

Quick Scan of Caregiver Research and Policy Documents

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Introduction

Canada's population is changing as the proportion of older adults continues to grow. The number of older adults in Canada is set to nearly double by 2030, at which point a critical mass of older adults will reach the age of 65 (Statistics Canada, 2015; Ontario Seniors Secretariat, 2013). By 2041, it is projected that 25% of Ontario's population will be 65 years or older, which is a significant increase from 16.4% in 2016 (Government of Ontario, 2017). Both the federal and provincial governments have taken action in response to Canada's aging population. The Government of Canada developed a national strategy to help understand and meet the growing needs of this demographic, which focuses on four pillars: 1) Independent, productive and engaged citizens; 2) Healthy and active lives; 3) Care closer to home; and 4) Support for caregivers (National Seniors Strategy for Canadians, 2016). In 2013, Ontario developed and began to implement Aging with Confidence: Ontario's Action Plan For Seniors. Since that time, community and home care funding has increased by \$250 million per year, allowing for an increase in nursing and personal support services, physical and speech therapy, and respite services for caregivers (Government of Ontario, 2017). The Action Plan recognizes the need to improve assistance for formal and informal caregivers of older adults through the launch of a provincewide organization that will provide caregiver resources and supports. Statistics Canada (2013) estimates that eight million Canadians over the age of 15 are serving as informal caregivers to family or friends (Statistics Canada, 2013), which is a huge cohort of people that will be able to benefit from such services.

As our population continues to age, there will undoubtedly be a growing need for the provision of caregiving. Often when people receive informal care at home it is from family members and friends, which can lead to physical, emotional and financial burden for the caregiver. It is estimated that between 35-60% of Canada's workforce holds unpaid caregiving responsibilities (Government of Canada, 2015). According to the Canadian Caregiver Coalition (2015), 15% of working caregivers reduce their work hours, 40% miss days of work, 26% take a leave of absence, 10% turn down job opportunities, and 6% eventually quit their jobs. It is estimated that the cost to the Canadian economy from lost productivity due to caregiving responsibilities is \$1.3 billion per year (Canadian Caregiver Coalition, 2015). In addition to economic losses, 19% further report that their physical and emotional health suffers as well.

Caregiving is complex and comprises both formal services and informal care. Given the critical importance of older adult caregivers now and into the future, a preliminary set of resources has been compiled to help paint a picture of where caregiving currently stands. The purpose of this Quick Scan is to provide researchers with important background information that may assist in identifying gaps and developing research directions relative to caregiving. An effort has been made to identify published literature and

other significant documents that focus on caregiving. Using academic databases such as Google scholar, the Gerontologist, and the Journals of Gerontology, as well as Government websites, the main entry point of the search was the concept of caregiver burden.

The Quick Scan is organized into nine sections. These sections include: community care settings, long term care, caregivers in the workplace, Indigeneity, surveys and reports, caregiver support services in North Eastern Ontario, laws and rights in Canada, caregiver strategies, and gender differences. Each section identifies the name of the document and the authors. Documents included in the Quick Scan were published in 2014 or later. The initial search led to the identification of other important concepts related to caregiving, such as gender differences. Documents focusing on gender that were included in the Quick Scan were published in 2005 or later. Throughout the Quick Scan, French language resources are identified in green text and reviews highlighted in yellow. Given that this is a Quick Scan, this resource is not comprehensive but rather a brief look at a number of topic areas related to caregiving. The final result is a compilation of caregiver literature and policy documents.

