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Piloting Patient Navigation for Dementia: A Mixed-Methods Study in Primary Care

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Article

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Abstract

Background: Dementia care is often fragmented and difficult to navigate. Patient navigation is a promising solution to support individuals with dementia and their care partners.
Objective: A bilingual patient navigation program was piloted in New Brunswick, Canada, embedding six patient navigators in primary care clinics across the province.
Methods: A mixed-methods study explored participant characteristics, satisfaction, and experiences with the program.
Findings: Among 150 navigation cases, primary needs included access to informational resources and social services. Survey results showed high overall satisfaction with the program, along with improved knowledge and access to dementia-related health and social services. Qualitative findings further emphasized that patient navigators successfully linked participants to appropriate resources and services while also reducing care partner burden. However, systemic barriers such as long wait times and financial constraints persisted.
Discussion: This study highlights the need for early intervention and sustained navigation support to enhance dementia care coordination and accessibility in aging populations.

Résumé

Les soins liés à la démence sont souvent fragmentés et difficiles d'accès. L'orientation des patients est une solution prometteuse pour soutenir les personnes qui vivent avec la démence et leurs proches aidants. Un programme bilingue d'orientation des patients a été piloté au Nouveau-Brunswick, Canada. Six conseillers en orientation ont été affectés à des cliniques de soins primaires dans l'ensemble de la province. Une étude à méthodes mixtes a examiné les caractéristiques, la satisfaction et les expériences des patients qui ont bénéficié du programme. Parmi les 150 cas d'orientation, les principaux besoins comprenaient l'accès à des ressources d'information et des services sociaux. Les résultats du sondage ont montré un haut degré de satisfaction générale à l'égard du programme, ainsi qu'une amélioration de la connaissance et de l'accès aux soins de santé et aux services sociaux liés à la démence. Les conclusions qualitatives confirment que les conseillers en orientation ont réussi à mettre en rapport les patients avec des ressources et des services appropriés, tout en allégeant le fardeau des proches aidants. Cependant, des obstacles systémiques comme les longs délais d'attente et les contraintes financières persistent. Cette étude souligne la nécessité d'une intervention précoce et d'un soutien en orientation permanent afin d'améliorer la coordination et l'accessibilité des soins liés à la démence parmi les populations vieillissantes.

Background

Worldwide, around 55 million individuals are living with dementia, and this number is anticipated to increase as the global population continues to age (CanAge, 2022). In Canada, the prevalence of dementia is rising quickly; currently, over 600,000 people are affected, and this figure is expected to triple over the next three decades (Alzheimer Society of Canada, 2022). Individuals with dementia and their care partners often face substantial challenges, including limited knowledge about dementia, difficulties accessing health and social care services, and a lack of coordinated support (Bernstein et al., 2020; Canadian Academy of Health Sciences, 2018; Macleod et al., 2017; Smith et al., 2021; Stephan et al., 2018).

Health and social care providers, while incorporating elements of coordination and navigation into their roles, frequently lack the necessary time, training, or resource awareness to effectively support individuals with dementia and their care partners as they manage various aspects of care (Heintz et al., 2020; Mansfield et al., 2019; Perales-Puchalt et al., 2023). This gap underscores the urgent need for targeted strategies to address the multifaceted needs of this population. One such promising approach is patient navigation, a person-centred strategy

designed to assist individuals in navigating complex health and social care systems by identifying barriers and connecting individuals with appropriate resources (Kokorelias et al., 2021; Valaitis et al., 2017).

Patient navigation is a flexible model of care that can be delivered by a range of providers, including health care professionals or trained laypersons and is often embedded in hospitals, community centres, or social services (Kelly et al., 2019; Kokorelias et al., 2021; Valaitis et al., 2017). This model of care supports patients by providing services such as care coordination, psychosocial support, education, advocacy, and help accessing appropriate resources (Kelly et al., 2019; Kokorelias et al., 2021; Valaitis et al., 2017). At its core, patient navigation emphasizes the development of a collaborative partnership between the patient, their family or care partners, and the navigator (Kokorelias et al., 2021). Indeed, although these programs vary widely in structure, responsibilities, and training backgrounds of navigators, they all share a foundational commitment to tailoring support to individual needs (Kelly et al., 2019; Kokorelias et al., 2021; Valaitis et al., 2017).

A growing body of evidence supports the potential of patient navigation in dementia care, including its feasibility and cost-effectiveness in supporting this population (Bernstein et al., 2019; Bernstein et al., 2020; Giebel et al., 2023; Kokorelias et al., 2023c; Possin et al., 2019). A recent systematic review of patient navigation programs for individuals with dementia and their care partners has highlighted numerous benefits, including delayed institutionalization, reduced care partner burden, and enhanced care partner self-efficacy (Kokorelias et al., 2023c). Recent scoping reviews have shown that successful patient navigation programs incorporate key elements such as tailored information support, service referrals, care coordination, and the involvement of trained staff specializing in dementia care (Anthonisen et al., 2023; Kokorelias et al., 2023b). Collaboration across health and social care providers further enhances the effectiveness of these programs, particularly when delivered through diverse modalities (e.g., in person, phone, online) to accommodate individual needs (Anthonisen et al., 2023; Kokorelias et al., 2023b). The integration of patient navigation into dementia care holds promise not only as a practical and cost-effective strategy, but also as a scalable model that centres the voices, goals, and needs of those most impacted.

The current study

In New Brunswick, an Atlantic Canadian province with one of the oldest populations in the country, dementia care poses unique challenges. The province's population of approximately 775,610 includes a high proportion (22.8%) of residents aged 65 or older (Statistics Canada, 2021). An estimated 11,800 individuals in the province are living with dementia (Alzheimer Society of Canada, 2022). However, dementia care in New Brunswick is often fragmented, uncoordinated, and difficult to navigate, particularly in rural areas where services are limited (Bayly et al., 2020; Canadian Academy of Health Sciences, 2018). Although the New Brunswick Aging Strategy emphasizes person-centred care and support for seniors (Council on Aging, 2017), a recent CanAge report (2022) suggests that the province remains unprepared to address the needs of individuals with dementia and their care partners. These shortcomings highlight the critical need for effective navigation services to support aging in place and enhance care access and coordination across the province.

