

CURRENT AND FUTURE CHALLENGES IN CAREGIVING

CONFERENCE PROGRAM



THURSDAY, NOVEMBER 10TH 2016 | 9 AM TO 5 PM
CONCORDIA UNIVERSITY, 1455 DE MAISONNEUVE BLVD. W. | ROOM HALL-767

Continuing education activity accredited by the OTSTCFQ (7 hrs)



Centre de recherche et d'expertise
en gérontologie sociale

Centre intégré
universitaire de santé
et de services sociaux
du Centre-Ouest-
de-l'Île-de-Montréal

Québec 

Conference program description



As part of the National Caregiver Week, the Concordia University Research Chair (CURC) in Aging and Public Policy and the Center for Research and Expertise in Social Gerontology (CREGÉS) of the Integrated Health and Social Services University Network for West-Central Montreal (West-Central Montreal Health) are organizing a thematic Conference on Caregiving, particularly on caregivers of older adults.

This event aims to raise awareness on caregiving issues and the implications for practice in health and social service organizations and the community sector. This will be a day of learning, exchanges, and networking where best practices, models, and intervention tools will be identified. It is aimed for practitioners, managers, community organizations, and the research community whose work touches older adults experiencing loss of autonomy and their caregivers.

Objectives



- ✓ Recognize and understand the needs of caregivers and the implications on the care of older adults with loss of autonomy.
- ✓ Exchange on best practices and new research to meet current and foreseeable needs of caregivers and the implications for their care receivers.
- ✓ Learn about the policies, procedures, and relevant standards for the practice of the profession in relation to caregivers.
- ✓ Learn about models, principles and techniques related to intervention with caregivers of older adults.
- ✓ To understand the cultural, political and social realities of caring for an aging population and the problems related to this environment.
- ✓ To comprehend the role and responsibilities of political partners, public, private and community networks in relation to caregivers of older adults.

Program Overview

8:30

REGISTRATION

9:00

WELCOMING REMARKS

- > Justin Powlowski – Interim Vice-President, Research and Graduate Studies, Concordia University
- > Spyridoula Xenocostas – Associate Director, Division of Social and Community Research, West-Central Montreal Health
- > Alan Maislin - President of the Board of Directors of West-Central Montreal Health

9:15

The Canadian Caregiving Policy Landscape

- > Patrik Marier – Professor, Political Science at Concordia University, Scientific Director of CREGÉS & CURC in Aging and Public Policy

9:40

PANEL #1 - Comparing Experiences on Caregiving in Canada, USA, and Quebec

- > Nadine Henningsen - Executive Director of CHCA & Signatory Partner of Carers Canada
- > Rajiv Mehta - Executive Director of Atlas of Caregiving
- > Christine Kabayiza - L'APPUI for Caregivers

10:45

BREAK

11:00

The Atlas of Caregiving Pilot Project

- > Rajiv Mehta - Executive Director of Atlas of Caregiving

11:45

LUNCH

13:30

PANEL #2 - What do human rights have to do with caregivers?

- > Nancy Guberman - Retired Professor, Social Work at Université du Québec à Montréal
- > Lucy Barylak – Social Gerontology Consultant, West-Central Montreal Health
- > Apostolia Petropoulos - Social worker & Coordinator of Caregiver Navigator Project, West-Central Montreal Health

14:30

BREAK

14:45

PANEL #3 - Latest research and practice methods

- > Mélanie Couture - Associate Professor, Psychology at Université de Sherbrooke & Researcher at CREGÉS
- > Pam Orzeck - Coordinator of the Caregiver Support Leading Practice at West-Central Montreal Health & Adjunct Professor, Social Work at McGill University and
- > Isabelle Van Pevenage - Researcher at CREGÉS & Associate Professor, Sociology at Université de Montréal
- > Robin Cohen – Professor, Oncology and Medicine at McGill University & Researcher at the Lady Davis Research Institute of the Jewish General Hospital

