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**National Profile of Family
Caregivers in Canada - 2002**

Final Report

Prepared for: Health Canada

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Introduction

In North America today, the aging population, coupled with fundamental changes in the provision of health care services, is translating into an increased requirement for individuals to care for family members in the home who have chronic health problems or disabilities. In 1996, it was estimated that close to 3 million Canadians provided care to someone with this type of condition. Such responsibility can place a considerable burden on the caregiver, in terms of the physical, emotional and financial requirements involved in providing such care. Because this form of care is informally provided (typically in the home), there are limited supports available to ease this burden.

In the 2001 Speech from the Throne, the Government of Canada announced its intention to improve the support available to parents and caregivers in times of family crisis, and to take steps to enable parents to provide care to a gravely ill child without fear of sudden income or job loss. As one of the initial steps in addressing this commitment, the government is conducting primary research to better identify who is providing such care, and the supports they may require to alleviate difficulties experienced in coping with care responsibilities. To date, most of the work in this area has focused on a broader definition of caregiving, including not only family members but friends and volunteers. As well, much of the focus has been on the aging population, so that little is known about informal care being provided to children and non-senior adults in the home.

To address these gaps in the current knowledge, Health Canada commissioned a national survey to establish an initial in-depth profile of family caregivers across Canada. The specific objectives of this research are to:

- Identify **who** are the family caregivers in Canada looking after a family member in their own household (by demographic characteristics);
- Determine **what** specific caregiving tasks are being performed (e.g. bathing, feeding) are being performed and for what period of time;
- Identify which family caregivers are coping with their caregiving responsibilities and which are not, as well as the factors that might explain this difference (e.g. stage of disease process, financial burden, lack of support, choice in providing such care); and
- Determine the **needs** of family caregivers who are most burdened and unable to cope (e.g., respite, financial assistance, education, formal home care).

The study was conducted by Decima Research Inc., on behalf of Health Canada. This research is based on telephone interviews with a representative sample of 471 family caregivers, conducted between February 28 and March 11, 2002.

For purposes of this study, a "family caregiver" was defined as an individual who is currently providing care to another family member in their home (or their family member's home), who has a physical or mental disability, is chronically ill or is frail (excluding short term care involved in injuries or illness).

Family caregivers were identified through a broad recruitment of the population, using a detailed set of screening questions to determine eligibility. The sample was stratified by region to ensure adequate representation of caregivers across the country.

A more detailed description of the methodology used to conduct this survey is provided at the back of the report, along with a copy of the survey questionnaire (Appendix A).

This report begins with an executive summary and key conclusions, followed by a detailed analysis of the survey findings. Provided under separate cover (Appendix B) is a set of detailed "banner tables" that present the results for all survey questions by key regional, demographic and care-related sub-groups. The detailed analysis section of the report denotes these tables by question number (e.g. *Question 1*) for easy reference.

Executive Summary

Based on the results of this survey, four percent (3.9%) of adult Canadians are currently providing care to a family member who is suffering from a physical or mental disability, is chronically ill or frail. This translates into roughly 933,000 individuals across the country, and would comprise about one-third of all types of caregivers based on previous estimates.

The following provides key highlights and conclusions from this survey, in terms of caregivers' characteristics, activities and experiences in looking after family members.

Profile of Family Caregivers

- Family caregivers are predominantly female (77%), and typically older than the population-at-large. Seven in ten (70%) are 45 years of age or older, and one-quarter (25%) are at least 65. Women aged 45 and older comprise 51 percent of the country's caregiver population.
- Consistent with these characteristics, caregivers are most likely to be either retired (31%) or homemakers (16%), particularly among older women. Just over one in five (22%) are employed full time, while a similar proportion work either part time or are self-employed (19%).
- Caregivers can be found in all income strata, but given their employment profile tend to have household incomes below the national average. Only one in three (35%) report household incomes of \$45,000 or more.
- The profile of family caregivers largely mirrors the Canadian population in terms of language and ethnic background. One in six (15%) have a first language other than English or French.
- Most caregivers are looking after only one individual, but close to one in ten (8%) are looking after a second family member (in most cases the other parent).

Profile of Care Recipients

- Recipients of family care are most likely to be either a spouse/partner (38%) or a parent (33%). Just over one in six (17%) recipients are children of the caregiver, with this group evenly split between minors (under 18 years of age) and adult children. Less common is family care being provided to other types of family members, such as siblings (5%) or other extended family (8%).
- Most care recipients are elderly, although this is not exclusively the case. More than half (57%) are 65 years of age or older, and 17 percent are at least 85. At the same time, one in four are under 45, most of whom are children (minors or adults) being cared for by a parent. Parents being cared for by their children are mostly 75 and older, while spouses/partners range more broadly in age, with most between 45 and 84.

- In almost all cases, recipients' illness or disability is defined as "long term" (requiring more than 6 months of care), and this is the case regardless of recipient's age. Six in ten (62%) of the caregivers interviewed have already been providing such care to their family member for at least three years, and one in five (20%) have been doing so for more than 10 years.
- Recipients are most likely to require care for physical disabilities (61%), with fewer suffering from mental disabilities (e.g. Alzheimers (39%). Almost one in five (18%) are have both physical and mental problems that require family care. The nature of disabilities is age-related, with older recipients more likely to require help with physical problems, while younger family members more apt to have mental disabilities (particularly children being cared for by parents).

Type of Care Provided

- Caregivers are most likely to say they are looking after family members because they see it as a family responsibility (67%) or because they simply choose to do so (63%). A significant minority, however, also indicate they have taken on this role because there is no one else available (35%) or because of the lack of home care services (25%). Moreover, only half (52%) believe they had a choice in taking on this responsibility, and a lack of choice is evident even among some who took on this role willingly.
- Most family caregiving is provided in the caregiver's homes (77%), and this is almost always the case when the recipient is a spouse/partner, a child, or someone with a mental disability. By comparison, just over half (55%) of parents are being cared for in their children's homes, with many still living independently or in some type of institutional setting.
- Caregivers provide a range of tasks in looking after their family member, the most common being providing medication, paying bills, driving them to destinations (e.g. doctor visits) and assisting with lifting and moving. These tasks are performed by a large majority of caregivers, although less than half report doing so on a daily basis. The incidence and frequency of tasks performed are related to the nature of recipient's disabilities (e.g. lifting assistance with older, physically disabled individuals).
- About one in four caregivers are providing daily assistance to family members in terms of basic hygiene, such as dressing, bathing, walking, feeding and assistance with toileting. Only small percentages provide daily assistance with caring for wounds or providing injections.
- Overall effort in providing caregiving assistance is most evident among women, those caring for recipients with both physical and mental disabilities, and those whose first language is other than English and French. While women as a group are more heavily involved in family caregiving activities, many male caregivers are as active in providing such care, particularly in such areas as paying bills, driving and lifting.

- A significant proportion (44%) of caregivers are paying out-of-pocket costs to provide care to their family member, with the most common expenses being for transportation (81%), non-prescription medications (71%), medical supplies (54%), prescription medications (43%) and other equipment (41%). Four in ten report spending between \$100 and \$300 per month on such expenses, with another quarter (24%) spending in excess of \$300.

Assistance in Providing Care

- Most caregivers believe they are generally equipped to handle the responsibilities involved in caring for their family member(s). More than eight in ten (83%) say they have the necessary skills and capabilities to fulfil this role, although this is somewhat less apt to be the case among those caring for a parent.
- Many identify ways in which they could use some assistance, but none emerge as areas where the need is broadly felt. Caregivers are most likely to say they could use some help in allowing them to have a break from this responsibility (i.e. respite) (15%), as well as with bathing (10%), in-home care generally (10%), cleaning/housework (7%) and medical or nursing assistance (6%).
- Less than one in four (23%) family caregivers are currently receiving any type of formal home care services to assist them in caring for their family member. Such assistance is somewhat more likely for those looking after parents and/or those with physical disabilities, and is most common in Ontario while least so in Quebec.
- Formal care is most likely to be provided in the form of a personal care worker (40% of those who receive any form of care), nursing visits (34%), and homemaking (housekeeping, light meals) (26%). Fewer than 10 percent of this group identify other types of assistance, such as physiotherapy, respite, occupational therapy or social workers.
- Caregivers receiving formal home care assistance are generally, if not completely satisfied with the services being provided. Close to half (47%) say the assistance provided meets the needs of their family member very well, while another four in ten (42%) feel it does so "generally well."
- Use of formal services appears to serve primarily as an important form of assistance for those family members requiring the most intensive care, rather than as a means to minimize involvement in these activities. Use of home care services increases along with the number and intensity of caregiving tasks performed.
- One in three (33%) caregivers identify the need for additional home care services, primarily in the form of housecleaning, a personal care worker, respite or nursing visits. This type of need is most widely identified by those caring for parents and for family members with both physical and mental disabilities.

- While many caregivers could use help in caring for family members, few (9%) believe their family member would be better cared for in an institutional setting. This view increases somewhat along with care recipient's age and among caregivers who feel they had little choice in taking on this responsibility.

Coping with Caregiving Responsibilities

- Caregivers are generally positive in assessing the success with which they feel they are coping with their care responsibilities, with most saying they are doing so very (43%) or generally (49%) well. Moreover, this assessment does not appear to be influenced by the number or frequency of caregiving tasks performed.
- The effectiveness with which caregivers feel they are handling this role does not mean it has not been difficult. Seven in ten (70%) acknowledge that providing this care has been stressful, and this is even the case among half of those who say they have been handling the responsibility very well. Almost seven in ten say they need a break from their caregiving duties either frequently (21%) or occasionally (47%).
- Caregivers are most likely to feel stressed in terms of their emotional health, with close to eight in ten reporting that caregiving has resulted in significant (29%) or some (48%) emotional difficulties for themselves. Smaller majorities of caregivers also report significant or some difficulties in terms of their finances (54%) and physical health (50%), although fewer than one in five indicate these impacts have been significant.
- Personal difficulties resulting from caregiving are most apt to be felt by younger women looking after younger family members, those dealing with both physical and emotional disabilities, allophones, as well as older individuals caring for a parent or spouse.
- The most significant predictor (or indicator) of caregiving stress is the lack of choice in taking on this responsibility. Other significant but less powerful predictors include caring for a parent or spouse (compared with a child or other family relation), younger caregiver age, younger recipient age, and the number of caregiving tasks performed.

Employment Impacts

- More than one in four indicate their employment situation has been affected by their caregiving responsibilities, either in terms of quitting/retiring early (9%) or having had to make other changes in their work situation (e.g. schedules, role) (18%). Leaving a job entirely is more widely reported by women and younger caregivers looking after a younger family member (e.g. under 45 years of age).

