Analysis in Brief

Supporting Informal Caregivers— The Heart of Home Care

Executive Summary

There are more than 2 million informal caregivers in Canada.[1] A recent conservative estimate of their economic contribution was $25 billion.[2]

Many of these caregivers are providing critical support to seniors who are living at home and receiving publicly funded home care for complex health conditions. In some cases, caregivers experience distress.

If they are unable to continue in their role, there is increased risk of institutionalization, potentially for both the home care client and the caregiver. In its 2009 report, the Special Senate Committee on Aging called for a national caregiver strategy for Canada.[3]

This study provides planners and policy-makers with a starting point for an evidence-informed discussion on caregiver distress and its potential impact on the health care system—from home care to community services, residential care facilities and hospitals.

Key findings include the following:

- Few seniors who are receiving publicly funded long-term home care are able to manage alone. In a sample of 131,000 home care clients age 65 and older, only 2% were coping without an informal caregiver. Caregivers provided emotional support along with a wide range of services, from meal preparation to medication management, shopping, dressing, bathing and toileting.

- Nearly 20,000 informal caregivers (16%) of seniors receiving home care reported distress related to their role. The rates of distress were significantly higher among those

  – Providing more than 21 hours of care per week: 28%

  – Caring for seniors with symptoms of depression: 32%

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- Caring for seniors with moderate to severe cognition problems (most would be suffering from Alzheimer's disease or other forms of dementia): 37%
- Caring for seniors displaying aggressive behaviours: 52%

The strongest associations with caregiver distress, while controlling for other factors, were found where the home care client suffered from significant problems with cognition and daily functioning, where the number of informal care hours was high and where the client exhibited depressive symptoms or difficult-to-manage behaviours. Among caregivers, it was the spouses, rather than children or friends of the senior, who appeared to be more at risk for distress and potential burnout.

Introduction

The majority of seniors wish to remain in their homes, maintaining their independence for as long as possible.[4] However, many require some form of assistance or care to stay at home safely.[5] Most (about 80%) of this care is provided by informal caregivers who may be family, friends or neighbours.[6] For seniors who also receive publicly funded home care services, the support provided by their informal caregivers becomes an integral part of the care plan.

Informal caregivers provide help with instrumental activities of daily living (IADLs), such as meal preparation, housework, medication management, shopping and transportation, as well as activities of daily living (ADLs), such as personal hygiene, toileting, locomotion and eating. They also provide emotional support.[7]

There are more than 2 million informal caregivers in Canada.[1] A recent conservative estimate of their economic contribution was $25 billion.[2] In its 2009 report, the Special Senate Committee on Aging acknowledged the critical contributions of informal caregivers and called for a national caregiver strategy for Canada.[3]

Providing care for a family member, neighbour or close friend can be very fulfilling and rewarding.[8, 9] In some cases, providing care is challenging, and caregivers experience distress. This study looks at caregiver distress among a subset of the overall caregiver population—those providing support for seniors receiving long-term home care related to chronic health conditions.

Caregiver distress has consequences for the home care client, the informal care provider and the health care system as a whole.[10–12] As a result of distress, caregivers may be unable to continue in their role. If there is no other family member or friend to assume the caregiving, the senior is more likely to require admission to a residential care facility, such as a long-term care or nursing home.[12] Interventions to reduce caregiver burden have the potential to reduce inappropriate or premature admission to residential care.[13]

The goals of this analysis are

- To shed light on the extent and nature of informal caregiving for seniors who are receiving publicly funded home care services;
- To estimate the prevalence of distress among informal caregivers;
- To highlight some of the key factors associated with caregiver distress; and
- To showcase clinical tools being used across Canada to identify home care clients whose caregivers may be at risk.

Methods

The Home Care Reporting System

The Home Care Reporting System (HCRS) was launched by the Canadian Institute for Health Information (CIHI) in 2007 as a pan-Canadian reporting system to provide information for planning, quality improvement and accountability. HCRS captures standardized clinical, demographic, administrative and resource utilization data on clients of publicly funded home care programs. The interRAI Resident Assessment Instrument—Home Care (RAI-HC©) is the HCRS data standard for long-stay home care clients, that is, those expected to require services for more than 60 days. The RAI-HC is being implemented in eight jurisdictions across the country. CIHI will launch a new module for HCRS in 2010–2011 to collect the interRAI Contact Assessment (interRAI-CA©), which will provide standardized information on all home care clients, short and longer term, at initial intake or screening.

Resident Assessment Instrument—Home Care

The RAI-HC is a comprehensive, standardized assessment instrument developed by interRAI, a not-for-profit research network in 30 countries. The assessment evaluates the needs, preferences and strengths of home care clients. It records measures of physical, cognitive and social function along with indicators of clinical status and services received. It also captures information on the informal caregiver and the care provided. The RAI-HC has undergone reliability and validity testing in a number of countries worldwide.[14]

The assessment generates real-time reports for clinicians to assist with planning for individuals and their caregivers. At regional or provincial/territorial levels, the information on client and caregiver populations supports system-level planning, quality improvement and policy development.

Defining Caregiver Distress

Caregiver distress has been defined as "the overall impact of physical, psychological, social, and financial demands of caregiving."[15] The RAI-HC captures two items related to caregiver distress. A home care client is flagged as having a caregiver in distress when one or both of the following are present:

- A caregiver is unable to continue in caring activities—for example, a decline in the health of the caregiver makes it difficult to continue.

- The primary caregiver expresses feelings of distress, anger or depression.

Factors Associated With Distress

A literature review guided the conceptual framework and selection of RAI-HC items and scales included in the analysis. The framework included six broad categories: demographics, function, health status, mood and behaviour, service utilization and informal support. The framework is found in Appendix A, and a guide to the scales derived from the RAI-HC assessment is in Appendix B.

In addition to the RAI-HC scales that shed light on factors associated with caregiver distress, the study looked at an algorithm derived from the assessment that is designed to identify home care clients with priority service needs. This algorithm, the Method for Assigning Priority Levels (MAPLe), also predicts caregiver distress.[16] Research has demonstrated that clients in the higher MAPLe levels are more likely to be admitted to a residential care facility within 90 days than those in the low-priority groups.

The Data

The data included assessments for 131,258 individuals living in the community who were age 65 and older and received a RAI-HC assessment through a publicly funded home care program. The assessments were conducted during 2007–2008 in Nova Scotia, Ontario, the Winnipeg Regional Health Authority and the Yukon.

