

# Emotional Distress among Family Caregivers in Canada: Longitudinal Analysis of the National Population Health Survey

by

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## Abstract

*Objectives: The emotional health of family members providing care in the community to individuals with disability is a vital public health concern as our population ages and more care is provided in the community. The objectives of this study were to determine factors associated with family caregivers' mental health and compare their mental health to a matched non-care-giving group using a large, representative, and longitudinal database representing a broad spectrum of disabilities.*

*Methods: We used Canada's longitudinal National Population Health Survey (NPHS) to identify a family caregiver group (n = 800) and a non-care-giving group (n = 748), matched with respect to sex, age, education, and marital status. Standardized measures included Kessler's Emotional Distress Scale, Health Utilities Index, Self-Reported Health, Mastery, and Self-esteem. Mixed effects models for longitudinal data analysis were used.*

*Main Findings: Caregivers experienced more emotional distress if they were male, younger, had lower personal mastery, were in poorer general and subjective health, or were providing care to individuals with more co-morbidity. No significant differences were observed between caregivers and a matched non-care-giving sample in emotional distress after controlling for potential differences between groups.*

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*Conclusion: Family caregivers representing a broad spectrum of disabilities did not report more emotional distress than a matched non-care-giving sample. Future research can increase our understanding of how disability type can affect family caregiver emotional health.*

Keywords: caregivers, depression, public health, longitudinal survey

## **Introduction**

The health and well-being of family caregivers is now recognized as a public health concern (1). In Canada, an estimated one in eight adults provide support to individuals residing in the community with a variety of serious health conditions (2). Estimates are similar for other industrialized countries (3;4). This phenomenon is increasing as health care systems encourage brief hospitalization, ambulatory treatment, and offer very limited community services (5). Family care entails providing assistance with activities and instrumental activities of daily living as well as medical care. Many studies suggest that family caregivers report elevated levels of emotional distress (6;7) threatening the sustainability of home care (8). Consistent with the stress theoretical perspective (9), caregivers experience more emotional distress as a result of primary (e.g. providing high levels of care (10)) and secondary (e.g. lifestyle disruption due to providing care (11;12)) stressors. Psychosocial resources (e.g. personal control or mastery (10;13;14) and social support (10;15)), can lessen the negative impact of care-giving.

To date, the majority of family care research focuses on dementia-related disability which only constitutes a small proportion of disability in the elderly and, therefore, disability in general (16). Family care-giving is common for many other disabilities not associated with older age (e.g. mental illness) and not associated with medical conditions (e.g. accidents) and little is known about care-giving across these situations.

Canada's Longitudinal National Population Health Survey (NPHS) provides an excellent data source to study caregiver emotional distress across a broad-spectrum of disabilities. This population-based survey assessed many factors associated with caregiver emotional distress that are prominent in the caregiver literature including general and subjective health, mastery, and self-esteem and included care recipients with a wide variety of disabilities. However, since it was not the purpose of the NPHS to study family care-giving, specific aspects of the care-giving situation (e.g. level of care provided) were not assessed.

Using a sample of individuals providing care in the community to persons with a variety of disabilities, the purpose of this study was to: 1) determine the influence of aspects of the care situation and psychosocial factors on family caregivers' mental health, and 2) compare family caregivers' mental health with that of a matched non-care-giving group.

## Methods

### *Data Source*

Data from the longitudinal NPHS were used for this study. Data were obtained at two levels: 1) sociodemographic and general health information were obtained for all members of the household and 2) one household member, 12 years of age or older, was randomly selected to complete the more detailed health survey. The sampling strategy is described in detail elsewhere (17). This longitudinal survey started in 1994, with subsequent interviews in 1996 and 1998 providing a three-wave longitudinal data set for these analyses. Institutional research ethics boards approved the secondary analysis of this data.

### *Caregiver Sample*

Primary respondents were not directly asked if they were providing care. For the purpose of this study, primary respondents were defined as family caregivers if they met the following criteria: 1) indicated that their primary daily activity was "caring for family" or "working and caring for family" or their reason for not being currently employed was "family responsibilities" and 2) have a household member with a disability limiting their ability to perform daily activities or necessitating assistance with an activity of daily living. The first criterion could be assessed only in 1994, so care-giving status at subsequent waves was not determined. Both caregivers and care recipients had to be at least 18 years of age. This procedure identified 855 family caregivers, 800 (94%) with complete data. The percentage missing was too small to warrant imputation (18).