- Among those currently employed, caregiving has been disruptive to their work, either to a significant (19%) or some (33%) degree. This type of impact is greater among those who had no choice in taking on the role, and among those caring for someone with a mental disability.
- While many caregivers are finding it difficult to balance work and caregiving responsibilities, a majority (66%) report they have benefitted from flexibility provided by their employers, in terms of adjusting their work hours or job responsibilities in order to accommodate their caregiving duties. One in six (17%) indicate they have not benefitted in this way, while a similar proportion (17%) are self-employed (and so are responsible for their own workplace situation).
- Caregivers show strong interest in additional workplace supports to help them balance their caregiving and employment demands. More than four in ten (42%) believe it would be very helpful to receive flexible work hours (42%), while an equal proportion express similar interest in short term job and income protection through the federal government Employment Insurance (EI) program (42%). By comparison, fewer than one in five (18%) see a significant benefit in having access to a leave of absence without pay, likely because they could not manage without their employment income.

Conclusion

This research reveals that family caregivers in Canada as a group appear to be coping surprisingly well with the responsibilities of caring for family members in their homes, with relatively little formal support. At the same time, this role is creating stresses and personal difficulties, particularly among those caregivers who are also employed (who must balance the competing demands of work and family). Of note is the fact that while many caregivers express a desire for various forms of help, no particular form of assistance emerges as predominant. Although many caregivers are spending considerable amounts in caring for their disabled family members, there is relatively little expressed need for financial assistance.

Among the various findings drawn from this research, three notable conclusions emerge:

First, whether or not caregivers have a choice in taking on this role is a significant factor influencing the degree of stress and disruption they experience. This finding is certainly intuitive, but has important ramifications given that close to half of all caregivers do not appear to have much choice in looking after ill or disabled family members.

Second, formal home care assistance is an important type of support to family caregivers, but it does not appear to be serving a role to significantly reduce the stresses that caregivers are experiencing in providing such care. Formal care may be critical in providing help with specific types of care or assistance that could not otherwise be managed, but those caregivers receiving such help are as stressed or more so, in part because it is this group that seem to be carrying the greatest caregiving load.

Third, many family caregivers are actively involved caring for their family members in a range of functions, but the predominant type of help appears to be more with "lighter" duties (e.g. providing help with medications, finances, transportation), rather than with the "heavier" tasks such as lifting, bathing and dressing. This finding could have important implications for identifying the types of resources and supports that might be most effective in aiding the tasks of this group.

The results of this study should provide policymakers with valuable empirical information on who is providing family care in Canada, and the pressures they face in fulfilling this role. This should provide a firm basis for identifying effective strategies for providing support to alleviate the burdens faced by those providing such care.

As an initial study of family caregiving, this research provides a valuable snapshot of this critical segment of the population, but it is by no means complete in terms of addressing all of the government's information needs on this topic. The sample of caregivers surveyed is statistically representative of the population, but is not large enough to provide for more in-depth examination of relevant sub-groups, such as those individuals caring for disabled children or those living in a particular region of the country (The size of the sample used for this survey was dictated by the high cost in conducting this type of research with such a small and hard-to-find segment of the Canadian population).

This survey provides an essential starting point, but further research will be needed to probe more deeply into the issues surrounding family caregiving in Canada, and how to best support these hardworking individuals and the family members who depend upon them. Such research might involve further surveys as well as qualitative research (e.g. focus groups, one-one-one interviews) with specific segments of caregivers on targeted issues such as employment support programs.

It is also recommended that the government use this initial survey as a baseline measure, against which to measure the profile and status of family caregivers over time. Conducting this type of research on a regular basis (every three to five years) will provide a basis for tracking both the evolving characteristics of this group, as well as measure the impact of new policy and program measures.

Detailed Analysis

Profile of Family Caregivers

The survey reveals that approximately four percent (3.9%) of adult Canadians (18 years and older) are currently providing care to a family member who is suffering from a physical or mental disability, is chronically ill or frail. While this number is small in percentage terms, it translates into 933,089 individuals (based on the 2001 census for the Canadian population, excluding the territories which were not included in this study). This number is well below previous estimate of 2.85 million Canadians, but this figure is based on a much broader definition of caregivers that includes non-family members and other types of volunteers. Taken together, these figures suggest that family caregivers comprise one-third (33%) of the total caregiver population in Canada.

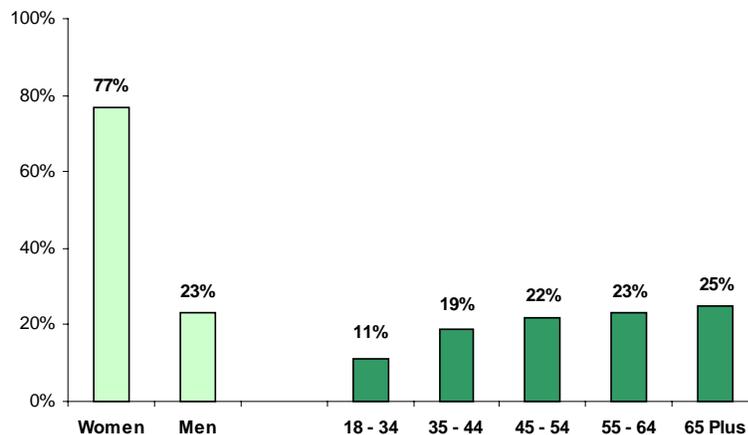
The following section presents a profile of the family caregivers that are the focus of this study.

Age and Gender Profile

Family caregivers in Canada are predominantly women aged 45 and older.

As would be expected, family caregivers are predominantly female (77%), and this is the case regardless of the type of family recipient or the type of care provided. This gender difference is greatest among caregivers under 45 years of age (where 82% are women), compared with 71 percent of caregivers 65 and older. (*Question 45*)

Age and Gender Profile of Family Caregivers



Canadian family caregivers also tend to be at least 45 years of age (70%), with one in four (25%) 65 or older. Predictably, caregivers 35 to 64 years of age are most likely to be caring for a parent, while those 65 and older tend to be looking after a spouse or partner. The small group of caregivers under

35 years of age (11%) are most apt to be caring for another type of family member (child, extended relative) who themselves tend to be younger, have a mental disability, and have been receiving care for a shorter period of time to date. (*Question 39*)

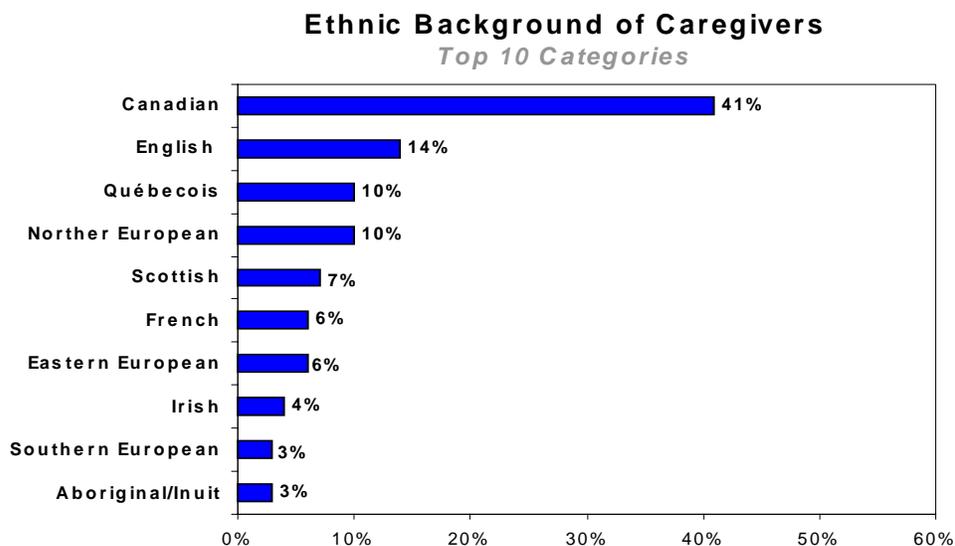
When the population of caregivers is segmented by age and gender, by far the largest segment consists of women aged 45 and over (51%). The remainder are divided among women under 45 (25%), men 65 and older (18%) and men under 45 (6%).

Language and Ethnic Background

The composition of family caregivers largely mirrors the Canadian population in terms of language and ethnic background.

The family caregiver population generally mirrors the general population in terms of language and ethnic background. Six in ten (61%) of this group identified English as their "mother tongue" (the language they first learned at home, which essentially matches the population-at-large (61%). One in four (24%) speak primarily French (the same as in the full population), while another 15 percent name another language, none of which is represented by more than two percent of this population. (*Question 40*)

Similarly, the ethnic background of family caregivers closely resembles the Canadian population, with a majority describing themselves as Canadian (41%), English (14%) or Quebecois (10%). As with the general population, there are notable regional differences in ethnic origin (e.g. those with northern and Eastern European roots in the Prairies, Irish descendents most evident in Atlantic Canada and Ontario).

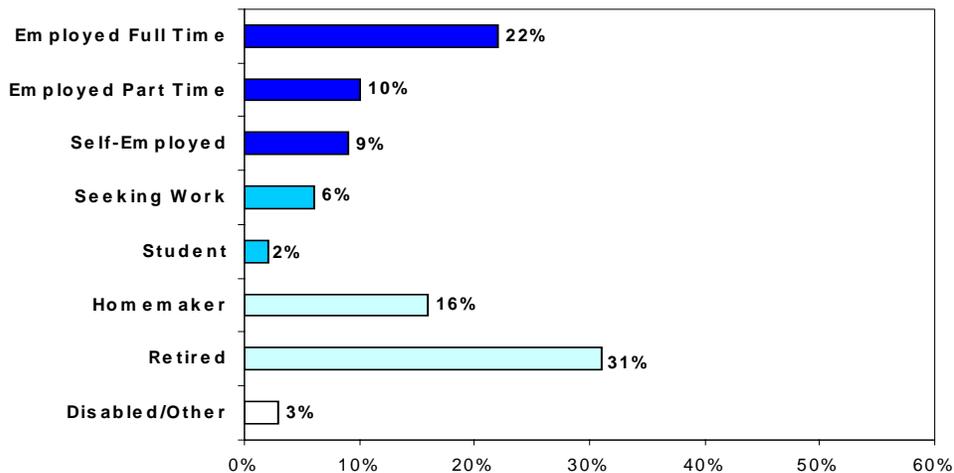


Income and Employment

Caregivers are more likely to be retired or homemakers than employed.