Statistical Considerations

Using items available from the RAI-HC assessments, this analysis highlights some of the factors associated with caregiver distress. Appendix C provides the prevalence of caregiver distress for subgroups of clients based on the conceptual framework. Logistic regression was used to identify the combination of factors most strongly associated with caregiver distress. Appendix D illustrates the results of the model.

A key strength of this analysis is the availability of comprehensive data about home care clients across multiple health domains, shedding light on factors associated with caregiver distress. However, limited information on the caregivers themselves and their health status somewhat constrains the scope of the study.

The large sample size, which provides the required power to detect statistical differences, also allows for the detection of very small differences that may not be clinically relevant. In addition, HCRS does not yet have pan-Canadian coverage, meaning this analysis may not fully reflect the diversity of home care clients and their informal caregivers across Canada.

The study is an initial exploratory snapshot of this population at a point in time. It does not look at changes in caregiver distress over time or the factors that may be associated with these changes.

Results

Informal Caregivers

The majority (98%) of seniors age 65 and older who received publicly funded long-term home care services had one or more informal caregivers.

Figure 1 illustrates that, among married clients, the primary caregiver was most often the spouse (75%). Children were the most common primary caregivers for non-married clients (75%). Non-married clients included those never married as well as those who were widowed or divorced.

Figure 1

Relationship of the Informal Caregiver to the Home Care Client, by Marital Status
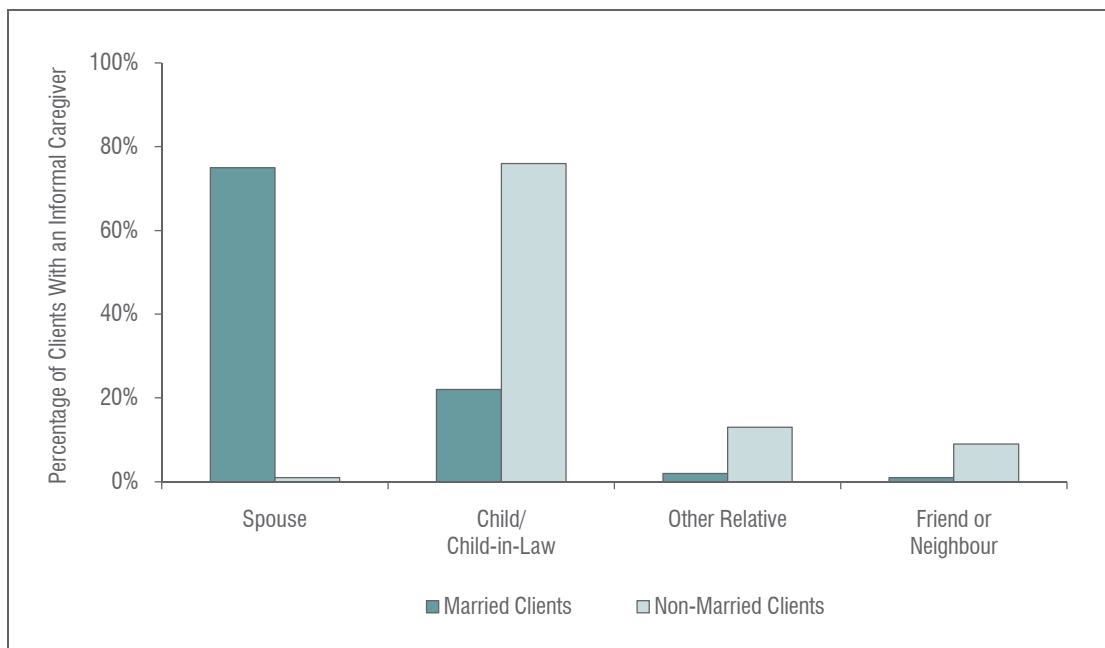
Source
Home Care Reporting System, 2007–2008, Canadian Institute for Health Information.

Figure 2 illustrates that nearly all home care clients with an informal caregiver (98%) received emotional support from one or more of their caregivers. Nine out of 10 also received assistance with IADLs, such as meal preparation, housework, shopping and transportation.

A smaller proportion of these seniors (43%) received help from informal caregivers with basic ADLs, such as bathing and toileting.

Figure 2

Types of Informal Care Received by Home Care Clients

Source
Home Care Reporting System, 2007–2008, Canadian Institute for Health Information.

Prevalence of Informal Caregiver Distress

Overall, nearly one in six home care clients (16%) had caregivers experiencing distress related to their role. However, the rate was considerably higher among those providing many hours of care and those caring for certain subgroups of home care clients. The following figures highlight the prevalence of caregiver distress among selected groups of home care clients with different characteristics and care needs. The results for all subgroups may be found in Appendix C.

Figure 3 illustrates that caregiver distress is related to the hours of informal care. Clients who received 21 or more hours of informal care per week were four times more likely to have a distressed caregiver than those who received 10 hours or less per week (28% versus 7%).

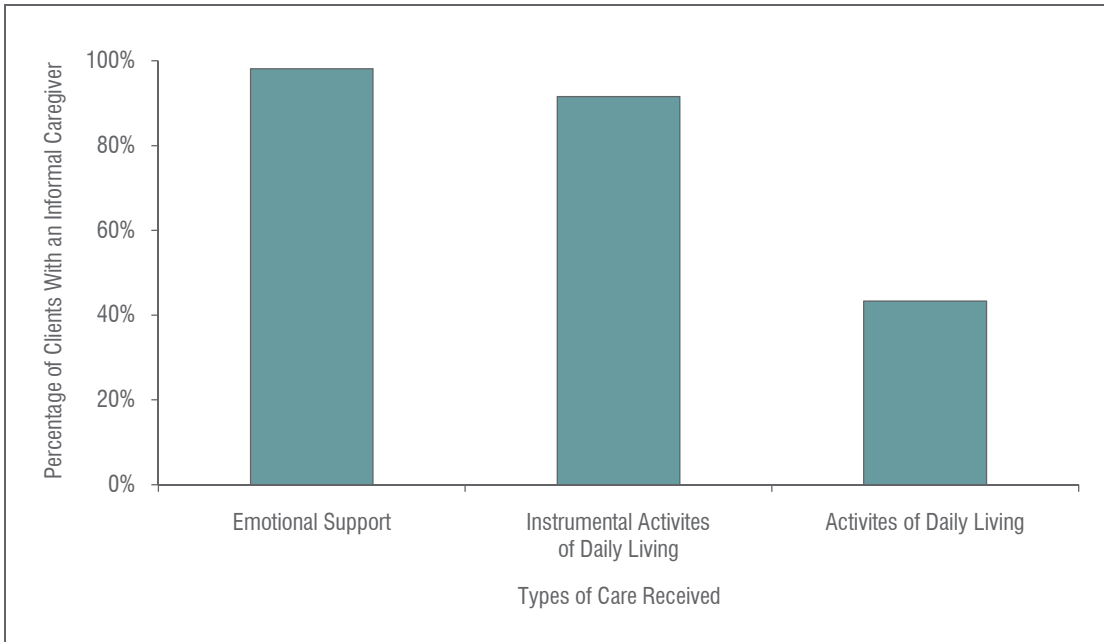## Figure 3

Caregiver Distress, by Number of Hours of Informal Care

Source
Home Care Reporting System, 2007–2008, Canadian Institute for Health Information.