15:45

WRAP-UP ACTIVITY: Lessons learned and moving forward

16:45

CLOSING REMARKS

Detailed Program



8:30	REGISTRATION
9:00	WELCOMING REMARKS
9:15	The Canadian Caregiving Policy Landscape
	<ul style="list-style-type: none">> <i>Patrik Marier – Professor, Political Science at Concordia University, Scientific Director of CREGÉS & CURC in Aging and Public Policy</i> <p>This presentation features a broad overview of the policy landscape within which caregivers operate. Most studies emphasise the formal policies developed within health and social services agencies that target specifically caregivers. This presentation aims to broaden the discussion by analysing other policies affecting them. Caregivers continue to fulfill other societal roles, each with their own set of expectations. As a result of coordination issues across public agencies and departments, caregivers frequently face contradictory messages from public authorities, which are likely to become more prevalent in an aging society.</p>
9:30	Question and exchange period
9:40	PANEL #1 - Comparing Experiences on Caregiving in Canada, USA, and Quebec
	<ul style="list-style-type: none">> <i>Nadine Henningsen - Executive Director of CHCA & Signatory Partner of Carers Canada</i> <p>Caregiving across Canada - This presentation will provide a summary of the policy, service delivery, and organizational advocacy climate of Caregivers in Canada. It will then illustrate the mandate and strategic plan of Carer's Canada. The Caregiver Strategy or Manifesto articulates the universal priorities that caregivers and caregiver support groups have identified. Launched in 2008 and updated in 2014, the Manifesto provides a foundation to facilitate a collaborative action plan and ensure carers have a voice in policy, programming and services.</p> <ul style="list-style-type: none">> <i>Rajiv Mehta - Executive Director of Atlas of Caregiving</i> <p>Caregiving across the USA - This will be a presentation of stories of caregiving in the USA, drawn from a wide variety of contexts — families participating in research on improving disease-specific care; enthusiasts in the self-tracking community; social-workers learning a new care-assessment tool; and academic-community collaborations for health improvement — that highlight current innovations and challenges.</p> <ul style="list-style-type: none">> <i>Christine Kabayiza - L'APPUI for Caregivers</i> <p>Caregiving across Quebec - This presentation will provide a portrait of caregivers in Quebec. It will outline the main issues faced by caregivers in Quebec related to security and judicial questions, housing, end-of-life planning and care, transportation, home-care services, nutritional support, respite care and psychosocial support. It will then share available programs, services, and resources for Quebec caregivers.</p>
10:30	Question and exchange period
10:45	BREAK

11:00 The Atlas of Caregiving Pilot Project

- > *Rajiv Mehta - Executive Director of Atlas of Caregiving*

The Atlas of Caregiving Pilot project explored new ways to study and map family caregiving. Mr. Mehta will discuss the results of this study involving fourteen diverse families, in the San Francisco region. Caregivers ranged in age from 30–73, and care recipients from 3–101. They had a wide range of health issues, including Alzheimer’s, autism, cancer, epilepsy, Parkinson’s, and more. Care context also varied widely: parents caring for young and adult children and couples of all ages caring for spouses, siblings and parents. Some caregivers had very little support; in other cases numerous family, friends and professional caregivers were involved.

11:30 [Question and exchange period](#)

11:45 LUNCH

13:45 PANEL #2 - What do human rights have to do with caregivers?

- > *Nancy Guberman - Retired Professor, Social Work at Université du Québec à Montréal*

Are caregivers’ human rights being respected? This presentation will discuss the policy brief “Caregiving & Human Rights in Canada”, a white paper aimed at the recognition of caregiver’s rights. International and national charters of human rights promote basic social, legal and economic rights for all people. These include the right to an adequate standard of living, the right to work, to rest and leisure, and the right not to be discriminated against on the basis of race, religion, ethnicity, family status, etc. To what extent do caregivers benefit from these universal rights? Beyond recognizing caregivers, shouldn’t we be defending their rights?

- > *Lucy Barylak – Social Gerontology Consultant, West-Central Montreal Health*

How can rights policy support caregivers, practitioners, managers, and directors? This presentation will discuss how policy based on human rights as outlined in the CREGÉS policy brief can be used in a way to question present service provision. Promoting the approach raised in the policy brief is one way of illustrating and defending the rights of caregivers in our health care system. As health care providers we have an obligation to advocate for our clients and their caregivers and question our present service provision in regards to caregivers and its impact on them and their care receivers. We will discuss how a rights’ approach can be a tool for doing so.

