The Aging, Community and Health Research Unit:
Key Messages Related to Community-Based Primary Health Care Interventions

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Trillium Primary Health Care Research Day, May 31, 2017, Toronto, ON
Objectives

1. Provide an overview of the Aging, Community and Health Research Unit (ACHRU).

2. Discuss key insights regarding designing, implementing, evaluating and scaling-up community-based primary health care interventions using the ACHRU-Community Partnership Program for older adults with MCC and diabetes.
Inspiration
Research in Home and Community-Based Care

**The Aging, Community and Health Research Unit—Community Partnership Program for older adults with type 2 diabetes and multiple chronic conditions: a feasibility study**

Maureen Markle-Reid, Jenny Ploeg, Kathryn Fisher, Holly Reimer, Sharon Kassalainen, Amiram Gafni, Andrea Grunke, Ross Kricunoff, Sam Marzouk, Noon Alsheiber, Lebreh Thobat, Carlos Rojas-Fernanda, and Ross Upshur

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**Nurse-led health promotion interventions improve quality of life in frail older home care clients: lessons learned from three randomized trials in Ontario, Canada**

Maureen Markle-Reid RN MScN PhD,1 Gina Browne RN PhD2 and Amiram Gafni PhD3

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3Professor, Centre for Health Economics and Policy Analysis and Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, Ontario, Canada.

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**Spreading and sustaining best practices for home care of older adults: a grounded theory study**

Jenny Ploeg, Maureen Markle-Reid, Barbara Davies, Kathryn Higuchi, Wendy Gifford, Immajean Bajok, Heather McConnell, Jennifer Plendefield, Sandra Foster, and Sue Boonie-Bassett

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**Effect of preventive primary care outreach on health related quality of life among older adults at risk of functional decline: randomised controlled trial**

Jenny Ploeg, associate professor,2 Kevin Brazil, professor,3 Brian Hutchinson, professor emeritus,2 Janusz Kaczorowski, associate professor,2 Dawn M Daby, assistant professor,4 Charles H Goldsmith, professor emeritus,2 William Furlong, research associate2
Acknowledgements

- CIHR Signature Initiative in Community-Based Primary Health Care (2013-2020)
- Ontario Ministry of Health and Long-Term Care, Health System Research Fund Program Award (2013-2016)
- CIHR Canada Research Chair Program (2012 – present)
- Labarge Optimal Aging Initiative, McMaster University (2013-2016)
- SPOR IMPACT award (2016-2019)
- Max Bell Foundation (2017-2019)
What is the problem?

- 33% of older adults (≥ 65 years) have multiple (≥ 2) chronic conditions (MCC)
- MCC is associated with:
  - lower quality of life
  - higher use and costs of health services
- Family caregivers experience a higher level of burden
- The system is poorly designed to meet the needs of the MCC population
- There is limited evidence on how to provide high quality care for this population
Research Program Goals

- To promote optimal aging at home for older adults with MCC and to support family caregivers
- To design, evaluate and translate new and innovative interprofessional community-based interventions to improve quality of life and care
Stakeholder Network

- **48** Agencies
- **5** Government Representatives
- **43** Researchers
- **48** Research Trainees: Post Doctoral Fellows, graduate students (PhD & Masters), undergraduates
- **20** Patients & Family Caregivers
- **5** Provinces
Program Provides Evidence From Design to Scale-up

**KT Events**
- Synthesis
- Integration

**KT Strategies**
- Planning for scale-up

1. Perceptions
2. Correlates, Costs & Outcomes
3. Sex & Gender
4. Mobile Post-Stroke Care
5. Alzheimer’s Transition Intervention
6. Type 2 Diabetes Self Management
7. Post-Stroke Navigation & Rehab
8. Mobile Post-Stroke Care
9. Community Assets Supporting Transitions
10. Health Links Evaluation
11. On-Line Caregiver Toolkit
12. Integrated Knowledge Translation

