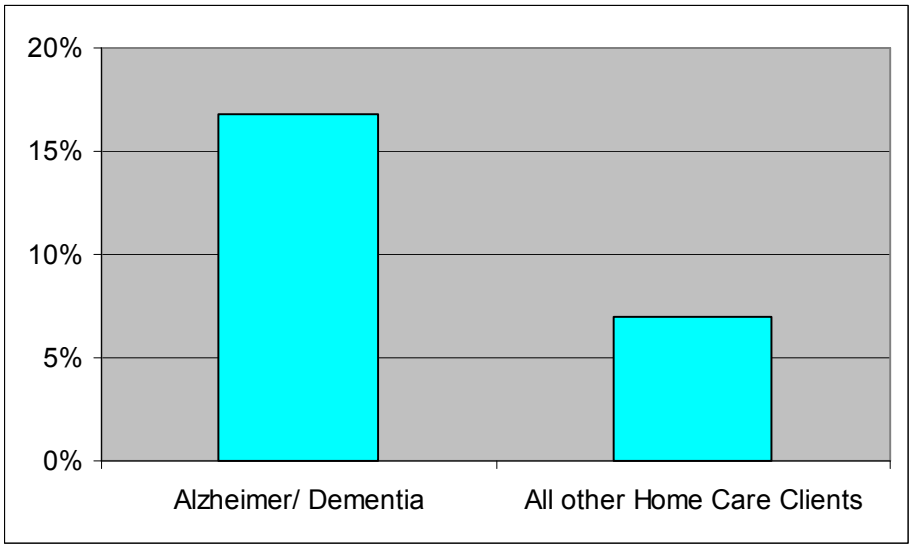
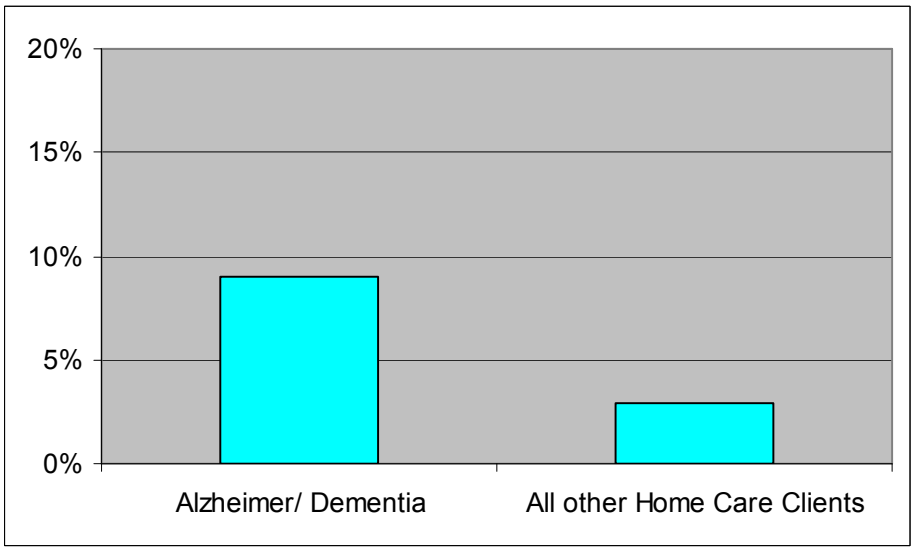


Figure 7 Unrealistic Fears



Memory and Cognition

Memory and executive function are notably more impaired among home care clients with Alzheimer's disease or other dementia.