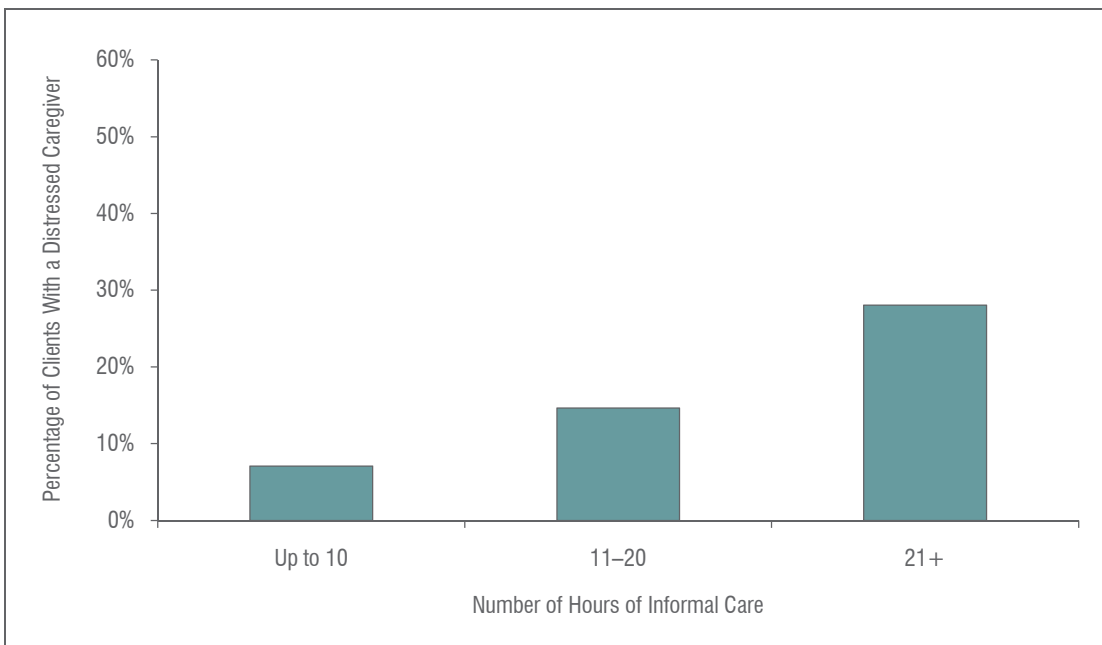Figure 4 illustrates that caregiver distress is also related to impairment in key areas of everyday function. Home care clients with impairment in IADLs were four times more likely to have a distressed caregiver than those without IADL impairment. The rates of caregiver distress among clients with impairment in either ADLs or communication were more than double those of clients without these impairments.

Figure 4

Caregiver Distress, by Client Function

Source
Home Care Reporting System, 2007–2008, Canadian Institute for Health Information.

Figure 5 illustrates two important client factors associated with caregiver distress—mood and behaviour. The RAI-HC supports screening for depressive symptoms using the Depression Rating Scale derived from the assessment. Nearly a third of those caring for home care clients with a score of 3 or more on the scale, indicating possible depression, exhibited signs of distress. The highest rates of caregiver distress, at more than 50%, were found among caregivers of home care clients who exhibited verbally and/or physically abusive behaviours—four times the rate for caregivers of clients who did not exhibit these behaviours.
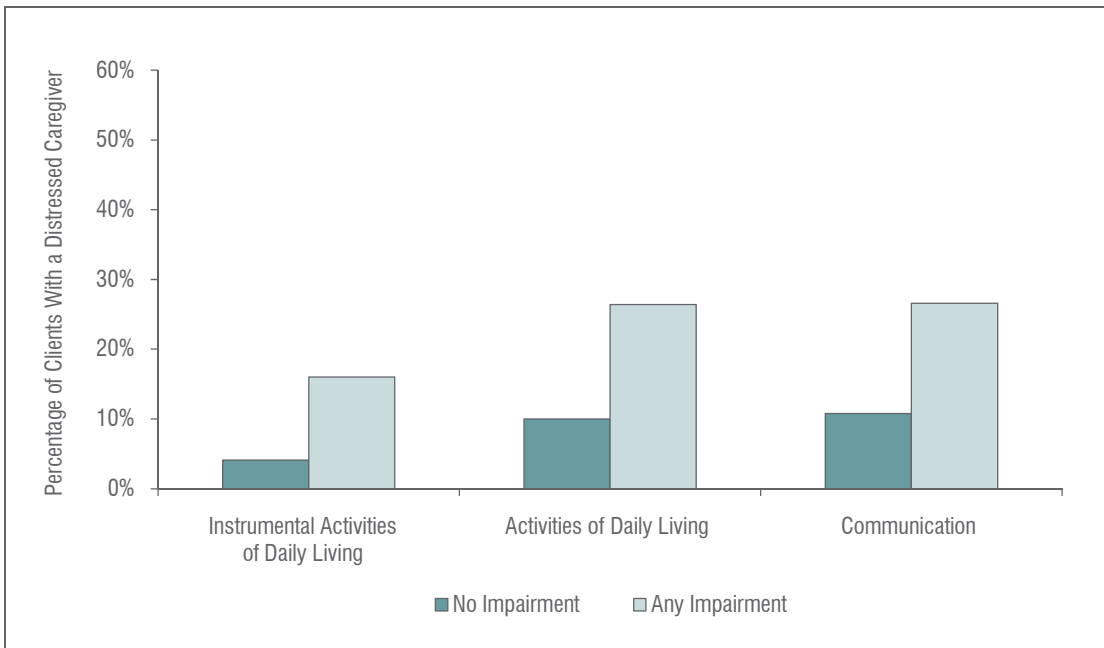
Figure 5