2012/13 – 2017/18

**Aging, Community and Health**
RESEARCH UNIT

2016/17
Research Program Themes

- Community- and Home-Based Care
- Patient Centred Care
- Implementation Science
- Equity
- Health Promotion
- Health System Performance & Sustainability
- Quality Improvement & Safety
- Prevention and Management of MCC

Aging, Community and Health
RESEARCH UNIT
Capacity Building

- 48 Trainees
  - Undergraduate
  - Graduate
  - Post-doctoral
  - New investigators
- Multi-disciplinary, e.g., nursing & others
- Trainee-led seminar series
- CRC seminar series – intervention research
- Training for multiple home and community care providers

Aging, Community and Health
Research Unit
Trainees have opportunities to

- Collect and analyze data
- Write reports
- Present results at conferences
- Publish papers
- Contribute to grant development
- Participate in seminars and workshops
- Complete course requirements
- Take on a part of one study as part of their thesis
- Develop a proposal that builds on the existing research program

Aging, Community and Health
Knowledge Translation Strategies

- Diverse IKT and end of grant KT strategies tailored to different user groups (e.g., patients, informal caregivers, decision makers, home and community and primary care providers)

- Patient and informal caregiver engagement in research is integral to each study

- Quantitative and qualitative approaches to assess which strategies work best, and the perceived impact of these strategies
Older Adult & Caregiver Engagement integrated through:

- Intervention co-design
- Grant development
- Study implementation
  - Adapting and tailoring
- Interpreting results
- Patient and public engagement workshop
- KT events, presentations
- Co-presenting at Ministry meetings
A Conceptual Model of the Role of Complexity in the Care of Patients With Multiple Chronic Conditions. Grembowski, David; Schaefer, Judith; Johnson, Karin E.; Fischer, Henry; Moore, Susan L.; Tai-Seale, Ming; Ricciardi, Richard; Fraser, James R.; Miller, Donald; LeRoy, Lisa; on behalf of the AHRQ MCC Research Network. Medical Care. 52():S7-S14, March 2014. doi: 10.1097/MLR.0000000000000045

With Permission from Wolters Kluwer Health, Inc.
Our Approach

✓ Identify contextual factors and their impact on health outcomes, service use, and equity of services

✓ Develop interventions to address these factors that are tailored to individual needs

✓ Meaningfully engage patients and caregivers in co-designing, implementing and evaluating the interventions

✓ Design and adapt the interventions to meet community needs and build on community strengths

✓ Work together (health and non-health sectors) to promote system transformation

✓ Create interventions that are potentially suitable for scaling up for maximum reach and outcomes

Aging, Community and Health
RESEARCH UNIT
PRECIS-2

Eligibility
Who is selected to participate in the trial?

Primary analysis
To what extent are all data included?

Primary outcome
How relevant is it to participants?

Recruitment
How are participants recruited into the trial?

Setting
Where is the trial being done?

Organisation
What expertise and resources are needed to deliver the intervention?

Follow-up
How closely are participants followed-up?

Flexibility: adherence
What measures are in place to make sure participants adhere to the intervention?

Flexibility: delivery
How should the intervention be delivered?

(Loudon 2013)
Example of Study

Aging, Community and Health Research Unit – Community Partnership Program for older adults with MCC and Type 2 Diabetes Mellitus
Aging, Community and Health Research Unit

Our vision: Working together with older adults with multiple chronic conditions and their family caregivers to promote optimal aging at home.

In 2013, Drs. Maureen Marrie-Reid, Jenny Pooc and their research team were awarded a combined $6.6 million to fund the new Aging, Community and Health Research Unit. The program will receive $3.5 million over five years from the Canadian Institutes of Health Research. Community-based Primary Health Care Signature Initiative and $3.1 million over three years from the Ontario Ministry of Health and Long-Term Care, Health System Research Fund Program Award. This funding will allow them to promote optimal aging at home for older adults with multiple chronic conditions (MCC) and to support their family caregivers, by designing and evaluating new and innovative community-based health care interventions to improve access to health care, quality of life, and health outcomes in this population, while reducing costs.