Community Care Settings

Title	Author(s)
The Association between caregiver-care recipient relationship and caregiver burden and depressive symptoms among community dwelling older adults with Dementia (2016)	Smolcic, E., Mavandadi, S., Streim, J., Oslin, D.
A Canadian qualitative study exploring the diversity of the experience of family caregivers of older adults with multiple chronic conditions using a social location perspective (2016)	Williams, A., Sethi, B., Duggleby, W., Ploeg, J., Markle-Reid, M., Peacock, S., Ghosh, S.
Caregiver burden: A clinical review (2014)	Adelman, R., Tmanova, L., Delgado, D.
Subjective burden among spousal and adult-child informal caregivers of older adults: results from a longitudinal cohort study (2016)	Oldenkamp, M., Hagedoorn, M., Slaets, J., Stolk, R., Wittek, R., Smidt, N.
Visual arts education improves self-esteem for persons with dementia and reduces caregiver burden: A randomized controlled trial (2018)	Richards, A., Tietyen, A., Jicha, G.
Assistive technologies in reducing caregiver burden among informal caregivers of older adults: A systematic review (2015)	Marasinghe, K.
Dimensions of caregiver burden in dementia: Impact of demographic, mood, and care recipient variables (2014)	Springate, B., Tremont, G.
Rural caregivers for a family member with dementia: Models of burden and distress differ for women and men (2014)	Stewart, N., Morgan, D., Karunanayake, C.
Caregiver burden for informal caregivers of patients with dementia: A systematic review (2015)	Chiao, C.Y., Wu, H.S., Hsiao, C.Y.
Caregiver burden characterization in patients with Alzheimer's disease or vascular dementia (2014)	D'Onofrio, G., et al.
The relationship of specific items on the neuropsychiatric inventory to caregiver burden in dementia: A systematic review (2017)	Terum, T., Andersen, J., Rongve, A., Aarsland, D., Svendsboe, E.

A national profile of family and unpaid caregivers who assist older adults with health care activities (2016)	Wolff, J., Spillman, B., Freedman, V., et al.
Comparative analysis of informal caregiver burden in advanced cancer, dementia, and acquired brain injury (2015)	Harding, R., Gao, W., Jackson, D., Pearson, C., Murray, J., Higginson, I.
Informal caregiving and its impact on health: a reappraisal from population-based studies (2015)	Roth, D., Fredman, L., Haley, W.
Burden in caregivers of long-term stroke survivors: Prevalence and determinants at 6 months and 5 years after stroke (2015)	Jaracz, K., Grabowska-Fudala, B., Gorna, K., Jaracz, J., Moczko, J., Kozubski, W.
Informal care and caregivers health (2014)	Do, Y., Norton, E., Stearns, S., Van Houtven, C.
The perceived burden of informal caregivers of independently living elderly and their ideas about possible solutions. A mixed methods approach (2016)	Peetoom, K., Lexis, M., Joore, M., Dirksen, C., Witte, L.
Caregiver burnout: The impact of adult day programs on caregivers (2015)	Zhang, Z., Joyce, L.
Projected costs of informal caregiving for cardiovascular disease (2018)	Dunbar, S., Khavjou, O., Bakas, T., Hunt, G., Kirch, R., Leib, A., Morrison, R.S., Poehler, D., Roger, V., Whitsel, L.
The effects of mindfulness-based stress reduction program on the mental health of family caregivers: a randomized controlled trial (2014)	Hou, R., Wong, S., Hung, A., Lo, H., Chan, P., Lo, C., Kwok, T., Tang, W., Mak, W., Mercer, S., Ma, S.
Aging in Place: Selecting and supporting caregivers of the older adult (2016)	Fernandez, J., Reckrey, J., Lindquist, L.
Differing Perspectives on older adult caregiving (2014)	Brank, E., Wylie, L.
What behavioral and psychological symptoms of dementia affect caregiver burnout? (2017)	Hiyoshi-Taniguchi, K., Becker, C., Kinoshita, A.
Problems experienced by informal caregivers with older care recipients with and without cognitive impairment (2016)	Van Bruggen, S., Gussekloo, J., Bode, C., Touwen, D., Engberts, D., Blom, J.

