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Informal/Family Caregivers in Canada Caring for Someone with a Mental Illness

Final Report

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Introduction

Background

In 2002, Health Canada commissioned a national survey to establish an initial in-depth profile of family caregivers across Canada   The specific objectives of that research were to: (1) Identify the demographic characteristics of Canadians looking after a family member in their own household (or their family member's home); (2) Determine what specific caregiving tasks being performed and over what period of time; (3) Assess the extent to which family caregivers are coping with their caregiving responsibilities; and (4) Determine the needs of family caregivers who are most burdened and unable to cope.

That study, entitled *National Profile of Family Caregivers in Canada – 2002*,[1] defined a "family caregiver" as an individual who is currently providing care in their home to another family member who has a physical or mental disability, is chronically ill, or is frail (excluding short term care due to injury or illness). Based on that research, it was estimated that about four percent of Canadian adults provide care to a person with a physical or mental disability, is chronically ill or is frail.

While the 2002 *National Profile* study was an essential starting point that provided a baseline for future research on the experiences and needs of family caregivers in Canada, it did not include informal caregivers who are not related to the care recipient. In addition, that research used a broad definition of "chronic health problem or disability" for care recipients that included most disabilities, and did not look at specific categories of illness or disability.

Mental Illness in Canada

Research indicates that a growing number of Canadians have been diagnosed with mental illnesses. For example, the recently released *Canadian Community Health Survey, 2003*[2] demonstrates that as many Canadians suffer from major depression as from other leading chronic conditions such as heart disease, diabetes or thyroid conditions. About 2.6 million Canadians reported symptoms over the past year of one of the five major mental illnesses surveyed. Health Canada recently noted that existing data provide a very limited profile of mental illness in Canada, and that priority data needs include the "impact of mental illness on the quality of life of the individual and family."[3]

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[1] The 2002 study was conducted for Health Canada by Decima Research Inc. The report is available online at: http://www.hc-sc.gc.ca/english/care/nat_profile02/1.html

[2] Canadian Community Health Survey, 2003. The report is available online at: http://www.statcan.ca/english/freepub/82-617-XIE/index.htm

[3] *A Report on Mental Illnesses in Canada*, *2002*, page 10. The report is available online at: http://www.hc-sc.gc.ca/pphb-dgspsp/publicat/miic-mmac/index.html

Research Objectives

This report presents the results of research commissioned by Health Canada to determine how many Canadians currently provide care to a friend, neighbour, or family member with a diagnosed mental illness. The report provides a comprehensive national profile of informal/family caregivers providing care to a person with a diagnosed mental illness, the extent of the care provided, gaps in service provision, and the impact on families.

More specifically, the objectives of this research are to:

- Develop a national profile (age, sex, province or territory, rural, urban, and employment status) of informal/family caregivers in Canada providing care to someone diagnosed with a mental illness, and to develop a similar profile of the care recipient;
- Determine what specific care-related tasks are being performed and the frequency and duration of these tasks;
- Ascertain what support services are in place, where unmet needs exist, and the impact this is having on informal/family caregivers;
- Examine whether there are differences between family caregivers and informal caregivers in terms of caring responsibilities and impact; and
- Ensure that all information is sex-disaggregated in order to develop a gendered analysis of the findings.

Consistent with the *Mental Illnesses in Canada Survey*, this study includes the following five diagnostic categories:

- Mood disorder (major depression, bipolar disorder/manic depression and dysthymia, post-partum depression);
- Schizophrenia;
- Anxiety disorder (generalized anxiety disorder, specific phobia, post traumatic stress disorder, social phobia, obsessive-compulsive disorder, panic disorder);
- Personality disorder; and
- Eating disorder (anorexia, bulimia, binge eating disorder).

This definition of mental illness does not include dementia type disorders such as Alzheimer disease, or addictions, developmental delays, or acquired brain injuries.

A “caregiver” is defined as someone who provides unpaid care in their own home or in the recipient’s home to a family member, friend, or neighbour who has been diagnosed with a mental illness. Unlike the 2002 research, which only included those actively involved in providing care at the time of the survey, the current research includes those providing care at the time of the survey, as well as those who had done so within the year preceding the survey.

This report is based on telephone interviews with a representative sample of 343 family and informal caregivers in Canada conducted between March 5 and April 4, 2004. A total of 123,557 telephone numbers were dialled, from which 343 households were qualified as eligible (informal or family caregiver fitting the criteria described above) and completed the survey. The overall response rate for this survey is 26 percent. The margin of error for a sample of this size is plus or minus 5 percent at the 95 confidence level.

The questionnaire for this survey was designed by senior Decima consultants, in close consultation with the Health Canada project team. The questionnaire incorporates many questions from the *2002 National Profile of Family Caregivers in Canada* study, with appropriate modifications throughout. Prior to being finalized, the questionnaire was pre-tested on a small number of respondents in both English and French. A more detailed description of the survey methodology used to complete this research is provided on page 51 of this report.

This report begins with an executive summary highlighting the key findings and conclusions, followed by a detailed analysis of the survey findings. Provided under separate cover is a set of detailed "banner" tables that disaggregate the results of all survey questions by key demographic and care-related subgroups, including sex, language, age, income, care recipient diagnosis, and others. Statistically significant differences between sub-groups (e.g. sex) are presented throughout this report. The detailed analysis section denotes these banner tables by question number (e.g. *Q.1*) for ease of reference.

Executive Summary

Based on the results of this survey, approximately two percent of the population (18 years and over) provides care to a family member, friend, or neighbour diagnosed with a mental illness. This translates into approximately one half of a million Canadians.

The following are the key highlights and conclusions from this survey, in terms of caregivers' characteristics, activities, and experiences in looking after someone diagnosed with a mental illness.

Profile of Caregivers

More than two thirds (70%) of the informal or family caregivers included in this study are women.

A majority of caregivers are of working age. Two thirds (64%) are aged between 18 and 54 years, and the remaining one third are between 55 and 64 years of age (21%), or 65 years and older (13%). Not surprisingly, younger caregivers are more likely to be caring for a parent and older ones are more apt to be caring for a child.

About six in ten caregivers are currently employed in addition to their caregiving responsibilities. Over one quarter (27%) report an annual income of less than $25,000, while one in six (17%) say they have a household income between $25,000 and $35,000. Similar proportions report annual incomes of between $35,000 and $54,000 (26%), and greater than $55,000 (30%).

Women caregivers are less likely than men to be employed full time, and are more likely to report household incomes below $25,000.

Most (82%) of these caregivers have additional family members in the household, and these are most often their children or spouses.

One in five caregivers also care for someone who is ill or disabled in addition to providing care to someone diagnosed with a mental illness. Among this group, these additional care recipients are generally an immediate family member, such as a child or a parent.

Close to half (47%) of caregivers have been providing on-going care for an extended period (at least 5 years), and most describe the condition for which care is required as something that is long-term. Those who are caring for someone who is not related to them are more likely to have been providing care for a shorter time (less than a year).

Caregivers who no longer provide care for someone diagnosed with a mental illness most often say this is because the recipient moved, or was institutionalized.

Seven in ten (72%) report that they had no other reasonable options when they decided to become the primary caregiver. Approximately half are providing the care because they believe there to be a lack of home care and/or mental health services. Caregivers also feel a sense of responsibility to provide the care.

Profile of Recipient

Caregivers are most apt to be caring for either a child (30%), most often an adult child (21%), or a spouse (24%). One in six are providing care to either a parent or another family member, such as a sibling, or grandparent. Just over one in ten (14%) caregivers provide care to someone who is not related to them.

Women are more likely to provide care to parents, while men are more likely to provide care to partners. Both men and women caregivers are equally likely to care for children.

A majority of care recipients are of working age. Equal proportions of recipients are between the ages 18 and 34 (29%) and 35 and 54 (29%), with another 12% aged 55 to 64. About one in five (18%) are aged 65 and older, and only one in ten are minors (under the age of 18, 11%).

The most common diagnoses are mood disorders (63%), followed by schizophrenia (27%) or anxiety disorders (17%). Few require care for a personality (6%) or eating disorder (1%). Spouses are more likely to be diagnosed with mood disorders while children are more often diagnosed with anxiety disorders.

A minority of care recipients have been diagnosed with multiple disorders, and the most common multiple diagnosis is mood disorder and anxiety disorder.

Type of Care Provided

A sizeable majority (69%) of caregivers provide the care in their own home and this is usually the case when caring for a spouse, and to a lesser degree, when caring for a child.

Caregivers perform a range of tasks while caring for someone diagnosed with a mental illness. The most common tasks performed are providing companionship and emotional support during a crisis. They also provide medications and monitor symptoms on a regular basis. Similar caregiving tasks are performed by both men and women.

The most effort is expended by those caring for someone who is under the age of eighteen, or for a parent.

About two-thirds of caregivers believe they have the necessary skills to adequately provide care to someone diagnosed with a mental illness, and this is the case for both men and women. Those caring for a parent and who have been providing care for an extended period are more confident than others in this regard.

Despite the fact that a majority of caregivers are confident they have the necessary skills, almost all would welcome help performing their caregiving tasks. However, when asked what would be most helpful, there is no clear consensus as to what types of assistance would be most beneficial.

Almost six in ten caregivers pay out-of-pocket expenses, mainly paying for transportation-related costs and medications. Three in ten are spending over $300 per month to care for someone diagnosed with a mental illness.

Formal Assistance

Less than half (45%) of caregivers say the care recipient received formal assistance as part of their care. Services are most often provided to care recipients under the age of eighteen, or to parents of caregivers. Care recipients between the ages of 18 and 54 are less likely than those under the age of 18 or older than 55 to receive some form of formal or professional home or community care services.

Care recipients receiving assistance are most likely to use psychological or counselling services, although these services are not often provided free of charge. Of those who are receiving some form of formal assistance, a majority (73%) are satisfied that these services are meeting the needs of the care recipient.

About half of all caregivers agree that additional formal assistance would be of help to them, primarily with psychological services and homemaking duties. Those caring for a family member other than their child are more likely to express a need for formal assistance. There is no difference in wanting formal assistance between men and women.

One-fifth (21%) of caregivers feel the recipient would be better cared for in a facility. This is expressed most often by those caring for someone with schizophrenia, and by those caregivers who are less confident about their caregiving skills.

Coping with Caregiving Responsibilities

Caregivers are coping reasonably well with the responsibilities associated with caring for someone diagnosed with a mental illness. However, caregivers who did not feel they had a choice in taking on the responsibility and those who are less confident in their caregiving skills are having more difficulty coping.

Although a majority of caregivers say they are coping reasonably well, many are experiencing at least some difficulties in other aspects of their life as a result of their caregiving duties. This is most often the case for balancing their personal and family needs, and least likely in terms of their own physical health.

The overall stress of caregiving is highest for women (47%), those who are caring for a child (34%), and for those who are caring for multiple people (35%). Men, and those caring for someone who is not a family member report the least amount of stress.

Three quarters of caregivers say they need a break at least occasionally from their caregiving duties, and half of this group (or 38% of all caregivers) get the break as often as they need it. Caregivers who report higher levels of stress, who are not coping well, and who perform multiple tasks are most in need of a break, but this group is less likely to have their need for respite met.

Other family members most often provide relief to family caregivers while friends provide relief to those caring for someone outside of their family.

Almost half (46%) of all caregivers say their caregiving responsibilities have not impacted their employment. Those caring for someone under the age of 18 are most likely to report an impact on their employment as a result of their caregiving.

Caregivers value employment support programs to balance caregiving and employment responsibilities, and they are most supportive of flexible work hours or short-term job and income protection. Women are more likely than men to say these two support programs would help them with their caregiving responsibilities.

Half of caregivers say a leave of absence without pay would not be helpful to them, although those caring for a spouse and caregivers who are not currently employed are more open to this benefit.

Sommaire

Les résultats de ce sondage démontrent qu'environ deux pour cent de la population (âgée de 18 ans et plus) fournit des soins à un membre de la famille, un ami, ou un voisin qui souffre d'une maladie mentale. Ces personnes représentent approximativement un demi-million de Canadiens.

Les sections suivantes présentent les faits saillants et les conclusions qui découlent de ce sondage en ce qui a trait aux caractéristiques des aidants naturels, ainsi qu'aux activités et aux expériences reliées à la prestation de soins à une personne qui est atteinte d'une maladie mentale.

Profil des aidants naturels

Plus des deux tiers (70 %) des aidants naturels informels ou membres de la famille qui ont été interrogés dans le cadre de ce sondage sont des femmes.

La majorité des aidants naturels sont en âge de travailler. Les deux tiers d'entre eux (64 %) sont âgés entre 55 et 64 ans (21 %), ou de 65 ans et plus (13 %). Il n'est pas surprenant de constater que les plus jeunes aidants naturels sont plus susceptibles de prendre soin d'un parent et les aidants naturels plus âgés sont plus susceptibles de prendre soin d'un enfant.

