A Spotlight on Qualitative Canadian Home Care Research: Insights and Findings

Presented by: Christine Kelly, Jennifer Baumbusch, Damien Contandriopoulos, Cynthia Cranford and Kelli Stajduhar

Long-term care homes are emphasized in provincial health care spending patterns, yet the vast majority of people want to, and do, receive care in the community. In policy spheres, home care is a long-standing priority of federal and provincial governments, and among many non-profit organizations. The pandemic demonstrates the urgent need for reliable at-home care options. Our interdisciplinary panel showcases innovative qualitative home care research from across Canada. Our panel considers home care from all angles –of those who use the services, unpaid caregivers, paid care workers, and implications for policy makers.

The panel opens with Contandriopoulos' systematic realist review that found definitions of home care are unclear in the literature and, that system integration, case management, and relational continuity are indicators of effectiveness. The panel moves from definitions to theory, as Cranford presents a framework to analyze tensions and alliances between workers and receivers, based on her empirical research. Cranford specifically describes the concept of intimate community unionism. We then share three current studies. Kelly draws on interviews and focus groups related to directly-funded home care in Alberta and Manitoba to consider how the service and work experience differ when using a home care agency as compared to hiring directly. Stajduhar's multi-site institutional ethnography finds organizational processes, time constraints, and system efficiency models serve to take providers away from actual care. Baumbusch shares findings from a longitudinal qualitative study with community-dwelling people living with dementia and their family caregivers.

The objectives of this panel are:

(1) To share findings and insights from distinct qualitative research projects related to Canadian home care

(2) To showcase different concepts and qualitative methods being used in current home care research

(3) To compare and contrast findings across studies through a facilitated discussion period

Invited Experts

Our panel includes five of Canada's leading qualitative home care researchers. Contandriopoulos' research is focused on the use of evidence in decision-making and the analysis of highly performing models of healthcare delivery. Cranford authored the groundbreaking book Home Care Fault Lines (2020, Cornell University Press), that proposes an innovative analytical framework for examining home care programs based on four case studies from Ontario and Los Angeles. Kelly is internationally recognized for her research on directly-funded or self-managed home care in Canada, and her work explores this mechanism from multiple points of view. Stajduhar's research is focused on the health services needs of older adults with chronic and life-limiting conditions in the contexts of home and community-based care. Baumbusch's research focuses on caring for people living with dementia in the community from the perspective of family caregivers.

The "kids" are alright: Practice patterns among early-career family physicians and implications for primary care policy and workforce planning

Presented by: Ruth Lavergne, Doug Blackie, Agnes Grudniewicz, David Rudoler and Ian Scott

Canadians report persistent problems accessing primary care despite an increasing per-capita supply of family physicians. Many have attributed this to generational differences, claiming early career family physicians are working less and making different practice choices than previous cohorts. If these claims are true, targeted intervention during training and early practice are needed. If not, this narrative may distract from broader reforms needed to strengthen primary care. The Early Career Primary Care (ECPC) Study explored if changes in family practice are different among recent cohorts and sought to understand factors shaping practice intentions and choices among early career family physicians.

Researcher panelists will briefly overview findings from the ECPC study, including results of multiprovincial province-wide quantitative age-period-cohort analysis of family physician activity over the last two decades using administrative data and qualitative framework analysis of 94 interviews with family medicine residents and physicians within their first ten years of practice. The study includes data from British Columbia, Manitoba, Ontario, and Nova Scotia. Panelists will react suggesting implications of results, and the audience will be invited to reflect and respond, considering ongoing policy discussions. Areas for discussion include:

• How findings apply to medical education, including reforms underway in postgraduate family medicine training.

• Alignment of practice and payment models with values and preferences of early-career physicians and opportunities for primary care renewal.

• Implications of changing practice patterns for workforce planning.

This session will integrate presentation of mixed-methods findings with robust discussion of national policy implications, featuring representation of key stakeholder perspectives, and complemented by audience participation.

This panel will explore findings and policy implications of a cross-jurisdictional, mixed-methods study, by:

1. Describing service volume, continuity, and comprehensiveness of care among early-career and established family physicians over two decades.

