Technical Report

Family/Friend Caregiver Services and Supports: Methods and Selected Descriptive Results

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TECHNICAL REPORT

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I. METHODS

The Ontario Family/Friend Caregiver Survey pilot was the result of a three-year project, funded through the Ontario Ministry of Health and Long-term Care's Health System Research Fund initiative. The objective was to develop and pilot-test an on-line survey suitable for all informal caregivers that would provide information to prompt and support government policy and program planning. A key ingredient was the project Advisory -- consisting of 22 individuals including family caregivers, caregiver organization representatives, and policy-makers – who actively shaped every development in this project. (Input from six researchers outside of the project team was provided through a separate advisory since there was concern that including them on the main Advisory might stifle participation from non-researcher participants.)

All aspects of the study were approved by the Research Ethics Review Boards at the Centre for Addiction and Mental Health.

The project had three phases: identification of critical domains, draft survey creation and testing, and pilot-testing of the final on-line survey.

A. Identification of critical domains

Critical domains were identified through a two-pronged approach based on a review of the scientific/grey literature and the 'lived experience' perspective of the Advisory.

The literature review followed an iterative process. Based on preliminary discussions about project aims with the project team, an initial set of 10 paper abstracts were provided by a librarian and reviewed by the team members. Discussion of these abstracts led to a narrowing down of search criteria as well as improved understanding of the causes for discrepancies among the abstractors. This process was repeated twice (a total of 30 papers pulled and abstracts reviewed) and resulted in the following inclusion/exclusion criteria for the full search:

- English-language articles or reports where the topic was family, informal, or unpaid caregivers
- Published or released from 2003 forward
  - For 2003 to 2007, only review articles would be included
  - For 2008 on, both review and primary studies would be included
- Measurement and provision of data specific to the caregiver (not the care recipient) experience
- Measurement of specific constructs (e.g., time spent) only if they were part of a broader construct (e.g., caregiver burden).

These criteria were applied to PsychINFO, Medline, CINAHL, EMB reviews (including the Cochrane review and DARE databases), and social work and sociological abstracts and yielded a total of 3989 articles and reports of which 202 were duplicates yielding a final total of 3787. Table 1 provides the strategy for the 2003-2007 Medline search.