Environ six aidants naturels sur dix travaillent présentement et ce, en plus d'accomplir leurs responsabilités de prestation de soins. Un peu plus du quart des aidants naturels (27 %) indiquent que le revenu de leur foyer est inférieur à 25 000 $, tandis qu'une personne sur six (17 %) affirment que le revenu de leur foyer se situe entre 25 000 $ et 35 000 $. Des proportions semblables de répondants révèlent avoir un revenu annuel entre 35 000 $ et 54 000 $ (26 %), ou supérieur à 55 000 $ (30 %).

Les aidants naturels qui sont des femmes sont moins susceptibles que les hommes de travailler à temps plein et il est plus probable que le revenu de leur foyer soit inférieur à 25 000 $.

La plupart de ces aidants naturels (82 %) indiquent qu'il y a d'autres membres de la famille qui vivent au sein du foyer et dans la plupart des cas, ceux-ci sont leurs enfants ou leur conjoint.

En plus de s'occuper d'une personne qui est atteinte d'une maladie mentale, un aidant naturel sur cinq prend également soin d'une personne malade ou atteinte d'une incapacité. Les autres bénéficiaires de ces soins sont généralement un membre de la famille immédiate, soit un enfant ou un parent.

Près de la moitié des aidants naturels (47 %) fournissent des soins continus depuis une période prolongée (au moins 5 ans), et la plupart décrivent la maladie du bénéficiaire de soins comme requérant des soins à long terme. Il est plus probable que les personnes qui fournissent des soins à quelqu'un qui n'est pas un membre de la famille, le fassent depuis une moins longue période (moins d'un an).

Les aidants naturels qui ne fournissent plus de soins à une personne atteinte d'une maladie mentale sont plus susceptibles de dire qu'ils ne le font plus parce que le bénéficiaire a déménagé ou qu'il a été placé en institution.

Sept aidants naturels sur dix (72 %) affirment qu'ils n'avaient pas d'autres options raisonnables lorsqu'ils ont décidé de devenir le principal aidant naturel. Environ la moitié des aidants naturels fournissent les soins parce qu'ils estiment qu'il y a un manque au niveau des services de soins à domicile et/ou des services de santé mentale. De plus, les aidants naturels ont l'impression d'avoir la responsabilité de prodiguer les soins.

Profil des bénéficiaires

Les aidants naturels sont plus susceptibles de prendre soin d'un enfant (30 %), et dans la plupart des cas il s'agit d'un enfant d'âge adulte (21 %) ou d'un conjoint (24 %). Une personne sur six fournit des soins à un parent ou à un autre membre de la famille, soit un frère, une sœur ou un grand-parent. Un peu plus d'un aidant naturel sur dix (14 %) fournit des soins à quelqu'un avec qui il n'a aucun lien de parenté.

Les femmes sont plus susceptibles de fournir des soins à leurs parents, tandis que les hommes sont plus susceptibles de s'occuper de leur conjoint. Les hommes et les femmes sont tout aussi susceptibles de fournir des soins à un enfant.

La majorité des bénéficiaires de soins sont en âge de travailler. Des proportions équivalentes de bénéficiaires sont âgés entre 18 et 34 ans (29 %) et entre 35 et 54 ans (29 %), tandis que 12 % des bénéficiaires sont âgés entre 55 et 64 ans. Environ une personne sur cinq (18 %) est âgée de 65 ans et plus, et seulement une personne sur dix est d'âge mineur (moins de 18 ans, 11 %).

Les maladies les plus courantes sont les troubles de l'humeur (63 %), suivies de la schizophrénie (27 %) ou des troubles anxieux (17 %). Peu de bénéficiaires requièrent des soins pour des troubles de la personnalité (6 %) ou de l'alimentation (1 %). Il est plus probable que les conjoints soient atteints de troubles de l'humeur, tandis que les enfants souffrent le plus souvent de troubles anxieux.

Une minorité de bénéficiaires de soins ont été diagnostiqués comme souffrant de plusieurs troubles. Le diagnostic multiple le plus fréquent est celui des troubles de l'humeur combinés aux troubles anxieux.

Types de soins fournis

Une forte majorité d'aidants naturels (69 %) fournissent des soins dans leur propre maison et cela est habituellement le cas lorsque la personne s'occupe d'un conjoint, et dans une proportion moindre, lorsque la personne prend soin d'un enfant.

Les aidants naturels effectuent une gamme de tâches liées à la prestation de soins à une personne atteinte d’une maladie mentale. Les tâches les plus courantes consistent à tenir compagnie à la personne et à lui offrir du soutien émotionnel en temps de crise. De plus, ils administrent les médicaments et surveillent les symptômes sur une base régulière. De telles tâches liées à la prestation de soins sont effectuées tant par les hommes que par les femmes.

Les personnes qui déploient le plus d’efforts sont celles qui prennent soin de quelqu’un qui est âgé de moins de dix-huit ans, ou d’un parent.

Environ deux tiers des aidants naturels croient qu’ils possèdent les aptitudes nécessaires pour fournir les soins de manière adéquate à une personne atteinte d’une maladie mentale, et cela est le cas pour les hommes et les femmes. Les personnes qui s’occupent d’un parent et qui fournissent des soins depuis une période de temps prolongée sont plus confiantes que les autres à cet égard.

Malgré le fait que la majorité des aidants naturels croient qu’ils ont les aptitudes nécessaires, presque tous souhaiteraient de l’aide pour accomplir leurs tâches liées à la prestation de soins. Cependant, lorsqu’on leur demande ce qui serait le plus utile, il n’y a pas de consensus quant aux types d’aide qui seraient les plus bénéfiques.

Près de six aidants naturels sur dix déboursent de menues dépenses, principalement pour ce qui est de payer des coûts liés au transport et aux médicaments. Trois répondants sur dix dépensent plus de 300 $ par mois pour s’occuper d’une personne atteinte d’une maladie mentale.

Assistance professionnelle

Moins de la moitié des aidants naturels (45 %) disent que le bénéficiaire de soins a reçu une assistance professionnelle dans le cadre de ses soins. Le plus souvent, les services sont offerts aux bénéficiaires de soins qui sont âgés de moins de dix-huit ans, ou aux parents des aidants naturels. Les bénéficiaires de soins qui sont âgés entre 18 et 55 ans sont moins susceptibles que ceux âgés de moins de 18 ans ou ceux âgés de plus de 55 ans de recevoir une quelconque forme de service professionnel à domicile ou de soins communautaires.

Il est plus probable que les bénéficiaires de soins qui reçoivent de l’assistance aient recours à des services psychologiques ou à du counselling, bien que ces services ne soient habituellement pas gratuits. Parmi les aidants naturels qui reçoivent une certaine forme d’assistance professionnelle, la majorité (73 %) d’entre eux disent que ces services répondent aux besoins des bénéficiaires de soins.

Environ la moitié de tous les aidants naturels s’entendent pour dire que le fait de recevoir de l’assistance professionnelle supplémentaire les aiderait, principalement pour ce qui est des services psychologiques et des tâches ménagères. Les personnes qui prennent soin d’un membre de la famille autre que leur enfant sont plus susceptibles d’indiquer avoir besoin d’assistance professionnelle. Il n’y a pas de différence entre les hommes et les femmes pour ce qui est de souhaiter une assistance professionnelle.

Un cinquième des aidants naturels (21 %) pensent qu’on prendrait mieux soin du bénéficiaire dans un établissement. Ce sentiment est partagé plus fréquemment par les répondants qui prennent soin d’une personne qui souffre de schizophrénie et par les aidants naturels qui sont moins confiants quant à leurs aptitudes de prestation de soins.

Faire face aux responsabilités liées à la prestation de soins

Les aidants naturels réussissent assez bien à faire face aux responsabilités liées à la prestation de soins pour une personne qui souffre d’une maladie mentale. Cependant, les aidants naturels qui ne croient pas avoir eu le choix d’accepter la responsabilité et ceux qui sont moins confiants quant à leurs aptitudes de prestation de soins ont plus de difficulté à faire face à leurs responsabilités.

Bien que la majorité des aidants naturels disent qu’ils réussissent assez bien à faire face à leurs responsabilités, plusieurs éprouvent au moins quelques difficultés dans d’autres aspects de leur vie des suites de leurs tâches de prestation de soins. Ces difficultés sont le plus souvent liées au fait de concilier leurs besoins personnels et familiaux, et dans un degré moindre à leur propre santé physique.

Le niveau global de stress lié à la prestation de soins est plus élevé chez les femmes (47 %), les personnes qui prennent soin d’un enfant (34 %), et chez celles qui s’occupent de plusieurs personnes (35 %). Les hommes et les personnes qui s’occupent d’une personne qui n’est pas un membre de la famille sont les répondants qui déclarent être le moins stressés.

Les trois quarts des aidants naturels déclarent qu’ils ont besoin d’un répit au moins sur une base occasionnelle de leurs tâches de prestation de soins, et la moitié de ce groupe (ou 38 % de tous les aidants naturels) bénéficient d’un répit aussi souvent qu’ils en ont besoin. Les aidants naturels qui disent être plus stressés, qui réussissent mal à faire face à leurs responsabilités, et qui effectuent plusieurs tâches ont davantage besoin d’un répit. Cependant, ce groupe est moins susceptible d’obtenir le répit dont il a besoin.

Il est plus fréquent que d’autres membres de la famille offrent un répit aux aidants naturels de la famille, tandis que les amis offrent une pause à ceux qui s’occupent d’une personne avec qui ils n’ont aucun lien de parenté.

Près de la moitié (46 %) de tous les aidants naturels disent que leurs responsabilités de prestation de soins n’ont eu aucun impact sur leur travail. Les répondants qui prennent soin d’une personne âgée de moins de 18 ans sont plus susceptibles de déclarer que cette responsabilité a un impact sur leur emploi.

Les aidants naturels apprécient les programmes d'aide à l'emploi qui permettent de concilier leurs responsabilités de prestation de soins et celles liées à leur emploi. De plus, ils sont grandement en faveur des heures de travail flexibles ou d'emplois de courte durée et de la protection du revenu. Les femmes sont plus susceptibles que les hommes de déclarer que ces deux programmes d'aide les aideraient à faire face à leurs responsabilités liées à la prestation de soins.

La moitié des aidants naturels disent qu'un congé sans solde ne leur serait pas utile. Par contre, les aidants naturels qui s'occupent d'un conjoint et ceux qui sont actuellement sans emploi sont plus réceptifs à cet avantage.

Detailed Analysis

Profile of Caregivers

The survey reveals that approximately two percent (2.1%) of adult Canadians (18 years and older) are currently providing care to a family member, friend, or neighbour who is diagnosed with a mental illness. While this number is small in percentage terms, it translates into approximately one half of a million individuals (based on 2003 population data from Statistics Canada).

A strong majority (84%) of the caregivers included in this study are *currently* providing care to someone diagnosed with a mental illness, while the remainder (16%) provided the care within the past twelve months but are no longer doing so.

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

Age and Sex

Caregivers are predominantly working age. A majority are women.

A majority of caregivers are of working age. Two thirds (64%) are between 18 and 54 years of age, with another 21% aged between 55 and 64. Just over one in ten (13%) caregivers are aged 65 years and older. Relative to the general population, fewer caregivers are between the ages of 18 and 34 (16% of caregivers versus 28% of Canadian adults[4]), and more are at least 35 years of age (82% of caregivers versus 73% of Canadian adults).

Caregivers aged 45 and older are more apt to be caring for a child (76%), which are mostly adult children (92% versus 8% for children under 18) while those under the age of 35 years are more likely to care for a parent (31%) or another family member (23%). *(Q.39)*

More than two thirds (70%) of family or informal caregivers are women (compared to 52% of Canadian adults who are women). *(Q.45)*

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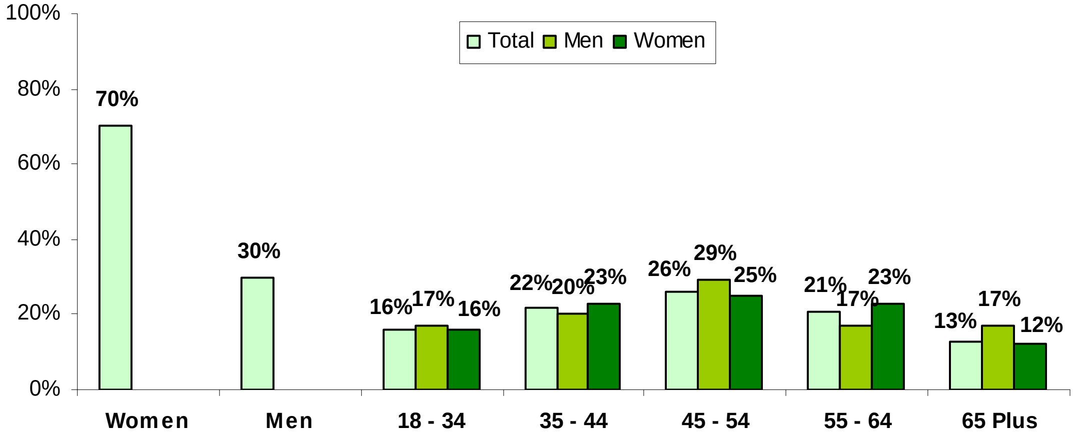
[4] Data for the Canadian adult general population is defined as Canadians aged 18 and older and is drawn from Statistics Canada Census 2001 data. Comparison data for age is based on Canadians aged 20 and older.



