

Piloting patient navigation for people with dementia, their caregivers/care partners, and members of the care team

Summary

- Dementia rates among Canadians are on the rise. As a result, dementia care has become an increasingly important issue for many families and healthcare providers.
- Dementia care can be complex and challenging, as there are many factors to consider. In addition to addressing the physical, emotional, and cognitive needs of the person living with dementia (PwD), it is also important to consider the needs of their caregivers/care partners.
- Seeking support and guidance from healthcare professionals, support groups, and other resources, such as patient navigation (PN) services, can be helpful in managing the many challenges that come with living with dementia and caring for someone with dementia.
- Navigating Dementia NB/Naviguer la démence NB is a program that aimed to guide PwD and their caregivers/care partners through the health and social care systems. The program helped to align their needs with appropriate services by connecting PwD and caregivers/care partners with services, providing information resources about dementia and care planning, and offering emotional support.
- The purpose of the evaluation was to assess the effectiveness of the PN pilot program at supporting participants to navigate health and social services, improving health and system outcomes, and enabling aging in place.
- Six patient navigators worked in primary care clinics/health centres throughout NB and provided services to 150 participants (PwD and caregiver/care partner dyads).

HSPF Focus Area
Project Start & End Date
Organization/Agency
Location

Developing innovative care pathways
 March 16, 2022-March 31st, 2024
 University of New Brunswick
 Province-wide [Horizon Health Network: Albert County Community Health Centre (Zone 1), Rogersville Health Clinic (Zone 1); Fundy Health Centre (Zone 2); Queens North Community Health Centre (Zone 3), Fredericton's Primary Health Care Network (Zone 3)]; [Vitalité Health Network: Lamèque Community Health Centre (Zone 6)]

Principal Investigator(s)

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Indicator	Impact / Outcome / Result	Quote
<p>Improved knowledge and access to services and resources for PwD, their caregivers/care partners, and the care team</p>	<ul style="list-style-type: none"> • The following findings emerged from the post-intervention participant surveys (n = 54). After working with the navigator: <ul style="list-style-type: none"> ○ 75% reported a greater knowledge of relevant services and resources. ○ 74% said they had greater access to services and resources. ○ 79% said they were satisfied with the informational resources they received. ○ 84% said they were satisfied with the patient navigator, overall. • Despite these positive findings, many interviewees indicated that even with the help of the navigators, they continued to experience barriers to accessing services within the NB health and social care systems (e.g., ineligible for services, long wait times). 	<p><i>"It was great. I've recommended it to several people already. The system shouldn't be this complicated, but as long as it is, navigators are essential. Everyone should know about and have access to this program. It's a huge benefit to both the person with dementia and their care partners."</i></p>

Indicator	Impact / Outcome / Result	Quote
Decreased Isolation	<ul style="list-style-type: none"> 65% of survey respondents said that working with a patient navigator helped reduce their feeling of isolation and loneliness. Several interviewees suggested that the patient navigators offered emotional support, which helped them feel less overwhelmed while caring for an individual living with dementia. 	<p><i>"So, the program with the dementia, the program, only lasted four months, so it wasn't very long, but I felt that with it, there was someone looking after us, that I wasn't all alone. In addition to my children, I had them."</i></p>
Improved experiences with health and social care systems	<ul style="list-style-type: none"> The following findings emerged from participant interviews (n = 36): <ul style="list-style-type: none"> the navigator provided appropriate informational support to participants. the navigator helped participants access appropriate supports and resources. the navigator was accessible and proactive in follow-ups with participants. Participants felt supported by the navigator throughout their care journey. Post-intervention survey findings indicate that 74% of participants agreed they had increased confidence navigating health and social care systems as a result of working with the navigator. 	<p><i>"Oh yeah! And it's [health care] ...as you said...fragmented, that...do you not have someone to give you all of that information? You're over here in a pile, and you're over here in a pile. It was nice to just go in and talk to just her, and being able to say, this is what's next; this is what you can expect; this is what the assessment will look like. You know that kind of stuff. "</i></p> <p><i>"The navigator was incredible! She knew her way around the system...she knew what to do, when to do it. She knew...I don't know how she did it? But she knew what she was doing, and she accomplished things quickly and efficiently."</i></p>

Methods and Comparison

The project used both quantitative and qualitative methods. Data was collected from patient navigator charts, satisfaction surveys, semi-structured interviews, and focus groups. The findings presented herein are based on 36 participants interviews, 54 post-intervention participant surveys, and 3 focus groups with project stakeholders (research team, patient navigators, patient and family advisory council).

Conclusions and Lessons Learned

- The findings suggest that the PN approach can help provide important guidance and support to PwD and their caregivers/care partners by improving their knowledge of available services, improving access to services, improving the experience of navigating complex social and health care systems, and reducing the burden on caregivers/care partners.
- Participants were mostly satisfied with the services offered by the patient navigator and agreed that the PN service provided important information and resources. However, many participants faced financial barriers and/or delays in accessing some services due to longer wait times.
 - Support for those with limited financial means should be more accessible within the NB health and social care systems. Relying solely on navigators is not enough if services and resources are unavailable. System-wide changes are necessary to help more people access the support they need.
- Participants suggested the PN program would be more beneficial if it was implemented sooner in the care process. For instance, many participants suggested that they had already reached the crisis point before engaging with the patient navigator.
- One of the major barriers faced by the team was the fixed timeline to implement the project. Building patient-partner relationships and interacting directly with clinics/health centers and care providers required more time.

Recommendations

- Integrate patient navigators into primary care in NB, with close connections to the Alzheimer Society NB and Geriatric Medicine.
- Although virtual delivery of the patient navigation intervention benefitted the participants in rural areas, the recommended approach is to include an in-person component and to incorporate the option for home-visits.
- Revise the Department of Social Development “co-pay” amount so that middle-income families can access the services related to homecare and long-term care services through Social Development.
- Decrease the wait times for long-term care placement by speeding up the process of the “History and Physical” form. Extramural nurses could complete these forms instead of physicians or nurse practitioners to avoid delay in the process.

Next Steps

- A database of resources and services was created for participants in each region. The navigators could access the forms for their participants (e.g., financial forms, program registration forms) which are not available outside the project. These documents and lists can be used to improve existing resource guides available in New Brunswick.
- The project team and the Government of New Brunswick are discussing the possibility of further funding and resources to expand the program to other areas of NB. They have also collaborated with several other clinics across NB to sustain the project.

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