Figure 8 Problem with Short Term Memory

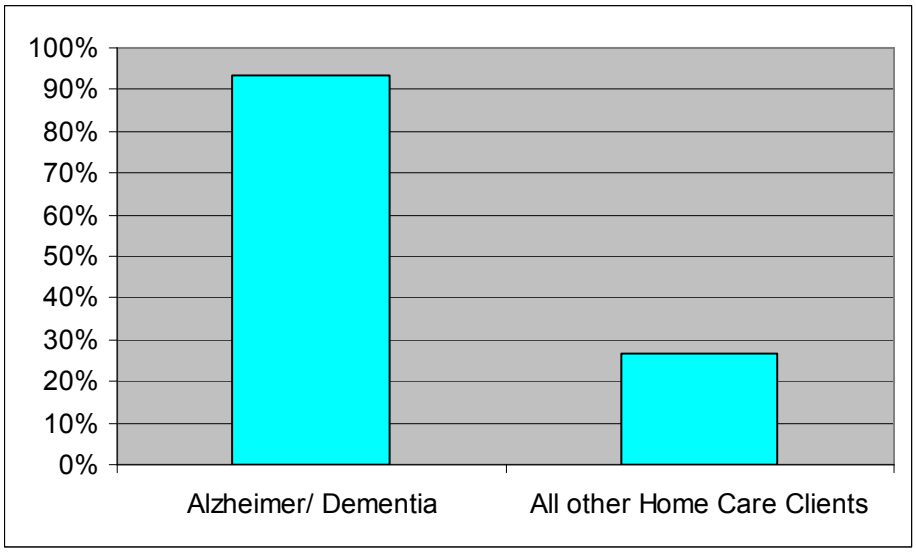
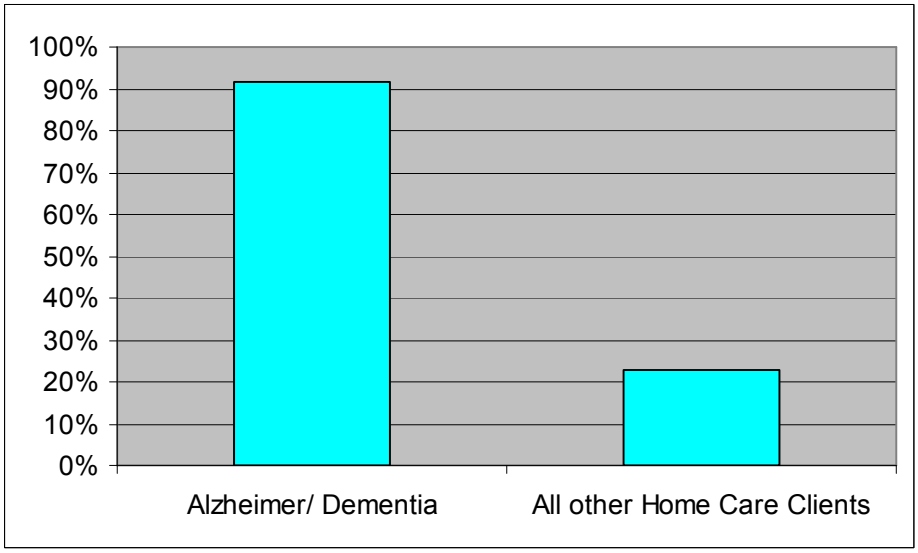


Figure 9 Problem with Cognitive Skills for Daily Decision Making



Physical Function and Independence

Several items of self-care are collected in the RAI-HC assessment, and selected ones are presented here. Difficulty with dressing and eating are more common in individuals with Alzheimer's disease or other dementia.

