



The Caregiver Experience in Ontario: Preliminary Results from a Pilot Survey

HEALTH SYSTEM PERFORMANCE RESEARCH NETWORK (HSPRN)

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Background

Caregivers are critical to Canada's health and social service systems. Twenty-eight percent of Canadians, aged 15-plus years, provide care to a family member or friend (Sinha, 2013). The 2009 estimated value of their contributions was over \$25 billion of unpaid care (Hollander, et al., 2009).

In Ontario, there is no organization or government ministry charged with caregiver support. Moreover, caregiver information is collected sporadically and not always aligned with provincial priorities. To address this gap, a team at CAMH and its stakeholder Advisory has developed the Family/Friend Caregiver Survey, examining the burdens, benefits, costs and support needs of Ontario caregivers.

Methods

Over 300 Ontario caregivers pilot tested the online survey. The survey combines two perspectives: caregiving as an individual 'labour of love' and caregiving as a job. The data will therefore be analyzed looking at both individual stress/burden and job demands. The main topics covered by the survey include: 'work' demands and impacts associated with caregiving; resources/supports used or needed by caregivers; attitudes and culture; and uncertainties. A subset of respondents completed a specialized module that focused on caregivers of young people with mental health and/or addictions problems.

Preliminary Results

Pilot results will be used to fine-tune the survey, which is scheduled for release in early 2016. The survey data will describe Ontario caregiver experiences and evaluate risk factors associated with less positive experiences. Results will be compared with key items from the Statistics Canada 2012 General Social Survey on Caregiving. As well, data from caregivers of young people with mental health and addictions problems will be compared to other caregivers in terms of their demographic characteristics, caregiving context, work-life balance, service utilization/access barriers, and employment/financial status.

Conclusion

Understanding the caregiver experience is critical for determining how this 'workforce' contributes to government strategic goals for Canadians with physical and mental health problems. Results will help inform health care decision-making in Ontario.

Acknowledgements

The project team would like to acknowledge and thank the many individuals and organizations that have contributed to the development of the Family/Friend Caregiver Survey. The members of the expert advisory committees include:

Core Advisory Committee

- Eleanor Baker, Family Caregiver; Volunteer, Schizophrenia Society of Ontario - Toronto Region
- Sarah Cannon, Family Caregiver; Executive Director, Parents for Children's Mental Health
- Tamara Daly, Associate Professor, York University Faculty of Health – School of Health Policy & Management
- Justine Giosa, Representative, Canadian Caregiver Coalition; Research Associate, Saint Elizabeth Research Centre
- Gillian Gray, Executive Director, Family Outreach and Response
- David Harvey, Chief, Public Policy and Program Initiatives Officer, Alzheimer Society of Ontario
- Paul Holyoke, Representative, Canadian Caregiver Coalition; Director, Saint Elizabeth Research Centre
- Bridget Hough, Family Caregiver
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- Donna Mackay, Associate Director, Community Engagement and Integration Services, March of Dimes Canada
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- Dena Maule, Executive Director, Hospice Toronto
- Carol Oliveira, Research Fellow, The Hospital for Sick Children
- Wendy Porch, Manager, Episodic Disabilities Initiatives, Canadian Working Group on HIV and Rehabilitation
- Daniela Sota, Toronto Central Community Care Access Centre
- Ralf Steinberg, Caregiver
- Ruth Stoddart, Senior Policy Advisor, Strategic Policy and Mental Health Council Secretariat, Ministry of Health and Long-term Care
- Taryn Tang, Manager of Research, Schizophrenia Society of Ontario
- Allison Williams, Professor, School of Geography & Earth Sciences, McMaster University
- Juliette Wood, Representative, Ontario Caregiver Association; Community Psychiatric Services for the Elderly, Sunnybrook Health Sciences Centre
- Peter Wright, Family Caregiver

Research Advisory Committee

- Janet Fast, Professor and Co-Director, Research on Aging, Policies and Practice, University of Alberta
- Nancy Guberman, retired Professor of Social Work, University of Quebec in Montreal
- Janice Keefe, Assistant Professor, Mount Saint Vincent University
- Yeonjung Lee, Assistant Professor, Faculty of Social Work, University of Calgary
- Donna S. Lero, Centre for Families, Work and Well-Being, University of Guelph
- Leslie Ruckman, Industrial Designer; Researcher, Mayo Clinic, Center for Innovation