The research program is made up of seven integrated studies to be conducted in Ontario and Alberta, in collaboration with a number of community partners and colleagues, and in partnership with a team of researchers from McMaster University, the University of Alberta, the University of Toronto, the University of Calgary, Mount Saint Vincent University, the University of Saskatchewan, the University of Waterloo, Mohawk College of Applied Arts and Technology, St. Joseph’s Health Care London, and Women’s College Hospital. The studies will focus on the prevention and management of multiple chronic conditions. Specifically, the studies will target seniors with MCC who have dementia, Type 2 diabetes and/or stroke.

McMaster Nurses are Creating Apps and Monitoring Systems of the Future

The ACHRU's Dr. Rabi Vaziri is featured in a McMaster School of Nursing website article on how nurses are changing healthcare delivery by using technology.

Congratulations to Anna Gamett on receiving the OGNA Buckingham scholarship

Anna Gamett, a PhD student in the School of Nursing at McMaster, won the prestigious scholarship on the weekend.

Read More

ACHRU's PhD Student Receives Award for Research on Older Adults with Incontinence Due to Diabetes

Congratulations to Melissa Johnsen on receiving the 2017 Registered Nurses' Foundation of Ontario (RNFO) Mary Ann Murphy Memorial Diabetes Award.

Read More
From Feasibility Study to Pragmatic RCT

**PRAGMATIC RCT**
Multi-site, Cross-jurisdictional

- **Alberta**
  Primary Care Networks
  Community Partners

- **Ontario**
  Diabetes Education Centres
  Community Partners (e.g. YMCA)

**PILOT STUDY**
Single Site – Diabetes Education Centre & a Community-based Seniors Association

**WORKSHOP**
Engage Stakeholders

**Scaling Up**

**Evaluation**

**Implementation**

**Intervention Design**

**Grassroots Participation**

**Sustainability & Spread**

_Aging, Community and Health Research Unit_
Building Collaborations

A Diabetes Education Centre (DEC)  A Senior’s Centre
Problem Analysis and Assessment

- Qualitative study (patients, caregivers, providers)
- CIHR-funded workshop (patients, caregivers, providers, professional associations, health system decision-makers)
- Literature review
- Practice analysis
- Analysis of population-level data (ICES)
Study Objective

**Primary**
- To evaluate the feasibility of implementing the Aging, Community and Health Research Unit – Community Partnership Program for older adults with MCC and Type 2 Diabetes Mellitus (T2DM).

**Secondary**
- To determine the effectiveness of the Program on self-management, health-related quality of life, anxiety and depressive symptoms.
- To determine the change in costs of use of health and social services over 6-months.
Eligibility, Recruitment and Study Setting

- To what extent are the participants in the trial similar to those who would receive this intervention if it was part of usual care?
- How much extra effort is made to recruit participants over and above what that would be used in the usual care setting to engage with patients?
- How different is the setting of the trial and the usual care setting?
Participants and Setting

Setting: Guelph, Ontario

Study Participants (n=45)

- Type 2 diabetes
- ≥ 65 years
- Receipt of diabetes services in past 2 years
- ≥ 2 chronic conditions
- English-speaking
- Living in the community
MULTIFACETED Intervention Components

- Home Visits
- Monthly Group Sessions
- Monthly Nurse-led Case Conferences
- Nurse-led Care Coordination

Source: CDC #14167

Aging, Community and Health Research Unit
Study Design and Outcomes (n= 36)

- Single arm pre-test/post-test design
- Mixed-methods (quantitative and qualitative)

**DATA FROM THE INTERVENTION TEAM**
- Semi-structured interviews with peer volunteers
- Focus groups with Registered Nurses, Registered Dietitians, Program Coordinators

