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Webinar Discussion Series - Community Dementia Care and Support:

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

Nov 17, 2020, Webinar Synopsis:

This webinar provided an overview of CFHI's Community Dementia Care and Support webinar discussion series**. Participants discussed two innovations:**

1. Rural Primary Health Care Memory Clinics
2. Rural and Remote Memory Clinic 2.0 (RRMC2.0)

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:

"Today a person's opportunity to be diagnosed well and live well with dementia depends on factors including their location, their ethnicity, their age and even whether they have a care partner with them. Two out of 5 Canadian physicians feel equipped and comfortable providing a diagnosis of dementia. To support people who require assessment then we need to support the Canadian family physicians who need help in diagnosing dementia. Canada's pathway is not easy to access or navigate, to connect people to the right health, social and rehabilitation supports needed immediately after diagnosis. Canadians need patient navigators to help them access supports and develop a care plan."

- Mary Beth Wighton

"As a result of COVID-19 we have begun to understand the role technology can play in supporting individuals. In the absence of a cure for dementia, technology-based solutions can promote cognitive heath and active lifestyles to delay the onset of cognitive decline and provide some assistance to those who have already experienced some level of impairment. The inclusion of technology innovation in the toolbox of Canadians facing dementia will ensure that the national dementia strategy is implemented with a forward-thinking mindset and takes into consideration the current and future needs of Canadians."

- Mimi Lowi-Young

Nov 17, 2020, Discussion Highlights:

(A) Presentation 1: Rural Primary Health Care Memory Clinics – Debra Morgan Ph.D., RN, Professor and Chair, Rural Health Delivery at the Canadian Centre for Health and Safety in Agriculture (CCHSA), University of Saskatchewan

- In 2004, the RaDAR team launched a specialist memory clinic at the University of Saskatchewan with the purpose of serving individuals living in rural Saskatchewan
- Due to the COVID-19 pandemic the Rural and Remote Memory Clinic (RRMC) is now being offered virtually
- In an effort to work with rural Primary Health Care (PHC) teams to develop an evidence-informed model for dementia care that is effective, feasible, sustainable & adaptable to diverse rural contexts a needs assessment was conducted that had the following findings:
    - Challenges in early identification and diagnosis
    - Lack of decision support tools and care pathways
    - Need for team-based care strategies for dementia
- They partnered with Sun County Regional Health to work with 4 PHC Teams to offer services to people living in rural areas
- The model is based on 3 domains found in best practices:
    - Interprofessional care
        - 1-day memory clinic (initial evaluation)
            - 2 patients can be seen per clinic day
            - Clinic day schedule (Team huddles, Team + Family Conferences, Individual Assessments, End of day Debriefing, Team + family conference including possible diagnosis and initial management)
        - Team composition:
            - Family Physician / Nurse Practitioner
            - Occupational Therapist / Physical Therapist
            - Social Worker / Home Care Nurse
            - Alzheimer Society First Link Coordinator
            - Primary Health Care Facilitator
            - Patient
            - Care Partner
    - Decision support tools
        - PC-DATA™ Primary Care Dementia Assessment and Treatment Algorithm (http://www.pcdata.ca/)
            - Based on most recent Canadian guidelines (CCCDTD5 including algorithms, visit flow sheets, education manual, education sessions)
    - Specialist to provider support
        - Education sessions 3-4 times/yr.
        - Remote support provided by RRMC Specialists:

        - Telephone administered neuropsychological battery and family interview used to tirage patients (Diagnosis by specialist RRMC team, diagnosis via remote collaborative care model, remotely delivered interventions from RRMC)
- Memory Clinic Teams
    - Kipling (Dec. 2017)
    - Weyburn (Sep. 2018)
    - Rural West (Nov. 2018)
    - Carlyle (Feb. 2020)
- RaDAR's role in spreading the clinics:
    - Developing & maintaining relationships with health authority leadership and management (inform about clinics, help RaDAR understand impact of regional re-organization, help identify new sites)
    - Public awareness
    - Adapt roles to clinics with different configurations
    - Hired NP and former team facilitator to support teams
    - Support mentorship across teams
    - Regional steering committee
    - RaDAR Memory Clinic Handbook
- RaDAR's role in sustaining the clinics:
    - Regular workgroup meetings with teams
    - Monthly check-in meetings with PHC facilitators
    - NP provides leadership and clinical mentorship
    - Former facilitator provides operational support
    - Provide resources (laptops, phone, MOCA training)
    - Targeted education sessions
    - Support team members to attend conferences
- Challenges to Scale-up/Spread:
    - Ongoing regional reorganization, leadership changes, competing priorities
    - Different EMR systems
    - Lack of human resources in some teams
    - Understanding and standardizing roles across teams
    - COVID-19 pandemic
    - Distance from teams
    - Wanting model and tools to be well-tested before wide scale-up
- To learn more about Rural Primary Health Care Memory Clinics visit their webpage.