TABLE 1: MEDLINE SEARCH STRATEGY

Database: Ovid MEDLINE(R) without Revisions <1996 to November Week 3 2013>
Search Strategy:
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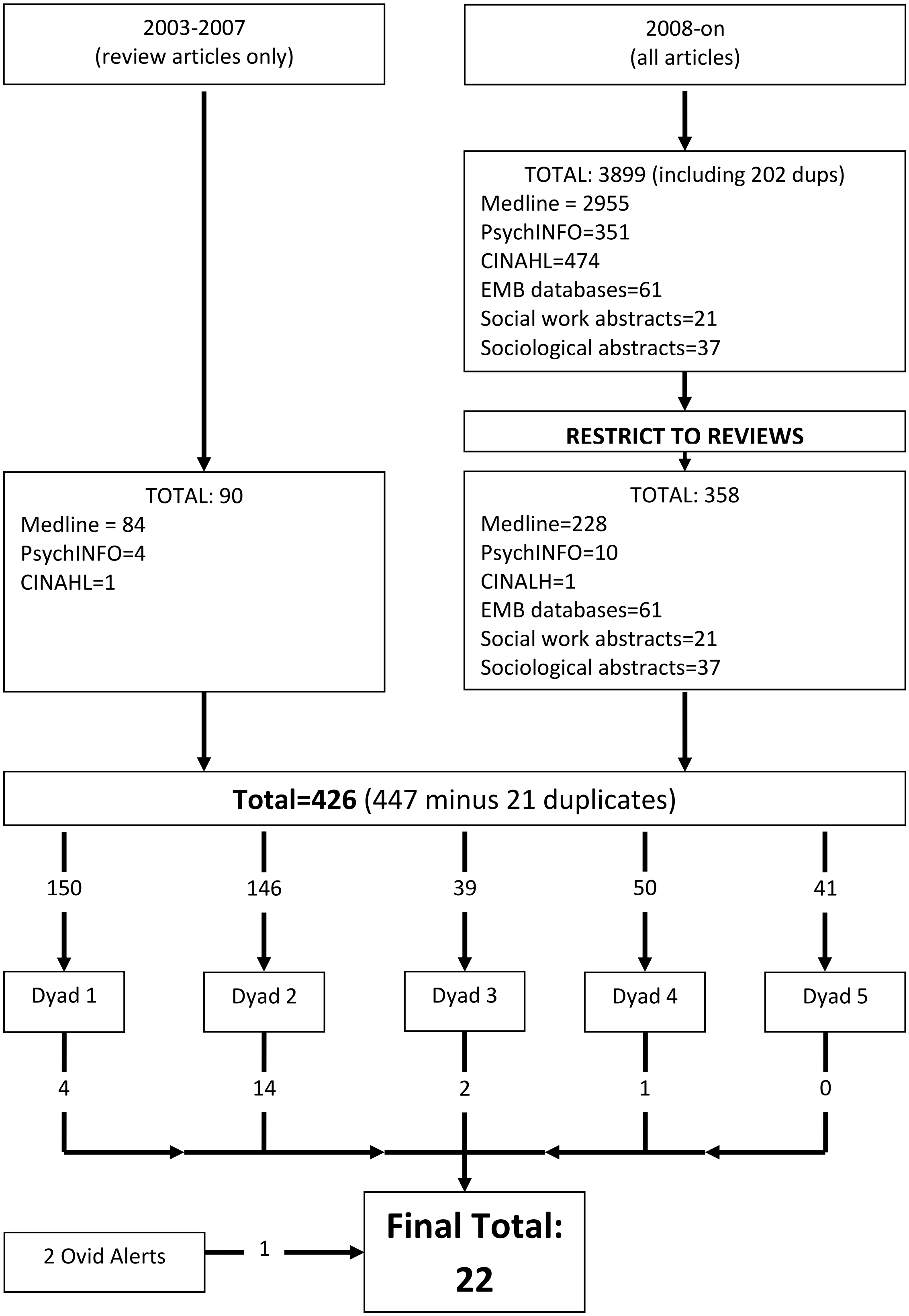
1 Caregivers/ (17986)
2 Questionnaires/ (239979)
3 Needs Assessment/ (21203)
4 data collection/ or health surveys/ or health care surveys/ (106524)
5 behavioral risk factor surveillance system/ (1083)
6 2 or 3 or 4 or 5 (343471)
7 Home Nursing/ (3230)
8 survey*.ti,ab. (249713)
9 (caregiver* or carer or carers).ti. (7824)
10 1 or 7 or 9 (20276)
11 6 or 8 (485999)
12 10 and 11 (6279)
13 limit 12 to (English language and yr="2008 -Current") (2854)
14 12 (6279)
15 limit 14 to (English language and yr="2003 - 2007") (1678)
16 limit 15 to (meta analysis or "review" or systematic reviews) (84)

Two pairs of team members then applied the inclusion/exclusion criteria to a sample of 100 abstracts each. Disagreements (6 and 12% for the two dyads) were resolved by discussion with a third team member. In addition, the decision was made to focus only on review articles (where allowed by the specific database) for identifying critical domains, given the time-intensive nature of abstracting primary studies. (The primary studies were incorporated, however, into the next phase.)

Limiting the focus to review articles reduced the total number of eligible abstracts to 426, which were reviewed by five dyads of team members with disagreements resolved by discussion with a third member. Two additional references (identified via Ovid Alerts) were also screened of which one was included resulting in a final total of 22 articles (see Figure 1).