To address these challenges, the present study piloted a bilingual patient navigation program in New Brunswick and explored its implementation and outcomes (Doucet et al., 2024). The program aimed to support individuals with dementia, their care partners, and care providers through a combination of in-person and virtual navigation services, ultimately seeking to improve health and system outcomes. Specifically, this mixed-methods study addressed the following research questions:

1. What were the characteristics of participants who took part in the dementia patient navigation program?
2. To what extent were participants satisfied with the dementia patient navigation program?
3. What were the experiences of participants in the dementia patient navigation program?

Methods

Study design

The complete details of the intervention and study design are outlined in a published protocol (Doucet et al., 2024). This study employed a mixed-methods design to explore participant characteristics, satisfaction, and experiences with the program. Quantitative data were collected through patient navigation chart reviews and post-intervention surveys completed by intervention participants. To complement and enrich these findings, qualitative data were gathered through individual, post-intervention interviews with a subset of participants, using a qualitative descriptive design. This approach allowed for the generation of clear, low-inference accounts of participants' experiences, remaining close to their own language and perspectives (Bradshaw et al., 2017; Kim et al., 2017). The integration of quantitative and qualitative data provided breadth and depth to our understanding of participant experiences with this intervention.

This study was situated within a pragmatic research paradigm, which emphasizes the use of methods best suited to addressing specific research questions and informing practical improvements in real-world contexts (Creswell & Creswell, 2018). Pragmatism supports methodological flexibility and is particularly well aligned with our use of qualitative description, which is grounded in the goal of providing clear, accessible accounts of participant experiences without extensive theoretical interpretation (Bradshaw et al., 2017; Kim et al., 2017). Pragmatism does not require adherence to a single ontological or epistemological stance; rather, it permits the integration of multiple perspectives that support the applied goals of the research (Creswell & Creswell, 2018).

Study setting

This patient navigation program was implemented in New Brunswick, Canada. New Brunswick offers a combination of publicly funded and private services to support dementia care. The province's two regional health authorities provide a continuum of publicly funded care that includes hospital services, geriatric and restorative care units, and outpatient geriatric and memory clinics. Professional home health care services (e.g., nursing, physiotherapy, occupational therapy, and other allied health services) are delivered by the New Brunswick Extra-Mural Program, which is also publicly funded. The Department of Social Development oversees programs such as home support services (e.g., personal care, meal preparation, housekeeping) delivered by private home care agencies, specialized memory care facilities, and assisted living and long-term care facilities. Many of these services are partially

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subsidized based on needs assessments and client contributions. Non-profit community organizations such as the Alzheimer Society of New Brunswick run a referral-based early intervention service that helps newly diagnosed individuals and care partners find supports. In addition, a range of private services, such as home care, respite services, meal delivery, personal emergency response systems, and assistive technology, are available for out-of-pocket payment or through private insurance.

This patient navigation intervention was embedded within New Brunswick's two regional health authorities and was offered at no additional cost to patients. Navigators were situated at six primary care sites across the province: four Anglophone sites and two Francophone sites. This pilot patient navigation program was developed with input from patients, regional health authorities, and other key informants to tailor the navigator role to local communities. Patient navigators were individuals with backgrounds in health or social care (e.g., nursing, social work), and all navigators completed mandatory training for their role in this intervention. This training included completion of a Patient Navigation Certificate course, which was offered virtually through a Canadian academic institution, and a series of learning modules offered by a provincial Alzheimer Society. The training ensured a standardized level of patient navigation skills across all sites, while allowing navigators to provide adaptable, person-centred navigation.

Participants and recruitment

To be enrolled in the current study, participants had to reside in New Brunswick and live in the community (i.e., not in a long-term care facility or adult residential care facility). Individuals could participate if they had a diagnosis of dementia, were actively seeking services to obtain a diagnosis, or were in the process of receiving a dementia diagnosis. They could enrol on their own or with a care partner. A care partner participant was an individual who provided informal and unpaid care or support for an individual with dementia. A care partner could enrol on their own, seeking support either for themselves or to enhance the informal care they provide.

Advertisements about the study were circulated in print (e.g., program brochures, provincial newspapers, and community newsletters) and through social media forums (e.g., Facebook). Referrals to the patient navigation program were facilitated through the clinic sites and through community outreach, which included specialist and primary care practitioner offices. The patient navigators also received referrals through the First Link® program offered by the Alzheimer Society of New Brunswick. Potential participants were directed to the patient navigator in their region for more information about the navigation service and the study.

Data collection

All study procedures were reviewed and approved by the Institutional Review Boards at the University of New Brunswick (No. 2022–060), Horizon Health Network (No. 2022–3106), and Vitalité Health Network (No. 101 562). Individuals interested in participating in the patient navigation program were provided with an informed consent form explaining that this intervention was part of a research project. Prospective participants were required to provide consent to enrol in the patient navigation program and agree to have their data collected for research purposes.

Navigation Chart Data. Patient navigators collected participant data and stored it in a secure database (i.e., University of New Brunswick SharePoint) that was accessible to designated members of the research team. This information was collected for the purposes of the patient navigation program and was not linked to paper or electronic health records. The following data were collected from each navigation chart: demographic information, dementia diagnosis information (if applicable), self-identified health and social needs/goals, number/type of goals met/not met, number of calls/e-mails, number of meetings, as well as the number and type of services and resources the client was successfully connected with.