Caregiver Distress, by Client Mood and Behaviour
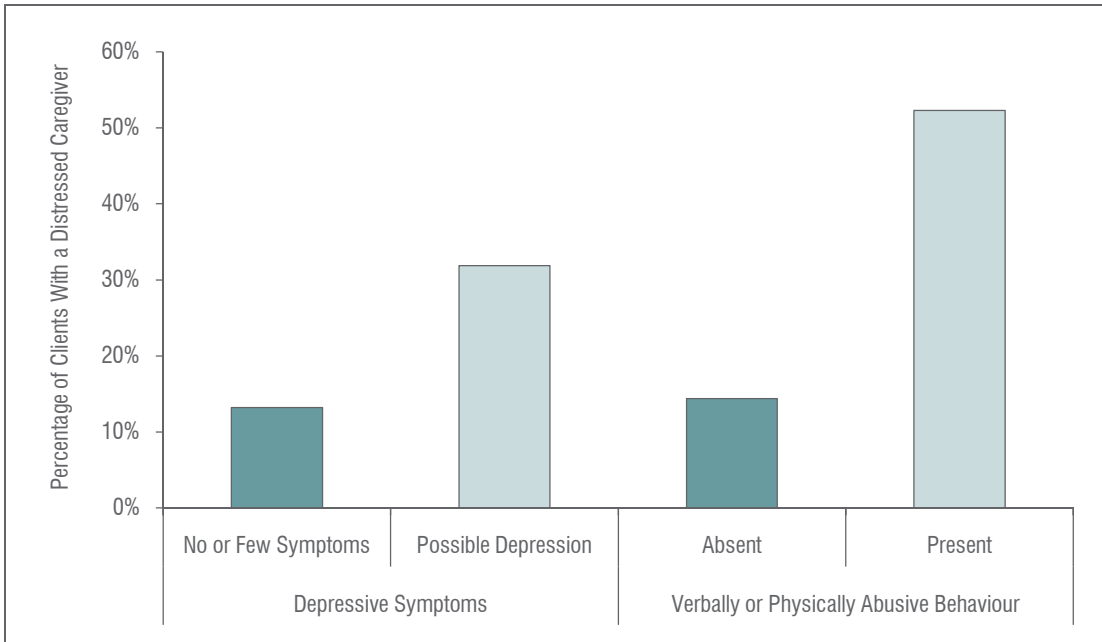

Source
Home Care Reporting System, 2007–2008, Canadian Institute for Health Information.

Figure 6 illustrates the strong association between the cognitive status of the client and distress among informal caregivers. The Cognitive Performance Scale is derived from the RAI-HC assessment and combines information on memory, understanding and decision-making. The likelihood of caregiver distress was almost five times greater when the home care client had moderate to severe cognitive impairment, compared with those with no cognitive impairment.

Figure 6

Caregiver Distress, by Client Cognition Level
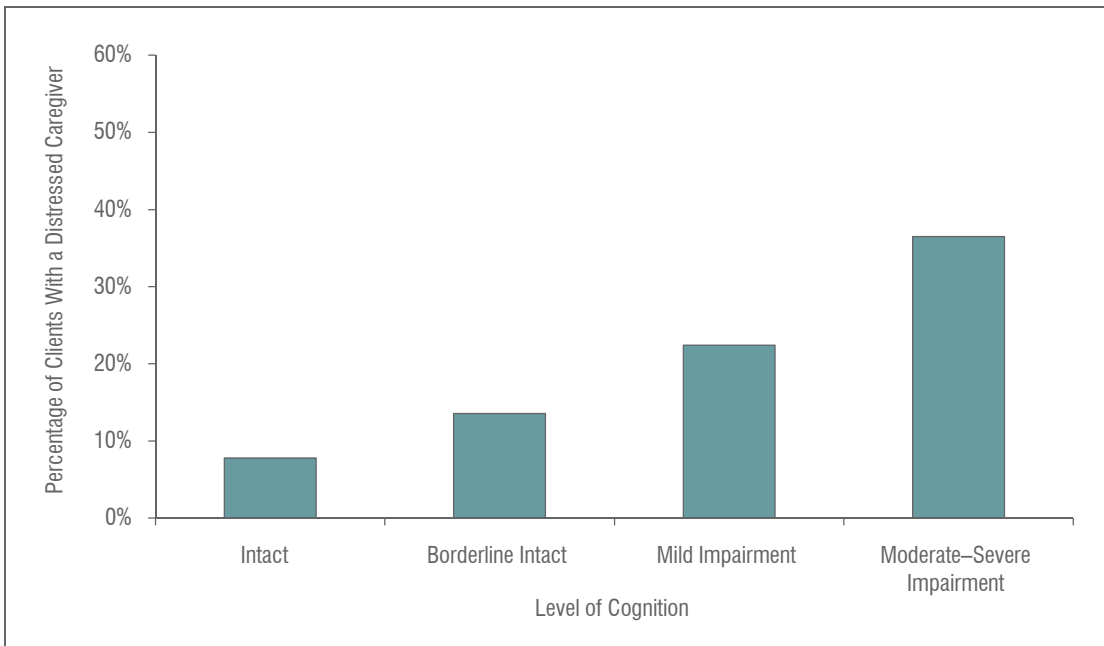
Source
Home Care Reporting System, 2007–2008, Canadian Institute for Health Information.

Supporting Caregivers and Policy-Makers

In addition to the measures and scales described above, the RAI-HC generates two other decision-support tools— the MAPLe and the Clinical Assessment Protocols (CAPs).

MAPLe—Method for Assigning Priority Levels

The MAPLe is an algorithm derived from the assessment that is predictive of adverse outcomes, including admission to residential care and caregiver distress. It provides clinicians with real-time information to flag home care clients who may need urgent services to remain safely at home. Figure 7 illustrates that the percentage of clients with distressed caregivers increased with each MAPLe priority level. Clients with high or very high priority levels were eight times more likely to have a distressed caregiver than those with a low priority level. This finding is consistent with the research that the MAPLe can be a useful tool for care planning and for understanding the relative needs of entire home care populations.

