

The Family/Friend Caregiver Experience in Ontario: Results of an Online Pilot Study

Presentation to:

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Background & Method (i)

- Informal caregivers = significant labour force
 - 13M Canadians, aged 15 years-plus*
 - ~\$25B/year of unpaid care**
 - Important cost containment role***
- Crucial to understand their working conditions and stress factors to design better supports
- Systematic data limited (e.g., GSS 1996, 2002, 2007, 2012)

* Sinha, M. (2013). *Spotlight on Canadians: Results from the general social survey: Portrait of caregivers, 2012*. Statistics Canada. Retrieved from <http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.pdf>

** Hollander, M.J., Liu, G., and Chappell, N.L. Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly* 2009, 12(2): 42-49

*** Keefe, J. M. *Supporting caregivers and caregiving in an aging Canada*. IRPP Study 23. Montreal: Institute for Research on Public Policy, 2011. Available at http://www.irpp.org/pubs/irppstudy/irpp_study_no23.pdf, accessed November 5, 2012.

Background & Method (ii)

- 2013-16 funding (MOHLTC-HSRF, U of T, W. Wodchis, Lead PI)
- Process: iKTE – 3 stakeholder Advisories
- Primary audience: government
- Combine theoretical approaches – caregiver as:
 - labour of love (e.g., stress/burden)
 - unpaid workforce (e.g., occupation stress)

Background & Method (iii)

- Deliverables:
 - Bird's eye view: Develop & test on-line Core Survey for all caregivers
- More specific view(s): Supplemental module for caregivers of children/youth with MH/A problems
- Include:
 - previously validated instruments (lit review)
 - selected GSS questions
 - new questions to fill gaps

Survey Measurement Plan

Framework					
DOMAIN	Caregiving Work Demands	Caregiving Work Impact	Caregiving Resources/ Supports	Attitude/Culture	Caregiving Uncertainties
CONSTRUCTS	<ul style="list-style-type: none"> Type Time Difficulty 	<ul style="list-style-type: none"> On Work On Family On Self 	<ul style="list-style-type: none"> Social network Publicly-funded Barriers 	<ul style="list-style-type: none"> Socio-cultural beliefs 	<ul style="list-style-type: none"> Current Anticipated
Coverage (level of detail)					
BROAD OVERVIEW (all caregivers)	Core Survey				
MEDIUM DEPTH (all caregivers)	<ul style="list-style-type: none"> Difficult behaviours (Core Survey) 	<ul style="list-style-type: none"> Impact on work (Core Survey) 	<ul style="list-style-type: none"> Publically provided services (Core Survey) 		
IN-DEPTH (specific groups of caregivers)	Supplemental Modules				

Pilot Testing Procedures

- **Phase 1:** Expert review of survey with Advisories
- **Phase 2:** Recruit 30 caregivers for three rounds of cognitive testing
- **Phase 3: Recruit 300 caregivers for online testing of revised survey (snowball sample)**

Phase III: Data Collection

- Data collection period – July 22 - Oct 9
- 624 opened the survey; 495 consented
- 302 completed (61% of those who consented)
- Completion time – 43 minutes (removing 2+hour outliers)

Survey Feedback (1)

- How relevant were the questions to your experiences?
 - Very – 47%
 - Somewhat – 38%
 - A little – 12%
 - Not at all – 1%
- To what extent was the format user-friendly?
 - Very – 74%
 - Somewhat – 19%
 - A little – 6%
 - Not at all – 0.3%

Survey Feedback (2)

- How close were you to quitting the survey early and NOT completing it?
 - Not at all – 50%
 - A little – 33%
 - Somewhat – 9% *
 - Very – 6% *
- Why? (* = 44 respondents)
 - Too long - 45%
 - Not relevant to my experience - 16%
 - Difficult to answer - 14%
 - Lack of time/confidentiality/
technology problems - .09%