Post-Intervention Survey. When a participant was discharged from the patient navigation program, the study coordinator sent the participant a follow-up survey. The survey was completed either online using Qualtrics XM or as a paper copy via post mail. This 38-item survey was developed by the research team, which included knowledge users such as health care providers and individuals with lived experience as informal caregivers for individuals with dementia. The questionnaire included items related to participant demographics, dementia diagnosis, and satisfaction with the program. The survey questions were rated on a 5-point scale (very dissatisfied to very satisfied) and assessed satisfaction with the patient navigator; satisfaction with the services they received; satisfaction with navigation materials and resources received from the navigator; knowledge of health and social services and resources; access to health and social services and resources; confidence in ability to navigate health and social care systems; social isolation and loneliness; perceptions of supports and clinical care in place to help the individual with dementia age in their community; and communication and care integration with the care team. Given its intended use for descriptive rather than inferential purposes, the questionnaire was not formally validated; however, it was shaped by the expertise and perspectives of key knowledge users to ensure relevance and appropriateness for the current context.

Semi-Structured Interviews. When a participant was discharged from the patient navigation program, the study coordinator sent the participant an invitation to take part in an individual interview with a member of the research team. The semi-structured interview guide was developed by the research team and included 12 questions to assess participants' experiences with the patient navigation program. These questions related to knowledge gained, resources and services accessed, and interactions with the patient navigators. All interviews took place via telephone or via video conferencing and were audio recorded and saved on a secure database (i.e., University of New Brunswick SharePoint).

Data analysis

Quantitative analysis

Chart data and satisfaction survey data were stored and analysed with the assistance of IBM SPSS Statistics (Version 29) software. Measures of frequency and central tendency were used to report participant characteristics and to describe the sample. Descriptive statistics were also used to assess participant satisfaction based on post-intervention survey data, with frequency counts (percentages) provided for overall levels of patient satisfaction and across various aspects of the patient navigation intervention.

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Qualitative analysis

The interviews were transcribed verbatim by a trained research assistant, and both the audio recordings and transcriptions were reviewed for accuracy. All transcripts were imported into NVivo 12 for organization and analysis. A thematic analysis, using a codebook approach, was employed to analyse interview data. While the overall study was guided by a pragmatic paradigm, our thematic analysis was informed by a critical realist ontology and a contextualist epistemology. We approached the data with the understanding that participant accounts reflect real experiences shaped by broader social and structural contexts, while also recognizing that knowledge is always situated and influenced by researcher interpretation (Braun & Clarke, 2022).

This thematic analysis was conducted following the phases outlined by Braun and Clarke (2022). In the first phase, the lead author (LM) became familiar with the data by listening to the audio recordings and highlighting relevant sections in the written transcripts related to the research questions. Next, two members of the research team (LM and AL) collaborated to generate initial codes and develop a coding guide based on a subset of transcripts (n = 6). This analysis focused on data at a semantic level to capture participants' explicit meanings as they were recorded and transcribed without extending far beyond surface interpretations (Braun & Clarke, 2022; Braun & Clarke, 2023). LM then applied this coding guide to analyse the full data set, allowing for the addition of new codes during the process. In the third phase, the codes were used to develop broader themes. In this analysis a theme captured a shared topic, reflecting the most frequently mentioned aspects of participants' experiences with the patient navigation program (Braun & Clarke, 2023). During phases four and five, these themes were reviewed and discussed by three co-authors (LM, AL, and SD) and were named and defined through consensus. Finally, the preliminary analysis was written up and feedback was gathered from all authors. Our sample size was determined by participant uptake within the intervention, rather than by the pursuit of thematic saturation. All individuals who participated in the intervention were invited to take part in a follow-up interview, and data collection continued until no additional participants agreed to be interviewed. This approach reflects the study's pragmatic design and our aim to gather as many perspectives as possible within the constraints of participant availability, rather than to achieve theoretical completeness. This codebook thematic analysis enabled us to produce descriptive results that are accessible and actionable for practitioners and decision makers (Braun & Clarke, 2022).

Results

Participant characteristics

Participants included 150 cases. Most cases were dyads (n = 137), where an individual with dementia and their care partner sought services together as one case, while a small number of care partners (n = 9) and individuals with dementia (n = 4) participated in the study on their own. Demographic information for individuals with dementia was not collected in cases where only care partners participated, as these care partners did not have legal authority to provide personal details, and consent could not be obtained from the individuals with dementia themselves. Table 1 summarizes demographic characteristics of the participants.

Table 1. Participant characteristics (N = 150)

Persons with dementia (PWD; n = 141)	
PWD location (*n* = 140)	
Rural	85 (60.7%)
Urban	55 (39.3%)
PWD gender (*n* = 141)	
Female	73 (51.8%)
Male	68 (48.2%)
PWD age (*n* = 139)	Range: 43–96 years (M = 76.77, SD = 9.21); Mdn = 78 (IQR = 13)
PWD primary language (*n* = 138)	
English	96 (69.6%)
Francophone	41 (29.7%)
Bilingual	1 (<1%)
PWD ethnicity (*n* = 136)	
Caucasian/White	134 (98.5%)
Indigenous/First Nations	1 (<1%)
Other	1 (<1%)
PWD diagnosis (*n* = 137)	
Alzheimer's disease	31 (22.6%)
Undefined dementia	28 (20.3%)
Mixed dementia	20 (14.5%)
Vascular dementia	16 (11.6%)
Lewy body dementia	5 (3.6%)
Mild cognitive impairment	5 (3.6%)
Frontal lobe dementia	3 (2.2%)
Early onset dementia	3 (2.2%)
Parkinson's dementia	2 (1.5%)
Korsakoff dementia	1 (<1%)
PWD years with dementia diagnosis (*n* = 137)	Range: 0–11 (M = 2.58, SD = 2.2); Mdn = 2 (IQR = 3)
PWD primary care provider (*n* = 150)	
No	13 (8.7%)
Yes	133 (88.7%)
Unknown	4 (2.7%)
PWD specialist (*n* = 150)	
No	74 (49.3%)
Yes	76 (50.7%)
Geriatrician	68 (89.5%)
Neurologist	8 (10.5%)
Care partners (n = 146)	
Care partner relationship to PWD (*n* = 143)	
Spouse	90 (62.9%)
Child	46 (32.2%)

