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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 22, 2021, Webinar Discussion Summary

June 22, 2021, Webinar Synopsis:

During this webinar Shelly Doucet and Alison Luke shared an overview of how their pediatric patient navigation model could be used to improve access to post diagnostic support for people living with dementia, their care partners and care team in New Brunswick, and other jurisdictions.

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 standard of care and access to timely diagnosis continues to vary across Canada. Today a person's opportunity to be diagnosed well and live well with dementia depends on factors including their location, ethnicity, age, and whether they have a care partner living with them with an understanding of the system itself. Once a diagnosis has been made each person and their care partner should be offered a consistent level of post-diagnostic support that is in line with recommended care. All people living with dementia and their care partner should be supported by a named coordinator of care to allow them to co-create a meaningful care plan in which they feel invested. Good dementia care should be personalized and life-long."

- Mary Beth Wighton

"The importance of the Covid-19 pandemic has demonstrated greater resilience and adaptability by health and support services providers across the system. This has led to greater interconnection and willingness for healthcare and support providers to work together. Many of the barriers seem to have diminished resulting in greater collaboration."

- Mimi Lowi-Young

June 22, 2021, Discussion Highlights:

Presentation: Exploring Patient Navigation for People with Dementia, their Caregivers and the Care Team in Canada

- Background:
  - Current system is fragmented
  - Populations with complex care needs can experience many gaps and barriers
  - This can affect health outcomes
  - Patient navigation is a model of care that can improve care integration
- Patient Navigation (PN)
  - Developed in 1990
  - The central premise is to guide, support, and orient patients through the healthcare system, matching patient's unmet needs to appropriate resources to decrease fragmentation, improve access, and promote the integration of care
  - It's patient-centred and supports the timely movement though a maze of fragmented services and program across settings and sectors
  - A patient navigator can be a professional or lay person
- Our past work with PN
  - NaviCare / SoinsNavi
  - NB Trauma Program
  - Most recently – Dementia
  - Scalability
    - Type of navigator
    - Setting / populations
    - Mode of delivery
- Current project:
  - An environmental scan of patient navigation programs for people with dementia, their caregivers, and the care team across Canada
  - A scoping review on PN for people with dementia, their caregivers and the care team
  - A needs assessment in New Brunswick to examine how PN can be implemented in the NB context for people with dementia, their caregivers and the care team
- Key findings: Environmental Scan
  - 14 dementia navigation programs in Canada
  - Information on:
    - Program services
    - Target population
    - Team composition
    - Setting
    - Method of delivery
    - PN title
    - PN training
    - Outreach
    - Referral
    - Evaluation
- Key findings: Scoping Review

    - 34 articles included in review
    - Information on:
        - Article type
        - Program description / services
        - Geographic location / setting
        - Target population
        - Team composition
        - Method of delivery
        - PN title
        - Main findings
        - Facilitators and barriers
- Key findings: Needs Assessment
    - 25 interviews across a variety of stakeholder groups
    - Themes grouped by:
        - Challenges with navigation
        - Goals of dementia care navigation
        - Who is the dementia care navigator?
        - Barriers to dementia care navigation
        - Opportunities for dementia care navigation
- Next steps
    - Implement a PN program for people with dementia, their caregivers and the care team in New Brunswick
        - Co-design phase
            - 6 months
            - Plan program
            - Plan for sustainability
        - Implement PN program
            - 12 months
            - 8 PNs embedded in clinics across NB
            - 3 Facebook navigational support groups
        - Evaluate program
- Resources to develop a patient navigation program
    - Environmental scan report
    - Scoping review report
    - Needs assessment report
    - Needs assessment methodology
    - Toolkit to implement a navigation program
        - Intake forms
        - Welcome emails
        - Policies
        - Information authorization form
        - Information for setting up a patient and family advisory council
        - Evaluation tools
- We can provide support with

    - Needs assessments
    - Implementation
    - Evaluation
- 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: Do you have an evaluation framework for the impact of the project?

A: We have the evaluation framework we used when we developed NaviCare which is the program that was serving children and youth populations. We can use a similar evaluation framework. Evaluating the effectiveness of navigation can be challenging. The approach that has worked for us is for the Patient Navigator and the client to set some goals together following the intake process and we can access if those goals were met. We also set up a satisfaction survey to understand if people were satisfied with the services they received through the patient navigation program. We also set up follow-up interviews with individuals to assess what their experience was with the patient navigation process, the patient navigator and if the programs they were connected with were useful.

Q: How were you able to embed patient navigation in primary care clinics?

A: Because we have experience building case manager roles in primary care clinics, so we've already built relationships with those involved in health administration and decision making. We met with folks across the province that we have partnerships with, and we engaged them very early on as we were developing the project to see which sites might be interested in implementing a patient navigator within their site. There were more sites who were interested in implementing a patient navigator than we had the capacity to support. In New Brunswick there is a keen interest in implementing them within the clinics and even providing in-kind support for space and other resources. They see it as an opportunity to alleviate the strain that many of the care providers are facing within their practices because they know they don't have the time or capacity to meaningfully care for these patients in the way that they hope to, so they see as an opportunity for their clients to receive optimal care but it also frees up their time so they can help their clients with other needs.

Q: Did you come across information that supports a dual model of virtual and in-person support?

A: It is more common than not to have a dual model. The literature shows that it's important to have telephone and web-based support as well as in-person. It ensures the services are patient-centered and personalized.