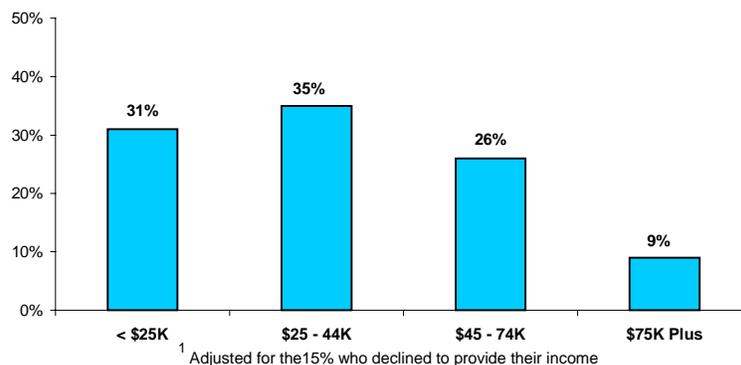
Given the age distribution of the caregiver population, the employment profile of this group is somewhat different from the general population. Among caregivers, only four in ten are employed, either full time (22%), part time (10%) or self-employed (9%). This group is most apt to be retired (31%), while another 16 percent define themselves as homemakers. (*Question 32*)

Employment Profile



Employed caregivers are more apt to be men, while women almost entirely make up those who are working part-time or homemakers. Employment is also tied closely to age, with close to six in ten (58%) caregivers under 45 currently working, compared with 50 percent of those aged 45 to 64, and only 3 percent who are 65 or older (almost all the caregivers in this group are retired or women who classify themselves as homemakers).

Household Income Profile¹



In terms of household income, the caregiver population is represented across all income categories. Consistent with the fact that this group has a higher proportion of retired individuals and homemakers, the caregiver population has lower incomes on average in comparison with the Canadian population-at-large. (*Question 42*)

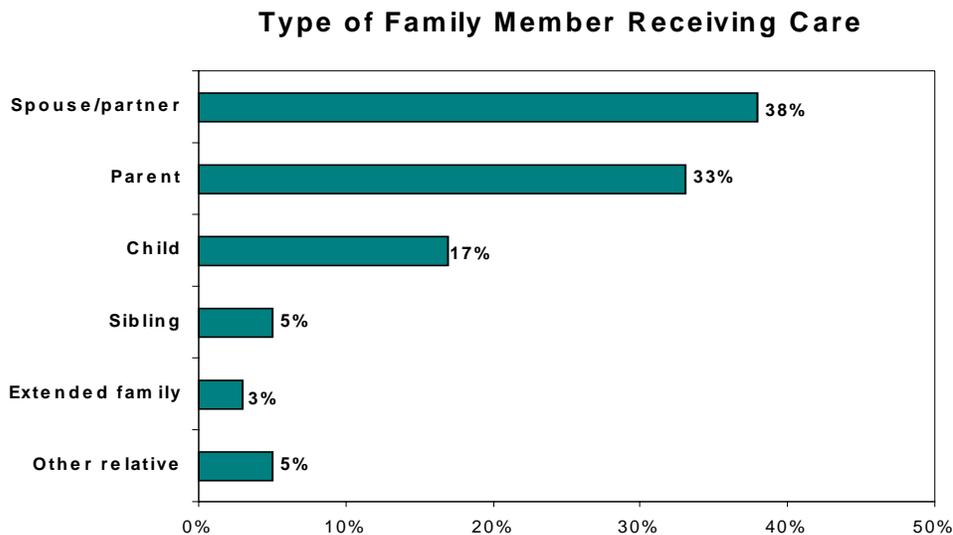
Recipient Profile

This section presents a profile of the family members who are currently receiving care.

Recipient Characteristics

Recipients of family care are most likely to be spouses or parents. One in six are children, many of whom have some form of mental disability.

Caregivers are most likely to be providing care to a spouse/partner (38%) or parent (33%). Fewer are looking after a child (son or daughter) (17%), a sibling (5%) or other family members (e.g. step parents or children, extended relative).¹ (*Question 6*)

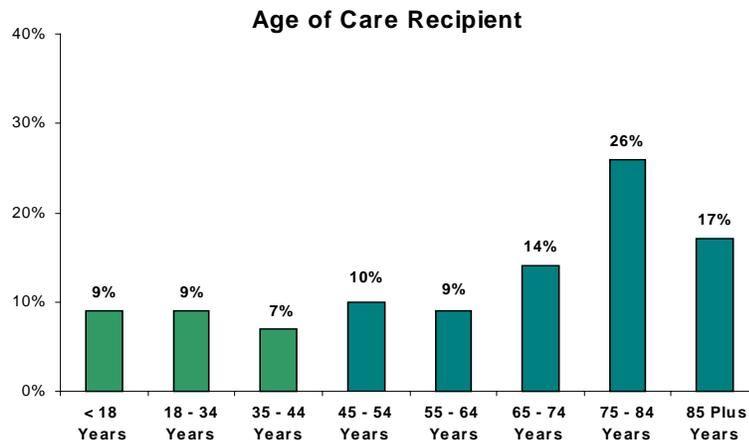


As would be expected, most care recipients are seniors. More than half (57%) are at least 65 years of age, with 17 percent at least 85. But family care in the home is by no means restricted to this older population, with one in four (25%) recipients under 45 years of age. This younger group is most likely to consist children of caregivers (63%), while the rest are a spouse/partner (21%) or sibling (9%). Among this group of children being cared for, close to half (47%) are under 18 years of age, while the remainder are young adults (18-24) (15%), 25 to 34 years of age (17%), or 35 to 54 (21%).

¹The sub-sample of family caregivers looking after children (N=78) is too small to provide for an in-depth analysis of this segment.

Children receiving care are most likely to be suffering from a mental disability (either alone or combined with physical disabilities) and have been receiving care for at least six years. (*Question 8a*)

Age is related to type of family member in a predictable pattern, with most (80%) of the spouses or partners being cared for between 45 and 84 years of age, while parents being cared for are primarily 75 or older (77%).



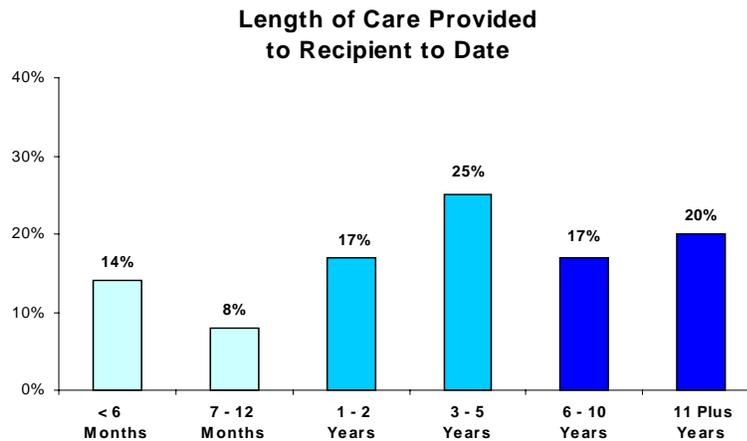
Close to one in ten (8%) of caregivers also report to be providing care to at least one additional family member in the home. These are most likely to be another parent (3%), a spouse or partner (2%), a sibling (2%), a child (1%) or another type of family member or extended relative (1%). Six in ten (60%) of this group are 55 years of age or older. (*Question 7*)

Nature of the Recipient's Disability

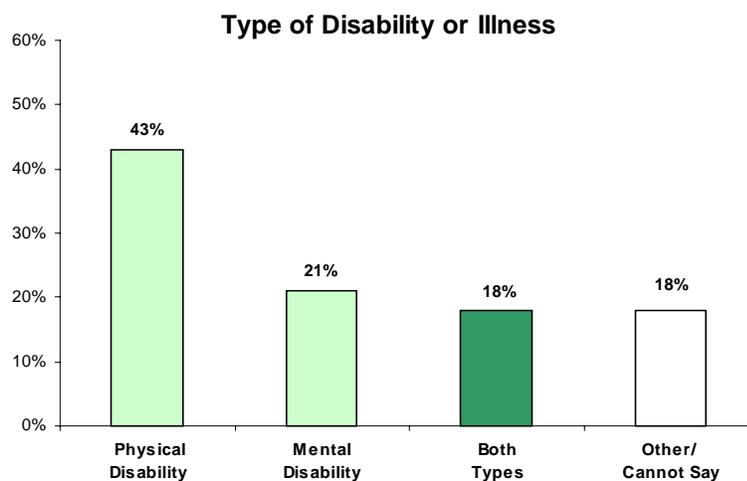
Recipients are most likely to be receiving care because of physical disabilities, but close to one in five have both physical and mental difficulties that require family assistance.

The length of time over which care has been provided to family members ranges significantly. One in five (21%) recipients have been receiving care for less than six months, while almost as many (20%) have been doing so for more than 10 years (20%). This long term group is most likely to consist of siblings and children of caregivers, those under 45 years of age, those who have a mental disability and those being cared for by a women (e.g. mother). (*Question 9*)

Regardless of how long these recipients have been cared for to date, in almost all cases (91%) caregivers define the type of illness or disability affecting this person as long term in nature (e.g. greater than six months). This is evident regardless of recipients' age, but is virtually always the case if he or she has a mental disability (97%) and has already been receiving care for more than 12 months (97%). (*Question 10*)



In terms of the nature of the disability or illness which is requiring family care, recipients are most likely to be suffering from one or more physical disabilities (61%), while somewhat fewer (39%) have some form of mental disability (e.g. Alzheimer's disease). When these data are combined, it shows that close to one in five (18%) suffer from both mental and physical problems that require family care (Note: Another 18% of the caregivers surveyed did not clearly identify the disability as either physical or mental, either because this may have been unclear at the time or because the caregiver declined to state). (*Questions 11a,b*)

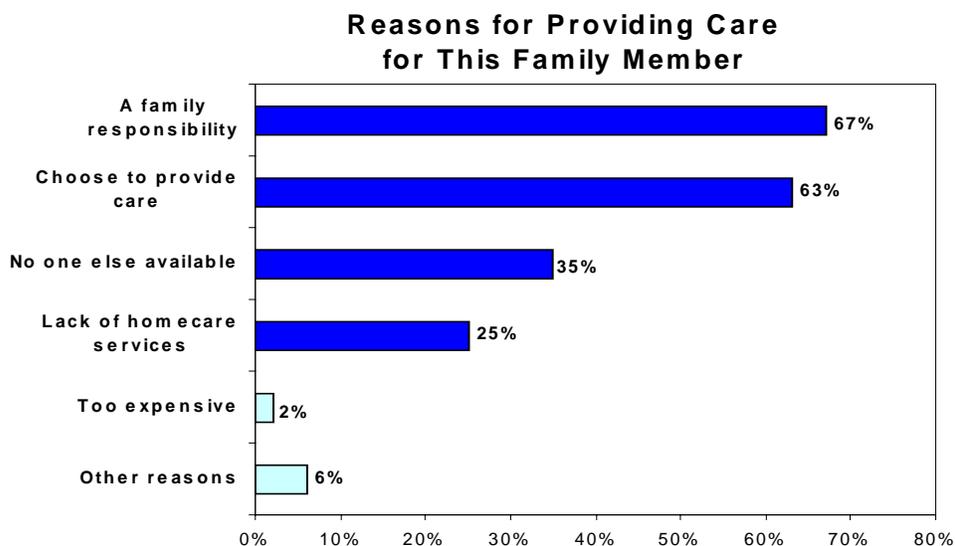


The type of disability is most closely associated with recipients' age. The incidence of physical disabilities increases with age (44% among those under 45 years of age, to 72% among those 75 and older). Mental disabilities are most prevalent among recipients under 45 (60%), who in most cases are children being cared for by a parent (67% of children being cared for have a mental disability). The incidence of mental disabilities is somewhat higher in the western provinces (47%) and in English-speaking households (43%, versus 31% in French-speaking households and 37% in others).