Age and Sex Profile of Informal/Family Caregivers

Language

Almost two-thirds of caregivers are English speaking.

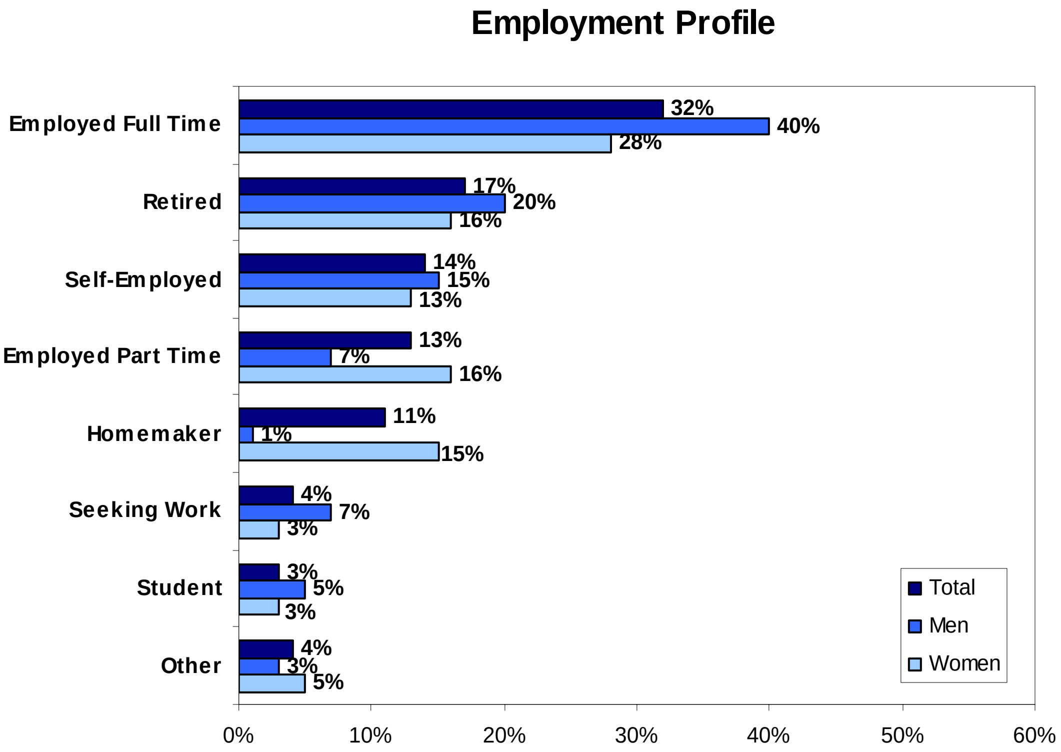
Consistent with the distribution in the Canadian population, a majority of caregivers are English speaking. Over six in ten (63%) identified English as their “mother tongue” (that is, the language they first learned to speak at home), while three in ten (28%) speak French. The remainder (9%) are allophones, who identified a language other than English or French as their mother tongue. *(Q.40)*

English speaking caregivers are most likely to say they provide care to their spouse or partner (74%), while those who speak French are more apt to report caring for a child (36%). Francophones are also more likely than others to be providing care to someone with a personality or eating disorder (62%).

Employment and Income

Almost six in ten caregivers are employed. One-fourth have a household income below $25,000.

In addition to their caregiving duties, a majority of caregivers are employed. Almost six in ten are employed either full time (32%), part time (13%), or are self-employed (14%). The remainder are retired (17%), homemakers (11%), seeking work (4%), or studying (3%). *(Q.32)*

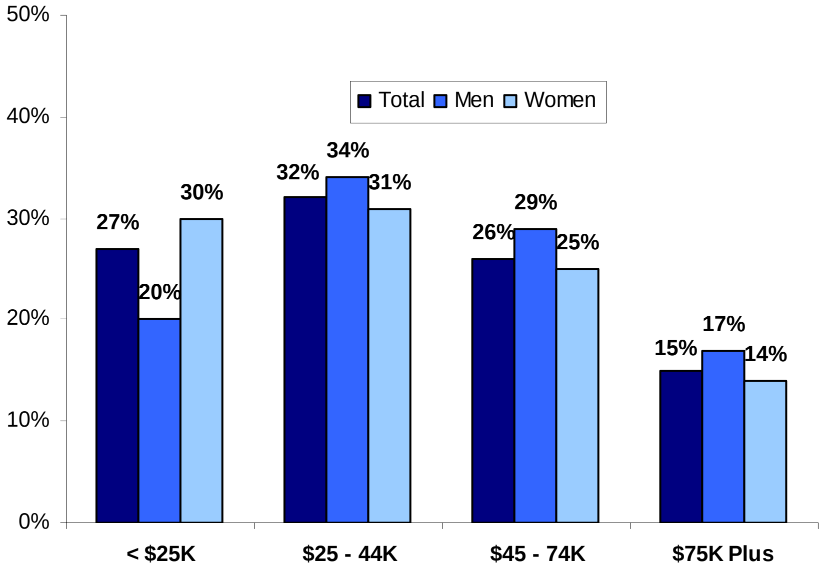


Compared to the overall adult population, more caregivers are outside of the labour force (40% of caregivers versus 32% of Canadians).

Over one quarter (27%) of caregivers report an annual income of less than $25,000, while one in six (17%) say they have a household income between $25,000 and $35,000. Similar proportions report annual incomes of between $35,000 and $54,000 (26%), and greater than $55,000 (30%). *(Q.41)*

In comparison to the overall adult Canadian population, more caregivers have an annual household income of $25,000 or more (73% of caregivers versus 43% of Canadians).

Household Income Profile[1]



[1] Adjusted to exclude 16% who declined to provide income information

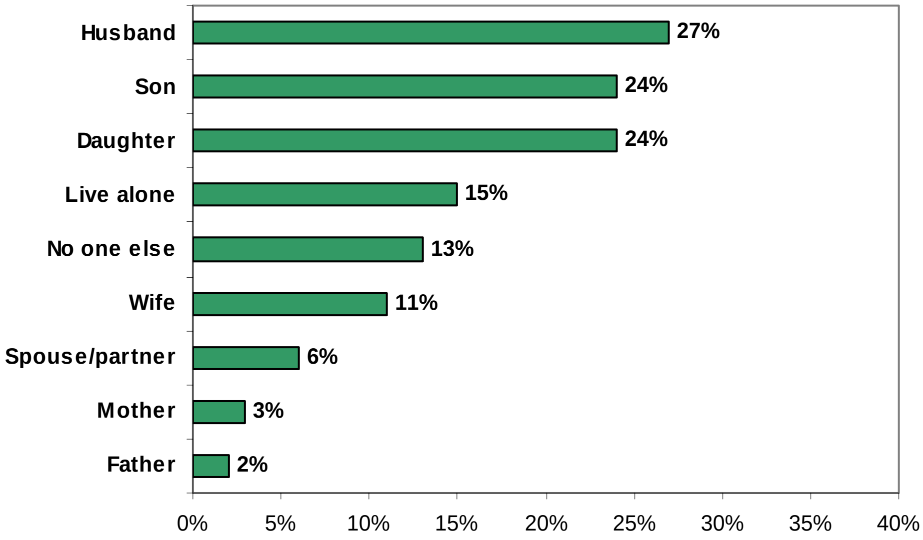
Women caregivers are less likely than men to be employed full time (28% versus 40%) and are more likely to report household incomes below $25,000 (27% versus 16%). In addition, caregivers who are not employed are more likely to say they have an annual household income of less than $25,000 (34%) than those who are employed (15%).

Household Composition

Most caregivers have additional family members living in the household.

A majority (82%) of those who care for someone diagnosed with a mental illness also live with additional family members in their household. These additional members of the household are most likely to be children or spouses. Fewer report that a parent (5%) or a sibling (3%) also lives with them, and just over one in ten (13%) live solely with the care recipient. The remainder (15%) live alone. *(Q.40n)*

Others Members of Household Aside From Care Recipient[1]



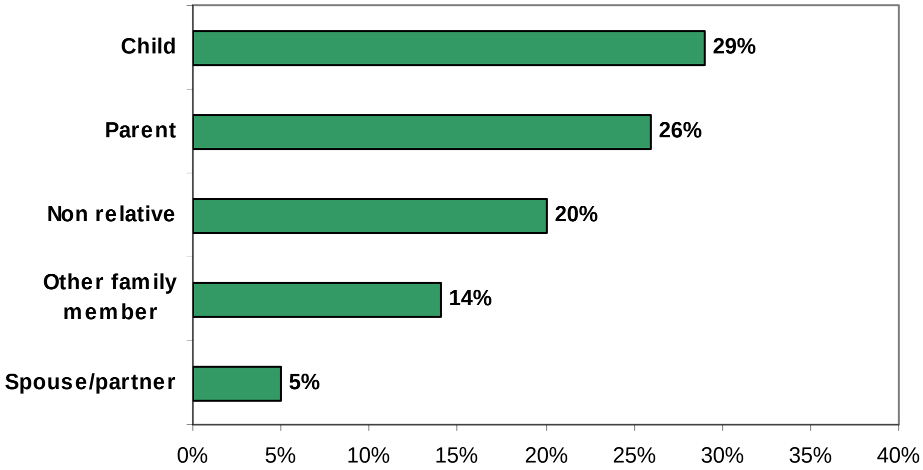
[1] Those w ho said the care recipient did not live w ith them w ere asked w ho else lives in the home

Additional Care Recipients

A minority of caregivers also provide care to someone who is ill or disabled other than the recipient person with a mental illness.

One in five (19%) caregivers also provide care to someone else who is ill or disabled. Among this small group (n=66), most also provide care to a child (29%) or a parent (26%) in addition to being the primary caregiver to someone who is mentally ill. Fewer (20%) report that they are also providing care to someone other than a family member. *(Q.7)*

Relationship of Additional Care Recipient Who is Ill or Disabled[1]



[1] Among those who are caring for someone else who is ill or disabled (n=66)

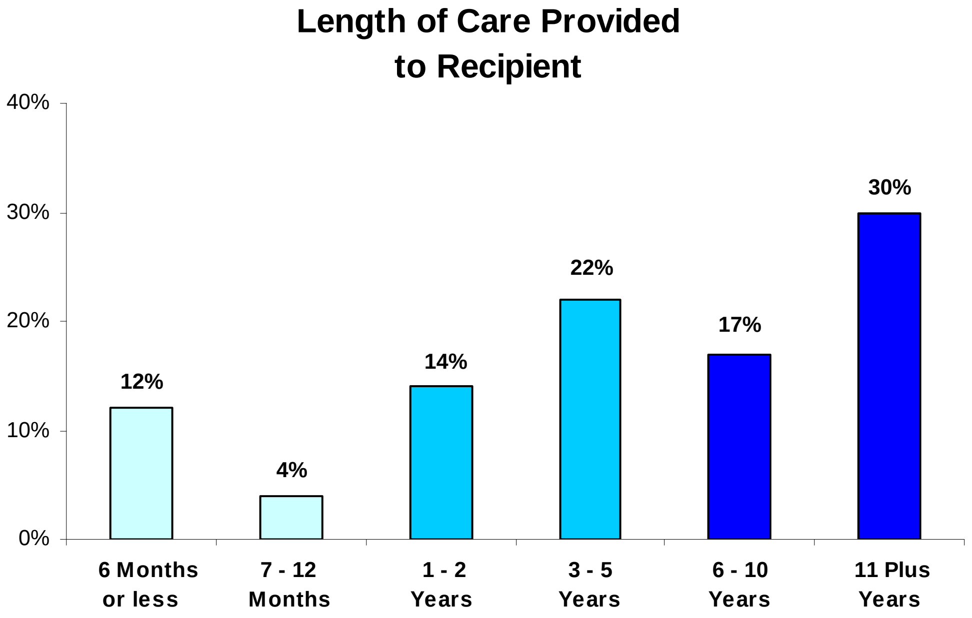
Women (22%) are more likely than men (12%) to say they care for additional recipients who are ill or disabled. Those who care for their spouse or partner (10%) are less likely than those caring for other family members (25%) or non-relatives (25%) to say they provide additional care to others.

Length of Time Providing Care

Half of caregivers have been providing care for at least five years.