FIGURE 1: LITERATURE SEARCH AND REVIEW PROCESS



Initial domains were selected informed by the review of these 22 articles and by a consideration of two theoretical frameworks: caregiving as a personal commitment (specifically, the stress process model – e.g., (Pearlin, Mullan, Semple, & Skaff, 1990) and as an unpaid labour force (specifically the demand-control job strain model -- e.g., Karasek, 1979; Molloy et al., 2008). This process resulted in the preliminary identification of five domains: caregiver 'work' demands; 'work' impacts; resources/supports; attitudes and culture; and uncertainties.

Discussion of these preliminary domains and some of the component constructs (e.g., time as a work demands domain construct) with the Advisory led to further refinements based on their practical and lived experience as well as the results of the draft survey testing (described below).

The result was a four-domain conceptual framework (Table 2) covering caregiving work demands, resource needs, resource utilization, and costs. The issue of how to balance broad concerns relevant to all caregivers versus those relevant to caregivers of individuals with specific

TABLE 2: FOUR DOMAINS

1. ***Caregiving Work Demands***
    - Type of tasks
    - Time devoted to caregiving
    - Intensity

2. ***Resource Needs***
    - Supports and services needed to carry out caregiving responsibilities (societal, from professionals, family and friends, and others)
    - Met and unmet needs
    - Barriers to access

3. ***Resource Utilization***
    - Services provided by various health and other support care providers (physicians, nurses, personal support workers, therapists, etc.)
    - Help provided by other family/friend caregivers
    - Supplies, equipment, and medications

4. ***Caregiver Costs***
    - Family financial impacts, financial strain
    - Out-of-pocket costs (e.g., for medications, treatment, appointments, travel)
    - Opportunity costs (e.g., time lost from employment, school, leisure/household work, etc.)

conditions was also discussed. The result was a hierarchical structure for the planned survey with a core set of descriptive questions and more detailed questions on issues important to government (the target audience) to be answered by all caregivers. Specific issues could be addressed later by adding supplementary modules (e.g., concerns relevant to those caring for the elderly, for children and youth with mental health problems, or other care recipient populations).

B. Draft survey creation and testing.

Several desired characteristics of the final survey were identified by the Advisory and the project team including the need for the survey to be short, caregiver-driven, rigorous, and relevant across diverse caregiver experiences. In addition, building on existing validated tools was a priority although in some cases modifications were made (with developer permission) and questions developed to enhance relevance, clarity and feasibility. To this end, the conceptual framework was used to drive a scoping literature review to identify relevant items (Lin et al., 2018).

Draft survey questions were developed within each domain, selecting from existing scales identified by the scoping literature review where possible and creating new questions for identified gaps. In addition, some items from the 2012 General Social Survey on Caregiving and Care Receiving conducted by Statistics Canada (2006) were added to allow comparison between the pilot respondents and the Ontario caregiver population (Sinha, 2013).

The draft survey was tested in three ways. First, it was reviewed by the main and research Advisories for content and coverage. Second, the main Advisory and the project team members completed the survey as if they were respondents and reported on their experiences. Feedback from these two methods was used to make some initial modifications.

Third, the clarity and comprehensibility of the modified draft was evaluated via cognitive testing (Jansen & Hak, 2005; Presser et al., 2004; Willis, 2005). Thirty caregivers, recruited by word-of-mouth through the Advisory, completed the survey either face-to-face or via telephone conversation with an interviewer. Two cognitive interviewing techniques were used: thinking aloud and verbal probing. The interviewer asked the participant to complete the questionnaire while reading and thinking aloud, meanwhile noting the participant's verbal (deliberations about the questions) and nonverbal (marking answers, skipping questions, hesitating etc.) behaviours. This was followed by semi-structured verbal probing by the interviewer both concurrently (i.e., as questions or sections of questions were being answered) and retrospectively upon survey completion. The probes explored participants' comprehension or interpretation of terms as well as their certainty regarding their answer. Questions about the survey's length, layout, and format were also asked.