### *Comparison Sample*

A comparison sample was randomly selected from the remainder of the NPHS using a three-stage process. First, individuals were excluded if they satisfied the first caregiver criterion described above to ensure that the respondent is not providing care outside of their household. Second, respondents were excluded if they had missing data on any of our variables (see below). Third, for each caregiver, one individual who was a match with respect to age (within five years), education level (primary, secondary, college/trade, university), sex, and marital status (married/living with/common-law vs. never married/separated/widowed/divorced) was randomly selected. Using these strict criteria, we identified our comparison group ( $n = 748$ ).

### *Measurement Instruments*

Sociodemographic characteristics included age, sex, education, income, and marital status. Marital status was coded as "0" married/common-law/living together or "1" never married/separated/widowed/divorced. Education and income levels were categorized into four quartiles ranging from lower to higher. The time variable was coded as zero, two, and four to

represent the 1994, 1996, and 1998 assessments, respectively. The dependent variable, emotional distress (ED), was assessed by questions contained in the Composite International Diagnostic Interview short form (CIDI-SF, (19)) based on the work of Kessler (20). Six items (e.g. so sad that nothing could cheer you up, nervous, restless or fidgety, hopeless, worthless, everything was an effort) were rated on a five-point scale. These items were summed to provide a distress score ranging from 0 to 24 with higher scores indicating more distress. Evidence of internal consistency ( $\alpha > .65$ ) and construct validity has been reported in the NPHS sample (21).

Pearlin's seven and six-item measures assessed Mastery and self-esteem, respectively (22). Items were rated on five-point scales. The derived total scores range from two to 28 and one to 24 with higher scores indicating more mastery and more self-esteem, respectively. Mastery and self-esteem have shown good internal consistency ( $\alpha > .65$ ) in the NPHS sample (21).

The Health Utility Index assessed general health (23). Scores range from zero to one with higher scores indicating better health. One question (i.e. In general, would you say your health is excellent (1), very good (2), good (3), fair (4), or poor (5)) assessed subjective health status. All three cycles of data collection included the above variables with the exception of mastery and self-esteem, which were assessed only at wave one.

Characteristics of care recipients included sex, reason for disability, receipt of home care services, need for assistance with activities of daily living, and number of chronic conditions. Respondents indicated their reason for disability by one open-ended question. This question was then coded and categorized by Statistics Canada. Respondents indicated the number of home care services received during the past 12 months. Respondents' limitations in each of the following domains: at home, school, work, and other activities (e.g. leisure activities) were summed. The total number of co-morbid conditions was summed from a list of 20 (e.g. asthma, arthritis, stroke).

### *Statistical Analysis*

All analyses were performed using SAS version 6.0 (24). Weighting and bootstrapping procedures (provided by Statistics Canada) derived point estimates (e.g. means) and variances that are representative of the population from which the NPHS sample was derived. These procedures are required because of the complex sampling procedure described previously (17;25). T-tests and chi-square analyses compared the characteristics and health outcomes of caregivers and non-caregivers. Effect size estimates were calculated to examine the magnitude of differences between groups (26). Pearson correlations examined the bivariate relationships between variables prior to conducting the multivariate analyses. The estimated minimum sample size to investigate up to 15 parameters (described above) is 150, based on a suggested 10:1 ratio of participants to independent variables (27).

Mixed effects (ME) modeling was used to examine changes in emotional distress over time, to identify factors associated with emotional distress, and to compare family caregivers with non-caregivers. ME modeling allows examination of relationships between variables as they occur within individuals and, thereby, increases the precision of the estimates of relationships between variables (28). Unlike repeated measures ANOVA, participants can miss one or more waves of data collection. As long as a participant completes one assessment they can contribute to the intercept; if they complete two assessments, they can contribute to the estimation of linear change; and if they complete three or more assessments they can contribute to estimates of non-linear change (e.g. quadratic). The time variable is treated as a continuous variable as opposed to a nominal variable (e.g. repeated measures ANOVA). ME modeling allows us to model individual growth over time because people may start at different levels (i.e. intercept) and have different rates of change (i.e. slope). This is accomplished by allowing the intercept and slope to be random variables (i.e. their relationship with the dependent variable can differ across individuals). Multivariate analyses identify factors associated with initial levels and rates of change in the dependent variable.

The first model included all independent variables. The Akaike Information Criterion (AIC) is used when comparing the fit of models with different independent variables but with a constant number of participants as in our study (29). Model building used the AIC in two ways: 1) to select the appropriate random effects and correlation structure and 2) to identify variables, among those with little strong prior evidence, which could be dropped to give the most parsimonious model. Specifically, variables with p-values greater than .2 were removed and the model was re-run to identify the variables that made a significant contribution to the explanation of caregiver emotional distress. The percentage of variance explained by the model was calculated by squaring the correlation between observed and predicted emotional distress (29). In violation of model assumptions, the residual variance was related to the predicted values, and transformations of the ED variable could not remove this relationship. As a check on the robustness of the ME model, the dependent variable was dichotomized and a generalized estimating equation logistic regression model was fitted. Since the logistic model identified the same set of important predictors as the ME model, it is not presented.