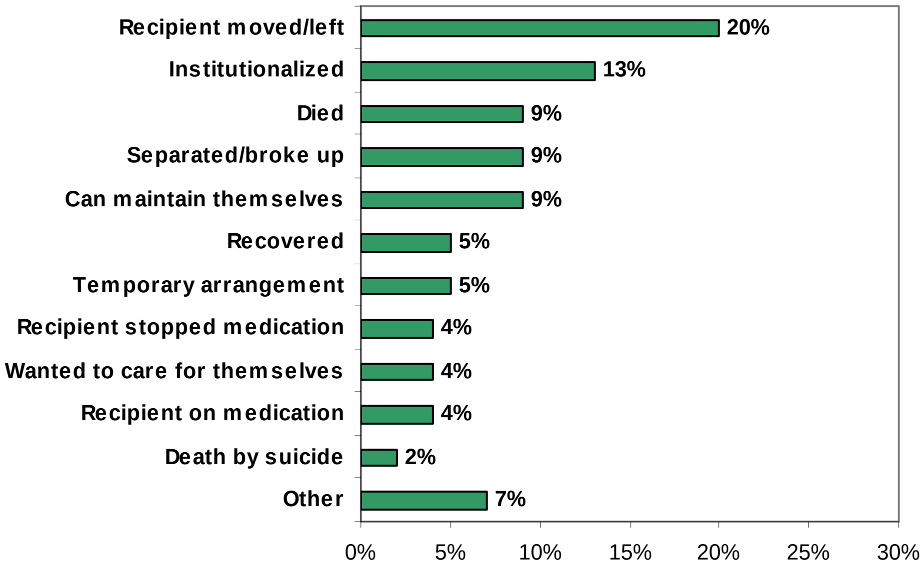
Caregivers are most likely to be providing care to the recipient on a long-term basis. Almost half (47%) of caregivers report providing care to someone diagnosed with a mental illness for five years or longer, while an additional one in five (22%) have been providing care for between three and five years. Fewer say they have been providing care for twelve months or less (16%), or between one to two years (14%). *(Q.9)*

Caregivers who are providing care to someone not related to them (33%) are more likely than others to say they have been providing this care for a short period of time (less than a year).



Those caregivers who no longer provide care to someone diagnosed with a mental illness (16% of caregivers, or n=56) were asked why they are no longer caring for this person. Most of the reasons given do not relate to the caregiver. The two main reasons cited include the recipient moved (14%), or was institutionalized (13%). Others said the recipient died, the relationship failed, or the recipient stopped their medications. On the other hand, a few stopped providing care because the recipient is able to maintain himself or herself, has recovered from the illness, or is now on medication that works. Among the "other" reasons each cited by very few caregivers, are that a professional caregiver was hired or that the recipient wanted to change caregivers. *(Q.11n)*

Reasons Why No Longer Providing Care[1]



[1] Among those who no longer provide care (n=56)

Recipient Profile

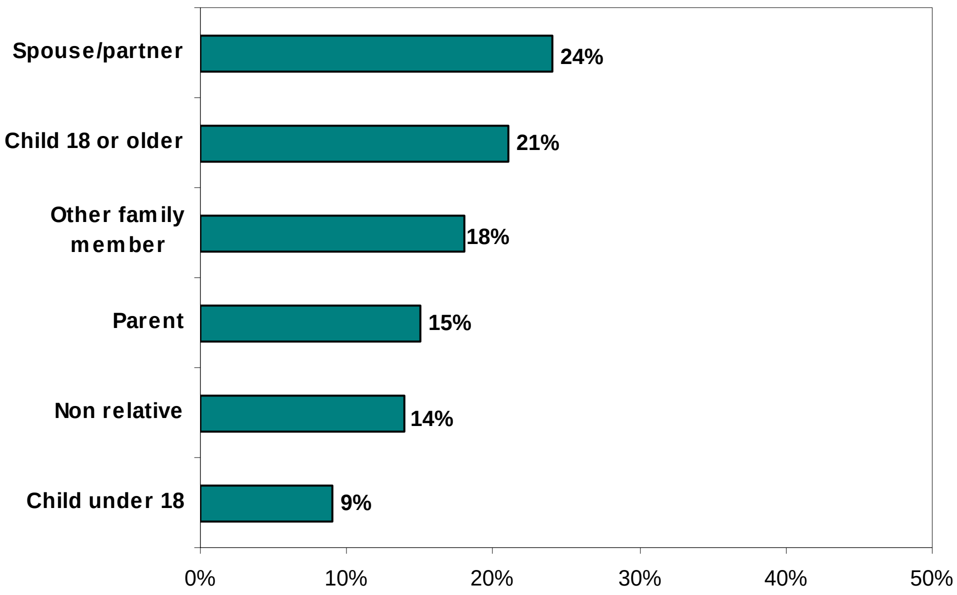
This section presents a profile of those who are receiving care.

Recipient Characteristics

Most caregivers are providing care to either a child or a spouse, and fewer provide care to someone who is not a relative.

Caregivers are most likely to be caring for a child, most often an adult child, than any other family member. Three in ten (30%) caregivers report they are caring for a child diagnosed with a mental illness (21% care for an adult child and 9% care for a child under 18), while almost one-quarter (24%) are caring for a spouse or partner. Fewer are caring for a parent (15%), another family member (18%), or for someone who is not a relative (14%). *(Q.6)*

Relationship of Person Receiving Care



Women are more likely than men to care for parents (16% versus 8%) while men are more likely than women to care for partners (17% versus 39%). There is no statistically significant difference between men (23%) and women (34%) caring for children.

A majority of care recipients are of working age. Equal proportions of recipients are between the ages 18 and 34 (29%), and 35 and 54 (29%), with another 12% aged 55 to 64. About one in five (18%) are aged 65 and older, and only one in ten are minors (under the age of 18, 11%). *(Q.8)*

Table 1: Age of Care Recipient by Sex of Caregiver

	Total (%)	Men (%)	Women (%)
Under 18	11	9	12
18 to 24	10	12	9
25 to 34	20	18	20
35 to 44	15	16	15
45 to 54	14	16	13
55 to 64	12	11	13
65 to 74	6	6	6
75 to 84	8	8	8
85 and older	4	4	5

Care recipients who are under the age of eighteen are most likely to require care for an anxiety (23%), or personality and eating disorder (33%).

Nature of Recipient's Illness

According to hospitalization data mental illnesses affect all ages, although the onset typically occurs during adolescence and young adulthood. According to the 2002 study *A Report on Mental Illness in Canada*, mental illness affects educational achievement, occupational or career opportunities and successes, and the formation of and nature of personal relationships. These extend throughout an individual's life.[5]

Most conditions are described as long-term by the caregiver. Caregivers are most likely to be caring for someone diagnosed with a mood disorder.

Almost all (91%) of those providing care to someone diagnosed with a mental illness describe the condition as something that is long term. The remainder indicate the condition is something that is acute (less than three months) (3%) or medium term (between three to six months) (4%). *(Q.10)*

Almost two-thirds (63%) of caregivers report caring for someone diagnosed with a mood disorder, whereas one-quarter (27%) provide care to someone with schizophrenia. Fewer are caring for someone with an anxiety (17%) or personality disorder (6%). One percent of caregivers are providing care to someone with an eating disorder. *(Q.11)*

Further analysis reveals that the illness for which the recipient requires care differs by their relationship to their caregiver. For instance, those providing care to someone with a mood disorder are more likely to say this person is their spouse (85%) or a parent (69%).

In contrast, those caring for someone with schizophrenia are more likely than others to say the recipient is their child (39%) or another relative (other than a spouse or parent) (37%).

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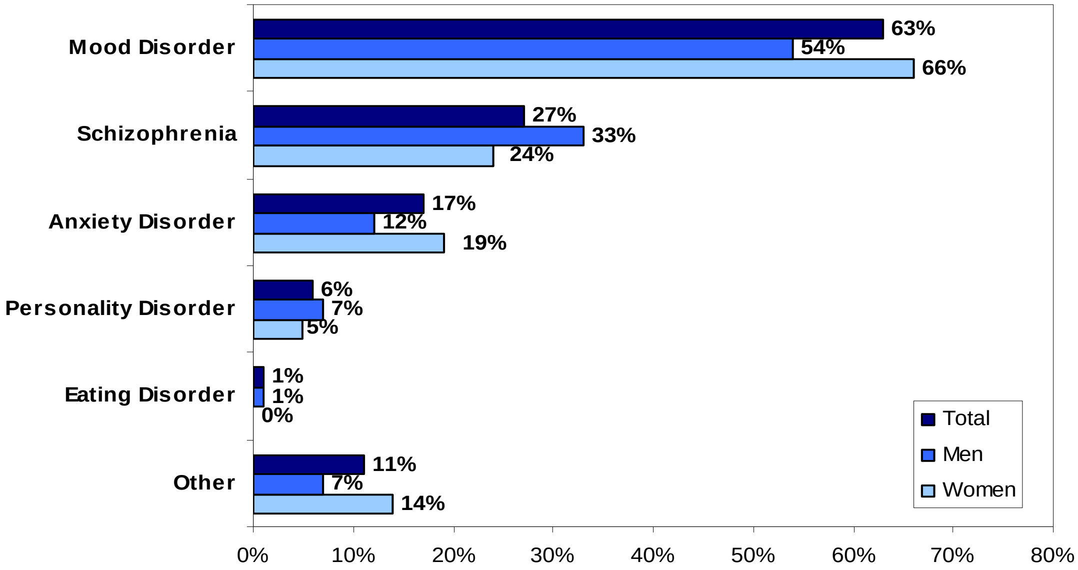
[5] *A Report on Mental Illnesses in Canada, 2002*, pages 18, 20, and 21. The report is available online at: http://www.hc-sc.gc.ca/pphb-dgspsp/publicat/miic-mmac/index.html

Recipient Diagnosis by Sex of Caregiver



A minority (24%) of caregivers care for someone diagnosed with multiple illnesses. The most common multiple diagnoses are:

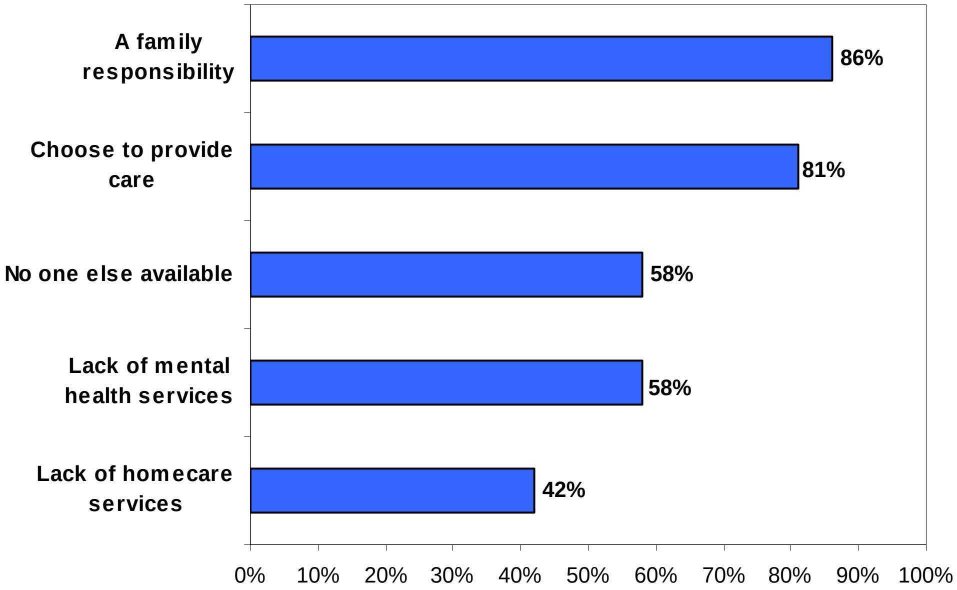
- Mood disorder and anxiety disorder (7% of all care recipients);
- Mood disorder and schizophrenia (4% of all care recipients); and
- Anxiety disorder and schizophrenia (4% of all care recipients).

Fewer care recipients are also diagnosed with other disorders, such as Alzheimer’s disease, dementia, or Tourettes syndrome in addition to their diagnosed mental illness.

Reason for Providing Care

Caregivers took on their role due to a sense of responsibility as well as a lack of available resources or services.

Caregivers were read five reasons for why someone might provide care to someone diagnosed with a mental illness, and for each reason, they were asked if it applied to their situation. Among the five reasons offered in the survey, caregivers are most likely to be providing care because they believe it is a family responsibility (86%), or because they choose to provide the care (81%). Over half are providing the care because they believe no one else is available (58%), or because there is a lack of mental health services (58%). Fewer (42%) are providing the care because there is a lack of homecare services. *(Q12a – e)*


Reasons for Providing Care
to Recipient

In addition to the reasons mentioned above for providing care to someone who is mentally ill, caregivers were asked if they felt they had other reasonable options when they chose to become the primary caregiver. Almost three-quarters (72%) did not feel other options were available to them, while one in five did (20%). Almost one in ten (8%) did not answer this question. *(Q.13)*

Those providing care either because of a lack of homecare (49%) or mental health (65%) services or a lack of other people to do the job (63%) are most likely to feel they had no other reasonable options.

