MEASURING THE FAMILY/FRIEND CAREGIVER EXPERIENCE IN ONTARIO: PILOT STUDY RESULTS (WORKING PAPER SERIES)

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CONTEXT

Family and friend caregivers are critical to Canada's health care system, contributing an estimated economic value of $25 billion annually. The impact of this contribution is both personal and societal. Results from the 2012 General Social Survey on Caregiving and Care Receiving (GSS Caregiving) reveal that 28% of caregivers have young children living at home; 27% provide care for more than one person; and 44% provide care during their peak earning years. Integrated policies are needed to support this valuable resource but systematic information from caregivers to inform policy is lacking.

OBJECTIVES

The objective of this study was to develop and pilot test an online survey to collect systematic and relevant feedback from diverse Ontario caregivers.

METHODS

An integrated knowledge exchange process guided the study, with extensive involvement of an interdisciplinary Knowledge User Advisory, comprised of representatives from government, family caregivers, service providers, caregiver organizations, and researchers. The Advisory guided key study decisions and provided input on the following: (1) Government as the primary target audience; (2) designing of the general survey that is relevant to all family/friend caregivers; (3) inclusion of short modules to address specific illnesses and conditions to supplement the general survey; (4) the identification of five domains: caregiver 'work' demands, 'work' impacts, resources/supports, attitudes and culture, and uncertainties; (5) pilot-testing in 3 phases: expert review and initial testing by Advisory members, recruitment of 30 caregivers for cognitive face-to-face interviews and survey revisions, and recruitment of 300 Ontario caregivers for online testing and final survey revisions. Survey items were selected from existing validated tools or developed to address identified gaps. Some items from the GSS Caregiving survey were added to allow comparison.

FINDINGS

Caregivers who completed the online survey indicated that it was both feasible and user-friendly. The majority of caregivers who started the survey (61%) completed it, and 90% of those took the time to provide lengthy responses to the last three qualitative questions. Tasks identified by caregivers as the most time consuming and most difficult to perform included emotional support (68.5%), monitoring symptoms (44.0%) and managing behaviour (40.7%). The most commonly used service by caregivers was "education and support services" (49.0%), while "respite" (28.5%) was the most needed but unused. The service most frequently used by care receivers was "heath and other therapies" (64.2%), with "system navigation" (24.5%) identified by caregivers as the most needed but unused service. The sample differed in a number of ways from provincial caregivers based on the Ontario General Social Survey population, such as the caregiver's age and caregiving time, as well as care receivers' main health problems.

CONCLUSIONS

Results from this Ontario pilot reveal much vulnerability faced by caregivers, revealing two overall themes as particularly significant: Emotional & Financial factors, and System Access & Navigation barriers. It was also evident that the Family/Friend Caregiver Survey can collect meaningful information in an acceptable and accessible manner. The pilot results have been presented to external stakeholders at the local, provincial, and federal levels, for further development of strategies. It will be important to increase caregiver and care receiver literacy for basic caregiving skills as well as awareness of health and financial support services. In addition, system readiness and response should be improved to address caregiver needs as part of the circle of care.

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