Figure 10 Receives Assistance with Dressing

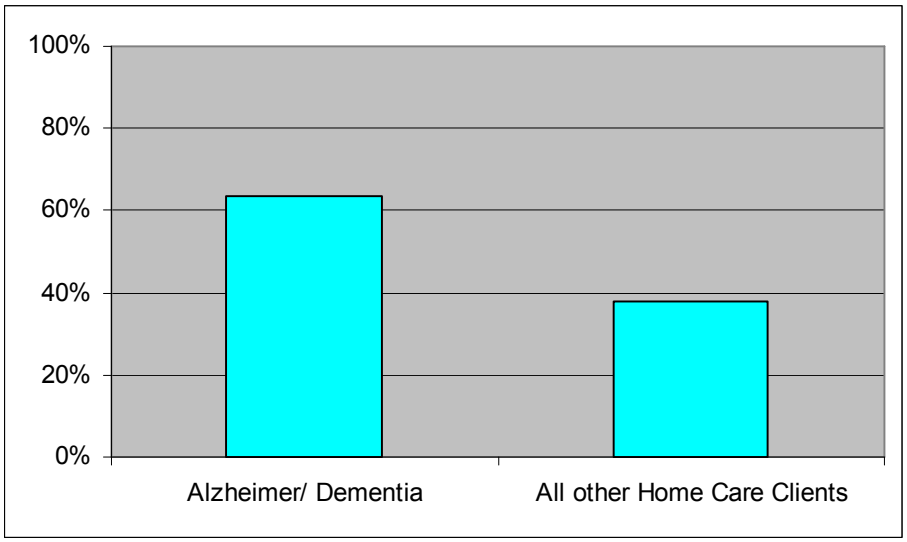
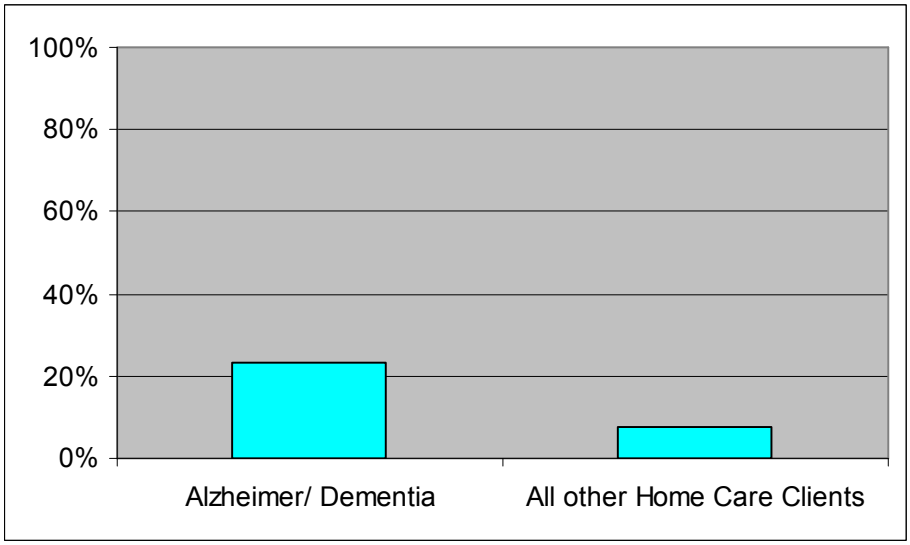


Figure 11 Receives Assistance with Eating



Continence

Proportions of individuals with urinary and bowel continence difficulties are notably higher among home care clients with a condition of Alzheimer's disease or other dementia.

Figure 12 Urinary Incontinence

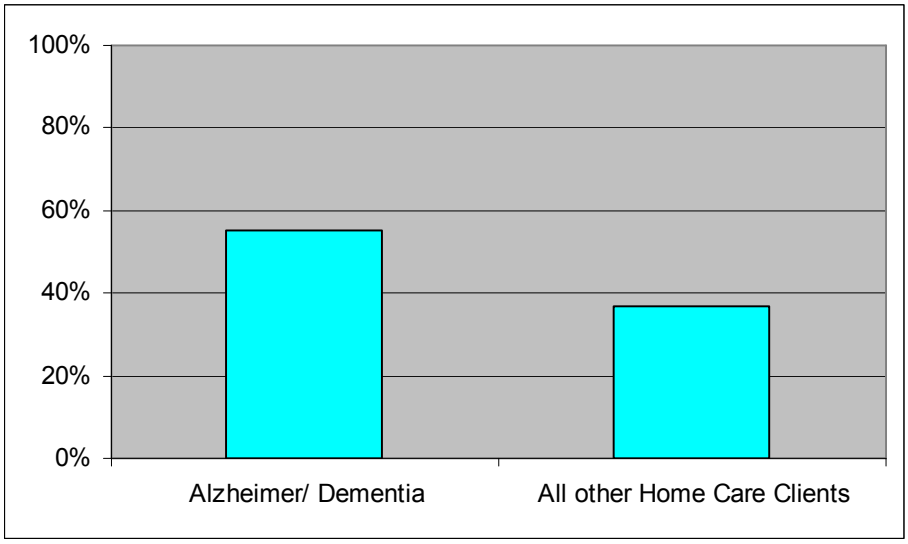
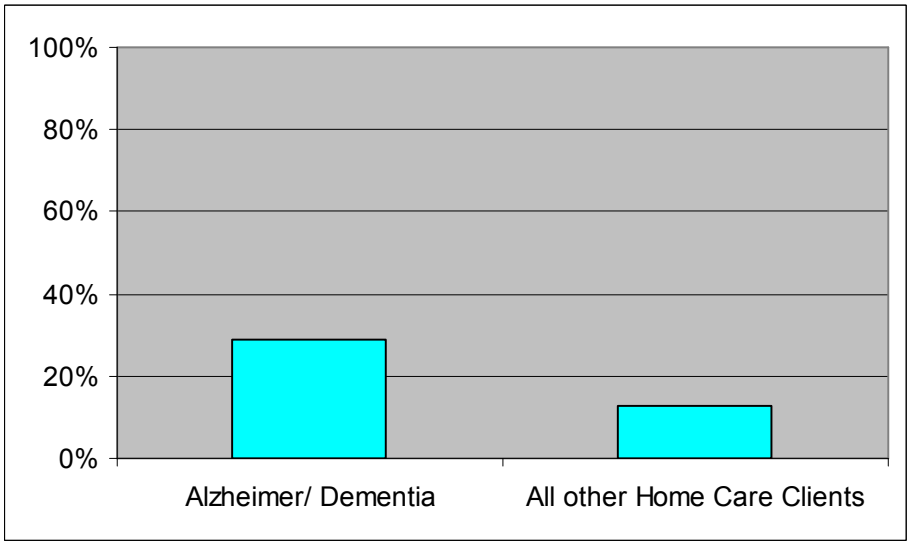