Men (28%) are more likely than women (17%) to feel that other options were available to them when they decided to be the primary caregiver.

Type of Care Provided

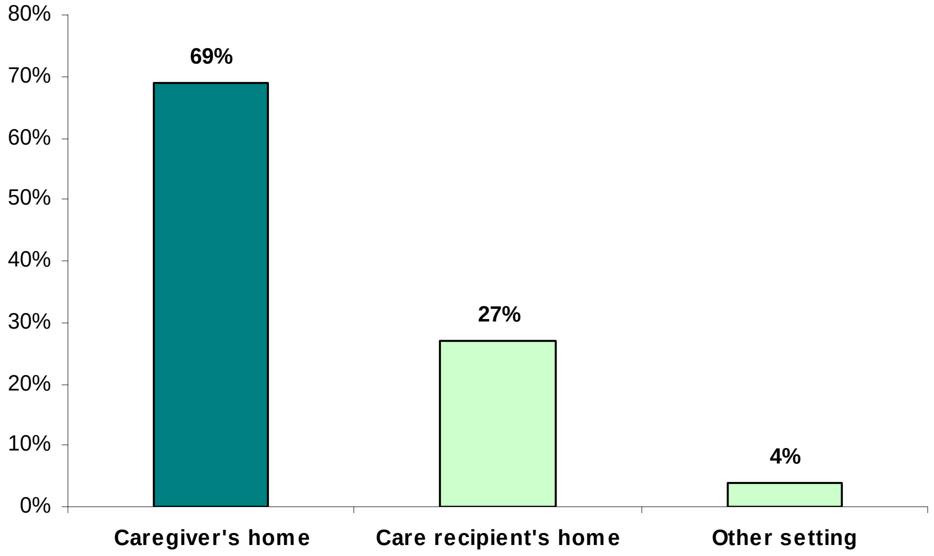
This section presents the findings of where the care takes place, the tasks and the frequency with which they are performed, and caregivers' perceptions of their skills. Findings are also presented about the expenses caregivers incur while providing care to someone diagnosed with a mental illness.

Location of Care

A majority of caregivers provide the care in their own home.

A majority of caregivers provide care in their own home. Over two-thirds (69%) of caregivers report providing care in their own home, while over one-quarter (27%) provide care in the recipient's home. The remaining four percent provide care outside of their home or the recipient's home. *(Q.1-5)*

Location Where Care Takes Place



Caring for a spouse (99%) or a child (75%) is usually done in the caregivers' home. Parents, other family members, and recipients who are not related to the caregiver are equally likely to receive care in their own home (43%) or in the caregiver's home (50%).

Caregiving Tasks Performed

Companionship and emotional support are the key tasks/services provided by caregivers.

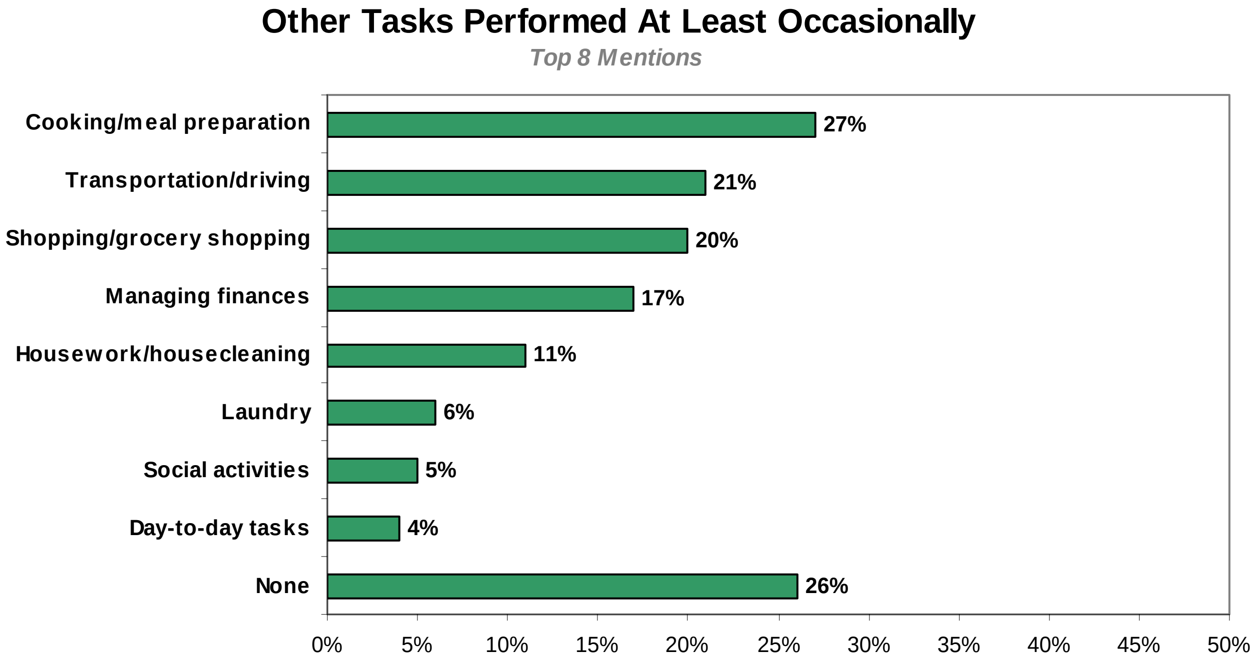
Caregivers were asked how frequently they perform ten common caregiving tasks while caring for someone diagnosed with a mental illness. The most common tasks performed by caregivers on a daily basis are providing companionship (78%), providing emotional support during a crisis (69%), and monitoring symptoms (62%). *(Q.14a-j)*

Table 2: Caregiving Tasks Performed

Task	Frequency			
	Daily %	Occasional %	Rarely %	Never %
i. Providing companionship	78	20	1	1
d. Providing emotional support during a crisis	69	25	3	2
c. Monitoring symptoms	62	27	3	7
a Providing or monitoring medications	46	25	6	23
j. Paying bills	41	30	9	18
f. Advocating for person to receive help	27	47	10	12
g. Arranging and coordinating services and appts.	23	52	8	15
e. Assistance with personal grooming	23	25	15	37
h. Going to appointments with person	17	61	11	11
b. Providing injections	3	2	2	93

These ten tasks were summed together to create a single index measuring the overall level of effort put into caring for someone diagnosed with a mental illness. This index is comprised of a five-point scale, from “1” (the least effort) to “5” (the most effort). Based on this index, the caregivers most likely to be putting in the greatest effort (a score of 5) are those caring either for someone under the age of eighteen (32%) or a parent (31%). There is no statistically significant difference between men (12% in the highest group) and women (19%) on this index.

Aside from the ten caregiving tasks specifically mentioned in the survey, caregivers were asked if they perform any other tasks at least occasionally, and they are most likely to say they performs tasks related to maintaining the household. These include cooking and meal preparation (27%), shopping (20%), transportation (21%), housework (11%), and laundry (6%). Caregivers also say they manage finances (17%) for the care recipient. Fewer report that they do social activities (5%) with the care recipient, or do day-to-day tasks (4%). A variety of other tasks are performed by fewer caregivers. One-quarter (26%) did not mention any other tasks that they perform. *(Q.15)*



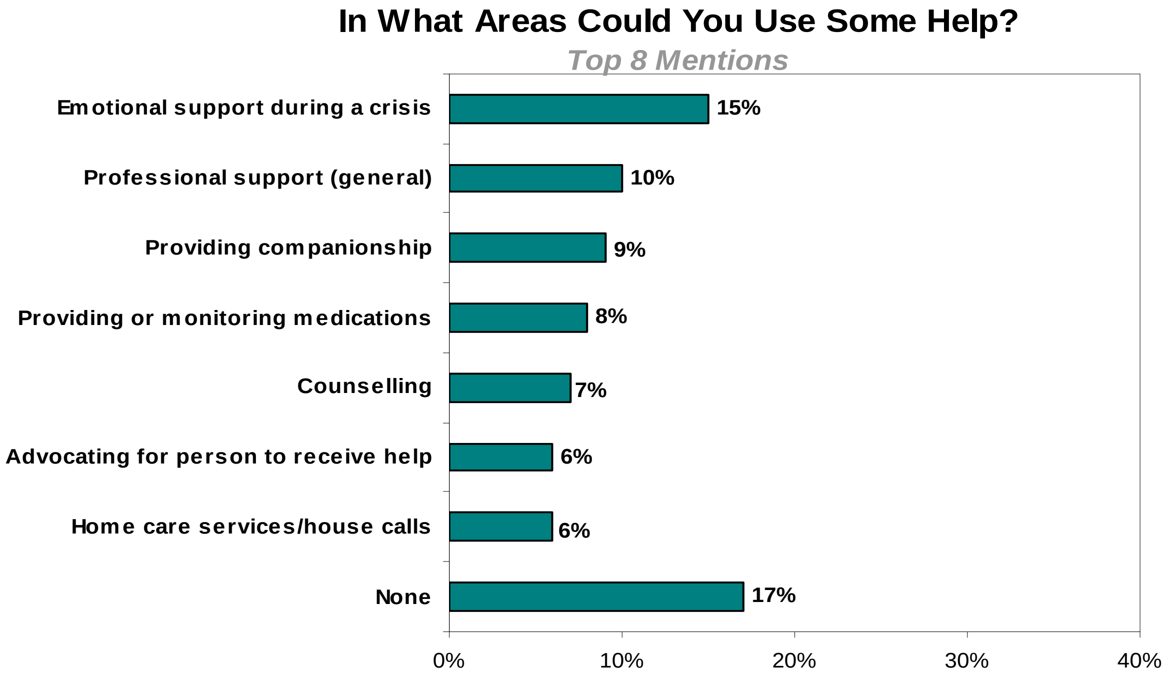
Caregivers’ Need for Assistance

Two thirds of caregivers agree that they have the required skills to care for someone diagnosed with a mental illness. Nonetheless, a majority would welcome assistance in performing their caregiving duties.

Two-thirds (65%) of caregivers agree that they possess the necessary skills to properly care for the care recipient, whereas three in ten (31%) disagree. The remaining four percent are unsure. *(Q.16)*

Some caregivers are more confident in their skills than others. Those who are providing care to a parent (77%) and who have been providing care on a long term basis (71%) are more likely than others to say they have the necessary skills to properly care for the recipient. Furthermore, those who are aged 55 years and older (71%) are more likely than younger caregivers to agree that they have the necessary skills to provide care. There is no statistically significant difference between women (63%) and men (71%) in terms of perceived caregiving skills and capabilities.

Despite the fact that a majority of caregivers say they have the necessary skills (65%) to provide care, a strong majority (79%) would like help with some caregiving tasks. However, there is no clear consensus on the *types* of assistance they would like. Some caregivers would like help with providing emotional support during a crisis (15%) and providing companionship (9%), while others would like more help with professional services, such as professional support (10%) or counselling in general (7%). A variety of other tasks are mentioned by fewer caregivers. One in six (16%) do not think they need help with any other tasks. *(Q.17)*



Caregivers who are employed are most likely to want assistance with providing emotional support during a crisis (19%) or professional support (13%). Those caring for a spouse (22%) or a child (16%) would also like assistance with providing support during an emotional crisis.

Out of Pocket Costs

A slight majority pay out-of-pocket expenses to provide care to the recipient. Most of these expenses relate to transportation.

Over half (58%) of caregivers pay out-of-pocket expenses while caring for someone diagnosed with a mental illness. Those who are caring for a child (70%), or for someone with an anxiety disorder (70%) are more likely than others to say they are paying out-of-pocket expenses. *(Q.18)*

Caregivers pay for a variety of out-of-pocket expenses related to their caregiving. Almost three-quarters (72%) of those who pay out-of-pocket expenses pay for transportation costs, such as gasoline, taxis, or public transit. A slight majority also say they pay for either prescription (56%) or non-prescription medications (51%). Others pay for professional services (33%), personal care workers (11%), and nursing services (10%). *(Q.19)*

Table 3: Out-of-Pocket Expenses Incurred While Caring for Someone Diagnosed with a Mental Illness

Expense	%[1]
Transportation (gas, taxis, public transit, parking)	72
Prescription medications/drugs	56
Non-prescription medications	51
Homemaking such as housecleaning	43
Professional services/therapy	33
Ambulance services	15
Someone to provide respite	12
Personal care worker	11
Nursing services	10
Care recipient's living expenses	9
Other	9

[1] Based on the percent of caregivers who report out-of-pocket expenses (n=200).

Those who provide care to either a spouse or a child are more likely to be paying out-of-pocket expenses for prescription medications (80% for spouses and 63% for children) and for professional services or therapy (56% for spouses and 41% for children) than are caregivers caring for other family members or non-relatives.