The relationship between the spiritual attitude of the family caregivers of older patients with stroke and their burden (2017)	Chafjiri, R., Navabi, N., Shamsalinia, A., Ghaffari, F.
Transition experiences of caregivers of older adults with dementia and multiple chronic conditions: An interpretive description (2016)	Lam, A.
Caregiver burnout: Application of dialectical behavioural therapy (2017)	Toledo, T., Akinyemi, E.
The role of compassion, suffering and intrusive thoughts in dementia caregiver depression (2016)	Schulz, R., Savla, J., Czaja, S., Monin, J.
Caring for disabled older adults with musculoskeletal conditions: A transactional model of caregiver burden, coping strategies, and depressive symptoms (2017)	Lu, N., Liu, J., Wang, F., Lou, V.,
Caregiver burden, health status, and learned resourcefulness of older caregivers (2014)	Chen, M., Chen, K., Chu, T.
Decision-making experiences of family members of older adults with moderate dementia towards community and residential care home services: a grounded theory study protocol (2017)	Low, L., Lam, L., Fan, K.
Concept analysis: Alzheimer's caregiver stress (2014)	Llanque, S., Savage, L., Rosenburg, N., Caserta, M.
The effectiveness of mindfulness - and acceptance - Based interventions for informal caregivers of people with dementia: A meta-analysis (2018)	Collins, R., Kishita, N.
Burden and benefits of caregiving: A latent class analysis (2018)	Pristavec, T.
Cognitive behavioural therapy for depression, anxiety, and stress caregivers of dementia patients: A systematic review and meta-analysis (2018)	Hopkinson, M., Reavell, J., Lane, D., Mallikarjun, P.,
Understanding and measuring the wellbeing of carers of people with dementia (2018)	Cunningham, N., Cunningham, T., Roberston, J.
The relation between multiple informal caregiving roles and subjective physical and mental health status among older adults: Do racial/ethnic differences exist? (2018)	Kim, G., Allen, R., Wang, S., Park, S., Perkins, E., Parmelee, P.

Falls and hospitalizations among persons with dementia and associated caregiver emotional difficulties (2018)	Leggett, A., Polenick, C., Maust, D., Kales, H.
Predictors of secondary role strains among spousal caregivers of older adults with functional disability (2018)	Polenick, C., DePascale, N.
Unmet expectations in Alzheimer's family caregiving: Interactional characteristics associated with perceived under-contribution (2017)	Ashida, S., Marcum, C., Koehly, L.
Improving policies for caregiver respite services (2015)	Rose, M., Noelker, L., Kagan, J.
Spouse's subjective socioeconomic status as a predictor of older adults' mental health (2016)	Zhang, F., Fung, H., Kwok, T.,
Carers as system navigators: Exploring sources, processes and outcomes of structural burden (2017)	Funk, L., Dansereau, L., Novek, S.
Relationship between caregiving and mortality after accounting for time-varying caregiver status and addressing the healthy caregiver hypothesis (2015)	Fredman, L., Lyons, J., Cauley, J., Hochberg, M., Applebaum, K.
Effect of transitions in caregiving status and intensity on perceived stress among 992 female caregivers and noncaregivers (2015)	Lyons, J., Cauley, J., Fredman, L.
Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: Systematic review and meta-analysis of randomised controlled trials (2014)	Jensen, M., Agbata, I., Canavan, M., McCarthy, G.
Burden of care, social support, and sense of coherence in elderly caregivers living with individuals with symptoms of dementia (2014)	Stensletten, K., et al.
A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? (2016)	Dam, A., de Vugt, M., Klinkenberg, I., Verhey, F., Van Boxtel, M.
Information, support and training for informal caregivers of people with dementia (2015)	Gonzalez-Fraile, E., Sola, I., Ballesteros, J., Rueda, J., Martinez, G., Santos, B.