Children's Mental Health & Addictions Advisory Committee

- Eleanor Baker, Family Volunteer, Schizophrenia Society of Ontario - Toronto Region
- Sarah Cannon, Caregiver; Executive Director, Parents for Children's Mental Health
- Evangeline Danseco, Director, Support Services, Ontario Centre of Excellence for Child and Youth Mental Health
- Betty-Lou Kristy, Peer Support Substance Use Systems Lead & Consumer Survivor Initiative Mental Health Lead, Mississauga-Halton LHIN Enhancing & Sustaining Peer Support Initiative through TEACH
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- Peter Szatmari, Clinical Scientist, The Centre for Addiction and Mental Health
- Nadine Zahlan, PhD student

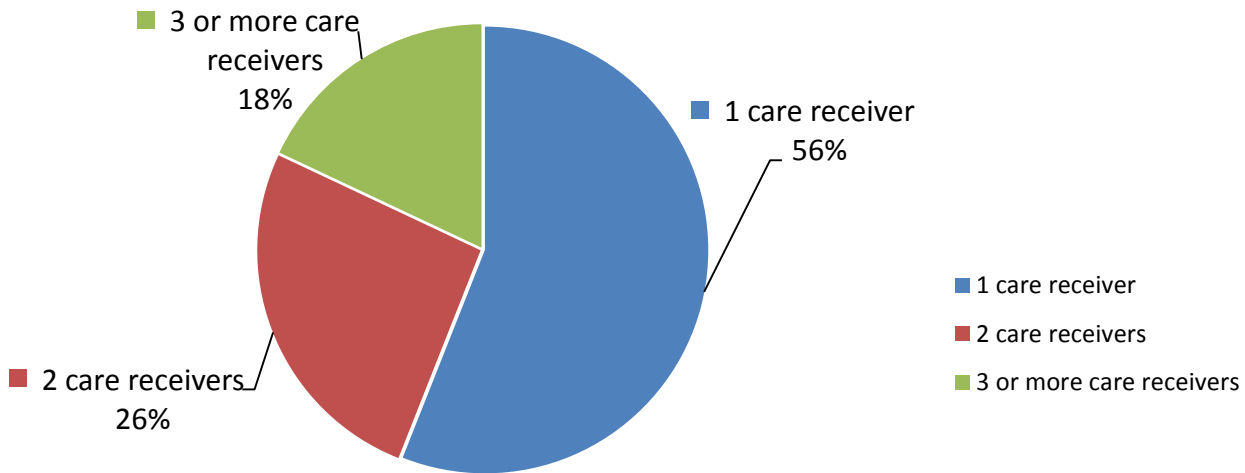
The project team responsible for the Family/Friend Caregiver Study includes:

- Elizabeth Lin, Principal Investigator; Research Scientist, Performance Measurement & Evaluation Research, Provincial System Support Program, The Centre for Addiction and Mental Health
- Janet Durbin, Co-investigator; Research Scientist, Performance Measurement & Evaluation Research, Provincial System Support Program, The Centre for Addiction and Mental Health
- Wendy Unger, Co-investigator; Senior Scientist, Child Health Evaluative Sciences, The Hospital for Sick Children
- Tiziana Volpe, Research Coordinator, Performance Measurement & Evaluation Research, Provincial System Support Program, The Centre for Addiction and Mental Health
- Avra Selick, Research Associate, Performance Measurement & Evaluation Research, Provincial System Support Program, The Centre for Addiction and Mental Health
- Nhi Vu, Research Associate (AHRQ Project), Performance Measurement & Evaluation Research, Provincial System Support Program, The Centre for Addiction and Mental Health

Family/Friend Caregiver Survey

The Family/Friend Caregiver Pilot Survey collected responses from 302 caregivers across Ontario. We are using this feedback to improve the survey and we plan to release the final version in early 2016. Please check back here for updates. Below, you will find some preliminary results from the pilot survey.

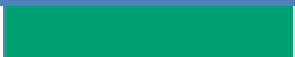







1. During the past 12 months, how many family members, friends or neighbours have you provided help to because of their long-term health condition, physical or mental disability, or problems with aging?