- > *Apostolia Petropoulos - Apostolia Petropoulos - Social worker & Coordinator of Caregiver Navigator Project, West-Central Montreal Health*

The paradox of care in homecare - a person's right to care. This presentation will reflect on the challenges inherent in caregiver interventions and the impact on caregivers' rights. Concepts such as ‘respite’, ‘self-care’ and ‘personhood’ will be deconstructed to illustrate the influence of the health system’s discourse on the caregiver advocacy. Finally, this presentation will include a brief description of the impact of homecare services on the collaboration of care among family caregivers, community organizations and the healthcare system.

14:15 [Question and exchange period](#)

14:30 BREAK

14:45 PANEL #3 - Latest research and practice methods

- > *Mélanie Couture - Researcher at CREGÉS & Associate Professor, Psychology at Université de Sherbrooke*

The complexity of choosing a living environment for a loved one with dementia. For family caregivers, choosing a living environment for a relative with dementia is one of the most stressful situations. Available data regarding this decision-making process needs to be synthesized to develop evidenced-based interventions aiming to better support caregivers. A systematic review of qualitative studies was performed to identify the main components of caregivers' decision-making process regarding the choice of a living environment for a relative with dementia and the contextual factors that inhibit or facilitate this process.

- > *Pam Orzeck - Coordinator of the Caregiver Support Leading Practice at West-Central Montreal Health & Adjunct Professor, Social Work at McGill University*
- > *Isabelle Van Pevenage - Researcher at CREGÉS & Associate professor, Sociology at Université de Montréal*

Post-caregiving and caregivers bereavement. Decades of research and clinical practice have confirmed that caregivers experience multiple challenges during their caregiving. One of the greatest challenges they may face is the transition out of care into bereavement. This presentation will discuss the difficulties caregivers experience in bereavement and the possible practice responses. As well, this presentation will introduce a clinical intervention tool for professionals to follow up and support caregivers along their care journey.

- > *Robin Cohen – Professor, Oncology and Medicine at McGill University & Researcher at the Lady Davis Research Institute of the Jewish General Hospital*

A volunteer service focused on the wellbeing of caregivers of people at the end of life. The wellbeing of family caregivers of people at the end of life suffers. Given that health care services already struggle to meet the needs of people at the end of life, these caregivers receive little support. Perhaps society needs to re-engage in helping these families, allowing health care services to focus on the most complex needs. This presentation will describe the findings of a study to implement a volunteer Caregiver Guide service with the aim of empowering caregivers to maintain their own wellbeing while providing care and in early bereavement.

15:30 [Question and exchange period](#)

15:45 [WRAP-UP ACTIVITY : Lessons learned and moving forward](#)

16:45 [CLOSING REMARKS](#)

Speakers



> **Christine Kabayiza L'APPUI for Caregivers**

Christine Kabayiza is a Registered Social Worker and a caregiver support counsellor for L'Appui Montreal. Through her work with the organization, she helps caregivers of seniors overcome the various challenges they may face and enhance their well-being.

L'Appui is a non-profit organisation created by the Quebec Ministry of Family and Seniors in partnership with La Fondation Chagnon to support the deployment of community based services for caregivers of seniors. There are various regional Appui organizations in the province, all supported by the National Appui. Every regional Appui works with community stakeholders to identify local priorities and improve the service delivery, through the development of information services, training, psychosocial support and respite care.



> **Lucy Barylak**

Consultant for the Social Gerontology University Affiliated Centre of West-Central Montreal Health. She is the former Coordinator of the Leading and Innovative Practices in Social Gerontology for the CSSS Cavendish. She has worked as a practitioner in the healthcare system for the past 25 years, focusing on issues related to seniors. In 2003 and 2012 she received the Queen's Jubilee award on the basis of dedication in developing a national coalition to support caregiver across Canada. In addition, she was a founding member of Carers Canada.