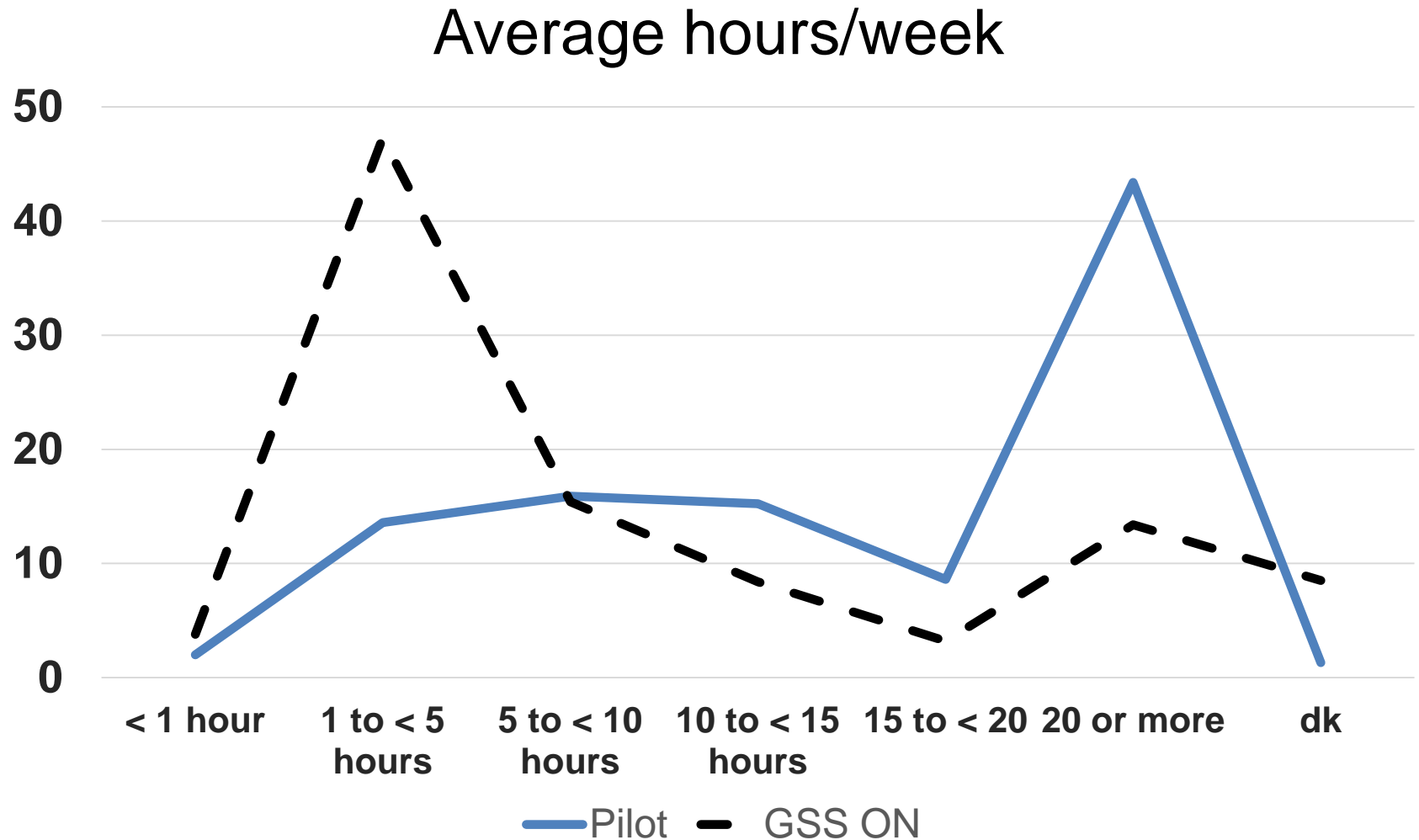
Who Filled Out the Survey?

- Caregiver Characteristics (i)

CG Characteristic	Pilot n=302	GSS ON
% Female	81.5	53.7
% wid/div/sep	18.6	8.5
% age 45-plus	76.2	53.9
% Excellent health	9.6	21.8

Who Filled Out the Survey?

- Hours Spent Caregiving



Who Filled Out the Survey?