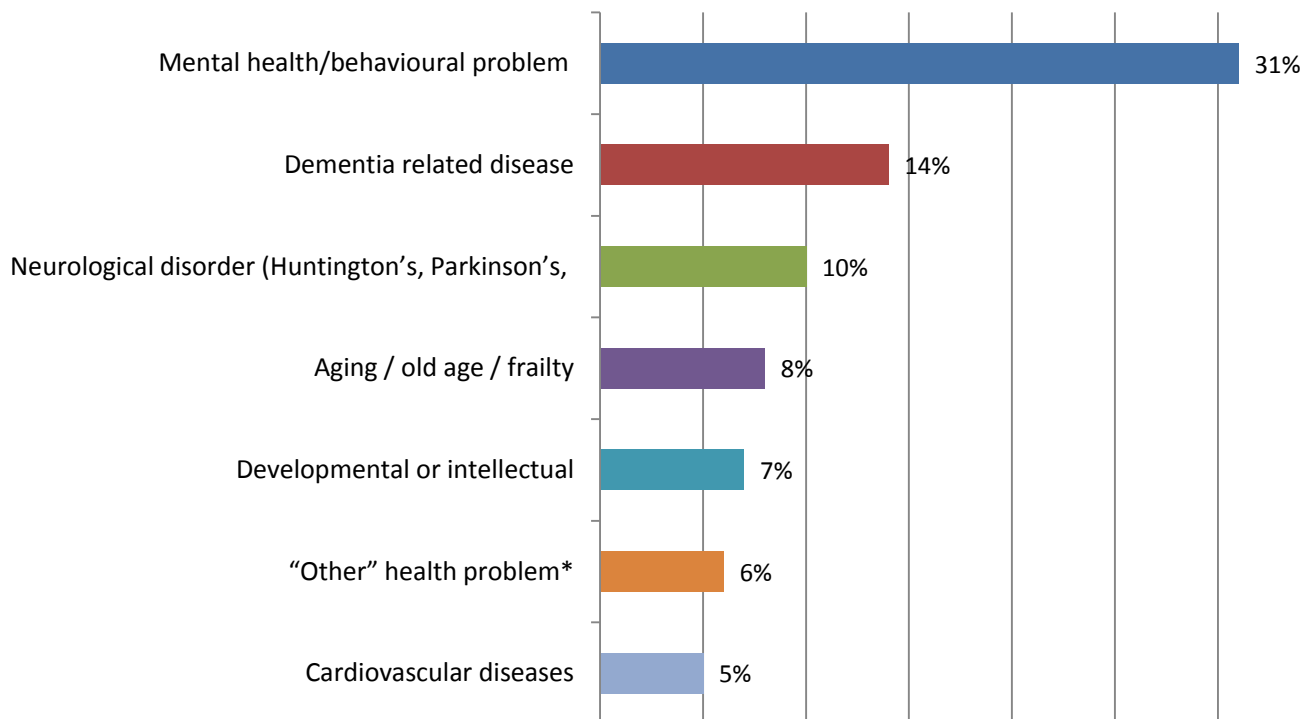
2. In a typical week over the past 12 months, how much time did you spend helping these family members, friends, or neighbours?

Response	Chart	Percentage
20 hours or more		46%
15 hours to less than 20 hours		11%
10 hours to less than 15 hours		12%
5 hours to less than 10 hours		16%
1 hour to less than 5 hours		13%
Less than 1 hour		1%
Don't know		1%