Reason for Providing Care

Caregivers are most likely to be looking after a family member because it is a family responsibility or because they want to do so. Only one in two feel they had a choice in taking on this responsibility.

Caregivers were asked about the reasons why they chose to provide care to a family member suffering from a disability or illness. Among four possible reasons offered on the survey, caregivers are most likely to say they are caring for this family member because they feel it is a family responsibility (67%) or because they choose to be the one providing this care (63%) (The total percentage exceeds 100% because caregivers can offer more than one reason). By comparison, this group is less apt to say they are taking on this responsibility because no one else is available to do it (35%) or because of a lack of available home care services (25%). A small number volunteered other reasons, including the high cost of formal care (2%), a belief they can do the best job (2%) or because it was the recipient's choice (2%). (*Question 12*)

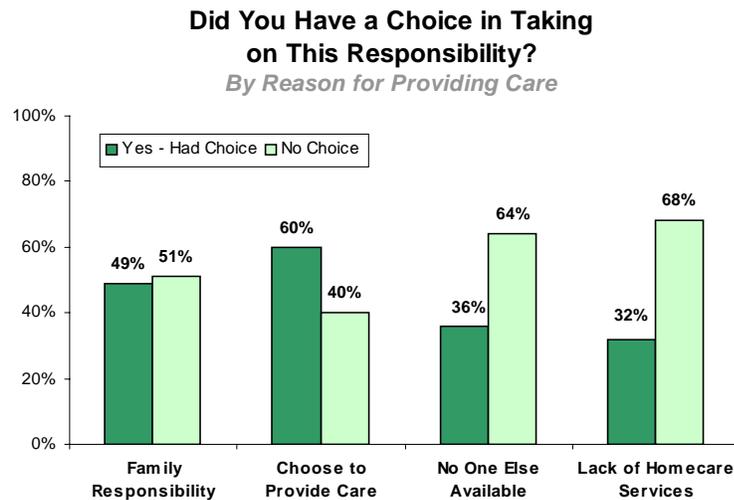


The type of reasons given for providing care are generally similar across the caregiver population. Those who say they are doing it because it is a family responsibility or because no one else is available are somewhat more likely to be caring for a parent who is 75 or older, with the former reason also most evident among caregivers in the top income bracket (household incomes of more than \$45,000). Women are more likely than men to say they are providing care because it is their choice, while the lack of available home care services is most apt to be mentioned by caregivers under 45 (35%) and those who are caring for a family member in this same age group as themselves (31%).

Caregivers were also asked more directly if they feel they had a choice in taking on this responsibility for a family member. Overall, the population is divided with just over half (52%) saying they did have a choice, while 44 percent felt they did not (the remaining 4% could not or would not respond to this question).

Choice is somewhat more likely to be indicated by men (57%), caregivers who are looking after a family member who has only mental disabilities (54%) and residents of Atlantic Canada (67%) and Quebec (60%), this response is less evident among caregivers dealing with both mental and physical disabilities (39%), as well as those with household incomes of at least \$45,000 (44%). (*Question 13*)

The results indicate that many caregivers do not believe they had much choice in this decision even if it is a responsibility they willingly took on. Among those who say they are caring for a family member because they choose to do so, a significant minority (40%) also acknowledge that they had no choice in doing so. Predictably, the absence of choice is much more prevalent among caregivers who are providing care because they say no one else is available (64%) or because of the lack of home care services (68%). Those who do not have choice are more likely to report stress in providing their caregiving responsibilities (see below).

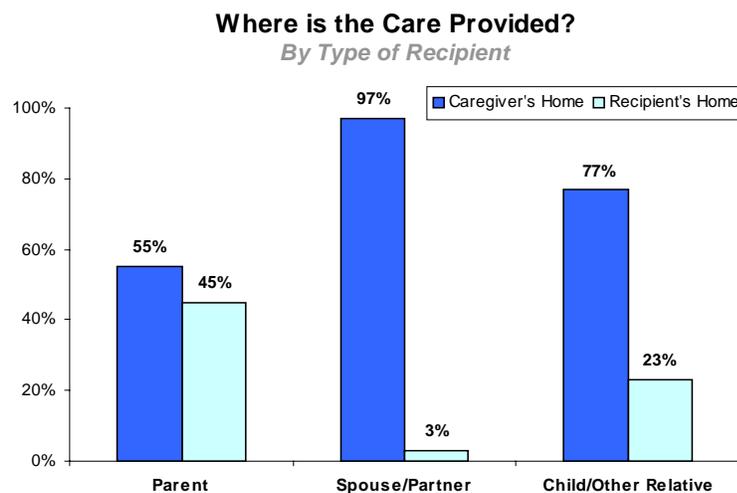


Type of Care Provided

Location of Care

Most caregivers are looking after family members in their own home.

As might be expected, most caregivers are looking after family members in their own home (77%), while less than one in four (23%) are doing this work in the recipient's home. Providing care in the caregiver's home is almost always the case when looking after a spouse or partner (97%). By comparison, just over half (55%) of caregivers looking after parents are doing so in their own homes. Care in the caregiver's home is also much more likely when the recipient is under 45 years of age (e.g. a child) (91%), suffers from a mental disability (86%), has already received care for at least six years, and if the caregiver is older (e.g. those looking after a spouse or partner).



Caregiving Tasks Performed

Caregivers perform a range of tasks for their family members on a regular basis, the most common being providing medication, paying bills and driving them to destinations as required.

The survey asked caregivers about the tasks they perform for their family member, specifically in terms of the frequency with which they do 12 of the most common types of assistance provided to people suffering from physical or mental disabilities. Most of these tasks are performed with some level of frequency. (*Questions 14a-m*)

Those tasks done most frequently (on a daily basis) include providing medications (48%), paying bills (36%), driving recipients to destinations such as doctor visits (39%), assisting with lifting and moving (29%) and dressing (28%). Each of these tasks is performed on at least on occasional basis by a majority of caregivers.

Table 1: Caregiving Tasks Performed

| Task (Questions 14a-m) | Frequency | | | |
|----------------------------------|-----------|--------------|----------|---------|
| | Daily % | Occasional % | Rarely % | Never % |
| d. Providing medications | 48 | 19 | 6 | 26 |
| m. Paying bills | 36 | 38 | 3 | 19 |
| k. Driving to destinations | 30 | 55 | 4 | 11 |
| h. Assisting with lifting/moving | 29 | 30 | 9 | 32 |
| c. Dressing | 28 | 23 | 10 | 39 |
| a. Bathing | 24 | 24 | 7 | 44 |
| j. Walking | 21 | 32 | 6 | 41 |
| i. Assisting with toiletry | 21 | 19 | 8 | 51 |
| b. Feeding | 20 | 10 | 5 | 64 |
| g. Foot care assistance | 14 | 28 | 6 | 49 |
| f. Caring for wounds | 8 | 25 | 12 | 53 |
| e. Providing injections | 6 | 3 | 2 | 90 |

Caregiving tasks somewhat less frequently performed on a daily basis include bathing (24%), walking (21%), assisting with toileting (21%), feeding (20%), foot care assistance (14%) and caring for wounds. A sizeable proportion (41-64%) of caregivers indicate they never do these tasks. Finally, less than one in ten caregivers provide their family member with injections on a daily (6%) or occasional (3%) basis.

The incidence and frequency with which these tasks are performed varies somewhat by caregiver and recipient characteristics. For instance, help with medications is more common in caring for spouses, older recipients and those suffering from both physical and mental disabilities. Assistance with lifting and moving is more likely to be provided to older parents, those with physical disabilities and by male caregivers. Help with other types of personal care (feeding, dressing, walking, assistance with toileting) is more commonly provided to recipients with both physical and mental problems.

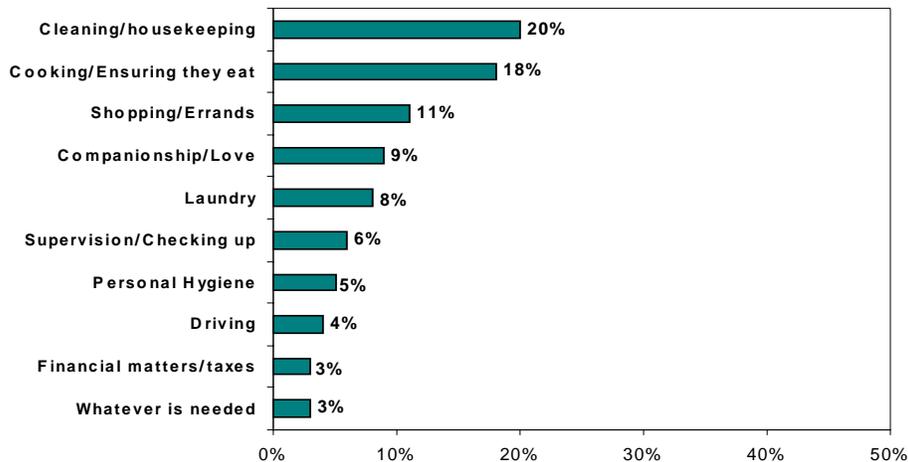
Responses to the 12 tasks were also summed together to create a single index measuring the overall level of effort put into family caregivers. This index consists of a five-point scale, from "1" (the least effort) to "5" (the most effort). Based on this index, caregivers most likely to be putting in the greatest overall effort (4 or 5) are women, those caring for someone with physical and mental disabilities, and those whose first language is other than English or French. (*Question 14X*)

Women as a group are more likely to be involved in family caregiving activities overall (and comprise the larger proportion of the family caregiver population), but many male caregivers are as active in the care being provided. Women are noticeably more likely to report providing care in the form of dressing, bathing and caring for wounds, and somewhat more so in terms of providing

medications, toileting, and providing injections. Male caregivers are more apt to be involved in paying bills, driving family members to destinations and lifting. Moreover, men who are providing these forms of care generally do so as frequently as women (e.g. on a daily basis).