- PCR Main Health Problem

Condition	Pilot	GSS ON
Aging/old age	7.9%	27.1
Cardiovascular	4.3%	9.3
Cancer	3.6%	9.9
Mental health	31.1%	6.6
Dementia-related	16.2%	5.9
Neurological	12.6%	5.3
Developmental/intellectual	4.6%	2.0
Addictions	2.0%	0.4
Other	< 5% each*	<5% each

* 40% of “other” conditions were included in survey list provided

OBERST: Tasks with Most Time & Most Difficulty

Large/great amt of time		Very/extremely difficult	
Emotional support	69%	Managing behaviour	44%
Monitoring symptoms	44%	Emotional support	36%
Transportation	44%	Arrange care while away	32%
Managing behaviour	41%	Seek/give information	28%
Household tasks	39%	Monitoring symptoms	26%
Managing finances	37%	Managing behaviour	44%

BAKAS: Areas with Negative, No, and Positive Change

Negative change		No change		Positive change	
Emotional well-being	81%	Self-esteem	42%	Relation w/ care receiver	31%
Energy level	80%	Financial well-being	33%	Relation w/ family	18%
Time for family activities	75%	Physical functioning	32%	Self-esteem	16%
Coping w/ stress	74%	Relationship w/ friends	29%	Ability to cope w/ stress	12%

Services for Caregiver

Service	Used	Needed but not used
Respite	23%	29%
Mental health services	46%	16%
Caregiver education, Support services	49%	20%
Other	8%	4%

Barriers for Caregivers Who Needed But Did Not Use Services

Barriers	Respite	MH services	Education/support
System confusing	27%	19%	33%
Hard to access	41%	32%	49%
Financial issues	47%	36%	20%
Services inappropriate	27%	13%	20%
Couldn't leave CR	40%	15%	10%
Afraid (stigma)	4%	19%	8%

Services for Care Receiver

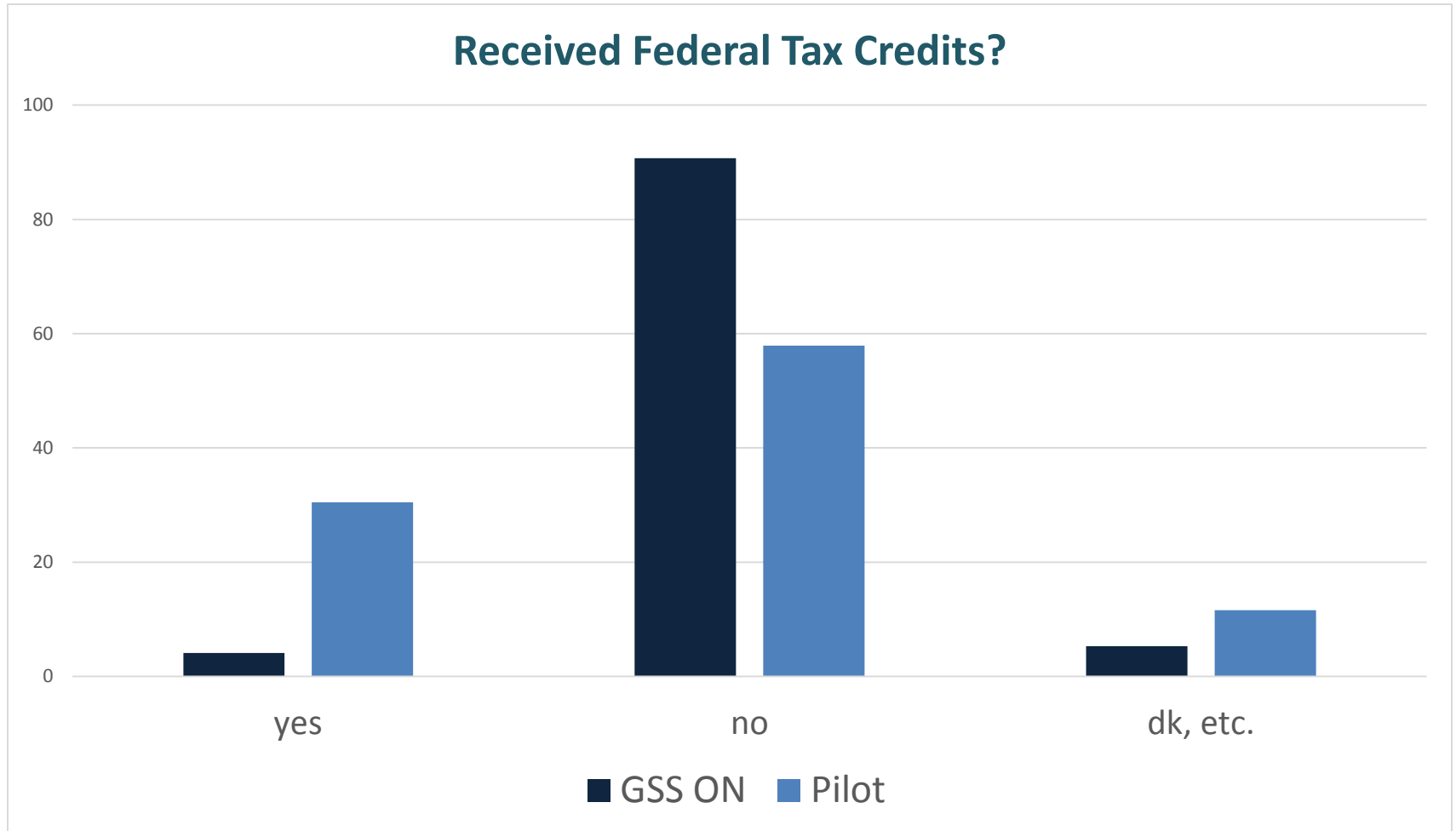
Service	Used	Needed but not used
Home-based	38%	15%
Long-term care	17%	14%
Health & other therapies	64%	12%
Recreation, social support	28%	6%
System navigation	32%	25%
Education-related	11%	3%