**DATA FROM PARTICIPANTS**
- Demographics
- Clinical outcomes
- Open-ended feedback regarding the intervention
Key Results

- CPP was viewed as acceptable and feasible by participants and providers.
- Participants had higher physical functioning at 6 months compared with baseline.
- Participants, volunteers and providers provided valuable feedback regarding suggested changes to the program.
Barriers to Adoption

- DEC staff overwhelmed with administrative tasks;
- Lack of resources to support home visits;
- DEC staffs’ emphasis on T2DM rather than co-morbid conditions.
Summary

- The intervention was effective and feasible to implement.
- Readiness for a scaled-up pragmatic RCT was established.
- Participants and providers gave valuable feedback that was subsequently used to inform scale-up to a pragmatic RCT.
Pragmatic RCT Study Objective

➢ To examine the **effects**, **costs**, and **implementation** of the ACHRU-Community Partnership Program for older adults with MCC and Type 2 Diabetes
Pragmatic RCT Study Partners

McMaster University
School of Nursing

Ross Memorial Hospital Foundation

Primary Care Network
Sherwood Park Strathcona County

Primary Care Network
Leduc Recreation Centre

Alberta Health Services

St. Joseph's Healthcare London

Strathcona County

Port Hope Community Health Centre
...building a healthier community together

PRHC
Peterborough Regional Health Centre

City of Kawartha Lakes
Catch the Kawartha spirit

Primary Care Network
Edmonton Oliver

Aging, Community and Health Research Unit
Study Sites: Ontario

- Peterborough
- Kawartha Lakes
- London
- Port Hope
Implementing the Intervention

- Implementation committee
- Standardized training manual
- Standardized training sessions
- Forms to capture intervention activities
- Monthly outreach visits to IP teams
- Audit and feedback
Implementation Challenges

- Reaching the target population
- Randomization
- Time and resources
- Ongoing changes in the study context
- Interventions required changes at individual provider and organizational level
- Inter-organizational collaboration
- Balancing intervention fidelity and intervention adaptability
Evaluating the Intervention

Difficult questions versus difficult answers:

- Which services to provide (type of provider)?
- How much to provide (dose)?
- When should services be provided (timing)?
- To whom should services be provided?
Selecting Outcome Measures

- To what extent is the trial's primary outcome relevant to participants?
- How different is the intensity of measurement and follow-up of participants in the trial and the likely follow-up in usual care?
- Is the follow-up data available in usual care?
- Are the outcome measures reliable and valid, sensitive to change, applicable to the population and easy to administer and score?
- What is the optimal time to measure the outcomes?
- What is the feasibility of the data collection process?
Evaluating the Effectiveness of the Intervention

- **PREMs**: patient-reported experience measures: e.g., satisfaction with health services

- **PROMs**: patient-reported outcome measures: e.g., health-related quality of life
PROMs

- Health-related quality of life:
  - Physical functioning (Pt, CG)
  - Mental functioning (Pt, CG)
- Depressive symptoms (Pt, CG)
- Anxiety (Pt)
- Self-management (Pt)
- Self-efficacy (Pt)
- Caregiver strain (CG)

(Note: Pt=patient, CG=caregiver)
Costs

- Self-reported use of health and social services, from a societal perspective:
  - Health and Social Services Utilization Inventory: frequency of Use x Unit cost ($)
- Linkage of individual study participant to administrative data
Evaluating Implementation

- **Implementation Outcomes:** acceptability, adoption, appropriateness, feasibility, fidelity, coverage, sustainability) (Peters et al. (2014)

- **Determinants of implementation:** Consolidated framework for implementation research (Damschroeder et al., 2009)

- **Implementation theory:** Normalization process theory which examines making practices routine (embedding) and including practices in social contexts (integration) (May & Finch, 2009).
Results

Total (n=159): Intervention (n=80), Control (n=79)

No significant differences between the groups at baseline.