Beyond these 12 specific types of care, caregivers were also asked if there are any *other* tasks they perform for their family member on a regular basis. More than half (56%) identify at least one such task, the most common being cleaning/housekeeping (20%), cooking meals (18%), shopping or running errands (11%), providing companionship or emotional support (9%) and laundry (8%). The likelihood of providing these types of assistance increases along with recipients' age. (*Question 15*)

Other Tasks Performed on a Regular Basis
Top 10 Mentions

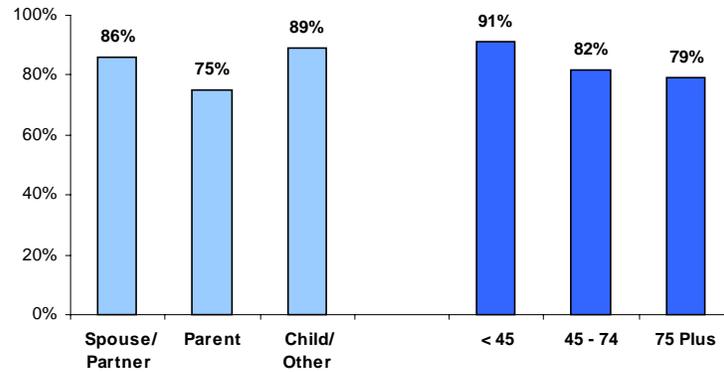


Caregivers' Need for Assistance

Caregivers generally feel they have the necessary skills to care for family members, but some could use help in doing basic tasks or simply getting a break.

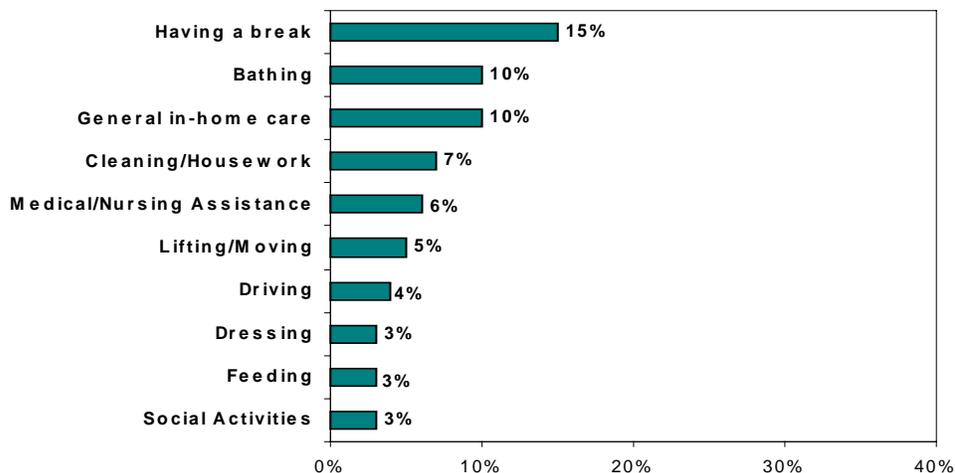
In broad terms, caregivers express confidence in their ability to handle this responsibility. More than eight in ten (83%) say they have the necessary skills and capabilities for properly caring for this family member in the home. This view is evident across the caregiver population, but is strongest among those caring for younger recipients, francophones and those who feel they had a choice in taking on this care. Such confidence is somewhat less widespread among those caring for older parents. (*Question 16*)

Confident in Having the Necessary Skills
By Recipient Type and Age



While most caregivers feel comfortable in having the necessary skills to look after their family members, at the same time many say they could use some help in terms of getting it all done and having some respite. When asked specifically about any areas in which they could use some help, caregivers are most likely to mention having some help from someone else simply to allow them to take a break (15%) or help with other basic tasks such as bathing (10%), cleaning (7%), lifting/moving (5%) and driving (4%). Few identify any types of assistance that require skills or expertise they might not already have, such as medical or nursing assistance, tutoring, physiotherapy or medical/health care information. (*Question 17*)

In What Areas Could You Use Some Help?
Top 10 Mentions



Caregivers most likely to identify any type of assistance are those looking after parents, family members 75 and older, recipients with physical and mental disabilities, and who have been receiving care for longer periods of time. Help is also more apt to be needed by women caregivers (58% vs.

48% of men), those who feel they have had no choice in taking on this responsibility (66%, vs. 46%) and who are not currently receiving formal home care services (67% vs. 53%).

Out-of-Pocket Costs

Close to half of all caregivers are paying out-of-pocket expenses to care for their family members, with two-thirds spending more than \$100 per month.

A significant proportion (44%) of caregivers are paying out-of-pocket costs to provide care for their family member in the home. This responsibility is common across the caregiver population, except in Quebec where only 19 percent report such expenses. The likelihood of paying such costs is somewhat higher for caregivers looking after younger recipients (under 45), those with both physical and mental disabilities, and those who have been receiving care for at least six years. (*Question 18*)

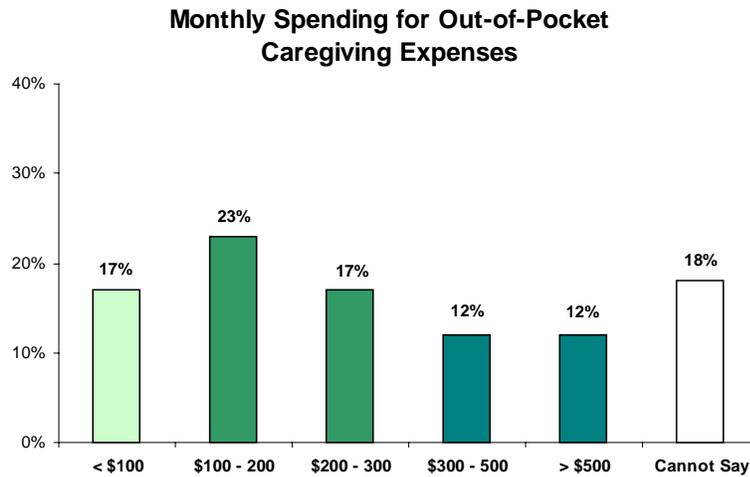
Not only are caregivers paying out-of-pocket costs, but they are paying for a wide variety of expenses in caring for their family members. Caregivers are most likely to report spending their own money on transportation (e.g. gas, taxis, public transit) (80%) and non-prescription medications (71%), while somewhat smaller percentages say they are paying for medical supplies (54%), prescription medications (43%), equipment (41%) and homemaking supplies (e.g. housekeeping, meals) (36%). (*Question 19*)

Table 2: Out-of-Pocket Expenses Incurred in Caring for Family Member

| Expense | % ¹ |
|--|----------------|
| Transportation (gas, taxis, public transit, parking) | 81 |
| Non-prescription medications | 71 |
| Medical supplies | 54 |
| Prescription medications | 43 |
| Equipment | 41 |
| Homemaking supplies (cleaning, food) | 39 |
| Home alterations/renovations | 29 |
| Professional services (eg: physiotherapy) | 20 |
| Someone to provide respite | 19 |
| Personal care washer | 17 |
| Ambulance services | 16 |
| Nursing services | 12 |
| Bills/utilities | 2 |
| Clothing | 2 |
| Other | 5 |

¹ Based on the percent of caregivers who report out-of-pocket expenses (44% of total population).

With the variety of out-of-pocket expenses being incurred, some caregivers are spending a considerable amount of money to look after their family member. Four in ten (40%) are spending between \$100 and \$300 per month on such expenses, while one in four (24%) are spending in excess of \$300 per month out-of-pocket to provide care. Of interest is the fact that close to one in five (18%) could not (or perhaps would not) say how much they are paying on their own to look after their family member. (*Question 20*)



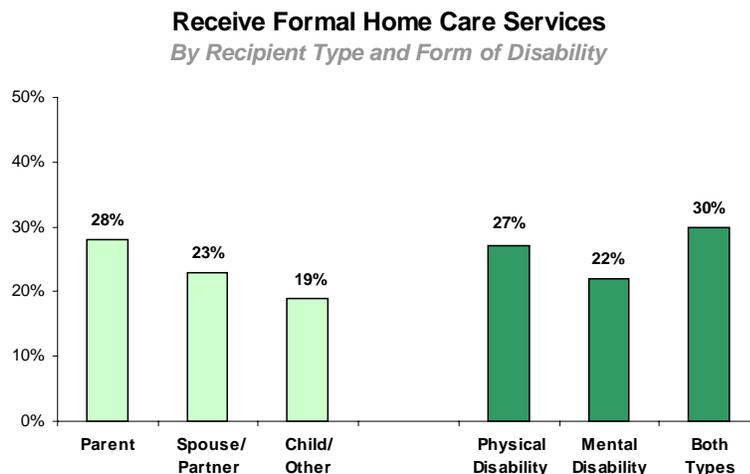
Formal Home Care Assistance

Type of Home Care Services

Less than one in four receive any formal home care services to assist in caring for their family member, mostly in the form of a personal care worker, nursing or homemaking assistance. Most are reasonably satisfied with the quality of care provided.

In many cases, formal or professional home care services are an essential or valuable support to caregivers looking after family members in the home. Based on the results to this survey, less than one in four (23%) family caregivers in Canada are currently receiving this type of support in some form. (*Question 21*)

The likelihood of receiving this type of assistance varies somewhat by recipient and caregiver characteristics. Such formal care is more apt to be provided for older recipients, those with a physical disability (either alone or in combination with a mental disability) and among caregivers 45 to 64 years of age. Residents in Ontario (30%) are most likely to report receiving formal care, while this is least evident in Quebec (12%).



While formal home care services is a way to reduce or manage the amount of personal involvement in family caregiving, this does not appear to be the case. The number and intensity of caregiving tasks performed is associated with the receipt of formal home care in a marginally positive direction (that is, those receiving home care assistance are also somewhat more active in performing caregiving tasks). This suggests that the use of formal care is more closely associated with care recipients requiring a lot of care (both family involvement and formal services) than as a means of minimizing such involvement.

Also of note is the fact that use of formal home care services is not associated with the amount that caregivers are paying in out-of-pocket costs.

In terms of the kinds of home care services provided to assist caregivers, the most common are personal care workers (40% of the group who receive any form of assistance, or 9% of all caregivers), nursing visits (34%) and homemaking support (e.g. housecleaning, light meal preparation) (26%). No other form of home care services (e.g. respite, physiotherapy) is reported by as many as one in ten of this group.