Figure 13 Bowel Incontinence



Co-Morbid Diagnoses

Conditions that are commonly seen among home care clients are recorded on the RAI-HC assessment. Table 4 gives rates of diseases with notably lower or higher rates among those with Alzheimer's disease or other dementia, compared to all other home care clients. Stroke and Parkinson's disease tend to show higher rates among those with Alzheimer's disease or other dementia, while other diseases show similar or lower rates.

However, even when rates of these diseases are lower than for other home care clients, in most cases they still represent significant proportions (e.g., 1 in 5 has coronary heart disease, 1 in 9 has congestive heart failure, etc.) and represent disease burden *in addition* to the Alzheimer's disease or other dementia. For many of the other home care clients, these diagnoses represent a sole problem. When considering all of the 28 disease diagnoses that the RAI-HC records, home care clients with Alzheimer's disease or other dementia had on average 3.9, compared to other home care clients who had 3.3.

Table 4 Disease Diagnoses

	Alzheimer's disease/other dementia	All other home care clients
More Common in A/D:		
Stroke	21.4%	17.4%
Parkinson's disease	6.0%	3.5%
Less Common in A/D:		
Arthritis	43.3%	53.0%
Coronary heart disease	21.5%	25.1%
Diabetes	18.7%	24.6%
Emphysema/COPD/asthma	10.8%	17.7%
Cancer	8.1%	15.8%
Congestive heart failure	10.5%	13.6%
Peripheral vascular disease	5.3%	8.7%
Fracture other than hip	6.2%	8.4%
Renal failure	2.9%	5.0%
Multiple Sclerosis	0.3%	2.2%

Living Arrangement

Shown below are characteristics of persons with Alzheimer's disease or other dementia when first admitted to home care, based on living arrangement. Persons in the first column reside in a congregate care setting, such as a retirement home or assisted living residence, and show the highest levels of physical and cognitive impairment, but the lowest levels of caregiver help and stress. Those living alone show the lowest levels of impairment. Among the last two columns (those residing with their primary caregiver, and those residing with others), the notable difference is in higher caregiver stress and informal care time among those clients who live with their primary caregiver.

Table 5 Characteristics by Living Arrangement

	Living Arrangement			
New admissions with Alzheimer's disease or other dementia, year 2005 n=7,601	Board & Care/Assisted Living/Group Home	Alone	With caregiver	With others (not caregiver)
n (%)	1099 (14.5%)	1492 (19.6%)	4584 (60.3%)	426 (5.6%)
Average ADL* long scale (0 independent, 28 max)	5.1	1.3	4.0	3.8
Average IADL** sum Scale (0 independent, 21 max)	18.0	10.9	16.5	15.1
Average Cognitive Perf. Scale (0 independent, 6 max)	3.1	2.4	2.9	2.8
Any of 5 behaviours	33%	20%	31%	31%
Caregiver Stress	17%	24%	42%	30%
Average Informal hours/week	11	16	38	22

** Activities of Daily Living: bed mobility, transfer, locomotion, dressing, eating, toilet use, personal hygiene*
***Instrumental Activities of Daily Living: meal preparation, housework, medication management, managing finances, phone use, shopping, transportation*