(Continued)

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Table 1. *Continued*

Other	3 (2.1%)
Sibling	2 (1.4%)
Parent	2 (1.4%)
Caregiver location (*n* = 140)	
Rural	85 (60.7%)
Urban	55 (39.3%)
Care partner gender (*n* = 143)	
Female	105 (73.4%)
Male	38 (26.6%)
Care partner age (*n* = 133)	Range: 29–90 years (*M* = 66.19, *SD* = 12.65); Mdn = 68 (*IQR* = 21)
Care partner primary language (*n* = 142)	
English	98 (69.0%)
Francophone	42 (29.6%)
Bilingual	2 (1.4%)
Care partner ethnicity (*n* = 142)	
White/Caucasian	136 (95.8%)
Black/African Canadian	1 (<1%)
Indigenous/First Nations	2 (<1%)
Other	3 (<1%)

Note: Median = Mdn.
Participants were permitted to skip questions; thus, sample sizes vary across items.

Table 2. Patient navigation program usage by case (*N* = 150)

Referral source (n = 150)	
Provincial Alzheimer society	59 (39.3%)
Self-referral	28 (18.7%)
Study site	15 (10.0%)
Extra mural program	14 (9.3%)
Primary care provider	9 (6.0%)
Long-term care facility	2 (1.3%)
Other	23 (15.3%)
Program enrolment duration (days) (*n* = 150)	Range: 1–351 (*M* = 116.8, *SD* = 91.1); Mdn = 91.50 (*IQR* = 112)
Discharge reason (*n* = 146)	
Goals completed	106 (72.6%)
Pilot project ended	16 (11.0%)
Long-term care admission	8 (5.5%)
Lost to follow-up	7 (4.8%)
Partial goals completed	6 (4.1%)
Patient died	3 (2.1%)

Note: Median = Mdn.
Discharge reason was missing for four cases.

Patient navigation program usage

Participants reported a range of goals related to navigating dementia care, which were grouped into six higher-order categories. Of all goals reported, the most common category was accessing dementia-specific information and resources (27.8%). These goals included seeking general information about dementia as well as connections to supports such as the Alzheimer Society and the First Link® program. Accessing programs through the Department of Social Development accounted for 26.9% of all goals, and included assistance with home care services, long-term care placement, and referrals to other government-funded supports. Support for caregivers and individuals with dementia at home represented 21.2% of reported goals, encompassing emotional and instrumental support for caregivers, guidance on home safety, and emotional support for the individual with dementia. Information on advance care planning comprised 12.7% of total goals, including assistance with Canada Revenue Agency forms and support for future care planning. Goals related to community-based respite and support services made up 11.8% of the total and involved accessing adult day programs, respite care options, and services such as Lifeline and Meals on Wheels. Finally, 5.6% of reported goals focused on accessing home health care, including referrals to home health care services and other professional health care providers.

The number of goals per case ranged from one to nine (*Mdn* = 4, *IQR* = 3), with some participants identifying multiple goals within the same category. The majority of goals were achieved, with the number of goals completed per case ranging from zero to nine (*Mdn* = 4, *IQR* = 3). The number of unmet goals per case ranged from zero to three (*Mdn* = 0, *IQR* = 0). Among these unmet goals, the majority were related to accessing programs offered through the Department of Social Development. These goals often went unmet due to policy barriers within the current system, such as financial ineligibility (e.g., inability to afford program co-pays) or long wait times for services. Beyond this category, only two other unmet goals were noted, both concerning support for caregivers and individuals with dementia at home, specifically, a grant application for home repairs and the absence of local support groups. Additional program usage data are summarized in Table 2.

Satisfaction surveys

Fifty-six participants returned satisfaction surveys. The survey sample consisted predominantly of care partners (*n* = 53), ranging in age from 42 to 86 years (*M* = 65.9, *SD* = 11.1), with 82.1% identifying as Anglophone and 78.6% identifying as female. Although survey respondents self-selected to complete the survey, the proportion of survey respondents from each site was similar to the distribution of participants enrolled at each site, indicating that the feedback is likely representative across sites. A large minority of participants (48.2%) reported that their primary communication method with the patient navigator was in-person, while 21.4% reported communicating mainly through telephone, and 19.6% communicated primarily through e-mail. Another 10.7% of participants reported using multiple communication methods regularly. Most participants (78.6%) reported being very satisfied or somewhat satisfied with their primary method of communication. The majority of participants felt they had the right amount of contact with the patient navigator (89.3%), while 10.7% felt that they had too little contact with the patient navigator.

General levels of satisfaction were high, with 82.2% of participants reporting being very satisfied or somewhat satisfied with the program overall. The majority of participants reported that all

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Table 3. Patient navigation program satisfaction scores (N = 56)

	Strongly agree	Somewhat agree	Neutral	Somewhat disagree	Strongly disagree
Satisfied with the health care services and/or social services received (n = 55)	29 (52.7%)	9 (16.4%)	9 (16.4%)	–	8 (14.5%)
Satisfied with the materials and resources received (n = 56)	32 (57.1%)	7 (12.5%)	5 (8.9%)	1 (1.8%)	4 (7.1%)
Improved knowledge of health and/or social services and resources (n = 56)	29 (51.8%)	12 (21.4%)	8 (14.3%)	2 (3.6%)	5 (8.9%)
Improved access to health and/or social services and resources (n = 55)	27 (49.1%)	14 (25.5%)	10 (18.2%)	1 (1.8%)	3 (5.5%)
Improved confidence in ability to navigate health and/or social care systems (n = 55)	27 (48.2%)	13 (23.2%)	10 (17.9%)	1 (1.8%)	5 (8.9%)
Improved communication with health and/or social care provider(s) (n = 53)	20 (37.7%)	9 (17.0%)	16 (30.2%)	2 (3.8%)	6 (11.3%)
Improved collaboration with health and/or social care provider(s) (n = 52)	16 (30.8%)	13 (25.0%)	17 (32.7%)	1 (1.9%)	5 (9.6%)
Decreased feelings of social isolation and loneliness (n = 55)	24 (43.6%)	12 (21.8%)	14 (25.5%)	–	5 (9.1%)
Increased ability to age in the community (n = 53)	22 (41.5%)	5 (9.4%)	17 (32.1%)	2 (3.8%)	7 (13.2%)

Note: Participants were permitted to skip questions; thus, sample sizes vary across items.
'Satisfied with the materials and resources received' row does not add to 100%, as 12.5% of participants reported they did not receive materials or resources.