(B) Presentation 2: Rural and Remote Memory Clinic 2.0 – Megan E. O'Connell, Ph.D., R.D.Psych, Associate Professor, Department of Psychology, University of Saskatchewan

- Rural and Remote Memory Clinic (RRMC) intervention: a suite of remotely delivered interventions
    - Sleep treatment
    - Cognitive rehabilitation
    - Driving cessation
    - RuralCARE App
    - Indigenous Caregiver Support Group
    - Social Network Intervention
    - Alzheimer Society of SK Navigators
        - First Link Program
        - Individual Support
        - Learning Opportunities
        - In-person Support Groups
        - TeleHealth Support Groups
        - Support for Clients with Complex Care Needs
        - Connection to Community Resources
- RRMC 2.0 is a triage and collaborative care model where RRMC specialists remotely engage with primary care providers to support a diagnosis of dementia
- This began just as the pandemic was beginning.
- The model is based on interviews with stakeholders, those with lived experience and rural healthcare providers
- People living with dementia or their families can make self-referrals to RRMC 2.0 and therefore do not need a physician referral.
- RRMC 2.0 staff are clinical psychologists with training in clinical neuropsychology
- There is a lack of standardization in cognitive assessment procedures in primary healthcare which can limit the implications of those tests. There was a need for a service that is centralized and uses technology that is accessible to people living in rural and remote areas.
- The service is telephone based as it is more accessible to people living in rural and remote regions than a stable internet connection and the team has access to good quality cognitive assessment tools that are valid for telephone use.
- A physical exam does need to be performed in-person asynchronously which requires a collaborative care approach to diagnosis.
- The collaborative care model allows for the diagnosis to be made collaboratively between the primary healthcare provider and RRMC 2.0. The level of involvement of the primary healthcare provider is to their discretion, however the primary healthcare provider needs to rule out medical causes before a clinical psychologist can made a diagnosis of dementia.
- To learn more about Rural and Remote Memory Clinic 2.0 visit their webpage.

(C) 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: Is there an identified point of contact for the person receiving the diagnosis and their family?

A: The physician or the nurse practitioner is generally the point of contact.

Q: Where can we find the articles that were mentioned in the Rural Primary Health Care Memory Clinics presentation?

A: Morgan, D., Kosteniuk, J., Seitz, D., O'Connell, M., Kirk, A., Stewart, N., . . . Sauter, K. (2019). A five-step approach for developing and implementing a Rural Primary Health Care Model for Dementia: A community–academic partnership. Primary Health Care Research & Development, 20, E29. doi:10.1017/S1463423618000968

Morgan, D., Kosteniuk, J., O'Connell, M.E. et al. Barriers and facilitators to development and implementation of a rural primary health care intervention for dementia: a process evaluation. BMC Health Serv Res 19, 709 (2019). **https://doi.org/10.1186/s12913-019-4548-5**

Q: How many families can currently be seen in one day?

A: Two patients and their families can be seen in one day. Each assessment takes about half a day therefore one assessment is conducted in the morning and the other in the afternoon.

Q: Is the support available through to end of life?

A: There are no limits on how long the team can provide care. The patients seen in the memory clinics are patients seen by that primary care team and therefore that care is continuous.

Q: Are all EMRs in Saskatchewan the same, and if not, how were the flow sheets adapted for use in different practices?

A: There are two EMR systems used in Saskatchewan. The flow sheets are currently only on one EMR system however we are working with the Ministry to understand how we can adapt the flow sheets in order to make them accessible on the other EMR system in the province.

Q: Is there a wait list for the clinic? If yes, how long is it?

A: RRMC 2.0 currently has a waitlist of 10 patients. There are four teams that currently provide the Rural Primary Health Care Memory Clinics and so the wait times vary based on the team. The wait is not generally long as the team is only seeing patients from their practice. Some teams are now accepting referrals from outside their practice and they are tracking these referrals to see how it affects demand for the service.

Q: Would a 24/7 dementia help line be a complementary support to mitigate both waiting time and lack of support in remote and rural jurisdictions?

A: The primary health care clinics do not run a helpline, but the Alzheimer Society does provide that support**.**

Q: Is the health authority interested in integrating with the memory clinic and using their clinicians?

A: The physicians at the rural and remote primary healthcare memory clinics are physicians from the region. They are the regular providers for that community. One of the strengths of these clinics is that patients and families are comfortable with the providers since they already know them.

Q: What are your goals to ensure tools will be tested before spread? What was the threshold? Any insights to share with this group from that process and decision making?

A: The PC Data EMR flow sheet tools were adapted based on the tools developed by Dr. Dallas Seitz in partnership with the team members. The process was done collaboratively, and it took many years. The flow sheets were adapted until there was a standardized set that worked for teams that had different configurations.