## Results

Care-giving and non-care-giving samples are described in Table 1. Participants in the caregiver group reported poorer subjective health, less mastery, and less self-esteem than the non-care-giving group. Effect size estimates were calculated to examine the magnitude of these differences but they were minimal (i.e. all standardized mean differences were <0.01, results are not shown).

TABLE 1. Sample Characteristics

Variable	Caregivers	Non-Caregivers
	(N = 800)	(N = 748)
	Mean (95% CI)	Mean (95% CI)
Age	47.1 (45.8 – 48.2)	46.7 (45.6 – 47.8)
Female†	82.0 (78.6 – 85.4)	81.1 (77.5 – 84.6)
Married†	92.8 (90.5 – 95.1)	93.9 (91.8 – 95.9)
Self-esteem*	19.9 (19.6 – 20.2)	20.5 (20.2 – 20.8)
Mastery*	18.8 (18.4 – 19.2)	19.7 (19.2 – 20.1)
Subjective Health W1	2.3 (2.26 – 2.43)	2.2 (2.12 – 2.32)
Subjective Health W2*	2.4 (2.32 – 2.50)	2.3 (2.17 – 2.34)
Subjective Health W3*	2.4 (2.34 – 2.51)	2.3 (2.16 – 2.34)
Health Status W1	0.84 (0.83 – 0.86)	0.86 (0.84 – 0.87)
Health Status W2	0.88 (0.86 – 0.90)	0.90 (0.89 – 0.91)
Health Status W3	0.87 (0.85 – 0.89)	0.88 (0.87 – 0.90)
Emotional Distress W1	3.6 (3.32 – 3.91)	3.3 (3.02 – 3.63)
Emotional Distress W2	2.9 (2.64 – 3.20)	2.6 (2.32 – 2.96)
Emotional Distress W3	3.2 (2.78 – 3.57)	2.9 (2.60 – 3.17)

Weighted estimates and bootstrapped confidence intervals are presented. W1, W2, and W3 represent the three waves of data collection. For continuous measures, higher scores indicate more of the variable except as indicated; Self-esteem range 1 to 24; Mastery range 2 to 28; Subjective Health range 1 to 5 (higher scores indicate poorer health); Health Status range 0 to 1.0; Emotional Distress range 0 to 24.

† Percentages Female and Married with 95% confidence intervals.

\*  $p < .05$  indicates differences between caregivers and non-caregivers.

The care recipients were mostly male (73%), 4.3% received formal home care services, 22.8% required help with at least one daily activity, and 20.5%, 35.3%, 19.9%, and 24.2% had zero, one, two, or three or more co-morbid conditions, respectively. Their primary reasons for disability were grouped as follows: disease or illness (n=188, 23.5%), work-related disability (n=130, 16.3%), home, sports or motor vehicle injury (n=83, 10.4%), congenital disability (n=58, 7.3%), age-related disability (n=50, 6.3%), and other (n=46, 5.6%). The reason for disability was missing in 245 cases (30.6%).

We examined the correlations between independent variables to identify any collinear relationships. The highest correlation was between mastery and self-esteem (.45,  $p < .001$ ) but this value does not approach the correlation value of .70 which would suggest multicollinearity (30). In our simplest model, we found that caregivers who were male, younger, had lower mastery, poorer health, and were providing care to individuals with more co-morbidity experienced more emotional distress (pseudo  $R^2 = .76$ , see table 2 for results). A small (less than 2% of baseline) but significant decrease in emotional distress was observed over the four-year follow-up period. Caregiver marital status, education level, income, self-esteem, and services received by the care recipient were not significantly associated with caregiver emotional distress. Therefore, these variables were removed when determining the simplest model. Reason for disability was not tested because of the large percentage (31%) of missing data.

TABLE 2. Factors Associated with Caregiver Emotional Distress

Effect	Estimate*	Standard Error	95% Confidence Interval	P-value
Intercept	12.70	0.59	11.54 to 13.86	<. 0001
Female Sex	-0.43	0.21	-0.84 to -0.02	.04
Age	-0.04	0.01	-0.06 to -0.02	<. 0001
Mastery	-0.17	0.02	-0.21 to -0.13	<. 0001
Subjective Health	0.36	0.07	0.22 to 0.50	<. 0001
Health Status	-6.23	0.36	-6.94 to -5.52	<. 0001
Number of co morbid conditions	0.11	0.04	0.03 to 0.19	0.0085
Time	-0.09	0.04	-0.17 to -0.01	0.0083

\* These are not standardized estimates.