Barriers for Care Receivers Who Needed But Did Not Use Services

Barrier	Home-based	LTC	Recrea/ Soc. Sup.	System Nav.
System confusing	21%	12%	13%	41%
Hard to access	39%	50%	34%	31%
CR reluctant to use	43%	45%	67%	18%
Financial issues	32%	26%	26%	15%
Poor quality	16%	10%	14%	3%
Afraid (stigma)	0%	5%	2%	0%
Guilty re: service use	9%	12%	3%	27%

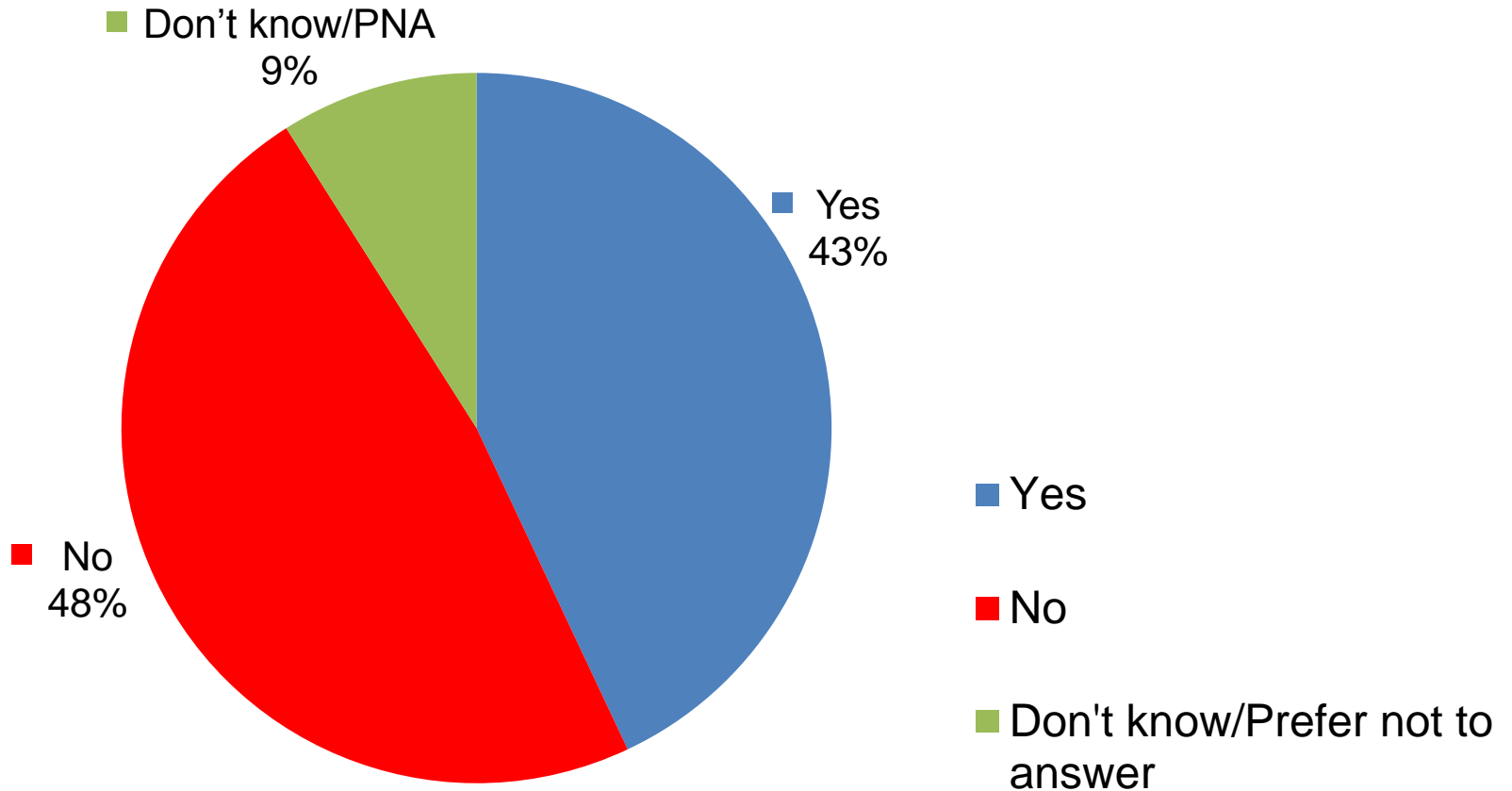
*Data suppressed for i) Health & Other Therapies, and ii) Education-related

Federal Tax Credits for Caregivers (1)



Financial Hardship (2)

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



Conclusions

- Survey is feasible & user-friendly
- Content highly relevant to primary audience & caregiver organizations
- Practical value of combining personal and occupation perspectives noted by some stakeholders

Thank You!

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Questions?

Team members:

- Elizabeth Lin, Principal Investigator¹; Research Scientist
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- Tiziana Volpe¹, Research Coordinator
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¹Performance Measurement & Evaluation Research, Provincial System Support Program, The Centre for Addiction and Mental Health

²Child Health Evaluative Sciences, The Hospital for Sick Children

Advisory Members

– Core Survey

Government: MOHLTC, MCYS, Senior's Secretariat (Citizenship & Immigration)

Researchers: York University, McMaster University

Caregivers: 5 caregivers plus – reps from

- Canadian Caregiver Coalition
- Ontario Caregiver Coalition/Saint Elizabeth
- Parents for Children's Mental Health
- Schizophrenia Society of Ontario
- Family Outreach and Response Program
- Alzheimer Society of Ontario
- Canadian Working Group on HIV & Rehabilitation
- Toronto Central Community Health Care Access Centre
- Stroke Recovery Canada/March of Dimes
- Hospice Toronto

Advisory Members

– Research Subcommittee

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

Advisory Members

– MH & A Subcommittee

- Dr. Peter Szatmari, Clinical Scientist, CAMH
- Mary Mannella, Manager, Children and Youth at Risk Branch, Ministry of Child and Youth Services
- Dr. Evageline Danseco, Director, Support Services, CHEO
- Sarah Connor, Executive Director, Parents for Children's Mental Health
- Eleanor Baker, Caregiver
- Betty-Lou Kristy, Caregiver
- Nadine Zahlan, Student