(35.7%), most (30.4%), or some (23.2%) of their needs had been met, while a small minority (10.7%) reported that their needs had not been met by the program. Participants reported moderate to high satisfaction with various aspects of the patient navigation program. They were satisfied with the health and social care services they received as a result of the program, the materials and resources provided by the navigator, and the enhanced knowledge of available services and resources. They also noted improvements in accessing health and social services, communication with their care team, collaboration within the care team, confidence in managing their care, ability to age in their community, and reductions in feelings of social isolation and loneliness. Satisfaction ratings across these program outcomes are reported in Table 3.

Participant experiences

Thirty-seven participants completed interviews about their experiences with the program; all identified as a care partner of an individual with dementia. Five key themes were developed regarding care partner experiences with the patient navigation program. These themes include care partner burn-out, practical guidance and instrumental support, compassionate care and reassurance, systemic hurdles and roadblocks, and program challenges and limitations.

Care partner burn-out

Although our study focused on exploring the implementation of the patient navigation program, many participants spent considerable time discussing the overwhelming challenges they faced before entering the program. Care partners frequently described feeling isolated and unsupported, highlighting a significant lack of resources available to them before engaging with the navigation program. For example, one participant said: 'I am sorry, my life has been such a blur, because there are other things besides that happening. And… I am just exhausted' (Participant 6). A lack of support was evident, as one participant shared: '[Primary care provider] confirmed it [dementia diagnosis] by e-mail. So, after that, that was it, there was no follow-up, there were no pamphlets, there was no "what's next"' (Participant 27). This sentiment was shared by another participant, who said: 'There's nothing here. There's absolutely nothing here. I'm on my own' (Participant 3).

The burden of care was a central theme, with participants expressing the emotional and physical toll it took on them before they were connected with the navigators. One participant said:

> I was his only caregiver. And my daughter, who lives next door, she came when she could. It was a lot, but it was just getting to the point where it was day and night work for me. I couldn't sleep, I hadn't slept. It was just hard. (Participant 7)

Similarly, other participants shared: 'I seemed to be in a void. I was getting nowhere…and looking for some help to get through it' (Participant 10) and 'You feel so guilty about everything, because I know at one point, I just wanted my life back [emotional, crying]. I just wanted my life back!' (Participant 13).

Practical guidance and instrumental support

Once participants were enrolled in the navigation program, they found the provision of practical and informational support invaluable. A primary role of the patient navigators was connecting individuals with appropriate services. Participants noted that navigators took a proactive approach, handling tasks such as filling out paperwork for clients and communicating directly with health and social care providers with consent from the participant. One participant shared:

> She [patient navigator] helped me with the forms. She said, let's go down to the Social Development building right now, and let's do it. And so, I followed her down, and she was able to contact someone there, and those papers were taken in that day, and whatever it was I needed… So, it was all taken care of, and she was right there and did it. (Participant 6)

Another participant echoed this experience:

> I had talked to Social Development about the day program, she [patient navigator] made a phone call about that as well, and just followed up and made sure that we were in the system and that, you know, my application for that would go through… getting us on board and making sure that we were in the system. It was reassuring to know that she was kind of willing to go to bat for us. (Participant 2)

This hands-on support was seen as critical for navigating complex systems and ensuring participants had access to the care their loved ones needed. For example, one participant said:

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> The navigator was incredible! She knew her way around the system -not around it- but 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. (Participant 6)

Another participant emphasized the difficulty of navigating a complex system alone: 'It's just so complicated. They don't make it easy. And all the details… no, I wouldn't even know where to start. Like I said, if I hadn't had help (from the patient navigator), I wouldn't have even gone as far as I did' (Participant 5).

In addition to linking participants with appropriate resources, participants reported receiving informational resources from the patient navigator that helped them care for their loved one. For example, one participant stated:

> I just felt like I was going down a hole. And they kind of brought me out of it with all the resources that I could call, and it just empowered me with different information. So yeah, it was really meaningful to me for sure. (Participant 3)

The information provided was also seen as useful for future stages of the care journey. One participant shared: 'She gave me a lot of good information and reading about what I probably will need in the future. She was very good. She was very knowledgeable in what she was doing' (Participant 22). Similarly, another participant appreciated how the navigator saved them time and effort:

> Well, she's given me information to help me when I need it, so it's saved me a lot of work…to find out where I'm going with my questions, with information or with forms I need to fill out to get services or placement for example, later on I know that it's something I'll have to consider, that information, those documents. (Participant 34)

Compassionate care and reassurance

Emotional support was another prominent topic discussed in the interviews. Participants spoke extensively about the proactive care and consistent follow-through they received from their navigators. This support included regular check-ins and the physical presence of navigators when needed. For example, one participant said:

> Anything I've needed or asked for I could just call her [patient navigator] at any time you know she would call me back…. She understood anything you mentioned or brought up or anything, she understood it… she was easy to talk to. (Participant 22)

Another participant echoed this sentiment:

> You know as [patient navigator] often said: 'If you have a question, call me, if you're not sure, call me, I'll find you the information.' So already knowing that there's someone there to help you takes a weight off your shoulders. (Participant 36)