2. Exploring if changes over time reflect cohort effects (attributes unique to the most recent cohort of physicians), or period effects (changes over time across all physicians).

3. Outlining the values and preferences that shape the practice intentions and choices of family medicine residents and early-career primary care physicians.

4. Discussing implications for medical education, primary care policy, and workforce planning.

Invited Experts
Ruth Lavergne holds a Tier II Canada Research Chair in Primary Care and is an Associate Professor in the Dalhousie Department of Family Medicine. David Rudoler holds a Research Chair in Population Health and Innovations in Mental Health at Ontario Shores and is an Assistant Professor at Ontario Tech University. Agnes Grudniewicz is an Assistant Professor in the Telfer School of Management at the University of Ottawa. Ian Scott is Director of the Centre for Health Education Scholarship, an Associate Professor in the University of British Columbia Department of Family Practice and has held medical education leadership roles in the College of Family Physicians of Canada. Doug Blackie is a health systems leader and educator based in Edmonton, with provincial and regional experience, and focused expertise in rural health and health human resources.

Taking a Collective Impact Approach to Build a Better System to Support Family Caregivers: Pandemic Lessons for Necessary Changes to Improve Caregiver Experiences

Presented by: Deirdre McCaughey, Sharon Anderson, Kim Brundit, Gwen McGhan and Janet McLean

Currently, 8.1 million Canadian family caregivers (FCGs) fulfill the essential role of caring for Canadians living with chronic conditions, disability, and frailty. FCGs are responsible for providing both emotional and physical care and organizing health services. To mitigate the effects of COVID-19, Provincial Health Ministries enacted public health measures that eliminated or reduced support services and resources for these FCGs. However well-intended, FCGs have since reported increased stress, greater difficulty caring for their family member and a general decline in wellness. There is significant evidence that distressed caregivers are often forced to stop caregiving when their wellbeing is in peril.

Using a multi-perspective stakeholder approach, the panel moderator will engage the panel to provide an overview of the current FCG experiences, challenges, and recommendations regarding support services and government initiatives. She will highlight themes and synergies amongst the panelists, with the goal of sharing lessons learned from a multitude of perspectives.

The panelists represent a breadth and depth of knowledge and expertise in family caregiving that includes care provision across the care continuum and caregiving role.

Outcomes expected will include highlighting the experiences of FCGs from a myriad of perspectives, identifying resources and gaps experienced due to public health measures, recommendations for better government initiatives to support FCGs, and mechanisms by which support agencies can work collectively to assist FCGs. This panel offers a diverse examination of FCG experiences through the inclusion of FCGs, community support agencies, healthcare providers, and researchers.

Our panel will present the experiences, challenges, and recommendations of FCGs from Western Provinces, highlighting how FCGs should and could be better supported. Specifically, the panel will address 1) the impact of public health measures enacted during COVID-19 and the resulting FCG experiences, 2) emerging and evolving challenges FCGs faced while providing care, 3) recommendations for relevant health measures, resources and support mechanisms for FCGs for the current pandemic and to assist in future public health emergencies, 4) initiating applicable policies and practices to address the challenges, and 5) how to best support synergy amongst FCG organizations.

Invited Experts
Dr Deirdre McCaughey (University of Calgary) will present findings from the Alberta Family Caregiver Study; highlighting FCG experiences and challenges during COVID-19. Kim Brundrit (Dementia Network Calgary & FCG) will share experiences as a community advocate and FCG and bring forward suggestions for government initiatives and the synergies across support agencies. Janet McLean (Family Caregivers of British Columbia & FCG) will share experiences as a FCG and of FCGs, highlight recommendations for supporting FCGs, and identify needed government initiatives. Dr Sharon Anderson (University of Alberta & FCG) will share experiences as a FCG and of FCGs, highlight recommendations for supporting FCGs, and suggestions for government initiatives. Dr Jasneet Parmar (University of Alberta & MD) will present findings from the Impacts of COVID-19 on Alberta Family Caregivers Study and will share the role of healthcare providers in supporting FCGs. Dr Gwen McGhan (University of Calgary & RN) will moderate the panel.