Figure 7

Caregiver Distress, by Client MAPLe Priority Level
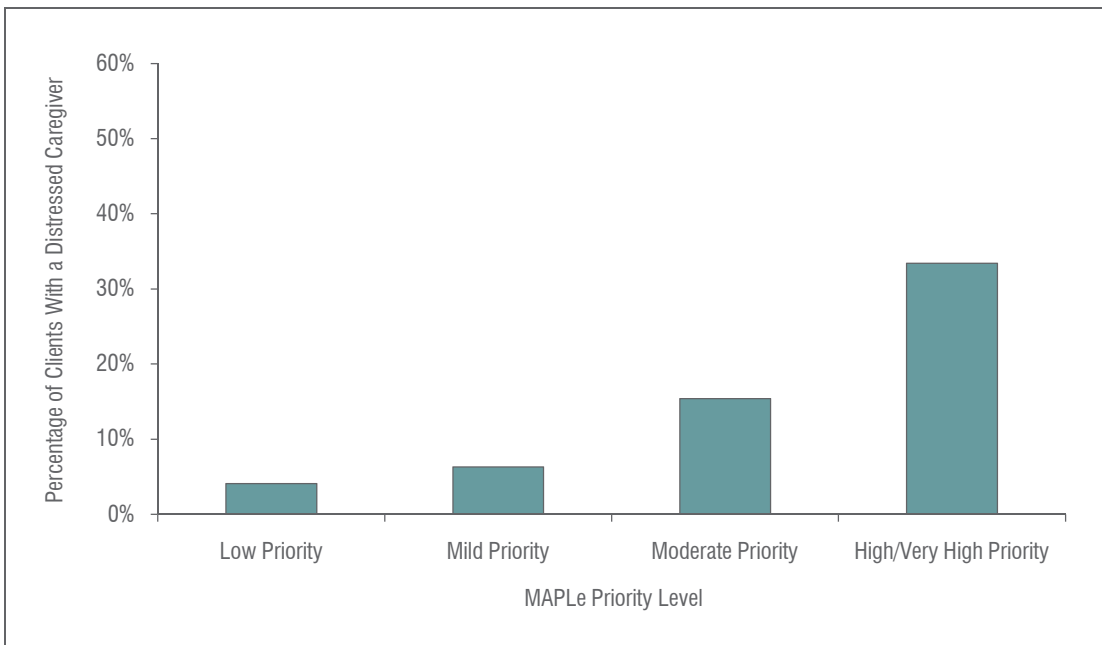
Source
Home Care Reporting System, 2007–2008, Canadian Institute for Health Information.

CAPs—Clinical Assessment Protocols

CAPs provide clinicians and families with real-time, evidence-based guidance on further assessment and intervention in key problem areas. Clients trigger one or more CAPs when items in their assessment indicate that they may be at risk of decline or failure to improve. The CAPs are used in planning for care, potentially relieving some of the pressures on the informal caregivers. The aggregate data may also be used at regional or provincial/territorial levels to monitor risk and inform program planning and policy decisions.

Figure 8 illustrates that clients triggering selected CAPs, including those related to IADLs, mood, communication, ADLs and behaviour, were more likely to have caregivers in distress, reflecting the previous findings.

Figure 8

Caregiver Distress, by Selected Client Clinical Assessment Protocols
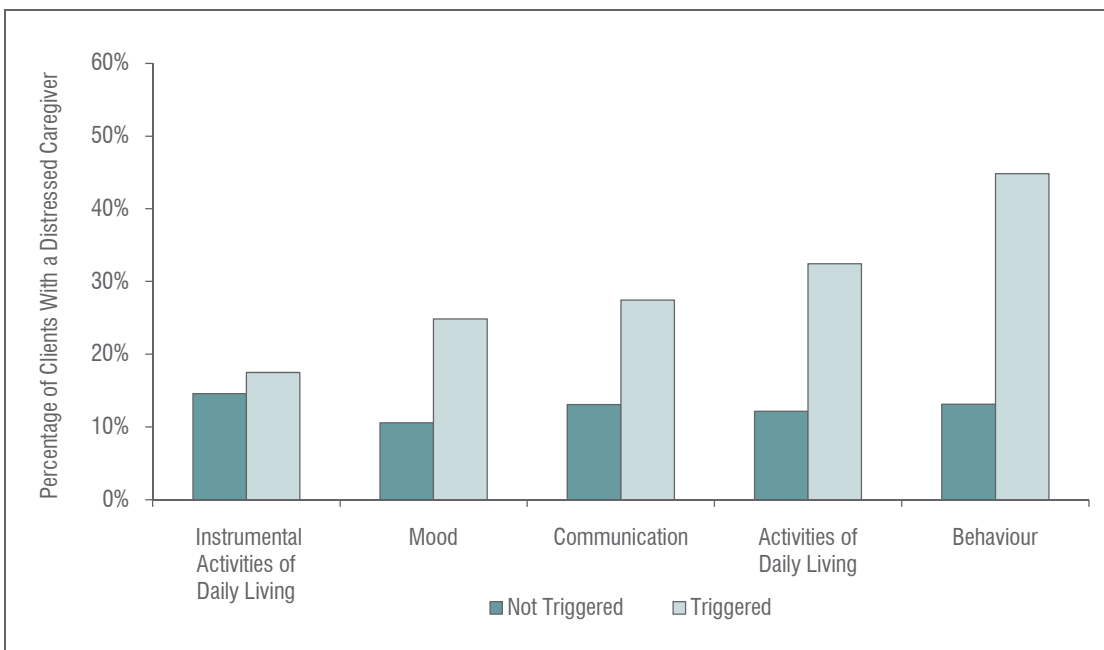
Source
Home Care Reporting System, 2007–2008, Canadian Institute for Health Information.

Predicting Caregiver Distress

There are clearly many factors contributing to caregiver distress. To identify the factors most strongly associated with distress, while controlling for other factors, a logistic regression model was developed using domains identified in the conceptual framework. Highlights of the results are found in Figure 9, with further detail in Appendix D. Descriptions of the scales used in the model are found in Appendix B.

The selected model did not include the MAPLe, a summary measure that is a very strong predictor of caregiver distress.[16] Its exclusion allowed for analysis of some of the individual factors that are used in combination in this decision-support tool. As well, there were close associations between cognitive status and Alzheimer's disease, other dementias and a person's ability to communicate and perform ADLs, as illustrated in Appendix D, Table 1. Therefore, only cognitive status, as measured by the Cognitive Performance Scale, was included in the model to eliminate potential interactions among these related items.

Turning to the results, caregiver distress was most strongly associated with the level of cognitive impairment of the home care client and the number of hours of informal care received. The odds of having a distressed caregiver were three times greater among home care clients with moderate to severe impairment, likely related to Alzheimer's disease or other dementia. Most of these seniors would need considerable assistance in ADLs related to their cognitive impairment.

The odds of having a distressed caregiver were two and a half times greater for clients receiving 21 or more hours of informal care per week. Certainly both of these situations can easily be seen as challenging for caregivers, particularly for a prolonged period.