Participants also valued the encouragement and validation they received, which empowered and reassured them that they were not alone in their caregiving journey. One participant shared: 'It was all good. And it empowered me and made me feel like I could do this, instead of falling down a really dark hole and, you know, losing it. So, it's really important to me' (Participant 3). The emotional support also helped participants cope with difficult decisions, such as transitioning a loved one to a long-term care facility. One participant noted:

> My big thing that I needed help with at the time was the emotional part of it, how to help him [partner with dementia] transition from somewhat independent to nursing home and the – I guess for lack of a better word – the guilt associated with it and struggling with knowing if I'm doing the right thing. How do I know if now is the right time [for care placement]. (Participant 18)

Systemic hurdles and roadblocks

Participants also discussed the systemic barriers they encountered while they were working with the patient navigator. Despite the navigator's assistance, they continued to encounter obstacles, such as a lack of available resources, whether due to non-existent programs, or excessively long waitlists. One participant mentioned that a different program was hindering their ability to locate services:

> She [person with dementia] needed help at home and I wasn't able to find any, that's where it was difficult, it wasn't the [dementia program] or the person who was helping me, it was really the other person, the other program [government program]. (Participant 33)

Even when the navigator was able to connect participants with services, lengthy waitlists frequently prevented them from receiving the necessary support. One participant shared these frustrations over lengthy waitlists:

> I called them…they said… the waiting list is about two to three years. And I'm thinking, this is crazy. When you have something as serious as this, you need support. No question about it. And waiting for something else to go wrong. And things could go worse. It's frustrating in my opinion. (Participant 1)

When attempting to access the services the navigator connected them to, some participants also faced financial barriers that the navigator was unable to address. For example, participants reported high co-payments required by the Department of Social Development and out-of-pocket expenses for necessary equipment. One participant declared: 'It would have cost us $695/month for anything from Social Development for him [person with dementia]. And we just don't have that kind of money' (Participant 6). Likewise, another participant shared: 'They [government agency] said I'm making too much money on my pension. And I don't think I am…And if I get somebody in for two hours a day, it's gonna cost me $1400, a month' (Participant 25). These financial barriers led some individuals to delay necessary care for their loved ones and themselves. For example, one participant explained:

> But like I say, then I'm scared, when I do have to put her in a home or something there is -it'll cost me so much I won't be able to pay the bills here, that's what I'm worrying-that's why I keep doing what I'm doing. (Participant 26)

Another participant experienced similar financial concerns:

> With the money, I don't know how some people do that. Like, even if you make that awful decision to move your spouse out of the home. I think, to me anyway, there is lots of people out there who keep people at home, because they cannot afford it. They just live and cannot afford it. And I have talked to my next-door neighbour. He thinks that his mother basically killed herself looking after his father, but if the father would have gone to a nursing home. She would have been left with no income. (Participant 13)

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Program challenges and limitations

When asked about challenges with the program, some participants emphasized the timing of their enrolment. They expressed a desire for the program to have been available earlier in their caregiving journey, particularly at the time of their loved one's diagnosis or during the initial adjustment period. One participant explained:

> We did have lots of resources, the things that I mentioned, but you know, earlier…having more care earlier, would have meant less stress… I know that if I would have met her [the patient navigator] earlier, she could have helped me a lot more. (Participant 17)

Another participant echoed this sentiment:

> If I had of had the resources to reach out to her [the patient navigator] back when my parents were first diagnosed and my sister and I were struggling in the home, that would have been the ideal time to have known about this program. (Participant 21)

Participants who joined the program later in their caregiving trajectory often noted that they had already independently located many of the services and resources shared by the navigator. For these participants, the challenge was not the program's content or structure, but rather the absence of earlier intervention. For example, one participant shared:

> I don't think the program was lacking. I think the improvement that I would suggest is that people that are in the situation as my husband and I are, I think that it should be something that's offered from the beginning. (Participant 20)

Another participant had a similar experience:

> Apart from support, the telephone, how things were going, really there was nothing [provided by the patient navigation program] because I'd already put everything in place, all the steps had already been taken to go to the shelter, and I already had support, so that's why the program for me, it's not their fault, they did everything they could, but they couldn't really contribute anything because I'd already organized everything in advance. (Participant 37)

While some participants initially expressed disappointment that the program did not offer additional resources or services beyond what they had already accessed, they acknowledged that having access to the navigator earlier would have been highly beneficial.

Another challenge was ensuring consistency in program delivery. Although the program was designed to offer holistic, personalized support, a small number of participants described their experience as less helpful than anticipated. For example, one participant mentioned: 'She didn't have enough-I don't know if I can say knowledge-or I don't know what the problem was, but it wasn't accessible enough and it didn't seem like she could give us the information that we needed' (Participant 35). Another participant highlighted the need for the program to offer more intensive support:

> I think this type of navigation program needs to be more patient, customer, client orientated 100%. It's not a matter of making one appointment. And leave it like that. You need to have ongoing support… I felt that they should have done more. (Participant 1)

These accounts differed from most in the study where navigators were described as proactive and responsive, going beyond sharing information to actively ensuring connections to services. The few suboptimal experiences appeared to be clustered at one site.

Discussion

This mixed-methods study drew on both quantitative and qualitative data to address research questions related to the characteristics of participants in the patient navigation program, their level of satisfaction with the program, and their overall experiences with the intervention. Quantitative data offered a demographic profile of participants, indicating that the majority of cases were dyads composed of a person with dementia and their care partner. Most individuals with dementia were older adults residing in rural areas and identified predominantly as White and English-speaking. Care partners were most commonly spouses or adult children, identifying predominantly as White, English-speaking, women, living in rural communities. These findings contextualize the care dynamics and potential service access challenges, particularly in underserved rural settings. Participants reported a wide range of individualized goals, with the most common related to accessing dementia-specific information and government-funded services. Most goals were achieved and those that remained unmet often reflected persistent systemic barriers. Quantitative satisfaction surveys indicated a high degree of satisfaction with the program. Participants reported increased knowledge and improved access to services, as well as enhanced confidence navigating health and social care systems.