The effectiveness of interventions in supporting self-management of informal caregivers of people with dementia; a systematic meta review (2015)	Huis, J., Verkaik, R., Mistiaen, P.
Évaluation du ressenti des aidants, filles et fils de personnes âgées dépendantes atteintes de démence (2016)	Vallée, A., Verdier-Parent, A., Vallée, J-N., Hervé, C.
A Review of Ethnicity, Culture, and Acculturation Among Asian Caregivers of Older Adults (2015)	Miyawaki, C.
Cost of Family Caregiving: Short and Long-term Financial Consequences of Canadian Caregiver (2017)	Li, L., Lee, Y.
What Family Caregivers Learn when Providing Care at the End of Life: A Qualitative Secondary Analysis of Multiple Datasets (2014)	Funk, L., Stajduhar, K., Outcalt, L.
Balancing needs as a family caregiver in Huntington's Disease: A qualitative Interview Study (2014)	Rothing, M., Malterud, K., Frich, J.
Family caregiving for Immigrants Seniors Living with Health Disease and Stroke: Chinese Canadian Perspective (2015)	Liu, L., McDaniel, S.
The Costs of Caring: Caregiver Strain and Work-Family Conflict Among Canadian Workers (2014)	Glavin, P., Peters, A.
Factors That Influence Self-Reported Health Changes with Caregiving (2016)	Danilovich, M., Xiang, X., Pinto, D.
Economic Impact of Family Caregiving (2016)	Schulz, R., Eden, J.
Do Spouse Caregivers of Young and Older Persons with Dementia have Different Needs? A Comparative Study (2017)	Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M.J., Antoine, P.
'This is Killing me Inside': The Impact of having a parent with young-onset dementia (2017)	Aslett, H., Huws, J., Woods, R.

Long-Term Care Settings

Title	Author(s)
Experiences of informal caregivers of older adults transitioned from nursing homes to the community through the money follows the person demonstration (2016)	Kristof, L., Fortinsky, R., Kellett, K., Porter, M., Robison, J.
Experience of burden in carers of people with dementia on the margins of long term care (2016)	Sutcliffe, C., Giebel, C., Jolley, D., Challis, D.
Effectiveness of psychosocial interventions on the psychological health and wellbeing of family carers of people with dementia following residential care placement: A systematic review protocol (2017)	Brooks, D., Fielding, E., Beattie, E., Edwards, H., Hines, S.

Caregivers in the Workplace

Title	Author(s)
More Caregiving, Less Working: Caregiving Roles and Gender Difference (2013)	Lee, Y., Tang, F.,
Caregiving Intensity and Retirement Status in Canada (2014)	Jacobs, J., Laporte, A., Van Houtven, C., Coyte, P.
Availability of caregiver-friendly workplace policies (CFWPs): An International Scoping Review (2016)	Ireson, R., Sethi, B., Williams, A.
Supporting Caregiver Employees: Manager's Perspective in Canada (2016)	Sethi, B., Williams, A., Ireson, R.

Indigeneity

Title	Author(s)
Dementia Caregiving Among Indigenous Communities in Ontario, Canada (2015)	Jacklin, K., Pace, J., Warry, W.
A systematic review of indigenous caregiver functioning and interventions (2018)	Hokanson, L., Quinn, M., Schuz, N., De Salas, K., Scott, J.
Informal Dementia Caregiving Among Indigenous Communities in Ontario, Canada (2015)	Jacklin, K., Pace, JE., Warry, W.
Caregiving For Elders In First Nations Communities: Social System Perspective On Barriers And Challenges (2012)	Habjan, S., Prince, H., Kelley, ML.

Surveys & Reports

Title	Author(s)/Organization
Measuring the family/friend caregiver experience in Ontario: A Pilot Study (2016)	Completed by CAMH, sponsored by the Ontario Ministry of Health and Long Term Care by Lin, E., Durbin, J., Volpe, T., Selick, A.
The caregiver voice Survey: A Pilot study surveying bereaved caregivers to measure the caregiver and patient experience at end of life (2016)	The Journal of Palliative Medicine, By Hsien, S., et al.
Accuracy of Caregiver Proxy Reports of Home Care service Use (2016)	Journal of Applied Gerontology By Chappell, N., Kadlec, H.
Report: Making Privacy and Consent Rules Work for Family Caregivers (2017)	The change foundation By Dykeman, M., et al.