Symptoms of depression or difficulty with IADLs (such as shopping, housework and medication management) were also strongly associated with having a distressed caregiver, although to a lesser extent (odds close to 2:1).

Other factors found to be associated with caregiver distress included difficult-to-manage behaviours exhibited by the home care client, such as resisting care, verbal or physical abuse, or conflict with family or friends. Home care clients with distressed caregivers were also more likely to have unstable health conditions and to rate their own health as poor.

Of note, spouses were more likely to experience distress than other informal caregivers. This is probably related to the 24-hour nature of their role. These spouses, who in most cases live with the home care recipient, serve as the primary caregiver and are seniors themselves.

It is also interesting to note the factors that did not seem to have a strong association with caregiver distress, such as the age or sex of the home care client and the types of formal and informal services provided.

Figure 9

Odds Ratios for Factors Associated With Caregiver Distress
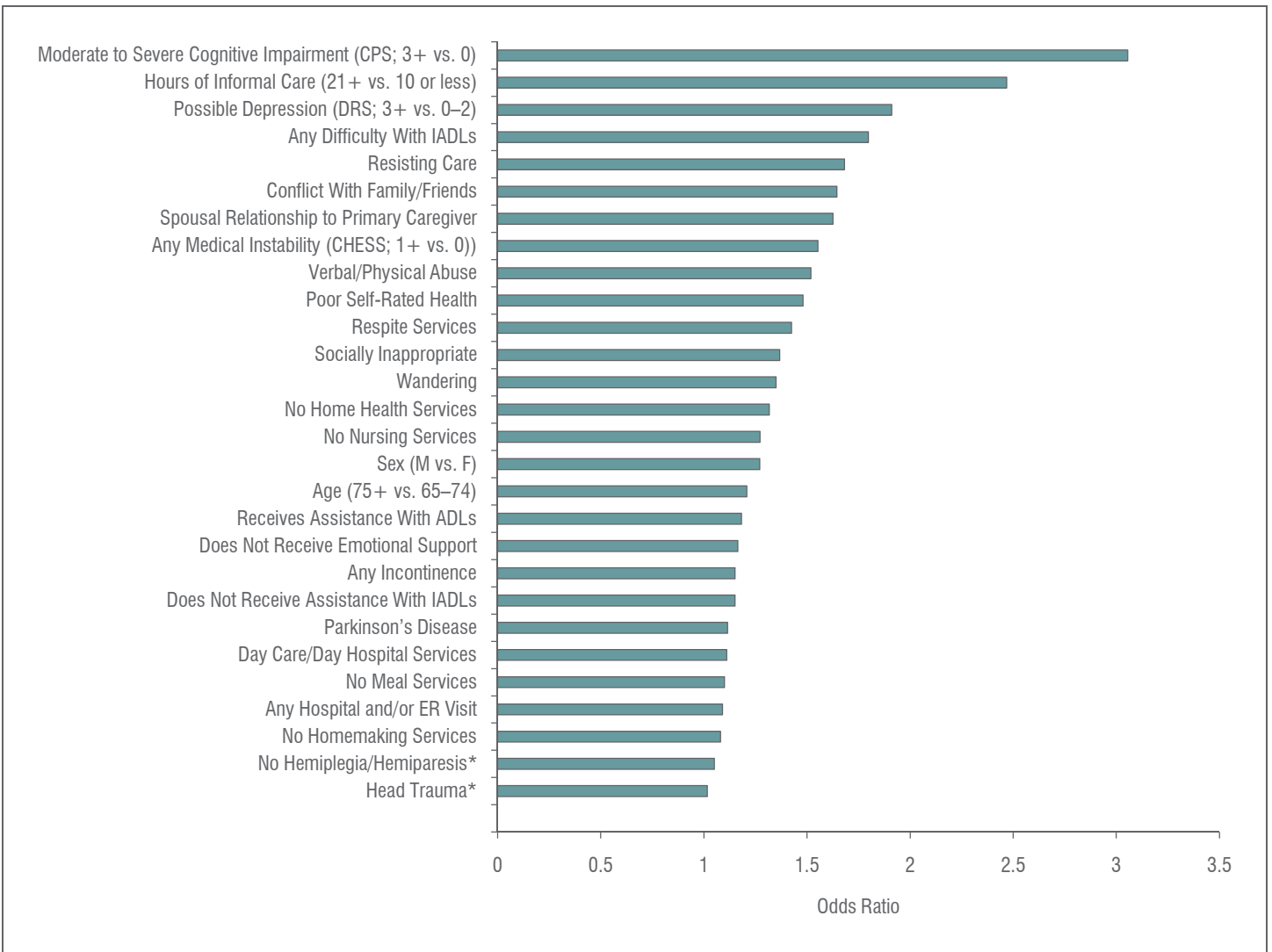
Note
* Not statistically significant.
Source
Home Care Reporting System, 2007–2008, Canadian Institute for Health Information.

Discussion

This study, with a sample of more than 131,000 seniors receiving publicly funded home care services across four Canadian jurisdictions, sheds new light on informal caregivers.

Only 2% of home care clients manage without an informal caregiver. This highlights the importance of the caregiver role to the health care system, given that many of the seniors in our study sample would have difficulty remaining safely at home without care.

Our analysis found that one in six caregivers reported distress related to their role; this is noteworthy given the vital role they play in keeping home care clients at home. It was also clear that the rates of distress were considerably higher in certain subpopulations of seniors receiving home care—in some cases higher than 50%.

The regression model identified the factors most strongly associated with caregiver distress. In summary, when controlling for many factors, the strongest associations with caregiver distress were found when the home care client suffered from significant problems with cognition and daily functioning, when the number of informal care hours was high and when the client exhibited depressive symptoms or various difficult behaviours. Among caregivers, it was the spouses, rather than children or friends of the senior, who appeared to be more at risk for distress and potential burnout.

The research-based assessment tools being adopted in home care programs across Canada effectively flag home care clients whose caregivers may be experiencing distress. They provide clinicians, seniors and their caregivers with real-time information to guide care planning. In particular, CAPs and the MAPLe identify those who may need further assessment and/or services to prevent caregiver burnout. Responding with appropriate support for the caregiver may prevent premature admission of the home care client to an institutional setting.

Conclusion

A sustainable health care system relies on the informal support network to help keep seniors at home and avoid institutionalization for as long as possible. Informal caregivers who are at higher risk of distress may require additional resources or respite to continue providing care. There is an ongoing policy discussion across Canada on the contributions of informal caregivers and potential strategies to avoid caregiver burnout.