Caregivers are spending a considerable amount of money each month to provide care to someone diagnosed with a mental illness. Over one-quarter (28%) of caregivers report spending at least $300 per month in out-of-pocket expenses to provide care to someone diagnosed with a mental illness. One quarter (26%) spend less than $100 per month to provide care, while one third (37%) spend between $100 and $300 dollars per month. *(Q.20)*

Table 4: Average Monthly Spending to Provide Care to Someone Diagnosed with a Mental Illness by Annual Household Income

		Annual Household Income		
Monthly spending	**Total (%)**	**Less than $25,000 (%)**	**$25,000 to $44,000 (%)**	**$45,000 or greater (%)**
Less than $100	26	22	29	25
$100 to $200	21	25	22	17
$200 to $300	16	25	24	10
$300 to $500	15	14	13	18
$500 or more	13	6	7	18

Note: shading denotes statistically significant differences at the 95% confidence level.

Caregivers who report higher levels of income are more likely to report higher monthly out-of-pocket expenses than caregivers in lower income brackets. Those with an annual household income of at least $45,000 (18%) are more likely to say they spend at least $500 per month in out-of-pocket expenses, compared to caregivers with lower annual incomes.

Formal Assistance

This section presents the types of formal or professional home or community care services recipients currently receive and additional care services that they feel are needed to care for someone diagnosed with a mental illness.

Type of Care Services

A minority of caregivers say their care recipient receives some type of formal assistance. The most common source of help is from providers of formal psychological services.

Less than half (45%) of caregivers receive formal assistance. Those who do are more likely than others to be caring for someone below the age of eighteen (55%), or over the age of 55 (51%). Caregivers caring for someone who is between 35 and 54 years of age are less likely (40%) to receive any form of formal assistance. Men (44%) and women (45%) caregivers are equally likely to say their care recipient receives formal assistance. *(Q.21)*

Among those receiving some type of formal support, psychological services (23%) are most common, followed by supports in the form of counselling (19%), medical care (18%), nursing visits (10%), or a personal care worker (10%). *(Q.22)*

Table 5: Formal or Professional Home or Community Care Services Received

Type of Service	Service Provided[1] %	Provided at No Cost[1] %
Psychologist	23	16
Counselling/Mental health counselling	19	6
Medical care/doctor	17	9
Psychiatric day hospital program	10	7
Social work	10	8
Nursing visits	10	9
Personal care worker	10	7
Support program/group	8	3
Psychiatrist	8	6
Homemaking, such as housecleaning	7	3
Occupational therapy	5	3
Physiotherapy	3	1
Nutrition	3	1
Other services	25	24
None	--	21

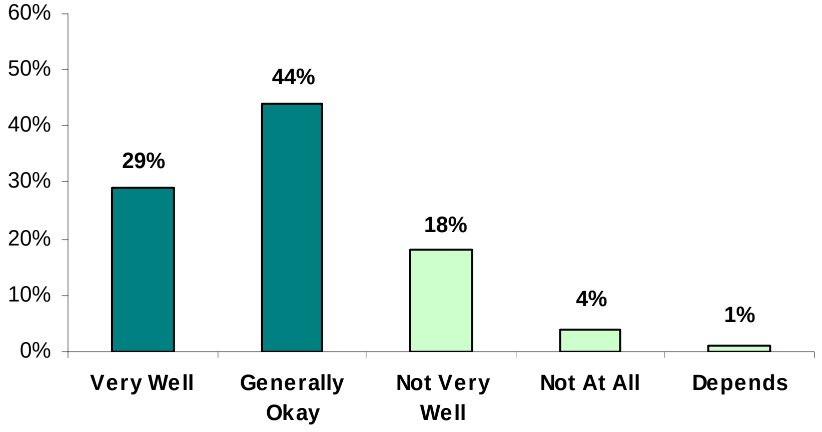
[1] Among those who receive any formal or professional home or community care service (45% of total population, n=154).

Some caregivers are more likely than others to say their care recipient receives different types of formal services. For instance, those caring for their spouse (36%), or a child (32%), or those caring for someone diagnosed with a mood disorder (28%), are more likely than others to say their care recipient receives services from a psychologist.

Caregivers were also asked which of the services provided to the care recipient are free of charge, and a majority report at least one service that is free. Some of the more commonly received services – e.g. counselling and medical care – are less often provided at no cost. *(Q.23)*

Not all caregivers are equally likely to report that services are available to their care recipient free of charge. Caregivers who are women (35%), younger (35%), or caring for a spouse (33%) are less likely than other caregivers to say their care recipient receives formal services free of charge.

Of those who currently receive formal services (n=153), the services currently received appear to be meeting the majority of the care recipients' needs. Three-quarters (73%) of caregivers say these professional services are generally (44%) meeting the needs of the recipient, or are meeting them very well (29%). More than one in five (22%) say these services are not meeting the needs of the care recipient very well (18%) or not at all (4%). These results are consistent for both men (75% very well or generally okay) and women (73%). *(Q.24)*



How Well Do the Home or Professional Services Meet the Needs of the Recipient?[1]

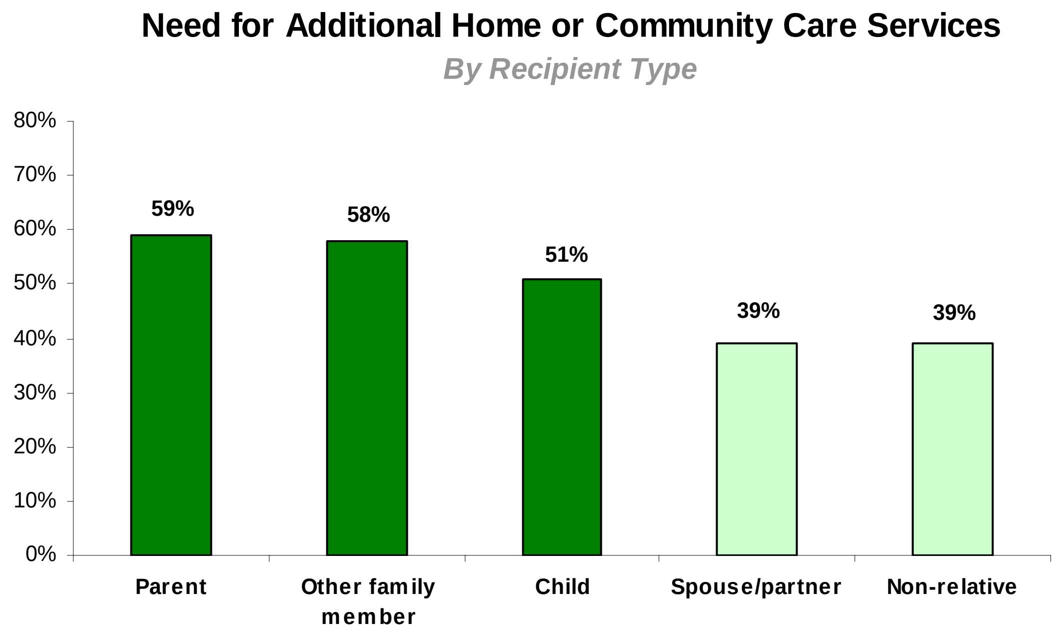
[1] Of those who have received some form of professional home or community care service (n=153)

Additional Care Requirements

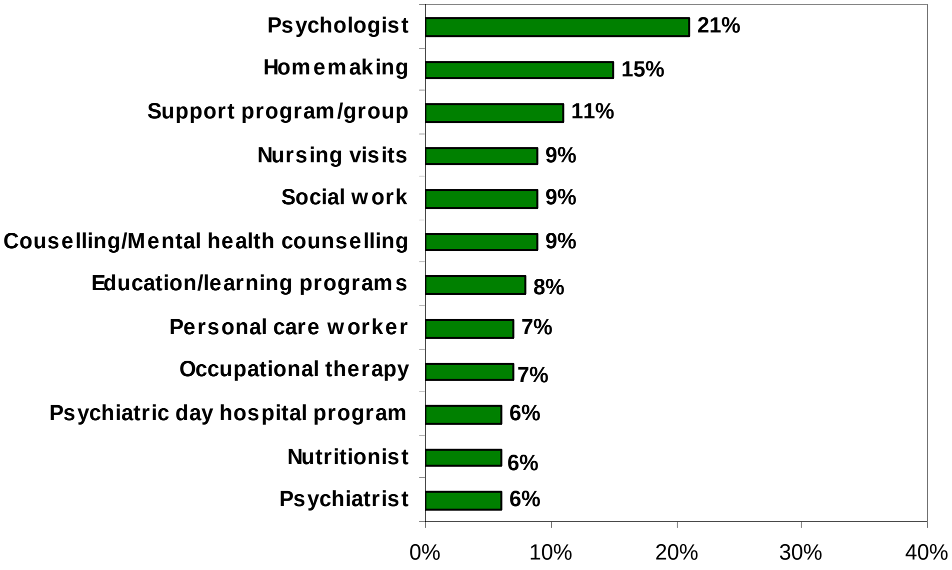
Caregivers are split as to whether they need additional services.

All caregivers were asked if there are additional types of formal or community care services that would be of help to them, and about half (49%) agree that additional services would be beneficial. Almost four in ten (39%) do not think additional services will be of help, and more than one in ten say it depends (2%) or are unsure (11%). *(Q.25)*

The need for additional home care services differs by the type of care recipient. Those caring for either a parent (59%), a relative other than their spouse or child (58%), or someone between the ages of 18 and 34 (58%) are most likely to express a need for additional home or community care services. Furthermore, those who did not feel they had a choice in caring for the recipient (57%) and those who do not feel confident that they have the necessary skills (66%) are also more likely than others to say they need additional services. There is no statistically significant difference between men (42%) and women (52%) in terms of needing additional home or community care services.



Those who expressed a need for additional home or community care services were asked what type of services would be most helpful to them. Caregivers would like more psychological services (21%) or counselling (9%), and assistance with homemaking (15%). Fewer indicate a need for help with support programs (11%), nursing visits (9%) or a social worker (9%). *(Q.26)*



Types of Additional Home or Community Care Services Required[1]

Top 9 Mentions

[1] Among those who could use additional help (n=174)

A large number of other services were each mentioned by less than five percent of caregivers, including: physiotherapists, "clubhouse" program[6], medical care/doctor, ambulance services, and dentists.

Men and women point to a need for help in different areas. Women are more likely to say they need assistance with counselling or mental health services (11% versus 2% for men), while men are more likely to want assistance with physiotherapy (11% versus 2% for women).

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[6] The Clubhouse program is a rehabilitation program that emphasizes self-help and work skills. Members of the clubhouse carry out all the functions required to run the program with the guidance of staff.

The Need for Institutional Care

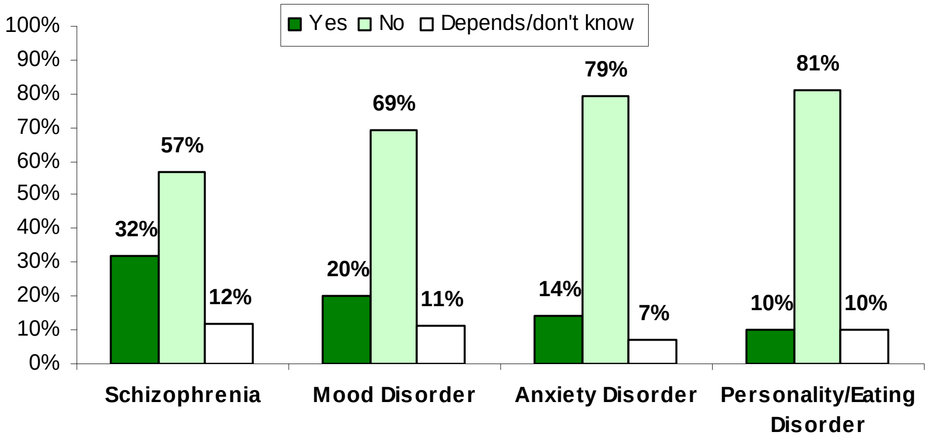
One in five caregivers feel the care recipient would be better cared for in an institutional setting.

One-fifth (21%) of caregivers think the person they are caring for would be better cared for in a hospital or supervised facility. As demonstrated in the following chart, those who are caring for someone with schizophrenia are most apt to think the care recipient would receive better care in a supervised or residential facility compared to those caring for people with other illnesses. *(Q.27)*

In addition, caregivers who are less confident that they have the necessary skills to perform caregiving tasks (41%) are more likely than others to think the care recipient would be better cared for in a facility.

Would Care Recipient Receive Better Care in a Hospital or Supervised Residential Facility?

