

Improving Care and Support for Unpaid Caregivers in Ontario: Findings from a Citizen Panel

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Michael G. Wilson, PhD

Assistant Director, McMaster Health Forum

Assistant Professor, McMaster University



Overview (and acknowledgements)

- Citizen panels
- Our approach for convening the panel
- Key findings from the **citizen brief**
- Key findings from the **citizen panel**

Co-authors: FP Gauvin, Jenny Ploeg and John Lavis

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Citizen Panels

- Each citizen panel brings together a group of 10 to 14 citizens for a one-day, off-the-record, dialogue that provides them with the opportunity to:
 - bring their own views and experiences to bear on an issue;
 - learn from the evidence and from others' views and experiences; and
 - share their newly informed views about the issue and how to address it.



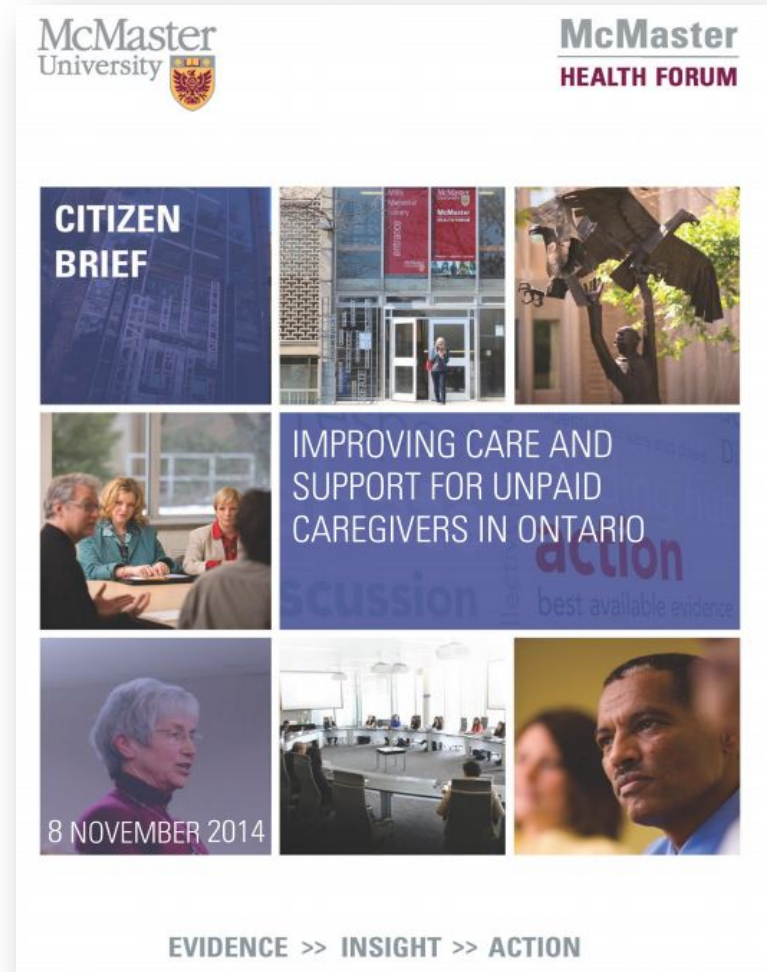
Our Approach (1)

- Participants were recruited using explicit criteria from the AskingCanadians™ panel
- We aimed to ensure fair representation among the diversity of citizens likely to be affected by the problem:
 - 3-4 current or recent unpaid caregivers who provided care to an older adult living in the community with relatively stable needs
 - 3-4 current or recent unpaid caregivers who provided care to an older adult living in the community with increasing needs (e.g., dementia)
 - 3-4 current or recent unpaid caregivers who provided care to an older adult living in a healthcare facility (e.g., nursing home or long-term care facility)
 - 3-4 current or recent unpaid caregivers who provided care to an older adult with palliative care needs
 - Approx. 7 men and 7 women
- Secondary criteria: SES, Age, geographical region and ethnocultural background



Our Approach (2)