The results of this study provide valuable information for decision-makers as they plan for an aging population. They showcase the value of the interRAI clinical assessment for identifying individuals and families at risk and for informing an evidence-based response that supports both quality of care and sustainability of the system.

CIHI's Home Care Reporting System provides health system planners and policy-makers with regional profiles of their home care population and the rates of distress among their caregivers—important information to support planning, resource allocation and quality improvement.

This first look at caregiver distress in four jurisdictions provides a starting point for future research. As participation in the reporting system grows across the country, it will be possible to look at similarities and differences in home care populations and levels of caregiver distress across the country. It will also be possible, over time, to look at the impacts of policies and practices across Canada for supporting informal caregivers—the heart of home care.

Appendix A: Conceptual Framework

Client Demographics	Function	Health Status	Mood and Behaviour	Service Utilization	Informal Support
Sex	Cognitive impairment	Incontinence	Depressive symptoms	Home health aides	Hours of care provided by an informal caregiver
Age	Communication	Self-rated health	Wandering	Visiting nurses	Relationship of primary caregiver to client
Marital Status	Instrumental activities of daily living (IADLs)	Method for Assigning Priority Levels (MAPLe)	Verbally abusive	Homemaking	Emotional support provided
	Memory impairment	Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS)	Physically abusive	Meals	IADL support provided
	Activities of daily living (ADLs)	Alzheimer's disease/ other dementia	Socially inappropriate	Day care/hospital	ADL support provided
		Head trauma	Resists care	Respite	
		Hemiplegia/ hemiparesis	Expresses anger/ conflict with family	Hospital admissions	
		Parkinson's disease		Emergency room visits	

Source
Home Care Reporting System, 2007–2008, Canadian Institute for Health Information.

Appendix B: RAI-HC Scales

RAI Scales	Description	RAI-HC Assessment Items	Score Range
DRS[17] Depression Rating Scale	This scale can be used as a clinical screen for depression. Validated against the Hamilton Depression Rating Scale (HDRS), the Cornell Scale for Depression in Dementia (CSDD) and the Calgary Depression Scale (CDS).	• Feeling of sadness or being depressed • Persistent anger • Expressions of unrealistic fears • Repetitive health complaints • Repetitive anxious complaints • Sad or worried facial expression • Tearfulness	**0–14** A score of 3 or more may indicate a potential or actual problem with depression.
CHESS[18] Changes in Health, End-Stage Disease and Signs and Symptoms	This scale detects frailty and health instability and was designed to identify clients at risk of serious decline.	• Worsening of decision-making • Decline in ADLs • Vomiting • Edema • Shortness of breath • End-stage disease • Weight loss • Dehydration • Leaving food uneaten	**0–5** Higher scores indicate higher levels of medical complexity and are associated with adverse outcomes such as mortality, hospitalization, pain, caregiver stress and poor self-rated health.
ADL Self-Performance Hierarchy Scale[19]	This scale reflects the disablement process by grouping ADL performance levels into discrete stages of loss (that is, early loss: personal hygiene; middle loss: toileting and locomotion; late loss: eating).	• Personal hygiene • Toilet use • Locomotion • Eating	**0–6** Higher scores indicate greater decline (progressive loss) in ADL performance.
IADL Involvement Scale[19]	This scale provides a measure of the client's self-performance of all seven IADL tasks.	• Meal preparation • Ordinary housework • Managing finances • Managing medications • Phone use • Shopping • Transportation	**0–21** Higher scores indicate greater dependency on others.
CPS[20] Cognitive Performance Scale	This scale describes the cognitive status of a client. Validated against the Mini-Mental State Examination (MMSE) and the Test for Severe Impairment (TSI).	• Short-term memory recall • Cognitive skills for daily decision-making • Expressive communication— making self understood • Eating impairment	**0–6** Higher scores indicate more severe cognitive impairment.
MAPLe[16] Method for Assigning Priority Levels	This algorithm assigns a client to a priority level. Found to be predictive of caregiver distress and risk of institutionalization.	• ADL Hierarchy Scale • Cognitive Performance Scale • Behaviours • Decline in decision-making • Managing medications • Ulcers • Self-Reliance Index/geriatric screener • Wandering • Risk of institutionalization • Meals • Swallowing • Falls	**1–5** Higher scores indicate higher priority level.

Appendix C: Individual Client/Caregiver Characteristics Associated With Caregiver Distress

Characteristic	Label	Value	Clients With a Caregiver Experiencing Distress		
			N	%	X² p-Value
Client Demographics					
Sex	Female	F	11,354	13.0	<0.0001
	Male	M	8,606	21.0	
Age	65 to 74	65–74	3,548	14.9	0.007
	75 and Older	75+	16,412	15.7	
Marital Status	Not Married	1, 3–6	8,787	10.9	<0.0001
	Married	2	11,173	23.4	
Function					
Cognitive Performance Scale	Intact	0	4,795	7.8	<0.0001
	Borderline Intact	1	2878	13.6	
	Mild Impairment	2	6,927	22.4	
	Moderate to Severe Impairment	3–6	5,359	36.5	
Communication	Understands/Understood	0	9,697	10.8	<0.0001
	Difficulty Understanding/ Being Understood	1–8	10,263	26.6	
Memory	No Memory Impairment	0	6,864	9.3	<0.0001
	Any Memory Impairment	1	13,096	23.9	
IADL Difficulty Scale	No Difficulty	0	196	4.1	<0.0001
	Some Difficulty	1–3	2,353	7.6	
	Great Difficulty	4–6	17,411	18.8	
IADL Capacity Scale	No Difficulty	0	62	2.9	<0.0001
	Some Difficulty	1–6	1,357	4.8	
	Great Difficulty	7+	18,541	18.9	
ADL Hierarchy	Independent	0	8,531	10.0	<0.0001
	Supervision to Some Assistance	1–2	6,992	24.5	
	Extensive Assistance to Dependence	3–6	4,437	30.0	
Health Status					
Bladder or Bowel Incontinence	Continent		9,014	12.5	<0.0001
	Any Incontinence		10,946	19.4	
Bladder Continence	Continent	0–1	9,935	13.1	<0.0001
	Any Incontinence	2–5, 8	10,025	19.1	
Bowel Continence	Continent	0–1	15,102	13.7	<0.0001
	Any Incontinence	2–5, 8	4,858	26.7	
Self-Rated Health	Not Poor	0	15,235	14.4	<0.0001
	Poor	1	4,725	21.2	
MAPLe	Low	1	1,200	4.1	<0.0001
	Mild	2	1,074	6.3	
	Moderate	3	6,165	15.4	
	High/Very High	4 or 5	8,811	33.4	
CHESS	No Health Instability/Frailty	0	4,293	9.9	<0.0001
	Any Health Instability/Frailty	1+	15,667	18.4	
Alzheimer's Disease/Other Dementia	Absent	0	12,163	11.9	<0.0001
	Present	1–2	7,797	29.7	
Head Trauma	Absent	0	19,703	15.5	<0.0001
	Present	1–2	257	22.9	
Hemiplegia/Hemiparesis	Absent	0	19,346	15.4	<0.0001
	Present	1–2	614	20.0	
Parkinson's	Absent	0	18,656	15.2	<0.0001
	Present	1–2	1,304	24.0	