In most cases, these services are being provided at no cost, although this is less likely to be the case for the most widely used services (e.g. personal care, homemaking) than for those being provided to only a handful of caregivers. (Note: The size of the sub-sample currently receiving any form of home care services (N=110) is too small to provide for meaningful analysis by recipient or caregiver characteristics). (*Questions 22,23*)

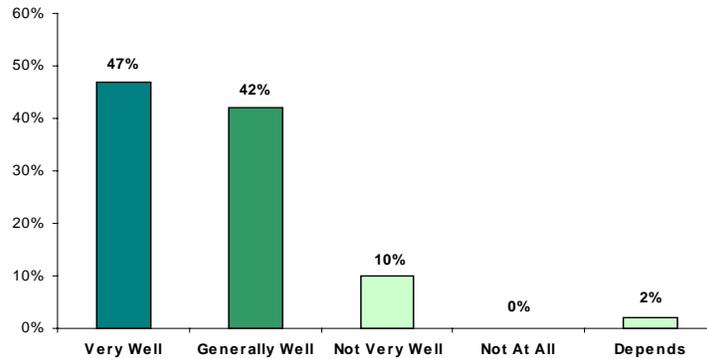
Table 3: Formal Home Care Services Received

| Type of Service | Service Provided ¹ % | Provided at No Cost ¹ % |
|--|------------------------------------|---------------------------------------|
| Personal care worker | 40 | 25 |
| Nursing visits | 34 | 29 |
| Homemaking (housekeeping, light meals) | 26 | 19 |
| Physiotherapy | 8 | 8 |
| Respite/Relief/Breaks | 7 | 4 |
| Doctor/Physician | 6 | 2 |
| Homecare provider | 5 | 5 |
| Occupational therapy | 5 | 5 |
| Nutrition | 3 | -- |
| Social worker | 3 | 3 |
| Equipment | 2 | 2 |
| Speech therapy | 1 | 2 |
| Ambulance service | 1 | 1 |
| Other service | 11 | 7 |

¹ Among those who receive any homecare service (23% of total population).

Caregivers who are currently receiving some form of formal home care for their family member are generally, if not completely, satisfied with the effectiveness of these services. Close to half (47%) say the services being provided meet the needs of their family member "very well", while most of the remainder say they are doing so "generally well." One in ten (10%) are less positive in their assessment, although none maintain these services are "not at all" meeting their family member's needs. (Note: the subsample size is too small to provide for analysis by recipient or caregiver characteristics). (*Question 24*)

How Well Do Home Care Services Meet the Needs of the Recipient?

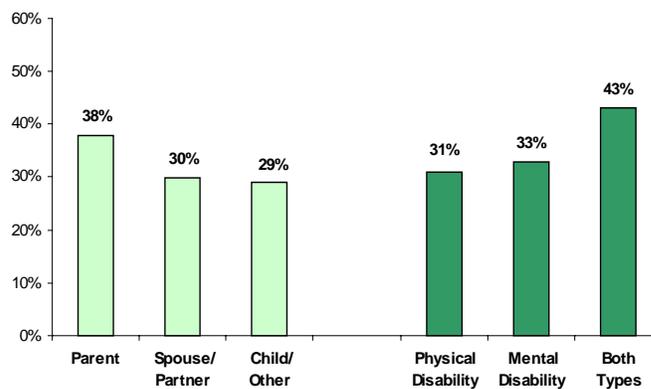


Additional Care Requirements

One in three caregivers feel they could use additional home care services, primarily in the form of housecleaning, a personal care worker or respite.

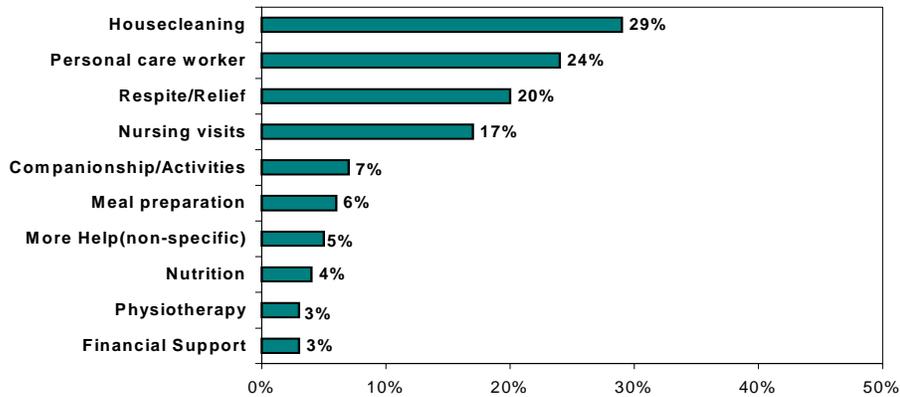
All caregivers were asked if there are any additional types of formal home care services that would be of help in caring for their family member. One in three (33%) say they could use such help, with most likely by caregivers looking after parents, and those 75 and older, and those with both physical and mental disabilities (these three characteristics tend to define the same segment). (*Question 25*)

Need for Additional Home Care Services
By Recipient Type and Form of Disability



The need for additional assistance is somewhat more prevalent among women, those who are employed, and those who are not) and those already receiving some form of formal care (46%).

Types of Additional Home Care Services Required¹
Top 10 Mentions



¹ Among those who could use additional help (33%).

Those who identify a need for more assistance are most likely to say they could use additional assistance in the form of housecleaning (29%), a personal care worker (24%), respite or someone to give them a break (20%), and nursing visits (17%). (*Question 26*)

The Need for Institutional Care

One in ten caregivers believe their family member would be better cared for in an institutional setting.

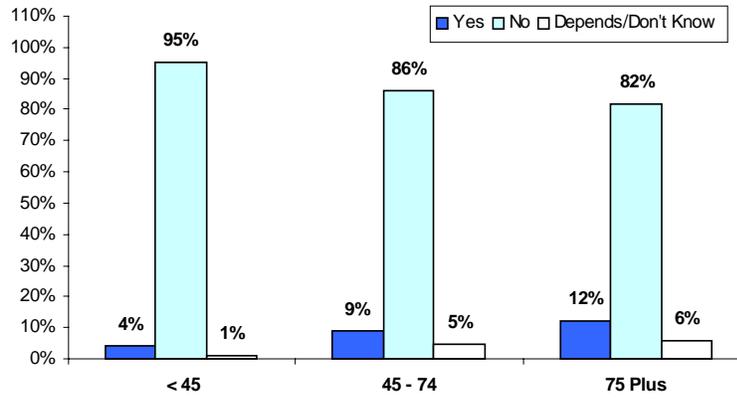
While many caregivers identify the need for additional forms of home care services, few (9%) express the view that their family would be better cared for in a nursing home or long term care facility. Close to nine in ten (87%) feel this would not be the case, while a small number (4%) are unsure or say it depends.

As might be expected, the view that their family member would receive better care elsewhere is somewhat more evident among caregivers who are caring for parents (14%) and family members 75 and older (12%) (who are also likely to be parents). This is also the case with caregivers who are already receiving some form of formal care (17%), those who are employed (12%) and those who feel they had no choice in taking on this responsibility (13%).² (*Question 27*)

²This subgroup is too small provide for an in-depth profile on the characteristics of either the caregivers or recipients).

**Would Your Family Member Receive Better Care
in a Nursing Home/Long Term Facility?**

By Recipient Age

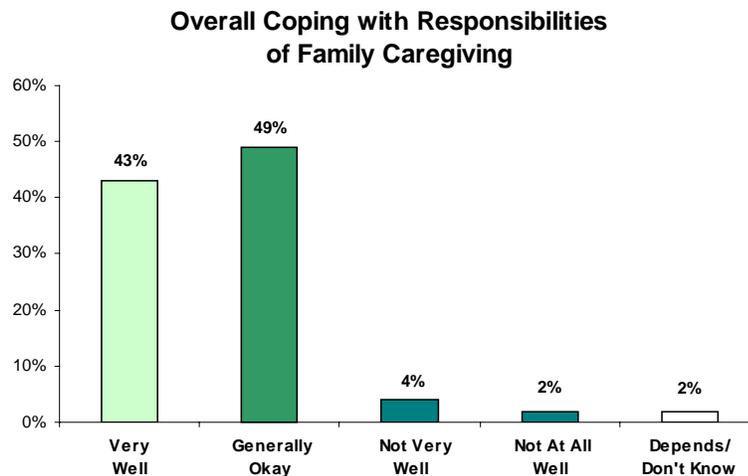


Coping with Caregiving Responsibilities

Overall Coping

Most caregivers say they are coping with the responsibilities of looking after a family member, but at the same time are experiencing some degree of difficulty or stress.

Caregivers were asked how well they feel they are coping with the responsibilities of caring for a family member in the home. Overall, caregivers are relatively positive about how they are managing this part of their lives, with more than four in ten (43%) indicating they are coping very well, while most of the remainder (49%) say they are doing "generally OK." Very few (6%) say they are not coping well with this caregiving responsibility. (*Question 28*)



Success in coping with family care responsibilities does not vary dramatically by type of caregiver or recipient, and no more than 10 percent of any group report to be doing not well in this area. At the same time, there are some notable differences across groups in the balance between doing "very well" and "generally OK." Those *least* apt to say they are doing very well include caregivers looking after parents (29%), those who did not have a choice in taking on this responsibility (27%), residents of Ontario (35%) and the Prairies (32%), women (40%), caregivers under 65 years of age (40%), and those who are employed (38%, versus 46% of those not employed). Not surprisingly, those who feel their family member would be better cared for somewhere else are among those least likely to say they are coping very well (12%).

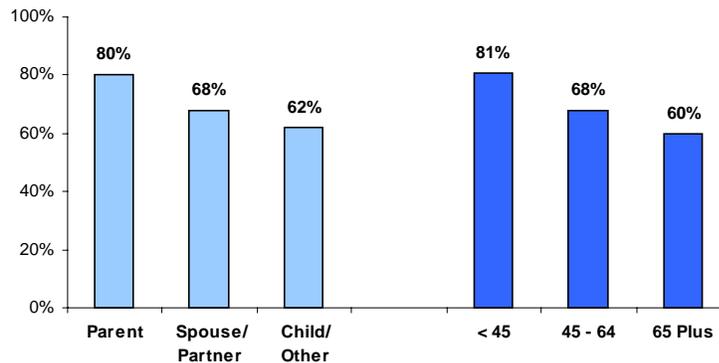
At the same time, coping success does not appear to be related to the overall burden of caregiving tasks performed: The likelihood of reporting that they are coping "very well" does not decline as the number or frequency of caregiving tasks increases.