The cognitive testing was conducted in three waves. Concerns raised by the first 10 caregivers were incorporated into a revised survey which then was tested by the second set of caregivers whose concerns, in turn, were addressed by another revision that was tested by the last set of caregivers.

These processes led to several significant revisions of the survey (and the underlying framework). Complete scales were deleted; new questions were added; and existing questions were modified to align more closely with the critical domains, shorten the survey, and improve clarity for the pilot participants. The most common revisions involved simplifying questions, particularly those that made complex cognitive demands. For example, an early draft asked caregivers to report on up to three care receivers because of our desire to capture the experiences of caregivers supporting multiple individuals. Respondents found this confusing, and the research team, upon reflection, realized that this information would be difficult to analyze, interpret and communicate in a clear fashion. Consequently, the final survey focused on the person who the caregiver self-identified as the one to whom he or she had devoted the most energy and resources to in the past 12 months.

Another significant revision involved questions that seemed clear from a research or policy perspective but, upon testing, were completely opaque to caregivers. The most notable example was the service utilization section. This was originally built on an existing instrument that inquired about whether or not a list of 15 services was used, which services were needed but not used, and (as requested by our target audience) how they were funded. Cognitive testing participants found these questions repetitive and confusing. They were not always sure what the different services were or how they were funded. This section was completely revamped and tested in the third phase of cognitive testing to ascertain whether the revised concepts and wording were more meaningful from the caregiver perspective. As a result, the final survey assessed only three major categories of services for the caregiver (respite, mental health, and education/support services) and six for the care recipient (services to help the care recipient stay in his/her home; long-term or residential care; health care; recreational and support services; system navigation services, and services to help the care recipient to enter or stay in school). The funding questions were shortened and moved to the economic section where caregivers were asked if they had any out-of-pocket expenses that were not reimbursed for specific expenditure categories (e.g., travel related to their caregiving responsibilities) plus an cost estimate of these expenses that they had incurred over the past year).

Formatting revisions resulting from this process included improving the online visuals, font size, and colours so that the response choices were clearer and the respondent did not have to scroll down to a second screen.

Throughout these revisions, the project team were keenly aware of the desire, expressed by caregiver Advisory members, to create a short and therefore less burdensome survey. The changes described above eventually resulted in a 50-percent decrease in time (from an average of 90 minutes to 43 minutes for the pilot). However, while caregiver Advisory members agreed that a shorter length was important, they simultaneously wanted to add items or expand existing questions to be more in-depth. Their response, when asked about this apparent contradiction, was that if meaningful questions were asked, caregivers would take the time to answer them.

C. Pilot-testing.

Content (Table 3). Pilot test respondents were asked to provide basic descriptive information (e.g., demographics, their total number of caregiving hours and care recipients, self-rated health). Those providing care to more than one person were asked to identify the individual to whom they devoted the most time and then to answer some basic questions about this 'main' care recipient. To allow comparability of the pilot sample to the larger population of Canadian caregivers, many of these descriptive questions were based, either directly or in slightly modified form from the Statistics Canada General Social Survey, cycle 26 (2006).

The domains of Caregiving Work Demands and Work Impact were assessed using two established instruments (the Oberst Caregiving Burden Scale and the Bakas Caregiving Outcomes Scales – (Bakas, et al., 2004; 2006) plus items drawn from the Work/School Interference Scale (Carlson & Frone, 2003).

The domain of Caregiving Resources/Supports/Barriers was assessed using a combination of existing questions from the GSS (particularly, the questions covering financial supports and hardships) and new questions developed by the project team and vetted by the Advisory to address the significant concerns raised during the cognitive testing.

Three open-ended questions were added at the end of the structured portion of the pilot survey. These inquired about the most important things that helped keep the caregiver going, the three most important messages (negative or positive) that they wanted to tell government and service agencies about caregiving, and any remaining subjects that they would like to have seen covered.