By Mental illness



*Totals may not add to 100% due to rounding

Coping with Caregiving Responsibilities

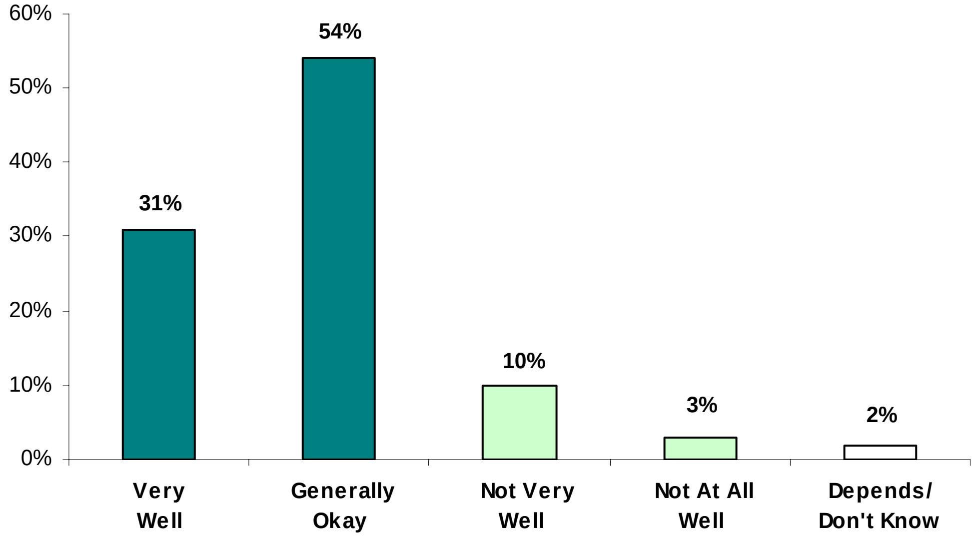
This section presents how well caregivers are coping with the responsibility of caring for someone diagnosed with a mental illness.

Overall Coping

Caregivers feel they are coping reasonably well with the responsibilities associated with caring for someone diagnosed with a mental illness.

Caregivers were asked how well they are coping with the responsibility of caring for someone diagnosed with a mental illness, and most say they are coping reasonably well. A large majority (85%) believe they are coping either very well (31%), or generally okay (54%), while few report not coping very well (10%) or at all well (3%). *(Q.28)*

Overall Coping with Responsibilities of Caregiving



Some caregivers say they are coping better than others. For instance, those who are caring for someone who is not an immediate family member are more likely to say they are coping not very or not at all well (21%). This also holds true for younger caregivers (22%), allophones (21%), and those who are employed (17%). There is no statistically significant difference in overall coping between men (86% very well or generally okay) and women (84%).

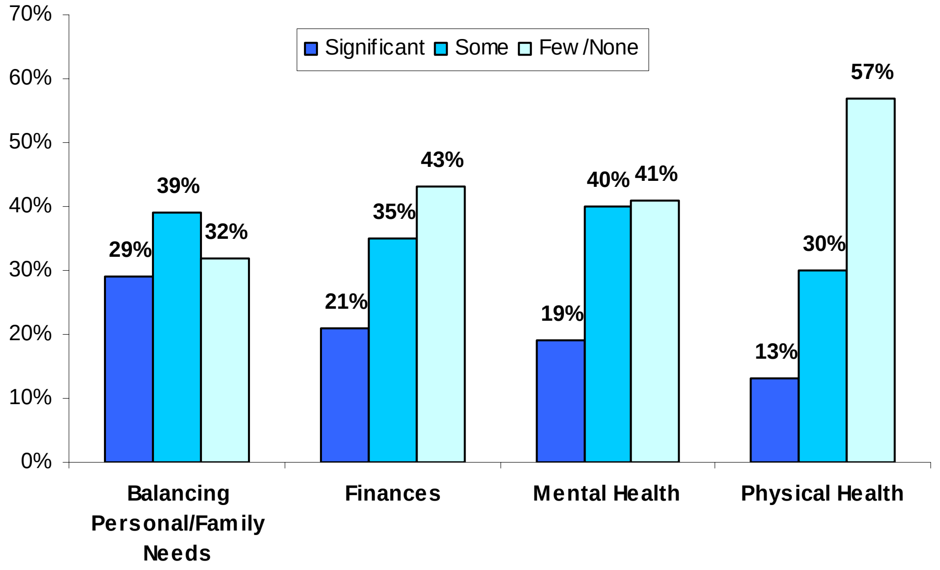
Caregivers who did not feel other reasonable options were available to them (16%), and those who are not confident they have the necessary skills to provide the care (28%) are also more likely than other caregivers to say they are not coping well with the responsibility of caring for someone diagnosed with a mental illness.

Specific Coping Difficulties

Caregivers are most apt to have trouble balancing their personal and family needs with their caregiving responsibilities.

All caregivers were asked the extent to which they experience difficulties in four areas as a result of caring for someone diagnosed with a mental illness. A majority say they experience at least some difficulty in all areas surveyed except their own physical health. *(Q.30a – d)*

Caregivers are most apt to report difficulties balancing their personal and family needs (68% significant or some), followed by difficulties with their own mental health (59%), their finances (56%), and their own physical health (43%).



Extent of Personal Difficulties Resulting from Caregiving

Women are more likely to say they experience difficulties as a result of providing care to someone diagnosed with a mental illness. In particular, they are more likely than men to report difficulties in terms of their own physical and mental health.

Table 6: Extent of Personal Difficulties Resulting from Caregiving by Sex of Caregiver

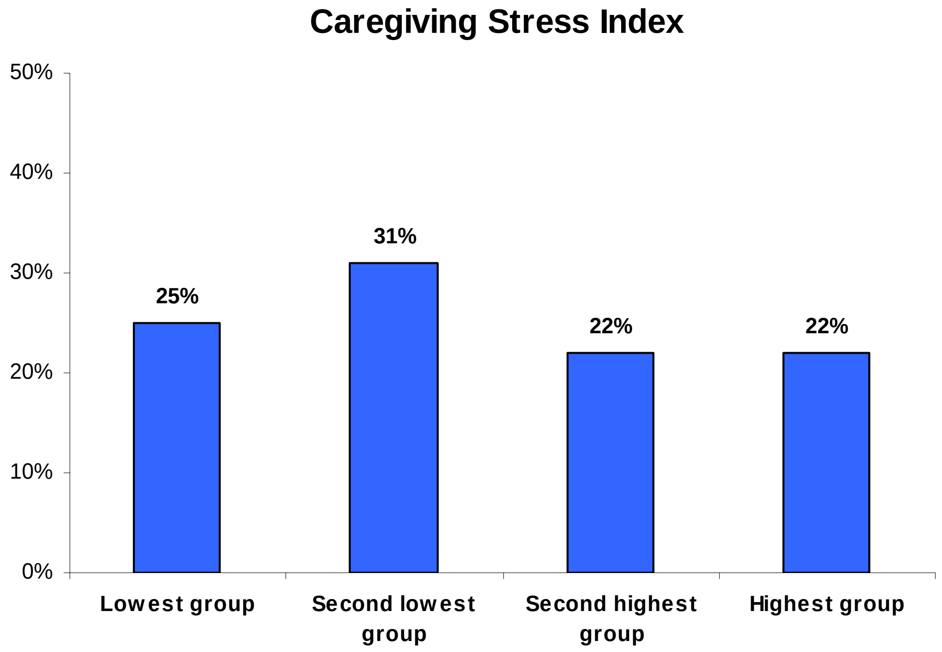
	Significant difficulties (%)		Some difficulties (%)		Few/no difficulties (%)	
	Men	**Women**	**Men**	**Women**	**Men**	**Women**
Balancing personal/family needs (d)	25	31	37	39	38	29
Finances (a)	19	22	36	34	43	43
Mental health (b)	16	21	25	42	48	37
Physical health (c)	8	15	26	32	66	53

Note: shaded percentages denote statistically significant differences at the 95% confidence level.

The responses to these four questions were combined to create a single measure of **caregiving stress**. This index consists of a 4 point scale ranging from “1” (no stress) to “4” (high stress – this group indicated stress in all four 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. *(Q.30)*

One in five (22%) caregivers fit into the high stress group and this group is more likely than others to be caring for a child (34%) or for multiple people (35%). Women are more likely than men (47% versus 22%) to report high levels of stress. Those who feel they lack the necessary skills (36%), did not have options available to them (27%), and are not coping well (44%) are also more likely than others to report having difficulties. The most stressed caregivers are also more likely than other caregivers to be performing more caregiving tasks, and paying out-of-pocket expenses while caring for someone diagnosed with a mental illness.

One-quarter (25%) of caregivers are in the low stress group. The least stressed caregivers are men (35%), those who provide care to someone who is not a family member (43%), and those caring for a recipient that is at least 55 years of age (33%).



The Need for a Break

A majority of caregivers say they get a break at least occasionally, and they most often rely on other family members for this break.

Given the responsibility of providing care to someone diagnosed with a mental illness, it is not surprising that a majority of caregivers say they need a break. Three quarters (74%) of caregivers report they either frequently (27%) or occasionally (47%) need a break from their caregiving responsibilities, while one-quarter say they rarely (16%), or never (10%) require a break. *(Q.31)*

Caregivers were also asked how often they *get* a break from their caregiving responsibilities, and a slight majority (55%) say they get one either frequently (17%) or occasionally (38%). The remainder say they rarely (25%) or never (19%) get a break from providing care to someone diagnosed with a mental illness. *(Q.31a)*

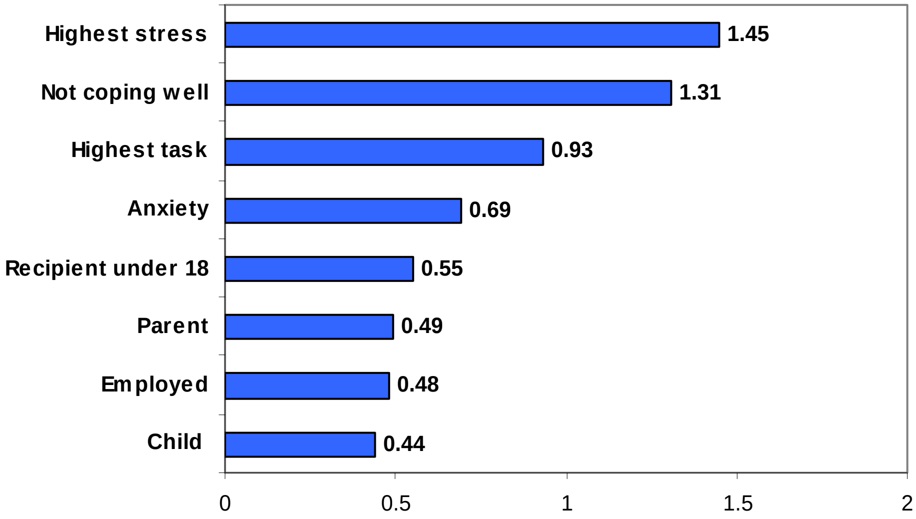
It is important to understand if those who express a need for a break are actually getting relief from their caregiving duties. The results reveal that overall one third (36%) of caregivers who say they need a break frequently or occasionally report they rarely or never get that break from their caregiving duties.

Table 7: Frequency of Needing and Getting a Break from Caregiving Duties

Frequency of Getting a break	Frequency of Needing a Break			
	Frequently (%)	Occasionally (%)	Rarely (%)	Never (%)
Frequently	10	11	36	35
Occasionally	35	44	34	27
Rarely	30	28	19	6
Never	25	17	9	27
Total	100	100	100	100

The caregivers who are not getting enough breaks to meet their needs are those reporting higher levels of stress, those who say they are not coping well, and caregivers who are performing multiple tasks while caring for someone diagnosed with a mental illness. Other groups of caregivers not getting enough breaks are those who are employed, those caring for someone diagnosed with an anxiety disorder, or someone under the age of eighteen. Those caring for a parent or a child are also not getting enough breaks compared to other caregivers.

Caregiver Segments Most in Need of a Break and Not Receiving One*



*The figures in the chart are the differences between the mean rating for each segment on "needing a break" and "getting one".[7]

Women are more likely than men to receive the breaks they feel they need. On average, women score 1.55 out of 3 on needing a break and score 1.96 out of 3 on getting a break, for a difference of -.41. Men on the other hand score 1.83 and 1.52 for needing and getting a break for a difference of +.31.

When caregivers were asked who they get help from when they need a break, a majority (60%) say they rely on a family member for assistance. Fewer rely on friends (16%) or formal help (8%) for respite from their caregiving responsibilities. *(Q.31b)*

Perhaps not surprising is the fact that those caring for family members are more likely to get relief from other members of the family, while those caring for someone who is not related to them are more likely to get relief from friends.