Patients First: A proposal to strengthen Patient-Centred Health Care in Ontario (2015)	Ministry of health and long term care
The Reality of Caring: Distress Among the caregivers of home care patients (2016)	Health Quality Ontario
Future of Canadian Seniors: A status quo forecast (2015)	The Conference Board of Canada By Stonebridge, C., Hermus, G., Edenhoffer, K.
Caregiving for Older Adults with Disabilities (2015)	IRPP Study By Fast, J.
Improving care and support for unpaid caregivers in Ontario (2014)	McMaster Health Forum
Policies in Support of Caregivers (2015)	Torjman, S.
Family Caregiving: What are the Consequences? (2015)	Turcotte, M.
Beyond Recognition - Caregiving & Human Rights in Canada: A Policy Brief (2015)	Canadian Caregiver Coalition

Caregiver Support Services in North Eastern Ontario

Agency	Support Service(s)
NE LHIN	Care for the Caregiver
Maison McCulloch Hospice (Sudbury)	Grief and Bereavement Discussion Group (offered in French)
Behavioural Supports Ontario (BSO)	Caregiver support, one-on-one support
Alzheimer Society Sudbury-Manitoulin & North Bay Districts	Caregiver support groups, one-on-one counselling Groupes de soutiens pour aidants, soutien individuel pour aidants (offered in French)
Metis Nation of Ontario (MNO)	One-on-one Counselling, group supports for caregivers, including family and friends

Hospice West Parry Sound	Bereavement support to family members, Bereavement Walking Group
Alzheimer Society Sault Ste Marie and Algoma District (East Algoma Satellite Office - Elliot Lake)	Support groups and programs for caregivers and families, Behaviour Support Facilitator offers caregiver support (<i>offered in French</i>)
Alzheimer Society Sault Ste Marie and Algoma District	Support groups and Programs for caregivers and families, Behaviour Support Facilitator offers caregiver support, Minds in Motion is a program that combines physical, cognitive, and social stimulation for individuals with dementia and their care partners (<i>offered in French</i>)
Alzheimer Society Sault Ste Marie and Algoma District (North Algoma Satellite office - Wawa)	Support groups and Programs for caregivers and families, Behaviour Support Facilitator offers caregiver support, Minds in Motion is a program that combines physical, cognitive, and social stimulation for individuals with dementia and their care partners (<i>offered in French</i>)
The Friends - Seniors Services Program - Parry Sound	Caregiver Support Group - helps maintain health and well-being of a caregiver caring for a loved one
The Friends - Seniors Services Program - Burk's Falls	Caregiver Support Group - helps maintain health and well-being of a caregiver caring for a loved one
Aging at Home - Hearst	Care for the Caregiver - One-on-one counselling and group supports for caregivers of people with dementia (<i>offered in French</i>)
Alzheimer Society Timmins Porcupine District	Caregiver support groups, individual supportive counselling - one-on-one counselling at home or in the office, education for caregivers, training sessions and workshops for caregivers (<i>offered in French</i>)
Share the Care Station	A model of care that has been introduced in the South West Region of Ontario in an effort to help local caregivers
Carers Canada	Engaging and listening to caregivers, enhance the quality of life for carers through synergistic partnerships and strategic advocacy, caregiver resources, caregiver strategies across Canada
Ontario Caregiver Coalition	The <i>mission</i> of OCC states: "The Ontario Caregiver Coalition is dedicated to recognizing the