The pilot also included feedback items regarding how the respondents found out about the survey, how close they came to stopping the survey early, how relevant the questions were to their own caregiving experience, and their assessment of how user-friendly they found the on-screen format. As an acknowledgement of their contribution, they were given the opportunity to choose a caregiver organization to receive a $5.00 honorarium from the research team.

Recruitment and data collection. Respondents were recruited using a snowball method in which Advisory members advertised the pilot to their membership and provided a hyperlink to the Pilot on Survey Monkey. A recruitment email was also sent to the 30 caregivers who participated in the cognitive testing phase of the project, as well as to approximately 50 individuals from 33 organizations representing various advocacy and community organizations in Ontario. Individuals accessing this link were presented with a description of the purpose and rationale of the survey as well as information to ensure that they provided informed consent for their results to be analyzed and reported if they decided to proceed.

Data were collected between July 22 and October 9, 2016. 624 individuals opened the survey among whom 495 consented to the pilot. The actual number who completed the survey was 302 (61% of those who consented). Their average completion time was 43 minutes.

TABLE 3: PILOT SURVEY CONTENT

Domain	Descriptive Information	Caregiving Work Demands • Type • Time • Difficulty	Caregiving Work Impact • On Work • On Family • On Self	Caregiving Resources/ Supports/Barriers
Survey items	**CAREGIVER** Sociodemographics* Self-rated health* Hrs/wk caregiving* # care recipients Employment status Total household Income **MAIN CARE RECEIVER** Sociodemographics* Main condition*	[1]Oberst Caregiving Burden Scale (Bakas, et al., 2004)	[2]Bakas Caregiving Outcomes Scale (Bakas, et al., 2006) [3]Work/School Interference Scale items (Carlson, et al., 2003)	Services & supports (caregiver, care recipient) *** Unmet needs Barriers [4]Employer Support for Caregiving** Receipt of caregiver-related federal tax credits* [5]Out-of-pocket expenses related to caregiving** [5]Financial barriers/supports**

*	= GSS questions
**	= modified and/or expanded GSS questions
***	= newly created content by project team

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[1] Permission to use the Oberst Caregiving Burden Scale provided by M Piotrowski, *American Association of Neuroscience Nurses*, personal communication, August 13, 2014.

[2] Permission to use the Bakas Caregiving Outcomes Scale provided by T. Bakas, personal communication, July 16, 2014

[3] Permission to use the Work/School Interference Scale item provided by D.S., Carlson, personal communication, May 14, 2014.

[4] GSS asks series of questions about flexibility in the workplace. In the GSS, the question is open-ended. We included a Likert scale. Personal communication, T. Volpe, June 25, 2019

[5] Janet Fast sent us the OOP expense module from Cycle 26 GSS with a couple of her suggestions for more detail. She also strongly recommended adding the Cycle 26 GSS financial hardship module. Personal communication, T. Volpe, June 25, 2019.

II. DESCRIPTIVE RESULTS RELATED TO THE PILOT

A. Recruitment

How did you find out about the survey?

– Org. website/newsletter	39%
– Org. email list	20%
– Word of mouth	16%
– UofT/HSPRN	4%
– Poster/Flyer	3%
– Other *(e.g. an organization, Twitter, Facebook, support group, workplace, internet search, etc.)*	23%

B. Relevance and User-friendliness

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%

C. Survey Burden

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	0.09%

D. Pilot sample representativeness

Characteristic	PILOT	ONTARIO GSS
% Female	81.5	53.7
Marital status		
% single	11.6	27
% widowed/divorced/separated	18.8	8.5
% Excellent health (self-rated)	9.6	21.8

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IV. Appendix A: Project files consulted for this report

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CAMH Acute care pgm (April 2018)
Results (1/8/2015)
Final report
Systematic review methodology (Feb 21 2014)
New files for Bank