



Nav-CARE

Making Connections, Making a Difference

Nav-CARE is a community-based family-centric service that uses specially trained volunteers to improve quality of life for seniors navigating the transitions of advancing chronic illness.

Findings From a Knowledge Translation Study

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Welcome to Nav-CARE

Nav-CARE is a community-based family-centric service that supports seniors living at home who have a chronic illness and are moving towards palliative care. This stage is called advanced chronic illness. In Nav-CARE, volunteer navigators receive specialized training and then visit clients regularly in their home to help enhance their quality of life amid the challenges of their illness.

Nav-CARE stands for **N**avigation = **C**onnecting, **A**ccessing, **R**esourcing, and **E**ngaging.

The goal of Nav-CARE is to optimize seniors' quality of life and independence through enhancing connections and social support.

Navigation includes:

- assessing quality of life
- providing education about and facilitating access to services and resources that could improve the quality of life
- advocating for the client
- providing social support and connection



There's plenty of evidence showing that older adults living with advanced chronic illness urgently need enhanced support. These older adults often live with a heavy symptom burden^{1,2,3} and are at risk for social isolation.⁴ Their need for support, signposting, advocacy, and assistance with decision-making is high.⁵ They may not know of the health and social services available in their community.⁶ Indeed, this time on the palliative trajectory may be more problematic than the actively dying phase due to the lack of suitable supports.⁷ Nav-CARE fits with the agenda of a recent Canadian Healthcare report that highlights the need to find innovative ways to better meet the needs of this population.⁸

People experiencing the transition from chronic illness to palliative are considered an upstream palliative population; they are not imminently dying, but death within a year would not come as a surprise. During this phase they experience transitions that influence quality of life.⁹ A palliative approach, which provides much-needed support early in the client's healthcare journey¹⁰, has been considered the ideal care for this population.^{11,12,13} Through Nav-CARE, specially trained volunteer navigators become trusted friends and advocates, helping to create connections, relieve feelings of loneliness and improve the quality of life for their clients.

Nav-CARE offers a robust toolkit for organizations interested in this program. The toolkit includes directions and resources to implement a Nav-CARE program successfully. Organizations are required to be registered users of Nav-CARE to deliver the program.

Background

Dr. Barbara Pesut at the University of British Columbia and Dr. Wendy Duggleby at the University of Alberta have been on a 12 year research journey with Nav-CARE and communities across Canada. Their work began with a focus on how to improve palliative care in rural areas. They were interested in developing a volunteer-led intervention that provided early care for seniors living at home with advanced chronic illness using a compassionate community-building approach.

The culmination of this work was Nav-CARE. They developed the conceptual and theoretical foundations for older adult navigation; created, tested, and refined curriculum for volunteer and healthcare navigators; and conducted three incremental pilots to determine the feasibility, acceptability and impact of Nav-CARE. Nav-CARE was subsequently implemented by eight community-based hospice societies in diverse urban and rural settings. Information in this document comes from evaluation interviews with participants from these communities. A more comprehensive evaluation document can be obtained by contacting the principal investigators.



Older adult participants showed statistically significant improvements in their knowledge of the services available to them and in making decisions about their health and healthcare. Further, when asked about their satisfaction with the program and how important it was to them, client responses ranged from 8 to 10, with the majority rating it as 10 (highly satisfied and very important).



Impact

Client Perspective

Clients found that the Nav-CARE program helped them develop social connection and support, understand their healthcare better, navigate life transitions and access community resources. They said that they would recommend the program to others, especially to those without strong support networks.

I need something that's reliable in my life. The navigator is usually a minute early. Because when you're in this condition, you really need stability and security knowing that this is one thing you can hang on to as things go sideways...It really has been profound. I've told her this, but I haven't been weeping when I told her. I'm getting all weepy as I think about this. (Client)

Social Connection and Support

Clients reported that the program provided extremely meaningful social support. They said that the volunteers were like friends who offered so much more than practical support. The impact of the Nav-CARE volunteer visits on clients included increased emotional and physical well-being, a greater “zest for life,” and heightened feelings of self worth. Nav-CARE volunteer visits were a “bright spot” that left those with advanced chronic disease feeling more positive.

By providing companionship and a listening ear, navigators helped clients decipher information and make decisions. For many clients, talking with their navigator made them feel like a neutral, supportive and knowledgeable friend had come into their life.

Participants remarked that it was easier to talk about issues surrounding their chronic illness and end of life with the Nav-CARE volunteer, compared to their family, friends or health care providers. These conversations resulted in increased emotional and physical well-being.

Nav-CARE was especially meaningful to individuals living alone and those in isolated situations. For them, having someone to call, and knowing that someone would visit, was pivotal in helping them feel less alone.