Characteristic	Label	Value	Clients With a Caregiver Experiencing Distress		
			N	%	X² p-Value
Mood and Behaviour					
Depression Rating Scale	No Symptoms	0	8,849	10.6	<0.0001
	Few Symptoms	1–2	5,925	20.8	
	Possible Depression	3–14	5,186	31.9	
Wandering	No	0	18,615	14.8	<0.0001
	Yes	1	1,345	45.9	
Verbally or Physically Abusive	No		18,026	14.4	<0.0001
	Yes		1,934	52.3	
Verbal Abuse	No	0	18,147	14.5	<0.0001
	Yes	1	1,813	52.9	
Physical Abuse	No	0	19,490	15.3	<0.0001
	Yes	1	470	52.3	
Socially Inappropriate	No	0	19,071	15.1	<0.0001
	Yes	1	889	49.3	
Expresses Anger/Conflict With Family	No	0	15,900	13.9	<0.0001
	Yes	1	4,060	28.7	
Resists Care	No	0	17,377	14.2	<0.0001
	Yes	1	2,583	45.3	
Service Utilization					
Home Health Aides	No	0	8,606	17.5	<0.0001
	Yes	1	11,353	14.3	
Visiting Nurses	No	0	15,395	16.3	<0.0001
	Yes	1	4,565	13.4	
Homemaking	No	0	13,097	17.7	<0.0001
	Yes	1	6,863	12.6	
Meals	No	0	17,594	16.4	<0.0001
	Yes	1	2,366	11.3	
Day Care/Hospital	No	0	18,897	15.2	<0.0001
	Yes	1	1,063	26.8	
Respite	No	0	19,221	15.2	<0.0001
	Yes	1	739	38.3	
Hospital Admissions	None	0	14,904	15.4	<0.0001
	1 or More	1+	5,056	16.1	
ER Visits	None	0	16,036	15.0	<0.0001
	1 or More	1+	3,924	18.5	
Informal Support					
Hours of Care Provided in Last 7 Days	Up to 10 Hours	0–10	4,308	7.1	<0.0001
	11 to 20 Hours	11–20	3,679	14.7	
	21 or More Hours	21	11,958	28.1	
Relationship of Primary Caregiver to Client	Spouse	1	9,292	25.0	<0.0001
	Child/Child-in-Law	0	8,873	12.5	
	Other Relative	2	1,195	10.3	
	Friend or Neighbour	3	588	6.9	
Emotional Support Provided	No	1	322	12.8	0.0002
	Yes	0	19,634	15.6	
IADL Support Provided	No	1	1,114	10.2	<0.0001
	Yes	0	18,842	16.0	
ADL Support Provided	No	1	7,192	9.9	<0.0001
	Yes	0	12,764	22.9	

Appendix D: Caregiver Distress Logistic Regression

Table 1

Correlation of Key Factors

Variable		Correlation Coefficient
Cognitive Performance Scale	Communication	0.64
Cognitive Performance Scale	Memory	0.85
Cognitive Performance Scale	Alzheimer's/Other Dementia	0.60
Memory	Communication	0.46
Communication	Alzheimer's/Other Dementia	0.42
Cognitive Performance Scale	ADL Hierarchy	0.40

Table 2

Logistic Regression Model Predicting Caregiver Distress

Logistic Regression Model Predicting Caregiver Distress: By Conceptual Framework Items		
Variable	**Odds Ratio**	**Confidence Limits**	
Demographics			
Sex (M vs. F)	1.27	1.22	1.32
Age (75+ vs. 65–74)	1.21	1.16	1.27
Function			
Moderate to Severe Cognitive Impairment (CPS; 3+ vs. 0)	3.06	2.89	3.23
Borderline Intact to Mild Impairment (CPS; 1–2 vs. 0)	2.38	2.28	2.48
Any Difficulty With IADLs	1.80	1.55	2.09
Health Status			
Any Medical Instability (CHESS; 1+ vs. 0)	1.55	1.49	1.62
Poor Self-Rated Health	1.48	1.42	1.55
Any Incontinence	1.15	1.11	1.19
No Hemiplegia/Hemiparesis*	1.05	0.96	1.17
Head Trauma*	1.02	0.87	1.19
Parkinson's Disease	1.12	1.04	1.20
Mood and Behaviour			
Depression Rating Scale (DRS; 3+ vs. 0–2)	1.91	1.83	2.00
Conflict With Family/Friends	1.65	1.57	1.73
Resisting Care	1.68	1.57	1.80
Verbal/Physical Abuse	1.52	1.40	1.65
Socially Inappropriate	1.37	1.22	1.53
Wandering	1.35	1.23	1.48

Table 2

Logistic Regression Model Predicting Caregiver Distress (cont'd)

Logistic Regression Model Predicting Caregiver Distress: By Conceptual Framework Items			
Variable	**Odds Ratio**	**Confidence Limits**	
Service Utilization			
Respite Services	1.43	1.28	1.58
No Home Health Services	1.32	1.27	1.37
No Nursing Services	1.27	1.22	1.32
Day Care/Day Hospital Services	1.11	1.02	1.21
No Meal Services	1.10	1.04	1.16
Any Hospital and/or ER Visit	1.09	1.05	1.13
No Homemaking Services	1.08	1.04	1.13
Informal Support			
Hours of Informal Care (21+ vs. 10 or Fewer)	2.47	2.35	2.59
Hours of Informal Care (21+ vs. 11–20)	1.68	1.60	1.77
Spousal Relationship to Primary Caregiver	1.63	1.56	1.69
Receives Assistance With ADLs	1.18	1.14	1.23
Does Not Receive Emotional Support	1.17	1.02	1.34
Does Not Receive Assistance With IADLs	1.15	1.07	1.24

Note
* Not statistically significant.
Source
Home Care Reporting System, 2007–2008, Canadian Institute for Health Information.

Acknowledgements

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