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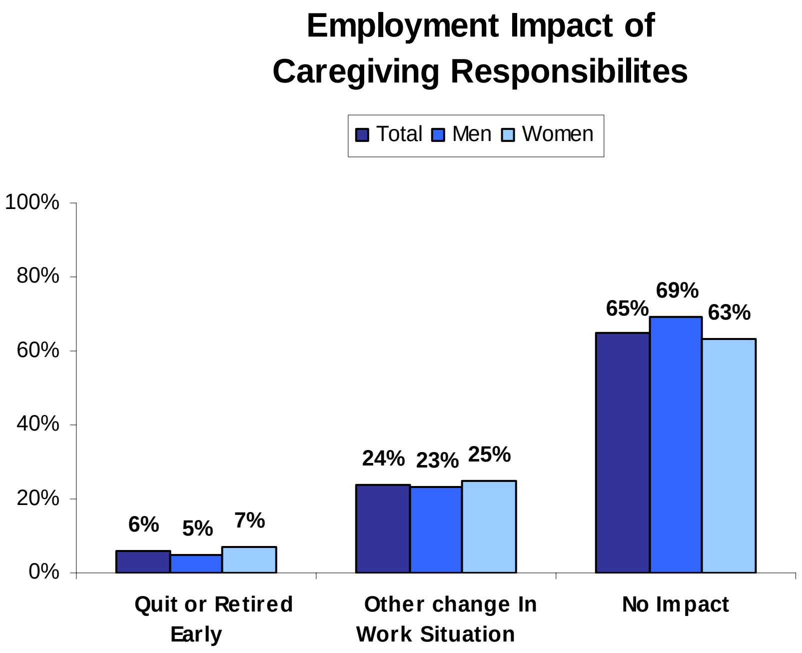
[7] The mean "need" and "getting" a break ratings were calculated using a recoded version of the variables where 0=never, 1=rarely, 2=occasionally, and 3=frequently.

Employment Impacts of Caregiving

Almost half of all caregivers say their caregiving responsibilities have not impacted their employment.

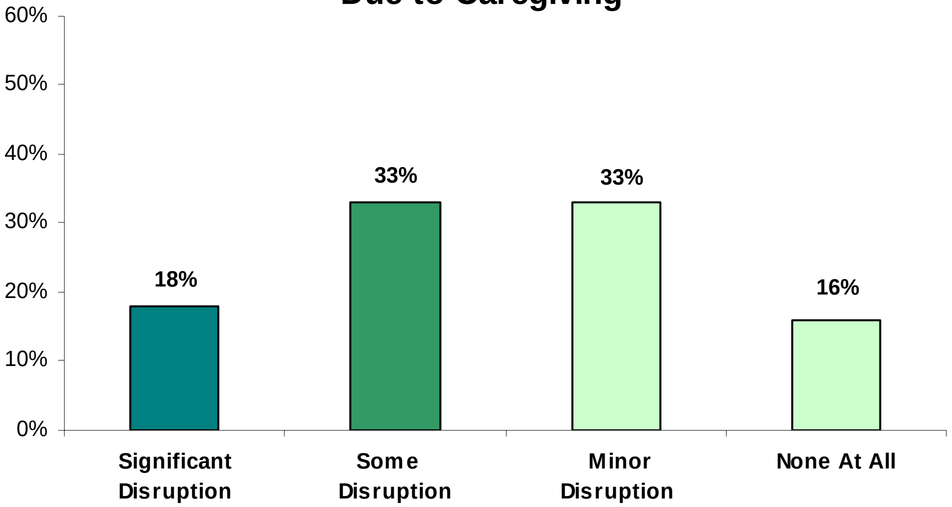
Among caregivers who are currently employed, currently seeking work, and students (n=242) two thirds (65%) say there has been no impact on their employment as a result of caring for someone diagnosed with a mental illness (this translates into 46% of all caregivers). The remaining one third (35%) report that their employment situation has changed in some way (24% of all caregivers). This change is most often felt by those caring for someone under the age of eighteen (59%). Reports of impacts on the employment situation of caregivers do not vary by income level. *(Q.34)*

Of those who are either retired or a homemaker (n=96), one in five (22%) say they have quit their job or retired early to provide care for someone diagnosed with a mental illness (this translates into six percent of all caregivers). *(Q.33)*


Employment Impact of Caregiving Responsibilites

Not all caregivers say their caregiving responsibilities have impacted their employment. For instance, those caring for someone with a mood disorder (84%) are more likely than others to say that there has been no impact on their employment as a result of their caregiving. There is no statistically significant difference between men (69%) and women (63%) in terms of the impact of caregiving on employment.

Among those who are currently employed, half say there has been either a significant (18%) or some (33%) disruption to their job as a result of their caregiving duties. The remainder say there has been a minor (33%) disruption or none at all (16%) to their job. No statistically significant difference exists between employed men (52% significant or some disruption) and women (50%) in terms of job disruptions. *(Q.35)*



Extent of Job Disruption Due to Caregiving[1]

[1]Among those who are currently employed (n=198)

Some caregivers are less likely to experience disruptions or interferences in their job. Disruptions are least likely to be experienced by those who chose to become the primary caregiver (28%) and by those who feel they have the necessary skills (21%), and who say they are coping well with their caregiving responsibilities (33%). In addition, those who are caring for someone who is not related to them (36%) and who have been providing care on a short-term basis (31%) are also less likely than others to experience any disruptions (31%).

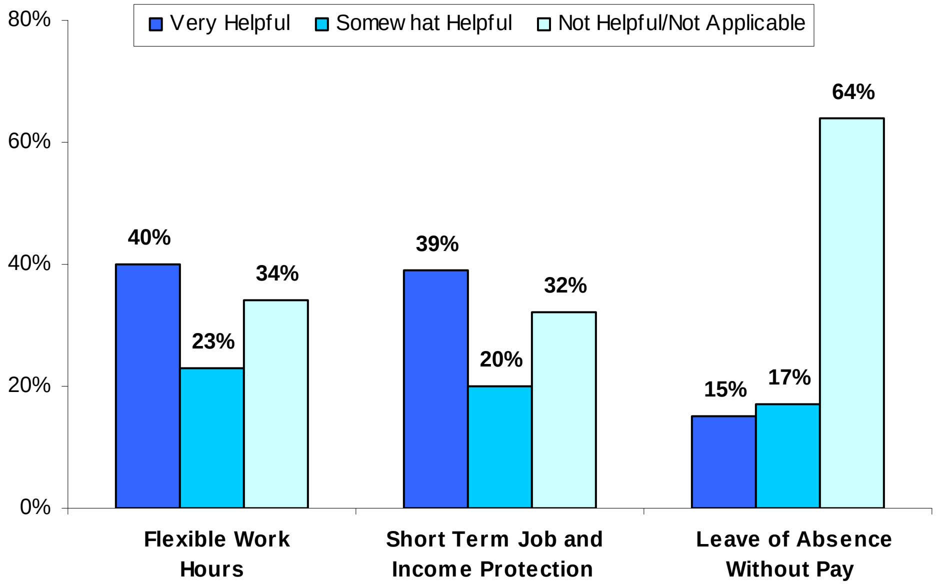
Among those who say their caregiving has created at least a minor disruption in their job, over half (58%) report that their employers have been flexible in adjusting work hours or responsibilities to accommodate their caregiving duties. One in six (17%) say this is not the case, while an additional one quarter (22%) say that this is not applicable to them or that they are self-employed. *(Q.36)*

Employment Support for Caregiving

Caregivers value additional employment support to balance work and caregiving, but are less supportive of leave of absences without pay.

Caregivers who are working, or who have quit or retired from their position to provide care to someone diagnosed with a mental illness were asked to what extent specific forms of work-related benefits would help them balance their work and caregiving responsibilities. Almost two thirds (63%) of caregivers say they would find **flexible work hours** very (40%) or somewhat (23%) helpful in balancing their caregiving and work responsibilities. One in five (18%) say this would not be helpful to them. A small group (5%) of caregivers have already arranged for flexible work hours. *(Q.37a)*

Value of Employment Supports in Balancing Caregiving and Work



Six in ten (59%) of employed caregivers say **short-term job and income protection** would be very (39%) or somewhat (20%) helpful to them in balancing their responsibilities. One in five (22%) say this type of program would not be helpful to them and an additional ten percent say this would not apply to them. *(Q.37c)*

A minority (31%) of working caregivers say a **leave of absence without pay** would be helpful to them to balance caregiving and work. Almost half (47%) say this would not be helpful to them and an additional 15 percent say this would not apply to them. Two percent say they already have this benefit available to them. *(Q.37b)*

These work-related support systems would be more helpful to some caregivers. Women and younger caregivers are more likely than other caregivers to agree that flexible work hours and/or short-term job and income protection would be of help to them. In contrast, those who are caring for someone who is between the ages of 35 and 54 (32%), and those who are not currently working (52%) are more likely to consider that a leave of absence without pay would be helpful.

Other Types of Assistance

Caregivers would like more support and services to help them handle their caregiving responsibilities.

At the conclusion of the survey, caregivers were asked if there was anything else that would help them handle their caregiving responsibilities, and most would like more support or services. This includes general support (8%), more services (6%), and more information on the services available (4%). Caregivers also suggest more financial support would be of help to them (10%). Other suggestions were made by caregivers, including having more respite help (2%), and better access to medical care (1%). Over half (53%) of caregivers could not think of anything not already covered in the survey that would help them care for someone diagnosed with a mental illness. *(Q.38)*

Table 8: Additional Services That Would Help Manage Caregiving Responsibilities

	%
Net – Support or Services	**22**
More support (general)	8
More services available	6
More information on the services available	4
More home care	3
More facilities	3
Better access to mental health services	3
Net – Financial Support	**11**
Financial support	11
Able to collect long term disability	1
Net – Other Help	**22**
Better understanding of mental illness from society	3
Trustworthy/knowledgeable staff	2
Earlier diagnosis/treatment	1
Other	16
Nothing else/Don't know	**53**

Caregivers who are caring for either a spouse (17%) or a parent (16%) are more apt than other caregivers to suggest that financial support would be of help to them, as are those whose employment situation has changed (19%) since they took on the responsibility of caring for someone diagnosed with a mental illness.

Survey Methodology

Questionnaire Design

This questionnaire was designed by senior Decima consultants, in close consultation with Health Canada. The questionnaire incorporates many questions from the *2002 National Profile of Family Caregivers in Canada* study, with appropriate modifications throughout. Prior to being finalized, the questionnaire was pre-tested on a small number of respondents in both English and French.

Sample Design and Selection

The sample for this study was designed to complete interviews with a representative sample of informal or family caregivers, meeting the criteria established by Health Canada for this study. Informal or family caregivers were defined as an individual who is currently providing unpaid, on-going personal care or social support to a family member, neighbour, or friend who has a diagnosis of a mental illness.

Informal or 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 process was used in part because there is no existing database of informal or family caregivers in Canada, and because a key objective of this research was to estimate the number of informal or family caregivers in Canada who provide care to someone diagnosed with a mental illness.

The sample was drawn using SurveySampler technology to ensure that all residential listings in Canada have an equal probability of being selected for inclusion in the survey. Up to eight call backs were used to reach respondents who may not have been available at the time of the initial call.

Survey Administration

The survey was conducted in English and French by telephone using computer-assisted-telephone-interviewing (CATI) technology, from Decima’s facilities in Ottawa, Toronto and Montreal, between March 5 and April 4, 2004. 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 21 minutes.

A total of 343 informal and family caregivers were interviewed as part of this study, based on a total overall incidence of 2.1 percent (that is, 2.1 households out of every 100 Canadian households that could be reached during the interviewing period).

Sample Distribution

A sample of 343 drawn from the population can be expected to be accurate to within plus or minus 5.3 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 Sex and Region

Region/Province	Sample	Margin of Error[1]
Sex		
Women	241	+/- 6.3%
Men	102	+/- 9.8%
Region		
Atlantic Canada	31	+/- 17.8%
Québec	86	+/- 10.6%
Ontario	128	+/- 8.7%
Prairies	47	+/- 14.4%
British Columbia	51	+/- 13.9%
CANADA	343	+/- 5.3%

[1] 95% Confidence Level

Completion Results

A total of 123,557 telephone numbers were dialled, from which 343 households were qualified as eligible (informal or family caregiver fitting the criteria described above) and completed the survey. The overall response rate for this survey is 26 percent. The response rate is calculated by taking the total number of cooperative contacts and dividing it by the total number of eligible numbers dialled. In this survey, 28,748 cooperative contacts were made. That is, 28,748 people said they would be willing to participate in the study prior to being screened for qualification (of which 343 qualified and completed the survey) out of the 108,824 eligible numbers dialled.

The following table (on the next page) shows the final dispositions of all telephone numbers attempted.

Sample Disposition Report

A. Total Number Attempted (Lines 1-14)	**123,557**
1. Not in Service	10,779
2. Fax	1,827
3. Invalid number/wrong number	2,127
B. Total Eligible Numbers (Lines 4-14)	**108,824**
4. Busy	2,700
5. Answering Machine	20,415
6. No Answer	19,600
7. Language barrier	2,193
8. Illness, Incapable	190
9. Eligible Respondent Not Available/Callback	6,388
C. Total Asked (Lines 10-14)	**57,338**
10. Household Refusal	10,584
11. Respondent Refusal	17,748
12. Qualified Respondent Break Off	258
D. Co-operative Contacts (Lines 13-14)	**28,748**
13. Not qualified	28,405
14. Completed Interview	343
Refusal Rate = (10+11+12)/C	**49.86**
Response Rate = D/B	**26.42**
Incidence = [(14+12)/(13+14+12)*100	**2.07**