3. What is the relationship to you of the primary person you care for?

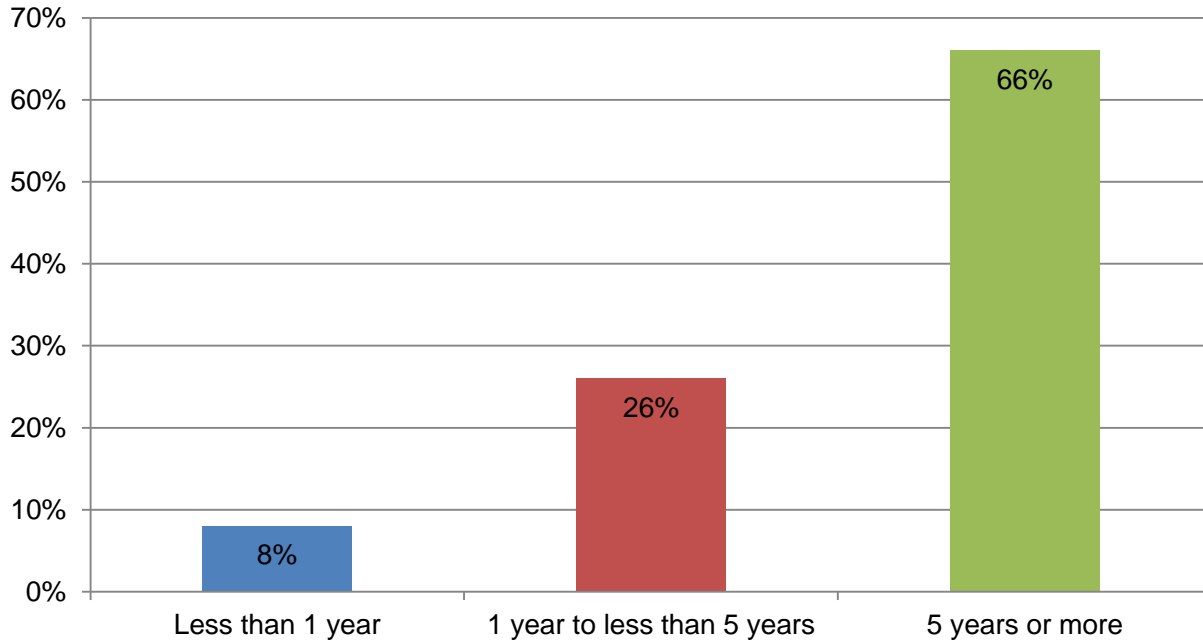
Response	Chart	Percentage
My son/daughter, step-child, foster child, or child-in-law		33%
My spouse/partner		25%
My parent, step-parent, or parent-in-law		25%
My sibling or step-sibling		5%
Other, please specify...		5%
My friend or neighbour		4%
My grandparent, step-grandparent, or grandparent-in-law		3%
My grandchild, step-grandchild, or grandchild-in-law		0%

