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Webinar Discussion Series - Community Dementia Care and Support:

Innovations supporting people living with dementia and care partners closer to home

June 8, 2021, Webinar Discussion Summary

June 8, 2021, Webinar Synopsis:

During this webinar participants learned about the experiences from the implementation and evaluation of the Québec Alzheimer plan.

The moderators for the session were Mimi Lowi-Young (Chair of the Board of Directors: AGE-WELL Network Centre of Excellence INC.) and Mary Beth Wighton (Chair & Co-founder: Ontario Dementia Advisory Group (ODAG) and Dementia Advocacy Canada (DAC); Member - Federal Ministerial Advisory Board on Dementia), who provided insights throughout the session, including these two quotes:

"The national dementia strategy mentions human rights as a principle, we need to ensure the solutions we adopt are driven by human rights."

- Mary Beth Wighton

"No technology can replace human contact. Technology like GPS tracking, socially assisted robots, adaptive telephones, and sensors can assist individuals living with dementia to live in a safer environment with dignity and assist to reduce caregiver burden."

- Mimi Lowi-Young

June 8, 2021, Discussion Highlights:

Presentation 1: Lessons learned from the implementation and Evaluation of the Québec Alzheimer plan

- The Québec Alzheimer plan was created at the request of the Quebec Minister of Health in May 2009.
- The plan had 7 priority actions with 24 recommendations:
    - Raise awareness, inform and mobilize.
    - **Provide access to personalized, coordinated assessment and treatment services for people with Alzheimer's and their family/informal caregivers.**

- In the advanced stage of Alzheimer's, promote quality of life and provide access to home-support services and a choice of high-quality alternative living facilities.
- Promote high-quality, therapeutically appropriate end-of-life care that respects people's wishes, dignity and comfort.
- Treat family/informal caregivers as partners who need support.
- Develop and support training program.
- Mobilize all members of the university, public and private sectors, for an unprecedented research effort.

- This webinar focused on priority action number 2 bolded above.
- The big challenge is access to personalized, coordinated evaluation and treatment
    - Poor access to:
        - Diagnosis, treatment (including behavioral issues), support for patients and their caregivers
        - Integrated management through the stages of the disease (including in crises)
    - Memory clinics cannot handle the volume nor assure comprehensive continuity of care, resulting in very long wait lists, delayed diagnosis and late intervention.
    - Primary care is generally not prepared to deal with Alzheimer disease and related disorders.
    - Many patients are not diagnosed or are diagnosed late.
- The objectives: Provide access to personalized, coordinated services
    - Rapid access to assessment and management of the disease following a comprehensive process
        - Pharmacological, psychological, social and environmental approaches
    - Personalized management and innovative access through a trusting relationship between patient/family and a credible clinician
        - With personalized access to a flexible range of primary care, community and specialized services
        - The approach must be patient-centered and not disease centered
- Collaborative Care Model: partnership between patient/caregiver and clinician team
    - Approach is based on the chronic disease collaborative model implemented in Family Medicine Groups (FMGs)
    - Integrated patient-centered management of chronic disease
    - MD/Nurse (the nurse is acting as a pivotal navigation support)
    - The model that was used follows the Diabetes model where 80% of services are provided in primary care and only 20% of the care is provided by specialized services.

- The group developed care pathways for use in primary care that describes who does what and when.
    - https://www.mcgill.ca/familymed/files/familymed/interdisciplinary_clinical_process_follow-up.pdf
    - https://www.msss.gouv.qc.ca/professionnels/maladies-chroniques/alzheimer-et-autres-troubles-neurocognitifs-majeurs/processus-cliniques-et-outils/
    - https://www.mcgill.ca/familymed/files/familymed/interdisciplinary_clinical_process_diagnostic.pdf
- Quebec Alzheimer Plan Distinctive Features:
    - Patient-centered Diagnosis and Follow-up by treating Primary Care Team
    - Inter-professional Primary Care Team Trajectories
    - Development of Tools and Training
    - Collaborative Governance and Strong change management strategy
    - Developmental evaluation
- The timeline:
    - 2009 – plan is tabled
    - 2011 – Ministerial decision based on QC AD plan recommendations
    - 2011-12 Pre-implementation phase
    - 2012-16 Phase 1 – Targeted implementation with independent peer review evaluation to improve and scale up
        - Implementation projects in 40 Family Medicine Groups (FMGs) – urban, rural, remote chosen by competition
    - 2017-20 Phase 2 – Scaling up
    - 2021 Phase 3 – Post COVID; transitions; behavior manifestations
- Key messages, results and impact from the evaluation conducted by the ROSA research team:
    - Primary care (FMGs) can meet the needs of persons living with dementia and their care givers
        - Strengthen the capacity to detect, diagnose, manage, offering high quality care
        - Utilizing specialty care for complex cases
        - Diabetes vs. cancer model (using specialty services only for complex cases)
    - A person-centered interdisciplinary approach by the patient's treating MD/clinical team resulting in:
        - Improved continuity of care, higher intensity of follow-up, improved quality of care, fewer/more appropriate specialist referrals and decreased ED visits and hospitalizations
    - Room for improvement:

        - Antipsychotics prescriptions
        - Evaluation of caregiver needs
        - Referral to community services
    - At the FMG level
        - At the baseline there was very good to excellent clinical knowledge on the part of the physicians
        - There were positive attitudes to the disease, patient care, the Alzheimer plan
        - Strongly support/appreciate/use interdisciplinary approach and access to MD and nurse expertise within the FMG
            - Identification of a champion in the FMGs
        - Clinicians appreciated the pathway/guidelines, training as well as access to outside expertise
            - This led to an increase in competency and confidence
        - Critical about the delay to access memory clinic and home care
    - How these results could be explained from a policy point of view
        - Ministerial policy decision that the Quebec Alzheimer plan is a priority
            - Anchored in primary care
            - Based on a person-centered approach
            - Enable/empower the patient's PCP/FMG Team
        - This led to an implementation plan with an ambitious change management strategy associated with funding
            - Active ministerial role in inspiring, stimulating and supportive change
            - Ministère de la santé et des services sociaux leadership with inclusive stakeholder governance
            - Continued engagement of provincial champion who has triple credibility (clinical, scientific & political)
        - The Québec Alzheimer plan integrates
            - Diversity in application: one size does not fit all
            - An independent collaborative (developmental evaluation)
- Key messages from the initial implementation
    - A pre-implementation study and consultations with clinicians
    - Mobilization of clinical champions (1st line & 2nd/3rd line)
    - Capacity building strategies (training, dissemination of clinical tools etc.)
    - Commitment of university partners
    - 4 project managers to support the implementation
- Key messages for scaling up the initiative:
    - A sequential approach to implementation in 3 phases

    - Phase 1: shed light on innovative projects/approaches, mobilized clinicians and drew key lessons to support scaling up (phase II and phase III)
- Significant challenges
  - From targeted projects to generalization
    - Beyond initial innovations/leaders/champions
    - MD mobilization/buy-in
    - Regional governance and leadership
    - Specialist access
    - Personnel turnover
  - Maintaining clinical responsibility in later stages
    - At home and assisted living facilities
  - Transitions
  - Behavior manifestations
  - Role of persons living with dementia and their caregivers
  - Advent of biomarkers/disease modifying medications
  - Post-COVID
- The ROSA team embarked on a project with Healthcare Excellence Canada to gather the lessons learned from the Quebec experience and create knowledge translation toolkit
  - Policy and Implementation Experience
  - Strategies/tools for improved sustainable primary care capacity
  - Evaluation and governance framework
- A Canadian perspective for innovation in health system improvement in dementia care
  - Collaborative care model anchored in primary medical care closely linked and supported by specialty care; interdisciplinary clinical leadership
  - Paradigm for management of multiple chronic disease
  - Implementation projects with evaluation with the perspective of scaling up
  - Training for students, residents and grad students
  - Basis for ongoing Canadian and international research and policy development
- Dr. Claude Patry provided an overview of the journey of a patient. You can view this journey in the webinar recording beginning at 37:58.
- To learn more visit this website.

Discussion and Participation: Questions, Answers, and Comments/Suggestions.

Participants were invited to ask questions and engage in a discussion. Below is the list of questions asked and the responses.

Q: Were there incentives for the family medicine clinics to provide this care?

A: In the first phase yes, there was a specific budget given to the family medicine groups that were chosen to assist them with hiring additional staff. In the second phase the most effective incentive was giving support and training to the family medicine groups.

Q: What percentage of primary care providers in Quebec are part of family medicine groups?

A: 60-70% of primary care providers in Quebec are part of family medicine groups and this number continues to grow. There is a specific government policy to continue to invest in family medicine groups.