Comparing admission to home care and subsequent reassessment

For 3,240 individuals in 2005 who were assessed within 14 days of their home care case being opened and who were subsequently reassessed (on average 5 ½ months later), the table below presents descriptive and service characteristics. It shows that personal care is the most used service, and is the service most often newly received. While most of these services show increases, they remain at low to modest levels. Services for meals appear to be relatively un-influenced by the introduction of home care and case management. Informal caregiver time remains approximately the same, on average, as do levels of caregiver stress. The persons with Alzheimer's disease or other dementia show some increased dependency in the intervening period, notably in activities of daily living.

Table 6 First Assessment and Follow-up Assessment Comparison

n=3,240, A/D, assessed within first 14 days of case being opened	First assessment	Same individuals on follow-up assessment
Services Received (last 7 days)		
Personal Care	24.5%	54.5%
Homemaking	23.8%	33.9%
Meals	19.1%	21.0%
Volunteer Services	1.2%	1.7%
Day Hospital/Day Program	4.3%	9.4%
Respite care services	1.1%	2.8%
Formal care hours/week	3.1	4.9
Informal Caregiving		
Informal care/week	26.2 hrs	25.6 hrs
Caregiver Stress	33.6%	34.4%
Client Characteristics		
Average ADL* long scale (0 independent, 28 max)	3.8	5.3
Average IADL** sum Scale (0 independent, 21 max)	15.5	16.4
Average Cognitive Performance Scale (0 independent, 6 max)	2.9	3.1
Any of 5 behaviours	29%	33%

** Activities of Daily Living: bed mobility, transfer, locomotion, dressing, eating, toilet use, personal hygiene*
***Instrumental Activities of Daily Living: meal preparation, housework, medication management, managing finances, phone use, shopping, transportation*

Summary

Home care clients who are assessed with the RAI-HC represent individuals with longer term health and care needs that are, on the whole, beyond what informal care (i.e., unpaid family, neighbours, and friends) can provide. Within this group of persons with high needs, those with Alzheimer's disease or other dementia represent a distinct group who:

- receive somewhat larger amounts of paid care
- receive much higher amounts of informal care
- have nearly 10 times the rate of responsive behaviours
- show higher rates of mood disturbance
- have much higher rates of memory and executive function problems
- have greater physical dependency in everyday tasks such as dressing or eating
- show acutely higher rates of incontinence.

Caregivers, who are mostly spouses and adult children or children-in-law:

- provide greater amounts of care, and on a proportional basis receive weaker support from formal care compared to other home care clients
- experience much higher levels of stress, especially where the clients are showing behaviour problems.

Characteristics of persons with Alzheimer's disease or other dementia tend to look different depending on their living arrangement. Those who live alone tend to be more capable of doing so (i.e., lower levels of dependency), while those living with others both need and receive higher levels of care. Not surprisingly, community-dwelling individuals with Alzheimer's disease or other dementia who reside in congregate care settings show the highest levels of dependency.

Individuals with Alzheimer's disease or other dementia tend to show higher rates of receipt of many services after becoming home care clients, although the rates of service generally remain low. Informal care time was not withdrawn, on average, once home care services were in place.

Limitations

This report reflects only those individuals who are receiving formal home care services. Outside of the home care system, there are very large numbers of individuals with dependencies, both with Alzheimer's disease or other dementia as well as other conditions, who reside in their own homes through support from unpaid family, friends, and neighbours. In addition, there are large numbers of individuals both in and out of home care who are experiencing symptoms of Alzheimer's disease or other dementia but who are undiagnosed. As a result, this report reflects individuals with more significant dependencies, or those for whom informal supports are inadequate. But it is not known in what ways or to what extent these un-assessed individuals differ from those who are included here.

As a standardized clinical assessment, the RAI-HC has been designed for general use in home care, and does not include some things that might be useful for this particular report, for example sleep disturbance in client or caregiver. The assessment's strengths are its ability to capture objective, observable health and care characteristics; capturing and interpreting detailed narrative accounts is impractical with very high numbers of assessments.

It would be useful to know which clients are discharged from home care, i.e., are admitted to hospital, die, or enter nursing home. Unfortunately, the date of discharge and the reason cannot be presently linked in these research data.