> **Robin Cohen**

Professor, Oncology and Medicine at McGill University & Researcher at the Lady Davis Research Institute of the Jewish General Hospital. She has focused her research on optimizing the quality of life of people at the end of life and that of their family caregivers. She has developed some of the most widely used measures of their quality of life. She is now focusing on developing and testing interventions, including through community involvement in supporting family caregivers and integrating quality of life measures into clinical practice to facilitate patient-centered care.



> **Mélanie Couture**

Associate Professor at the Université de Sherbrooke & Researcher at the Center for Research and Expertise in Social Gerontology (CREGÉS). Mélanie is the scientific lead of the Health interventions and technology assessment unit at the West-Central Montreal Health Network and provides support for researchers, administrators and health care professionals. Recently, she developed a decision-aid for caregivers to help them choose a living environment for their relative with dementia and improve partnerships between caregivers and health care professionals.



> **Nadine Henningsen**

Executive Director of Canadian Homecare Association (CHCA) & Signatory Partner of Carers Canada. Carers Canada is a federally incorporated not-for-profit organization that allows distinct organizational entities to pool resources and combine efforts in order to effect change for caregivers. They embrace a collaborative process to influence the political agenda and initiate a social movement for carers. Their goals are to: promote awareness of the role and value of carers, support a Carer Manifesto that informs and influences government policy and programs, and stimulate collective action that addresses carers' priorities and needs.



> **Nancy Guberman**

Retired Professor of Social Work at Université du Québec à Montréal (UQAM). She is involved in research and activism on caregiving issues for over 30 years. She is particularly interested in social policy around care and front-line practice with caregivers. She has published several books and articles and participated in numerous documentaries and conferences on these subjects. With colleagues she developed the CARE Tool that helps practitioners understand the global situation of the caregivers they work with.



> **Patrik Marier**

Professor of Political Science at Concordia University, Concordia University Research Chair (CURC) in Aging and Public Policy & Scientific Director of the Center for Research and Expertise in Social Gerontology (CREGÉS). His research focuses on the impact of aging populations on a number of public policy fields including pensions, labour, and social services and programs across comparative cases. He is currently completing a book length manuscript on how Canadian provinces are preparing themselves to face the consequences and opportunities of an aging population. His research activities and numerous scientific publications have led him to develop an international network focused on social gerontology.



> **Rajiv Mehta**

Executive Director of Atlas of Caregiving. Mr Mehta is also a board member of the Family Caregiver Alliance (FCA), co-organizer of Quantified Self events and conferences, and founder of Bhageera, a Silicon Valley-based strategy consultancy. In addition to leading Atlas of Caregiving, he previously held executive positions at Apple and Adobe, is a graduate of Columbia (MBA), Stanford (MS) and Princeton (BS).



> **Pam Orzeck**

Coordinator of the Caregiver Support Leading Practice at West-Central Montreal Health & Adjunct Professor at the School of Social Work of McGill University. Pam has worked in gerontology for the past twenty four years both as a front-line social worker and as a research-practitioner. Pam has given trainings and lectures related to caregiving and co-authored various publications. She is a founding member of the Canadian Caregiver Coalition and acts as a consultant on various committees and boards related to social policy and clinical practice.



> **Apostolia Petropoulos**

Social worker & Coordinator of Caregiver Navigator Project for West-Central Montreal Health. She is also the current group facilitator for the spousal caregiver support group at CLSC René-Cassin. Prior to her current role, she worked as a social worker in the homecare departments of the CLSC's René-Cassin and Benny Farm. Since 2011, she has been a board member of the community organization Services Sociaux Hélléniques du Québec (SSHQ), where she was involved in the development and implementation of the first Greek language workshops and support groups for caregivers in the Laval and Montreal regions.



> **Isabelle Van Pevenage**

Researcher at the Center for Research and Expertise in Social Gerontology (CREGÉS) & Associate Professor in the department of Sociology at Université de Montréal. Her research interests focus on social gerontology and palliative home care as well as on the transformative spousal and family relationships in old age. She has developed expertise on issues of care to the elderly, on the informal care systems, as well as on the concepts of needs, autonomy and identity in relation to caring for elderly parents.