- Exclusion criteria:
 - Current or past employees of healthcare organizations or healthcare professionals
 - Elected officials
 - Individuals working for market research, advertising, public media or public relations firms
- Two weeks before the panel, all participants were sent a “citizen brief” the described (in lay language), the problem, three options for addressing it and implementation considerations



Key Findings – Citizen Brief (1)

- Providing care and support for unpaid caregivers in Ontario is challenging because:
 - ❑ An aging and diverse population has significant need for unpaid caregivers;
 - ❑ Unpaid caregivers aren't always available, are getting older, and can face demanding roles;
 - ❑ Existing programs and services often don't fully meet the values, needs and preferences of unpaid caregivers; and
 - ❑ Health-system arrangements (e.g., limited availability of financial aid) complicate the situation.



Key Findings – Citizen Brief (2)

- **Option 1 - Addressing the economic security of unpaid caregivers**
 - This could include:
 - flexible employment arrangements;
 - government-provided income supports; and
 - supportive housing both for older adults and their caregivers to allow them to continue living at home or in the community
 - **Key findings:** Improving housing conditions can help to improve health but there is a lack of evidence about flexible employment models or income supports



Key Findings – Citizen Brief (3)

■ Option 2 - Engaging and supporting unpaid caregivers

□ This could include:

- opportunities for caregivers to engage in decision-making about how care and support is organized;
- handbooks or toolkits to help identify full range of services available; and
- education and supports to reduce burden and help them cope/build resilience

□ **Key findings:** A range of interventions were found to be beneficial for caregivers, including:

- engaging caregivers in decision-making about how care and support is organized;
- providing materials that help caregivers or the individuals they provide care to make decisions about their care; and
- providing education/training to caregivers



Key Findings – Citizen Brief (4)

- **Option 3 - Providing tailored training and supports to unpaid caregivers providing care to older adults with complex conditions**
 - This could include:
 - programs that provide education and support that is tailored to caregivers of people with complex conditions; and
 - system navigators or coordinators that help to identify and make connections to needed care and support.
 - **Key findings**
 - Teaching coping strategies and communication skills helps to improve caregivers' psychological health, communication skills, knowledge and quality of life of people with dementia
 - Incorporating a mix of educational and supportive interventions in one package for caregivers helps to reduce their burden and stress



Participant Characteristics (n=10)

- **Regions covered:** Hamilton Niagara Haldimand Brant (n=8); North East (n=1); and North Simcoe Muskoka (n=1)
- **Age:** 25-44 (10%), 45-64 (30%), 65 and older (60%)
- **Gender:** Men (50%) and women (50%)
- **Education:**
 - 40% completed high school;
 - 10% completed community college;
 - 40% completed a bachelor's degree/post-graduate training or professional degree; and
 - 10% completed postgraduate training



Participant Characteristics (n=10) (2)

■ Employment status:

- ❑ 10% working full-time
- ❑ 20% working part-time
- ❑ 50% retired
- ❑ 10% homemakers
- ❑ 20% disabled (one participant identified their work status as both homemaker and disabled)

■ Income level

- ❑ 10% earned less than \$20,000
- ❑ 10% between \$20,000 and \$40,000
- ❑ 30% between \$40,000 and \$60,000
- ❑ 10% between \$60,000 and \$80,000
- ❑ 10% more than \$80,000
- ❑ 30% preferred not to disclose their income.



Key Findings – Citizen Panel (1)

- **Four challenges were consistently raised:**
 - 1) Caregivers' heavy burden can cause anxiety about its impact on their own and other's health
 - 2) Financial and employment impacts of caregiving are substantial
 - 3) Many caregivers don't know about available services or how to access them
 - “That's the rub - if you don't know about it, how are you going to access it.”
 - “Everything is online because they assume you're going online even though many older people don't have a computer, let alone internet.”
 - 4) Caregivers' roles are not fully recognized or supported



Key Findings – Citizen Panel (3)

- Several values-related themes emerged during the discussion about the options, with two emerging with some consistency:
 1. **competence**
 - educating and training unpaid caregivers to provide optimal care
 - also clearly defining the scope of duties of unpaid caregivers versus other healthcare providers
 2. **empowerment**
 - supporting unpaid caregivers to become strong advocates for their loved ones and for themselves
 - equipping them with practical tools to manage the complex care needs of their loved ones