Embedding Inclusion Diversity Equity and Accessibility (IDEA) in Health Data Research: Data Research Centres and Approaches to IDEA

Presented by: Amy Freier, Nicole Aitken, Lisa Nowlan and Robyn Rowe

Data, especially big data and administrative data, has become one of the critical infrastructures of the 21st century. Data and data research, however, are not neutral. Colonialism, racism, gender discrimination, ableism, and other forms of oppression have shaped the data that are available. Data can thus perpetuate inequities in appropriate medical care, lifesaving and enriching treatments, and other social services. Moreover, the same systemic issues are baked into health data research, including: i) the data that is collected and stored; ii) the questions that are asked of the data iii) the people and teams that are assembled to analyze and interpret health data; and iv) the dissemination of results.

The panel approach will be focused on methods that aim to embed Inclusion, Diversity, Equity, and Accessibility (IDEA) within health data research – with a focus on the Health Data Research Network and its member organizations. The Chair's of HDRN Canada's IDEA Team and Indigenous Data Team will provide information about their distinct portfolios and efforts to define overlaps and differences between IDEA and Indigenous Data Sovereignty within the network. Panelists from CIHI, MCHP, and Statistics Canada will briefly introduce programs that they are leading/facilitating within their local contexts. The moderator will ask panelists about challenges, successes, and opportunities for embedding IDEA within data research – especially as it relates to the creation of policies and standards, working in relation with Indigenous data sovereignty initiatives, public and stakeholder engagement, and data analytics. The last 15 minutes of the session will be reserved for Q&A and dialogue with the audience.

The purpose of this panel is to provide participants with knowledge about different approaches to IDEA in health data research environments – emphasizing the need for site-specific solutions and opportunities for streamlined approaches across research centres. Presenters will cover two broad areas of concern: i) Operations: tools, processes, and practices to embed IDEA in the day-to-day work of data research centres (e.g.: job postings, mentoring programs, meetings, and team composition); and ii) Data Research: tools processes, and practices to embed IDEA in the data research cycle (e.g.: data flags and process guides, governance, analytics, and dissemination).

Invited Experts
This presentation will bring together individuals across Canada who each lead or advocate for Inclusion, Diversity, Equity, and Accessibility in health data research environments. Dr. Amy Freier is a Research Associate at the Manitoba Centre for Health Policy, where she leads the Data Equity Initiative. Dr Freier also chairs the IDEA Team at Health Data Research Network Canada, which brings together experts and practitioners working to embed IDEA in data research spaces. Dr. Robyn Rowe is a Staff Scientist at ICES and the Chair of the Indigenous Data Team at HDRN Canada. Dr. Rowe is an executive member of the Global Indigenous Data Alliance (GIDA) and a long-standing member of the International Indigenous Data Sovereignty Interest Group. Lisa Nowlan (Med, BJournalism) is a Program Consultant at the Canadian Institute for Health Information and leads the Diversity and Inclusion portfolio. Dr. Nicole Aitken is an Analyst with the Centre for Population Health Data at Statistics Canada.

Towards a Pan-Canadian Health Data Strategy

Presented by: Eric Sutherland, Ewan Affleck, Steven Hoffman and Kim McGrail

For decades, Canada has been largely unsuccessful in addressing health data challenges, despite significant investments in health systems and data infrastructure. The COVID-19 pandemic highlighted the profound impact poor data collection, sharing, access, and use can have on myriad areas of health services and policy, not least health outcomes, costs, and patient experience. At the heart of the issue is the need to address the root causes of heath data fragmentation. As a result, in December 2020, a pan-Canadian Health Data Strategy (pCHDS) Expert Advisory Group (EAG) was created to help chart a path towards a cohesive health data ecosystem.

The EAG reviewed hundreds of reports and articles, some dating as far back as the 1960s, and created working groups (Policy, Governance, and Interoperability & Architecture) for deeper analysis and deliberation. The EAG published its advice and recommendations (three reports, with final report scheduled to be published Spring 2022), and these are being considered by federal, provincial, and territorial governments in support of the development of a long-term pan-Canadian Health Data Strategy.