See Table 1 footnote for description of variables.

Time – three assessments.

The unadjusted comparison between caregivers and the matched non-care-giving sample suggested that caregivers reported more emotional distress but this was not statistically significant (mean difference=.17, SE=.14,  $p = .24$ ). Adjustment for differences between caregivers and non-caregivers with respect to mastery, subjective health rating, and health status reduced the mean difference in emotional distress further (see Table 3). No significant interactions between groups with respect to self-esteem, mastery, and subjective health rating were observed (results not shown).

TABLE 3. Comparing Caregivers with a Matched Non-Care-giving Sample

Effect	Estimate*	Standard Error	95% Confidence Interval	P-value
Intercept	12.21	0.44	11.35 to 13.07	<. 0001
Female Sex	-0.48	0.15	-0.77 to -0.19	.001
Age	-0.04	0.01	-0.06 to -0.02	<. 0001
Mastery	-0.16	0.01	-0.18 to -0.14	<. 0001
Subjective Health	0.45	0.05	0.35 to 0.55	<. 0001
Health Status	-5.79	0.27	-6.32 to -5.26	<. 0001
Caregiver	0.03	0.11	-0.19 to 0.25	0.8169
Time	-0.08	0.02	-0.12 to -0.04	0.0010

\* These are not standardized estimates. SE = standard error of the estimate.

See table 1 footnote for description of variables.

## Discussion

Using Canada's longitudinal NPHS, we determined factors associated with emotional distress in a large population-based sample of family caregivers providing care to individuals with a variety of disabilities. Consistent with previous research, more emotional distress was observed in caregivers who were younger (31), reported less mastery (14), were in poorer health (32), and who were providing care to individuals with more disability (33). The finding that males may be more emotionally distressed is contrary to existing literature (see review by Yee and Schulz (34)). This may be explained by our definition of caregiver. Males who indicate that their primary daily activity is caring for family, usually considered a female role, may be in more demanding care-giving roles. In addition, the emotional distress scale derived from questions in the CIDI-SF, which is a clinical diagnostic interview, may not be as vulnerable to gender bias as some other measures more commonly used in caregiver research (e.g. CES-D (35)). For example, no gender differences in mood disorders assessed by the CIDI were observed in a large representative sample of the Dutch population (36). In comparison, the CES-D, a common measure of emotional distress in care-giving studies, has been found to systematically overestimate emotional distress in females as compared to males (35).

Although our family caregivers were in poorer physical health and had less mastery and self-esteem than our non-care-givers, we did not observe differences in emotional distress between these groups. These results are consistent with newer findings (37) where smaller differences in mental health between the two groups were found when caregivers provided non-dementia care and when studies used more representative samples (37).

This study makes a significant contribution to the understanding of family care by: 1) examining family care to individuals with a variety of disabilities; 2) using a large population-based sample



of caregivers representative of the Canadian population; and 3) comparing with a matched non-care-giving sample.

This study also had some limitations. Participants were not asked directly if they were providing care to a disabled family member. However, since an individual in the caregiver's household was limited in everyday activities due to a disability, it is highly likely that the "caregiver" was providing necessary care to this individual. In addition, not all measures were used at each wave. One of the questions used to define caregivers, primary daily activity, was not asked at waves two and three. Therefore, we have no reliable way of identifying changes in care-giving status in our samples. Lastly, reason for disability was missing for a large number of participants and could not be included in the analyses.

This study has implications for public health strategies and public health professionals. Our findings suggest key characteristics that can help us to identify community-based family caregivers who may need more support and assistance to promote their health and well-being. Specifically, male, younger, those in poorer health, with lower sense of control over life (i.e. mastery) and providing care to individuals with more co-morbidity are at increased risk of experiencing poor mental health outcomes. Public health strategies and professionals can monitor the health and well-being of this high risk group of caregivers with the aim of providing any necessary care and assistance. These strategies should enhance the health and well-being of our growing care-giving population.

## **Conclusions**

This is the first study to examine emotional distress in a large longitudinal population-based sample of family caregivers providing care in the community to individuals with a variety of disabilities. Although a number of studies have observed differences between care-giving and non-care-giving samples, we did not observe a difference. Future population-based research would further our understanding of how disability type may differentially affect family caregiver emotional health.

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