4. What is/are the primary care receiver’s health problem(s)? Select all that apply

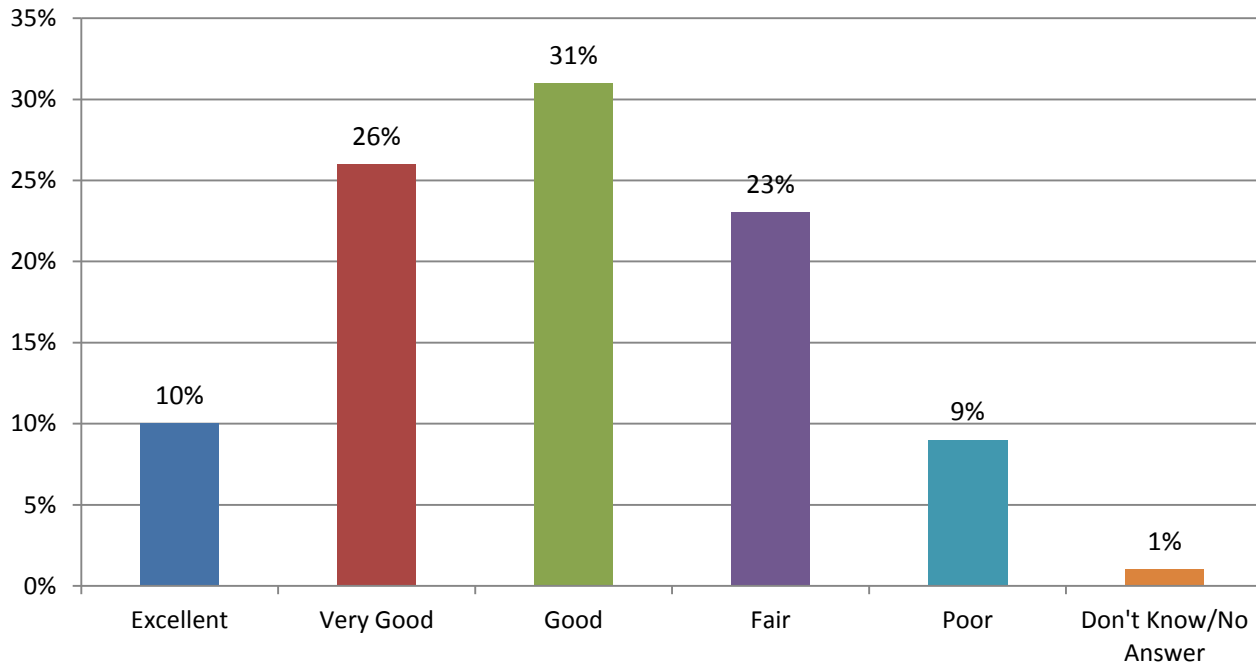


All other health conditions < 5%

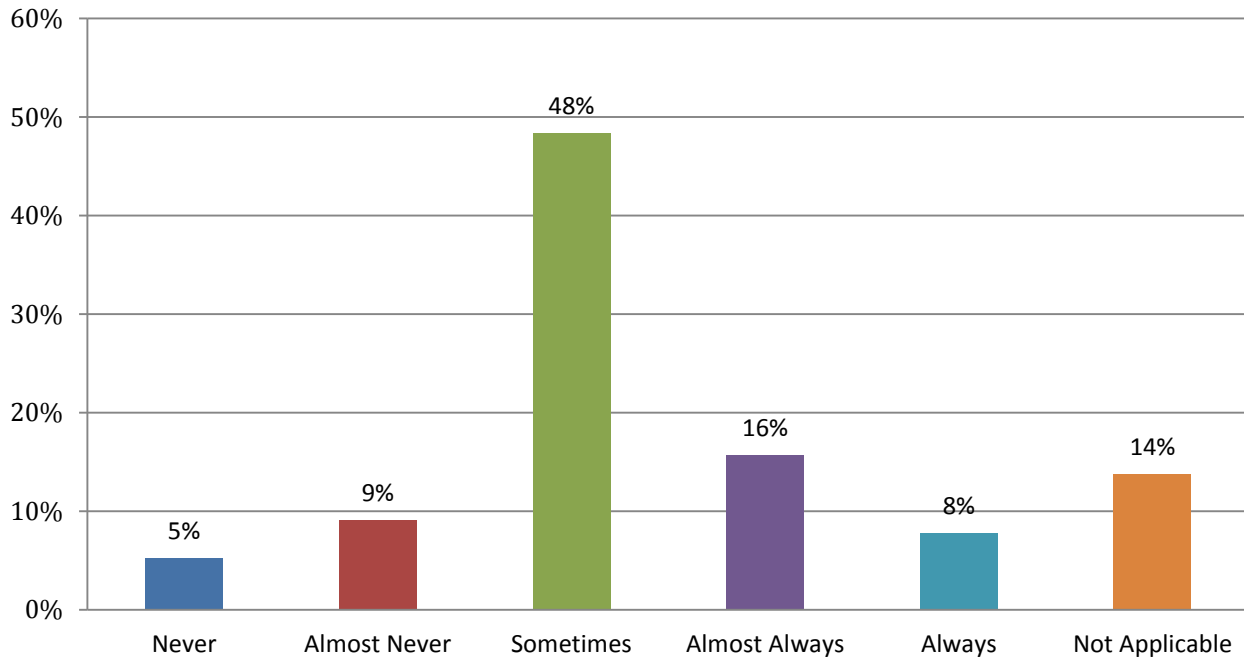
5. How long have you been helping your primary care receiver?



6. In general, would you say your health is:



7. In the past 12 months, how often did your caregiving responsibilities interfere with your responsibilities at work or school, such as getting to work/school on time, accomplishing daily tasks, or working overtime?



8. In the past 12 months, as a result of your caregiving responsibilities, have you: (select all that apply)

Response	Chart	Percentage
Modified your spending, such as deferred spending on personal needs or spending money on vacations, etc.		48.7%
None of the above		31.1%
Used savings, such as RRSPs, TFSAs, etc.		25.5%
Deferred savings, such as RRSPs, TFSAs, etc.		18.9%
Taken loans from a bank or financial institution, such as credit card loans, second mortgage, etc.		16.9%
Borrowed money from family or friends		14.9%
Sold investments or assets		13.6%
Don't know/prefer not to answer		5.0%
Other, please specify...		3.0%
Filed for bankruptcy		0.7%

9. During the past 12 months, have you experienced financial hardship because of your caregiving responsibilities?