By integrating quantitative and qualitative findings, we were able to triangulate participant-reported satisfaction with rich narratives that contextualize those ratings. While surveys quantified improvements in access, knowledge, and confidence, interviews explored the mechanisms through which these improvements were achieved. Interviews revealed that participants greatly valued the proactive, hands-on assistance of navigators. Moreover, the emotional support provided by navigators was considered vital and contributed to participants' overall sense of satisfaction. However, qualitative data also provided important nuance. While most experiences were positive, some participants reported unmet expectations, often linked to timing or systemic barriers to accessing care. Overall, this study suggests that the patient navigation program effectively addressed barriers to accessing dementia care by offering support to individuals with dementia and to care partners who often felt overwhelmed, isolated, and under-resourced.

Core elements of the patient navigation program

Acknowledging care partner burn-out

Recognizing the challenges caregivers experienced before participating in this patient navigation program is crucial to understanding its impact and the needs it addressed. Care partners entered the program already experiencing high levels of stress, burn-out, and, in many cases, crisis, due to the intense demands of supporting loved ones with dementia. They often reported feeling isolated, overwhelmed, and without adequate resources before joining the program, pointing to substantial gaps in existing support systems for this population. The responsibilities taken on by care partners have been widely examined in the literature, with many experiencing strain and associated health impacts due to the demanding nature of caregiving (Bernstein et al., 2020; Chiao et al., 2015; Giebel et al., 2023; Kallmyer et al., 2023). These challenges underscore the importance of implementing supportive interventions

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early in the dementia care journey to alleviate the mounting pressures on care partners. By providing these individuals with resources and guidance, patient navigation programs can help mitigate burn-out, improve well-being, and ensure that care partners are better equipped to handle the complex, evolving needs of dementia care (Bernstein et al., 2020; Chiao et al., 2015; Merrilees, 2016).

Providing emotional support

Given this high-level of burn-out, it is unsurprising that care partners in the current study considered emotional support as a highly valued aspect of the patient navigation program, reflecting its essential role in alleviating the feelings of isolation and overwhelm commonly experienced by care partners. Indeed, many participants entered the program without a trusted source of support, often feeling alone in managing the complex demands of dementia care. Having a patient navigator who actively listened, validated their concerns, and prioritized their needs provided substantial relief and a sense of connection. This emotional support not only helped care partners feel heard but also empowered them to make informed decisions for their families and loved ones. These findings built on the survey data, where participants not only expressed overall satisfaction with the program and the amount of contact they had with their navigator, but also reported feeling more confident in managing the complexities of health and social care. Many also noted a reduction in their sense of social isolation, mirroring the interview findings that navigation support offered both a lifeline and a sense of connection during an otherwise isolating and uncertain time. Existing research underscores the importance of this dimension of patient navigation, noting that emotional support enhances program effectiveness (Bernstein et al., 2020; Kokorelias et al., 2023c). Recent patient navigation programs for individuals with dementia have also been shown to reduce feelings of stress, guilt, and frustration in care partners, while improving care partners' sense of competence, quality of life, and addressing their unmet needs (Bernstein et al., 2020; Giebel et al., 2023; Kallmyer et al., 2023; Kokorelias et al., 2023c). As such, integrating emotional support into patient navigation programs is critical for improving care partner experiences and fostering long-term confidence in managing dementia care.

Providing hands-on support

A crucial element of patient navigation for individuals with dementia and their care partners, who feel underserved and overwhelmed, is the program's capacity to improve their knowledge of and access to dementia care resources. Patient navigation does this by providing hands-on support to identify and address barriers to care. In the current study, the most frequently reported goals involved accessing dementia-specific information and resources and government funded programs, most of which were successfully achieved. Survey findings supported this, with participants expressing satisfaction with the materials and resources provided, as well as reporting improved knowledge of and access to health and social services. Interview accounts reinforced these findings, with navigators being described as essential in navigating complex systems by completing paperwork, initiating referrals, and proactively linking families to supports. These results are consistent with the existing literature, which emphasizes instrumental support as a fundamental component of patient navigation programs (Bernstein et al., 2019; Kallmyer et al., 2023; Kokorelias et al., 2023b; Kokorelias et al., 2023a). Indeed, by helping participants identify barriers and connecting them with necessary resources, navigators provide vital support that enables care partners and patients to overcome logistical and systemic obstacles commonly encountered in complex health care environments (Kallmyer et al., 2023; Kokorelias et al., 2023b). The role of patient navigators in facilitating these connections was highly valued by participants in the current study, reflecting the importance of instrumental support in reducing stress and improving care access.

A small number of participant goals remained unmet in the current study, typically due to systemic barriers like long wait times and financial ineligibility. Qualitative data enrich these findings by highlighting participants' struggles with non-existent local programs, excessive out-of-pocket costs, or service unavailability, demonstrating that goal achievement depended not just on patient navigator effort but on external conditions beyond their control. Based on what participants in the current study identified as most important and beneficial, future programs should continue to prioritize both emotional and instrumental support. These complimentary elements address the psychological and practical challenges faced by individuals with dementia and care partners, ensuring a more holistic approach to dementia care.

Key considerations for patient navigation program implementation

Navigator competency and compatibility

Since participants' experiences were strongly influenced by both emotional and practical support, it is essential for navigators to build strong relationships with clients and their circle of care. Selecting navigators with the appropriate background, experience, and personal compatibility is critical for success in this role. Indeed, navigators with an understanding of dementia's complexities and empathy for the challenges care partners face are likely to be more effective in providing the tailored, compassionate support needed (Kokorelias et al., 2023b; Kokorelias et al., 2023a). Although navigators in the current study received standardized training, qualitative feedback revealed variability in participants' experiences. This highlights the importance of not only formal training but also strong interpersonal skills and practical experience. A few participants reported receiving insufficient support, which may reflect a mismatch between the navigator's approach and participants' expectations, particularly in cases where patient navigators were unable to address the broader systemic barriers participants encountered when trying to access services. Indeed, those with unmet needs often faced barriers, such as service inaccessibility or long wait times, factors that may have contributed to the perception that navigators were unresponsive or ineffective. Notably, unmet needs also tended to coincide with navigators managing the heaviest caseloads, suggesting that high workloads may compromise the ability to provide personalized and timely support (Kokorelias et al., 2021; Kokorelias et al., 2022). These findings highlight the need for enhanced training in communication, relational competencies, and caseload management, as well as ongoing monitoring of navigator capacity (Kallmyer et al., 2023; Kokorelias et al., 2021; Kokorelias et al., 2022; Kokorelias et al., 2023b; Kokorelias et al., 2023a). Ensuring that navigators are well-equipped to address the complex and evolving needs of dementia care is essential for maximizing the program's responsiveness and impact (Kallmyer et al., 2023; Kokorelias et al., 2023a).