Key Findings – Citizen Panel (4)

- **Key values related to option 1 (addressing the economic security of unpaid caregivers)**
 - ❑ selflessness (e.g., need to address economic security but in a way that doesn't compromise this as a core value of caregiving);
 - ❑ inclusiveness (reach all those in need);
 - ❑ fairness (especially towards those most in need);
 - ❑ attuned to the needs of unpaid caregivers (e.g., flexible working arrangements);
 - ❑ Innovation (in terms of economic and fiscal measures); and
 - ❑ evidence-based (i.e., documenting the costs and benefits of different interventions, and building a business case).



Key Findings – Citizen Panel (5)

- **Key values related to option 2 (engaging and supporting unpaid caregivers)**
 - Competence (education/training to provide optimal care)
 - “I will cope better if I’m trained to better manage his care.”
 - empowerment (to become strong advocates for their loved ones and for themselves)
 - holistic care (providing care to both patients and their unpaid caregivers)
 - timeliness (of information – e.g., making printed or online toolkits easily accessible)



Key Findings – Citizen Panel (6)

- **Key values related to option 3 (providing tailored training and supports to unpaid caregivers providing care to older adults with complex conditions)**
 - ❑ compassion (most vulnerable group of caregivers –ensure they have access to all the resources they need);
 - ❑ collaboration (among caregivers, providers and organizations – need ICT, in-person supports and system navigators);
 - ❑ solidarity (trusting relationships)
 - ❑ competence (of unpaid caregivers to manage the complex care needs of their loved ones); and
 - ❑ empowerment (equipping caregivers with practical tools to manage the complex care needs of their loved ones).



Key Findings – Citizen Panel (7)

- **Barriers** to implementation identified:
 - 1) Sustainability of a universal and equitable financial supports
 - 2) New tax measure likely face resistance from taxpayers
 - 3) Deteriorating community cohesiveness
 - 4) Too many competing demands to meaningfully engage in decision-making processes
 - 5) Lack of access to family doctors

- **Facilitators** to implementation identified:
 - 1) Advocacy activities targeting health system-leaders and elected officials
 - 2) Activities to promote public dialogue and support experiential learning to build sensitivity to the needs of older adults and their unpaid caregivers.

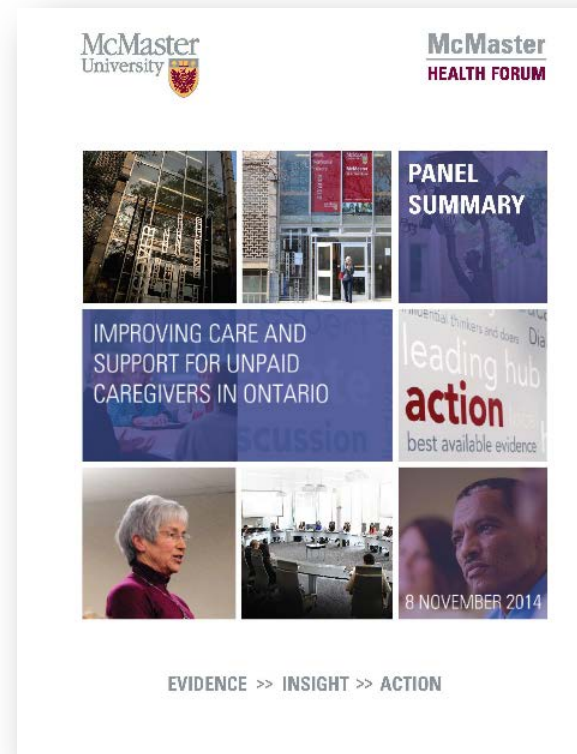


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Citizen brief



Panel summary



Contact: **Mike Wilson** (wilsom2@mcmaster.ca)



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McMaster Health Forum
McMaster University
1280 Main St. West, MML-417
Hamilton, ON Canada L8S 4L6
Tel: +1.905.525.9140 x 22121
Email: mhf@mcmaster.ca

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