	<p>importance of unpaid caregivers in Ontario by raising awareness of the value they add to the health care system, and by advocating for improved, fair access to needed supports.” OCC strives to be the ‘voice’ of caregivers in the province.</p> <p>Providing a caregiver allowance to alleviate the financial burden, advocate for caregivers, giving caregivers time off when they need it through the Leave to Help Families Act., caregiver resources are offered</p>
Elizz - All Things Caregiving	<p>Caregiver coach - one-on-one assistance for developing plans to manage the impacts of caregiving on the caregivers life,</p> <p>Group support - weekly online or telephone session to share stories, gain knowledge, and get support from other caregivers</p> <p>Webinars - one-time online learning sessions on various caregiving topics</p> <p>Counselling - one-on-one counselling for a caregiver needing care to manage negative emotions, such as stress, anxiety, conflict, guilt, or grief. Available online or by telephone.</p>
Caregiving Matters	<p>Older Caregivers Cafes - podcasts and/or workshops for caregivers to rejuvenate, get resources and support,</p> <p>ABC's of Golf for Family Caregivers - for women who are family caregivers to take a break and socialize with other caregivers</p>
Canadian Virtual Hospice	Forums for caregivers to connect with one another and get support online (offered in French)
Huddol	Chat and connect with experts and other caregivers, join care communities that focus on caregiver needs, provides resources to caregivers (offered in French)

Laws and Rights of Caregivers

Name	Origin	Level of Government
Family Caregiver Leave (2000) Congé Familial pour les aidants naturels (2000)	Employment Standards Act of Ontario, The Ministry of Labour	Government of Ontario

Personal Emergency Leave (2018) Congé d'urgence personnelle (2018)	Employment Standards Act of Ontario, The Ministry of Labour	Government of Ontario
Family Medical Leave (2000) Congé familial pour raison médicale (2000)	Employment Standards Act of Ontario, The Ministry of Labour	Government of Ontario
Canada Caregiver Credit (2018) Crédit Canadien pour Aidant Naturel (2017)	Non-Refundable Tax Credit	Government of Canada
Family Caregiver Day Act (2015) Jour des aidants naturels (2015)	Bill 138 (Gelinias, F.)	Government of Ontario
Service de Soins à Domicile et les Services Communautaires (Loi de 1994 sur les) L.O 1994, chap 26.	Recherche de Textes Législatifs	Government of Ontario

Caregiver Strategies

Title	Author(s)/Organization(s)
Mobilizing Action: Integrated Action Plan (2015)	Canadian Cancer Action Network, Canadian Homecare Association, Canadian Caregiver Coalition
A Canadian Carer Strategy (2013)	Carers Canada
Advancing Collective Priorities: A Canadian Carer Strategy (2017)	Canadian Cancer Action Network, Canadian Homecare Association, Canadian Caregiver Coalition
An evidence-informed national seniors strategy for Canada (2016)	Sinha, S.K., Griffin, B., Ringer, T., Reppas-Rindlisbacher, C., Stewart, E., Wong, I., Callan, S., Anderson, G. CIHR and National Institute on Ageing at Ryerson University

Gender Differences

Title	Author(s)
Understanding gendered expectations and exemptions experienced by male double-duty caregivers: A qualitative secondary analysis (2012)	Anjos, A., Ward-Griffin, C., Leipart, B.
The incomplete revolution: Theorizing gender when studying men who provide care to aging parents (2007)	Campbell, L., Carroll, M.
Formal Service Practitioners' views of Family Caregivers' Responsibilities and Difficulties (2006)	Guberman, N., Lavoie, J., Pepin, J., Lauzon, S., Montejo, M.
Gendered Stories of Parental Caregiving Among Siblings (2005)	Hequembourg, M., Brallier, S.
Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada (2012)	Lily, M., Robinson, C., Holtzman, S., Botorff, J.
The Experiences of sons caring for a parent with dementia (2013)	McDonnell, E., Ryan, A.
Men family caregivers' experience of non supportive interactions: Context and expectations (2009)	Neufeld, A., Kushner, K.