In addition to one-on-one support, navigators must be capable of facilitating collaboration within the broader care team. While the

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program did lead to some improvements in communication and coordination, survey responses suggested these gains were modest. This could reflect ongoing systemic barriers to integrated care but may also indicate a need for enhanced training in interprofessional collaboration and care coordination. Navigators must be equipped to bridge gaps between settings and sectors, and to advocate effectively within fragmented health care systems. Embedding navigation services into broader care coordination frameworks could strengthen their impact, ensuring navigators are supported in fostering meaningful collaboration across providers and agencies (Giebel et al., 2023; Kallmyer et al., 2023; Kokorelias et al., 2023b). Ultimately, the success of navigation in promoting integrated dementia care depends not only on patient navigator skill but also on system-wide commitment to collaborative care models (Giebel et al., 2023; Kallmyer et al., 2023; Kokorelias et al., 2023b).

Early intervention and sustained support

Participants in the current study expressed a need for earlier access to navigation services. While this feedback was not a direct critique of the pilot program, it underscores the need for earlier intervention. For example, over half of the participants had received their diagnosis relatively recently, within the past 2 years. Nonetheless, many believed that earlier access to navigation services would have reduced their care burden significantly. This feedback highlights the need to align referral timing with caregiver needs and to raise awareness of these programs among health care providers and service agencies, who are well-positioned to facilitate early referrals (Lindeza et al., 2020; Rasmussen & Langerman, 2019). Participants also experienced moderate improvements in their sense of support in aging within their community. However, the limited gains in this domain may be attributed to the advanced stage of many participants' care needs, with some having already progressed to the point of considering long-term care options. Early intervention through navigation support could enable individuals to remain in their communities and homes longer by facilitating timely access to necessary resources, including early diagnosis (Lindeza et al., 2020; Rasmussen & Langerman, 2019; Watson et al., 2021). Additionally, some participants in the current study were discharged prematurely due to the pilot's end, underscoring the necessity for sustained, long-term support rather than time-limited programs (Kokorelias et al., 2020; Kokorelias et al., 2023a; 2023b). Understanding the program's implementation within this context highlights both the critical timing and the intensity of support required to make a meaningful difference in the lives of individuals with dementia and their care partners.

Addressing systemic barriers to care

A key insight from the study is that even with navigators' assistance, participants encountered persistent barriers that patient navigation alone could not overcome. These systemic barriers, including limited programs, services, and resources in rural regions of the province; long wait times for services; and high out-of-pocket costs restricted the program's overall impact and may have contributed to participants' desire for more support. Addressing these external barriers is critical for the effectiveness of patient navigation programs, as they can limit navigators' ability to offer comprehensive support. Future patient navigation programs should advocate for policy and system-level changes to address these limitations, thereby enhancing navigators' capacity to connect clients with the most appropriate resources.

Study limitations

The findings of this study should be interpreted with certain limitations in mind. A key limitation was the short timeline for planning and implementation, as the project was restricted to a 16-month window, including a 12-month pilot period. This compressed timeframe necessitated rapid deployment of the program, which impacted the design, implementation, and assessment phases. For example, although collaboration with several clinics and health centres was achieved, an extended timeline could have allowed for more comprehensive co-design efforts and more robust planning for intervention implementation. Additionally, health service use data were not collected for participants, as securing data-sharing agreements required time beyond the study's constraints. Future research should include these metrics to enhance an evaluation of program impact.

Another limitation of this study was the relatively low response rate of 37.3% for the satisfaction surveys distributed after the intervention. Given the considerable stress experienced by care partners in the study interviews, this response rate is not unexpected. Many care partners face intense daily demands, which can limit their time and energy to engage in follow-up activities such as survey completion. Despite the low response rate, the responses received provide valuable insights into participant satisfaction with the program.

Overall, there was a lack of direct input from individuals with dementia, as most survey respondents and all interview participants were care partners. While this makes sense given the progression of dementia and the associated challenges with communication and autonomy, future studies could explore alternative methods for including the voices of individuals with dementia, particularly those in earlier stages. Furthermore, a significant portion (16 out of 37) of the interview participants were drawn from a single site, although this site also had the highest proportion of program participation. While this may have led to a site-specific overrepresentation, the majority of themes identified in the study were consistent across all sites, suggesting that the experiences captured are likely representative of the program as a whole.

Finally, the current sample was composed primarily of individuals who identified as White/Caucasian. As a result, the findings may not reflect the experiences or needs of individuals from diverse racial or cultural backgrounds. Future research should explore how dementia navigation programs can be adapted and implemented to support ethnically and culturally diverse populations, ensuring more equitable and culturally responsive care.

Conclusion

This mixed-methods study exploring participant characteristics and experiences with a pilot patient navigation program for individuals with dementia and their care partners indicates significant benefits, particularly in improving resource access and providing emotional support for care partners. This study also identified opportunities for growth in achieving fully integrated care and addressing systemic barriers. These insights underscore the importance of early, sustained, and integrated navigation support and a call for systemic improvements to better support navigators in their roles. By addressing these challenges, patient navigation programs can become more effective in enhancing care for individuals with dementia and their families.

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