While most caregivers feel they are coping well with their responsibilities, a clear majority (70%) also say it has been difficult or stressful. Even among those who say they are coping very well with

this role, half (50%) report stress or difficulties, with this percentage higher among those coping generally well (83%) and including all of those who are not coping very well or at all (100%).

This impact is most widely identified by caregivers under 45 years of age (81%), those caring for a parent (80%), those whose first language is other than English or French (81%), those who receive some form of formal care (80%) and those who feel they had no choice in taking on this responsibility (87%). Caregivers who are employed are somewhat more apt to mention such stress (74%) than those who are not (67%). Reported stress is least apt to be mentioned by residents of Quebec (51%), caregivers 65 and older (60%) and those looking after children or other family members (62%). (*Question 29*)

Experience Stress from Caregiving
By Recipient Type and Caregiver Age



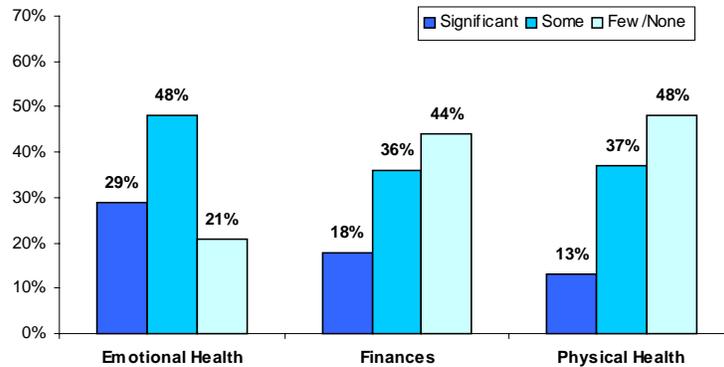
Specific Coping Difficulties

Caregivers are most likely to feel stressed in terms of their emotional health, but also experience problems with their finances and physical health.

Those who report experiencing difficulty or stress in caring for a family member in the home were also asked about the extent to which this was affecting them in several specific areas. This group is most likely to say that caregiving has created significant (29%) or some (48%) difficulties in terms of their own **emotional health**. (*Question 30b*)

Significant problems in this area are most widely reported by women (32%), younger caregivers (36%), allophones (37%), those caring for family members under 45 (39%), and those caring for someone with a mental disability (47%). This impact is also more prevalent among those who are both employed (36%) but also among those in the lowest income bracket (35%). Such difficulties are least likely to be reported by male caregivers (19%), those over 65 years of age (19%), those caring for someone with a physical disability (22%) and those who feel they had a choice in taking on this responsibility (22%).

Extent of Personal Difficulties Resulting from Caregiving



Just over half of the caregivers reporting stress say they are experiencing significant (18%) or some (36%) difficulties affecting their **personal finances**. In this area, the impact is most noticeable among younger caregivers (29%), those looking after a younger family member (under 45 years of age) (26%), and where the recipient has both physical and mental disabilities (25%). As with emotional impact, financial difficulties are most likely to be reported by those who are employed (23%) and in the lowest income bracket (29%). (*Question 30a*)

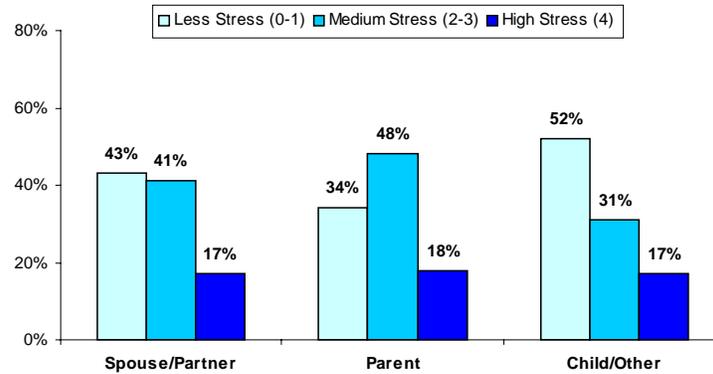
Finally, caregivers are least likely to report that looking after a family member has taken a significant toll on their own **physical health** (13%), with another 37 percent saying it has caused them some difficulties in this area. In this case, a significant impact is mostly mentioned by women (16%, versus 4% of men) and by allophones (21%). (*Question 30c*)

The responses to these three questions were combined to create a single measure of **caregiving stress**. This index consists of a five-point scale, ranging from "0" (no stress - this group did not report any stress or difficulty in Question 29) to "4" (high stress - this group indicated significant or some difficulties in all three areas). This index was created to provide an overall measure of the stress experienced by caregivers that likely provides a more accurate indication of difficulty than their self-reported success in coping. (*Question 30X*)

One in six (17%) of caregivers fit into the high stress group (a rating of 4), and this group is more likely to include women, younger caregivers, those looking after younger recipients, those dealing with both physical and mental disabilities, and those whose first language is neither English nor French. Age of recipient is a factor, but primarily for parents or spouses - those caring for children and other family members are least apt to experience a high degree of caregiving stress.

The low stress group (ratings of 0 or 1) is more apt to be represented by caregivers living in Quebec, those who have taken on caregiving by choice, and those looking after a family member 65 and older.

Caregiving Stress Index
By Type of Care Recipient



Consistent with findings presented above, caregivers currently receiving some form of formal care assistance are somewhat more likely to rate higher on the stress index, compared with those who are not receiving such assistance. This provides further evidence to suggest that formal care may be playing an important support role to those caregivers facing the greatest care burden, rather than displacing this burden.

Predictors of Caregiving Stress

Caregivers most likely to experience stress are those who had no choice in taking on this role, younger caregivers, those looking after a parent or spouse, and those performing a greater number of caregiving tasks.

Further analysis of the survey results was performed to identify which factors might best explain or predict the overall amount of stress experienced by caregivers. A number of characteristics of both the caregiver and the recipient were incorporated into a multivariate analysis (multiple regression) to identify which are most closely associated with the index of overall caregiving stress.

The analysis reveal five specific characteristics as the ones that together are the strongest predictors of overall caregiving stress. In order of significance, caregivers are more likely to experience such stress if: 1) they feel they had no choice in taking on this responsibility; 2) if they are caring for a parent or spouse (versus a child or other relative); 3) if the caregiver is younger; 4) if the recipient is younger; and 5) if they are performing a greater number of caregiving tasks. Together these five characteristics account for close to one-quarter (22%) of the variance in caregiving stress.

The following table present the relative strength of association between each of the five characteristics and caregiving stress, as measured by "Beta" coefficients. These statistics show that lack of choice (B=.40) is more than twice as powerful a predictor of stress as caregiver age (B=.20)

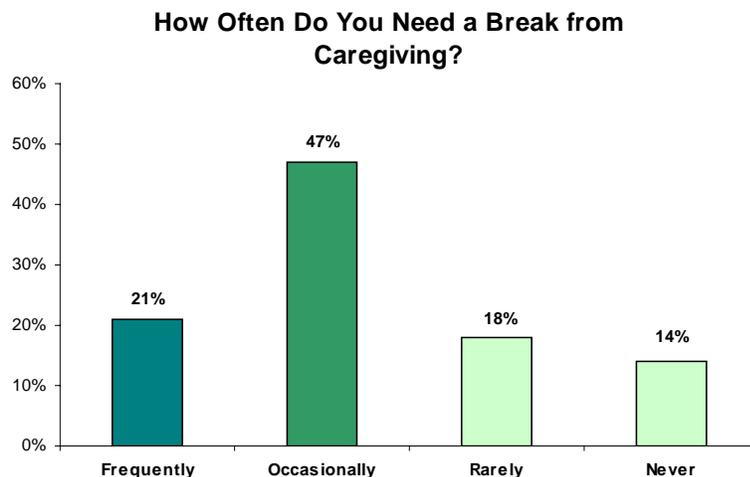
Table 4: Predictors of Caregiving Stress

| Predictor | Beta Coefficient |
|---|------------------|
| 1. No choice in taking on caregiving responsibility | .40 |
| 2. Caring for spouse or parent (versus child/other) | .26 |
| 3. Caregiver is younger | .20 |
| 4. Recipient is younger | .15 |
| 5. Greater number of caregiving tasks performed | .11 |

The Need for a Break

Most caregivers feel the need for a break from this responsibility, but only one in five identify this as a frequent requirement.

Given the responsibilities and stress involved in looking after a disabled or ill family member in the home, it is no surprise that most caregivers find the need for a break or respite from this task. Only one in five (21%), however, say this is something they need on a frequent basis. By comparison, close to half (47%) say they need such respite on an occasional basis, while another third indicate it is necessary only rarely (18%) or never (14%). (*Question 31*)



The frequency with which a break from caregiving is needed does not vary significantly across the population. The need for frequent breaks is most evident among caregivers who already receive some form of formal care (35%) and by those caring for a family member with both physical and

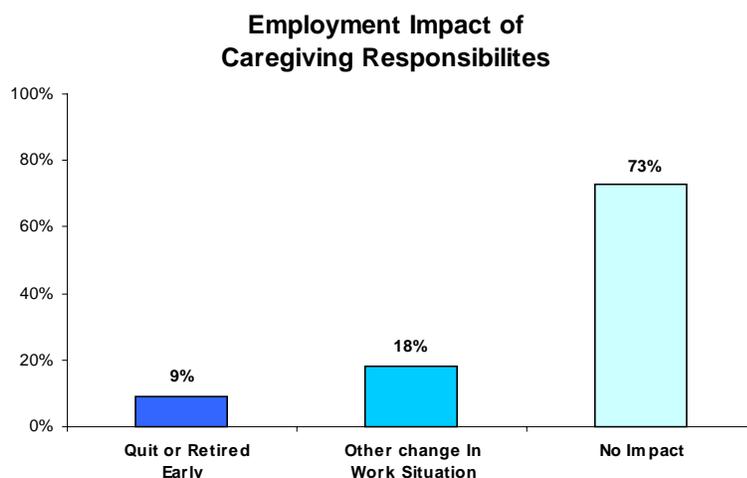
mental disabilities (32%). By comparison, respite is least apt to be seen as necessary by caregivers who had a choice in assuming this responsibility, men, allophones, and those with the least income. Caregivers who are employed are only marginally more likely to identify the need for frequent breaks, compared with those who are not employed.

Employment Impacts of Caregiving

More than one quarter of caregivers have quit, retired or experienced other job changes as a result of their care responsibilities.