- **33%** lived alone
- **76%** had 6 or more other chronic conditions
- **56%** took 8 or more prescription medications
Key Results

96% received at least 1 in-home visit (average 2.6 visits)
84% attended at least 1 group session (average 4.0 sessions)

- Intervention group had better mental health, lower depressive symptoms, better diabetes self-care compared to control group

- Improvements achieved at no additional cost to society as a whole

- Results from AB expected soon
Patient Perspective

- I wanted to learn more about diabetes and its relationship to my age. I will be 85 next June. Having been a diabetic for 16 years, and surviving well, I was interested in learning anything new about the treatment and developments. My wife had always managed my medications and when I lost her to cancer eight years ago it was obvious I had to accept the responsibility.

- I was interested in the study participation because it helped me re-focus on my own personal requirements. This lead to more exercise and a better diet. I also enjoyed meeting new people and was surprised at the wide variance in the ages and physical condition, appearance and attitudes of co-members.
Community Partner Perspective

YMCA of Central East Ontario – Our team was comprised of two staff, a registered dietician and nurse, as well as a program coordinator with health and fitness expertise from the YMCA. Throughout the year we had the opportunity to work with 20 participants that were introduced in stages to complete a six month session. Being part of the team to implement the process and celebrate the accomplishments of people living with chronic conditions was a rewarding experience for the YMCA. This client-driven intervention model has the potential to be instrumental in life changing behavior and the YMCA was a partner in both teaching and learning through the process. Thank you for this opportunity to work in partnership with McMaster University to enrich lives. It supports the work the YMCA does each day to strengthen the foundations of communities.
Challenges Evaluating Interventions

- Including older adults with cognitive impairment
- Difficulty reaching older adults and scheduling in-home interviews
- Inability to utilize data available in usual care
- Including non-English speaking older adults
- Respondent and interviewer burden
- Short funding cycles resulting in: (1) short-term evaluation, (2) limited time and resources
- Understanding which factors or combination of factors are responsible for the outcome
Key Insights

- Engaging partners in all phases of the research is critical.
- Evaluation of interventions should examine both implementation and effectiveness using quantitative and qualitative methods.
- Detailed description of intervention is required to enable replication – TIDieR framework.
- Theory-informed interventions are superior to non-theory informed interventions.
- Design and evaluation of intervention studies should reflect the complexity and context of clinical practice.
Next Steps: Plans for Scale-Up

• Collaboration with Diabetes Action Canada and *Better Access and Care for Complex Needs (BeACCoN)*
• Working with administrative data bases such as UTOPIAN
• Partnership with YMCA
• Partnership with Diabetes Education Programs and Primary Care
• Patient and caregiver involvement in PREM and PROM development
ACHRU - CPP for Older Adults with Type 2 Diabetes and MCC
Published Papers

**STUDY PROTOCOL**
The ACHRU-CPP versus usual care for older adults with type-2 diabetes and multiple chronic conditions and their family caregivers: study protocol for a randomized controlled trial


**Research**
The Aging, Community and Health Research Unit—Community Partnership Program for older adults with type 2 diabetes and multiple chronic conditions: a feasibility study

Maureen Markle-Reid, Jenny Ploeg, Kathryn Fisher, Holly Reimer, Sharon Kasalainen, Amiram Gafni, Andrea Gruneir, Ross Kirkconnell, Sam Marzouk, Noori Akhtar-Danesh, Lehana Thabane, Carlos Rojas-Fernandez and Ross Upshur

**Original Research**
Comorbidity Burden and Health Services Use in Community-Living Older Adults with Diabetes Mellitus: A Retrospective Cohort Study

Andrea Gruneir PhD, MA, Maureen Markle-Reid RN, PhD, Kathryn Fisher PhD, Holly Reimer PhD, Xiao Ma MSc, Jenny Ploeg RN, PhD

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