The panel discussion will provide the audience with a summary of the work of the pCHDS EAG centred on a vision for a person-centric health system supported by data stewardship. Panelists will discuss the principles for implementation of a common, coherent cross-jurisdictional approach, and the policy, governance, engagement, and interoperability factors that will be critical for success. The audience will also have the opportunity to raise further issues and broaden the discussion.

Invited Experts

Dr. Steven Hoffman - international lawyer specializing in global health law, global governance and institutional design.

Dr. Kim McGrail – Professor, UBC School of Population and Public Health and Centre for Health Services and Policy Research, Director of Research for UBC Health, and Scientific Director of Population Data BC and Health Data Research Network Canada. Her research interests are quantitative policy evaluation and all aspects of population data science.

Dr. Michael Wolfson - Fellow of the Canadian Academy of Health Sciences, Former Assistant Chief Statistician of Statistics Canada; areas of expertise include design of health information systems and microsimulation modeling of socio-economic policy and health dynamics.

Dr. Ewan Affleck - Senior Medical Advisor, Health Information, College of Physicians & Surgeons of Alberta; practicing clinician and digital health information systems expert.

Advancing multi-regional research in Canada through collaboration

Presented by: Nicole Yada, Laurie Lambert, John McLaughlin and Michael Schull

COVID-19 has accentuated the importance of data for understanding social determinants of health, informing clinical care, and facilitating decisions and policy making across Canada. Partnerships to broaden and expand data availability and improve Canada's health data landscape are needed. The Canada Health Data Research Alliance (HDR Alliance), led by Health Data Research Network Canada (HDRN Canada), is aligning partners to facilitate and accelerate multi-regional data linkage and access. The HDR Alliance is designed to expand sources and types of data available in a coordinated way; enabling research that supports health policy and improves health and health equity.

Leading health experts in Canada that share a collective imperative for data access and use will describe key initiatives to strengthen the data landscape.

The panel will describe: 1) HDRN Canada's progress in convening key stakeholders across the data continuum; 2) how a network of clinical trialists is embedding administrative data into a national COVID-19 RCT; 3) progress on a collaboration between HDRN Canada and CanPath, Canada's largest population cohort, that is enabling a multi-province COVID-19 study; and, 4) the potential for real-world data to be used for health technology assessments during the drug life cycle, including during the pandemic.

Panelists will each speak to the aligned incentives for data access, collection and use that were highlighted during the pandemic, and how we are working to maintain that alignment. Attendees will be encouraged to ask questions and collectively explore what further collaborative efforts may be needed.

This panel will:

-        Share challenges and opportunities with data linkage and access during the COVID-19 pandemic, from the perspectives of clinicians, researchers, policy makers and a coordinating data infrastructure

-        Describe three HDR Alliance-related pan-Canadian initiatives underway to better coordinate COVID-19 data collection, access and use

-        Explore the importance of multi-stakeholder collaboration to advancing the data landscape in Canada, during and post-pandemic

Attendees of the panel session will gain an understanding of the complexity of making data usable in a timely way and can engage directly with experts about opportunities ahead.

Invited Experts
Dr. Robert Fowler is a Senior Scientist at Sunnybrook Health Sciences Centre, Professor of Medicine at the University of Toronto, and Chair of the Canadian Critical Care Trials Group.

Dr. Laurie Lambert is the Lead, Real-World Evidence (RWE) at the Canadian Agency for Drugs, Technologies and Health (CADTH). For 15+ years, Dr. Lambert worked for the Institut National d'Excellence en Santé et en Services Sociaux (INESSS).

Dr. John McLaughlin is a Professor of Epidemiology at the University of Toronto and Executive Director for the Canadian Partnership for Tomorrow's Health (CanPath).

Dr. Michael Schull is Senior Scientist and CEO at ICES, Professor of Medicine at the University of Toronto, Emergency Physician at Sunnybrook Health Sciences Centre, and member of the Executive Committee of HDRN Canada.

Nicole Yada is HDRN Canada's Manager of Partnerships. Previously, Nicole worked in digital health and healthcare strategy at Ontario Health (Quality) and Trillium Health Partners.