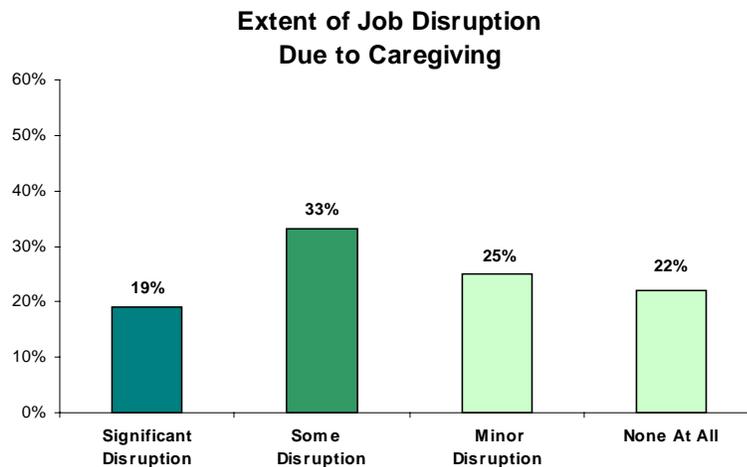
Given the responsibilities often involved in family caregiving, this role can often affect caregivers' working life. More than one in four (27%) of the caregivers surveyed indicate they have been affected in this way.

Of those not currently in the workforce (e.g. homemaker, retired), one in five (20%) say they have quit their job or retired early in order to provide care to a family member in the home (this translates into 9% of all caregivers). This action is most likely reported by younger caregivers looking after a family member under 45 years of age (e.g. a child) (61%). Women (22%) are twice as likely as men (11%) to have quit or retired in order to care for a family member. As might be expected, quitting is more prevalent among those saying they had no choice in taking on this care (28%, versus 12% among those who did feel they had a choice). (*Question 33*)



Among those currently employed or seeking work (47% of the caregiving population), one-third (34%) report their employment situation has changed as a result of their caregiving responsibilities (or 18% of all caregivers). This group is most likely to include those dealing with a mental disability (47%), those receiving some type of formal care (44%) and women (40%, compared with 15% of men). (*Question 34*)

Among those currently employed, half say their caregiving has resulted in significant (19%) or some (33%) disruption to their job, while the remainder say there has been minor (25%) or no (22%) such disruption. Significant job impacts are much more likely to be reported by those who had no choice in taking on the caregiver role (28%) compared with those who did (11%). Those caring for a family member with a physical disability are less apt to experience significant work disruption (17%) compared with those dealing with mental functioning (26%). (*Question 35*)



The degree of work disruption appears to have some impact on the success with which caregivers are coping with this responsibility, although not to a substantial degree. Those who say they are coping very well are somewhat less likely to report experiencing a change in their employment situation as a result of the family care required and are less likely to find that caregiving has caused significant or some disruption to their job.

Employment Support for Caregiving

Many caregivers are benefitting from flexibility provided by their employers, and this is a valued source of support. A government-sponsored job and income protection program is also seen as a helpful way to balance caregiving and work responsibilities.

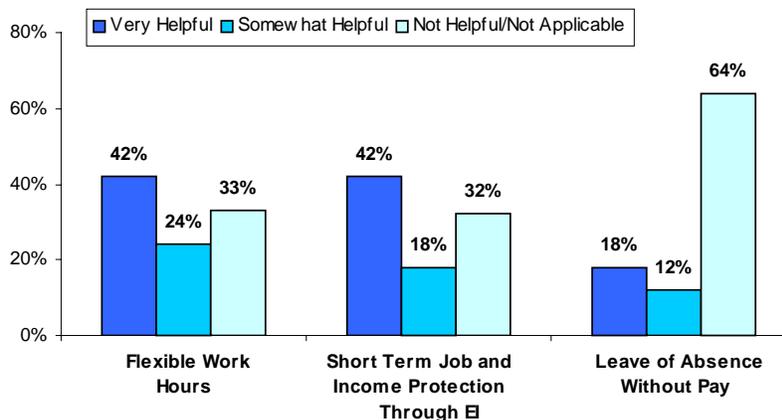
While caregivers are experiencing job impacts due to their care responsibilities, many are also benefitting from support from their employers. Among those currently employed, two-thirds (66%) say their employer has been flexible in adjusting their work hours or responsibilities to accommodate their family caregiving role. Another one in six (16%) say they have not received such support from their employer, while an equivalent number (17%) indicate they are self-employed. (*Question 36*)

Such support is most likely to be mentioned by those who have been providing care for less than 12 months (74%), and declines somewhat as the length of care lengthens over time (to 60% among those

who have been doing so for more than six years). Employer flexibility is also more widely identified by English-speaking caregivers (71%), compared with those whose first language is French (58%) or other (56%).

Caregivers were also asked how helpful they would find each of three specific forms of work-related support in helping them to deal with their family care responsibilities. Two-thirds say they would find **flexible work hours** to be very (42%) or somewhat (24%) helpful to them in balancing their job and caregiving roles. Others say this would not be very (3%) or at all (11%) helpful, or say it is not applicable because they are self-employed or are in some other work arrangement where this would not be relevant (12%). A small group (7%) maintain they already have access to flexible work hours. This form of employment support is most likely to appeal to caregivers looking after a spouse or partner (54% very helpful), those already receiving formal care (49%), and those in lower income brackets. (*Question 37a*)

Value of Employment Supports in Balancing Caregiving and Work



A significant majority of caregivers also say it would be very (42%) or somewhat (18%) helpful to them to have access to **short term job and income protection through the government's Employment Insurance program**. One in five (21%) feel this would not be helpful to them, while another 11 percent say it would not apply to them because of self-employment or because of other reasons.

The value of this type of program is most widely endorsed by caregivers looking after a spouse or partner (52% say very helpful), those whose family member has physical and mental disabilities (52%), those who had no choice in taking on this responsibility (53%), English-speaking caregivers (46%) and those in the middle income bracket (\$25,000-\$44,000) (52%). Those who feel this program would not apply to them are most apt to be caring for a child or other relative (20%) or at least 45 years of age (15%). (*Question 37c*)

In contrast to these two forms of employment support, caregivers are much less likely to see a benefit in having access to **leave of absence without pay**. Less than one in five (18%) see this as being very helpful, while two-thirds say it would not be helpful (47%) or not even apply to them (17%). This type of support does not appear to be of particular appeal to any particular type of caregiver or recipient. (*Question 37b*)

Other Types of Assistance

Few caregivers identify the need for other types of support or assistance not already covered in this survey.

At the conclusion of the survey, caregivers were asked to identify anything not already covered which they feel might make a difference in helping them handle their family caregiving responsibilities. Notably, six in ten (60%) stated there was nothing else they could think of that would help them in this way, and of the specific responses given none was mentioned by as many as one in ten. This suggests that there are no unidentified forms of support or assistance that are currently in significant demand among caregivers across Canada. (*Question 38*)

Among those who did provide a specific response to this question, caregivers are most likely to mention financial help or compensation of some type generally (8%), or more specifically in the form of tax relief (2%), salary (2%) or a drug plan (2%). Others would like to see more homecare provided (4%), more advice and information to help them cope with the role (3%) and respite (2%). No other response is identified by more than one percent of this group. Identification of supports of any type is more common among younger caregivers than among older ones.

Survey Methodology

Questionnaire Design

The questionnaire was designed by senior Decima consultants, in consultation with Health Canada. Prior to being finalized, the survey was pre-tested on a small number of respondents.

Sample Design and Selection

The sample for this study was designed to complete interviews with a representative sample of family caregivers, meeting the criteria established by Health Canada for this survey. Family caregivers include Canadians 18 and older who are currently providing care to another family member (in either their home or their family member's home), who has a physical or mental disability, is chronically ill or frail (this would include those who are terminally ill).

Family caregivers were identified in the population through a broad-based recruitment process with Canadian households, involving initial telephone contact followed by a detailed screening to establish eligibility. This approach was used in part because there is no existing database of family caregivers in Canada, and in part because a central objective of this survey is to establish a profile of this group.

The initial sample of households was drawn using SurveySampler technology which ensures that all residential listings in Canada have an opportunity to be selected for inclusion in the survey. Up to five call backs were used to reach selected respondents who may not have been available at the time of the call.

Quotas were established to ensure that caregivers were identified and interviewed in each of the 10 provinces, proportionate to population (see table below).

Survey Administration

The survey was conducted in English and French by telephone with family caregivers, using computer-assisted-telephone-interviewing (CATI) technology, from Decima's facilities in Ottawa, Toronto and Montreal, between February 28 to March 11, 2002. All interviewing was conducted by fully trained and supervised interviewers, and a minimum of 10 percent of all completed interviews were independently monitored and validated in real time. The average length of time required to complete an interview was 15 minutes.

A total of 471 family caregivers were interviewed as part of this study, based on an overall incidence rate of 3.9 percent (that is, there are 3.9 households with an eligible family caregiver out of every 100 Canadian households that could be reached during the interview period). Another one percent (.06) were identified as having previously been family caregivers in the past 12 months.

Sample Distribution

A sample of 471 drawn from the population family caregivers would be expected to provide results accurate to within plus or minus 4.5 percent in 95 out of 100 samples. The margin of sampling error will be greater for regional and provincial sub-samples, as presented below.

Sample Distribution by Region

| Region/Province | Sample | Margin of Error ¹ |
|------------------|------------|------------------------------|
| Atlantic Canada | 36 | +/- 16.2% |
| Québec | 114 | +/- 9.1% |
| Ontario | 179 | +/- 7.3% |
| Prairies | 78 | +/- 11.0% |
| British Columbia | 64 | +/- 12.2% |
| CANADA | 471 | +/- 4.5% |

¹95% Confidence Level

Completion Results

A total of 27,931 telephone numbers were dialled, from which 471 households were qualified as eligible (family caregiver fitting the criteria described above) and completed the survey. The overall response rate is 56 percent. This is a very high level of response for this type of survey, and reflects the level of interest and cooperation from caregivers when contacted about the survey.

The following table shows the final disposition of all telephone numbers dialled.

| | |
|--------------------------------------|---------------|
| Answering machine | 1,942 |
| No answer | 2,787 |
| Language barrier | 592 |
| Ill/Incapable | 0 |
| Eligible not available/Callback | 380 |
| Quota Full - NOT QUALIFIED | 4 |
| Total Asked | 17,594 |
| Household refusal | 864 |
| Respondent Refusal | 2,981 |
| Termination <i>before qualifying</i> | 464 |
| Qualified <u>Termination</u> | 33 |
| Co-operative Contact | 13,252 |
| Not Qualified (No family caregiver) | 12,781 |
| Quota Full-QUALIFIED | 0 |
| Completed Interviews | 471 |
| | |
| RESPONSE RATE | 55.91 |
| | |
| INCIDENCE | 3.86 |