It's easier to talk to somebody that isn't really close to you personally... to listen and not get rolled up into it...So, I don't know how she did it but she kind of just drew me out of the space that I was occupying at the time. (Client)

Sometimes I sit here and feel sorry for myself because I don't get out and that. But after she leaves, I feel kind of important to have somebody like her come and visit me. (Client)

Understanding Healthcare

Through listening and conversing, Nav-CARE volunteers assisted their clients in making sense of, and processing health care information. This engagement subsequently helped clients make health care decisions.

For many, the navigators' visits were a chance for clients to seek understanding about future medical appointments and debrief about past appointments. Additionally, clients found it was valuable to have support in deciphering medical language and in gaining tips for interacting with the medical world.

Many navigators sourced credible medical information for their clients to help them better understand their health condition. Some navigators would go to medical appointments with their client so there was an additional person present to take in information. Clients greatly appreciated both these actions.



Well, when I described my frustration with my doctor and him not being willing to do what the internist had prescribed, she just supported me by saying, "that would be frustrating and you need to get the prescription happening, what are you going to do?" But she didn't push me on it. She just provided support. So, I looked at my options and I worked it through on my own. (Client)



Life Transition Support

Navigators were able to assess clients' needs and broach relevant discussion topics that would help improve their clients' quality of life, especially during health transition periods. Examples included: arranging advance-care planning, noticing a health-status shift that warranted considering a change in housing, or facilitating access to extra health care support services.

Conversations with their navigator also helped clients gain a sense of peace in coming to terms with end of life and facing end of life tasks, such as visiting a hospice house or drawing up a will.

One really important thing was having a will drawn up. I didn't have anything in place at all and my volunteer helped me get into a pro bono program where they helped me out financially with doing a legal will and actually showed me an awful lot that I wasn't aware of that is required in a legal will nowadays. It really helped a lot. (Client)

Access to Community Resources

As well as receiving social support from spending time with their Nav-CARE volunteer, clients also found value in their navigator's ability to locate resources. Resource navigation was tailored to the client's unique needs and included finding everything from gardeners and maintenance workers to affordable housing, transportation and meal preparation services.

Many of these services helped clients remain independent. Clients expressed appreciation for their navigator's assistance in finding medical care closer to home and sourcing financial support services, such as medication subsidies.

Navigators also helped find support groups or day programs that would benefit their client. Connecting clients with these local resources provided another way to alleviate client's isolation.

Some navigators extended friendship beyond the home visit and offered to do activities with their client, such as going for coffee or attending a sporting event. Clients found these outings a welcome change of scenery.

Family Perspective

Family members found value in the Nav-CARE program for many of the same reasons as Nav-CARE clients. Like clients, family appreciated that the Nav-CARE program helped their family member experience social connection and support, gain an understanding of the healthcare system, move through health transitions, and access resources.

Family also appreciated their navigators' knowledge and ability to predict what could happen next in the illness trajectory. Navigators were then able to present options to the family and the client for the next steps. These skills helped family caregivers feel supported, which reduced their stress.

Family also reported that Nav-CARE provided them with much needed emotional and physical respite. Family caregivers appreciated that the navigators visits provided them with an opportunity to have a break. Furthermore, family reported that their own emotional strain was reduced because the navigator offered them friendship and social connection.



*Anything that came up,
she would say,
I'll look into that for
you. (Client)*

*She kind of knew what
we needed and she knew
what mom needed,
and was just, you know,
a friend. (Family Caregiver)*

*When you're feeling
really low, like, 'Oh my
gosh, how much more
can I take?' Then she
would build you up. She
would say, 'You're doing
something amazing and
you're making a
difference in your
Mum's life and your
kid's life. (Family Caregiver)*

Volunteer Perspective

Volunteers recognized the need for Nav-CARE in their community and welcomed the opportunity to participate in making their communities a better, more compassionate place.

How volunteers' viewed the impact of their contributions aligned with the impact of Nav-CARE reported by clients and their families. Volunteers felt successful in enhancing their client's motivation and independence, providing them with companionship and friendship. They also saw value in the important conversations they had with their clients' about their illness and advance-care planning and the work they did connecting clients with community resources.

Many navigators described their clients as a real friend and said that the relationship had become mutually fulfilling. However, they recognized that their role was different from those their client had with other friends and family members. Navigators were able to play a more neutral role, and this benefitted their client because the client could share feelings without being concerned about meeting the expectations of family members or friends with whom they had a shared history. The navigators felt the nature of this relationship was helpful for clients as they prepared for dying.

Many clients did not have family nearby or involved family members, and in these circumstances some navigators filled that gap in family support. For those clients with family, navigators appreciated being able to provide respite to family.

Navigators also talked about the benefits for themselves in assisting a family through transitions at the end of life.



Friends and family want you to get better, they don't want to think about the fact that you might be dying, whereas somebody in this volunteer role is looking at it from a realistic point of view...I'm more open to listening to her expressing concerns. (Volunteer Navigator)

I know it's pretty hard to be stuck at home 24 hours, seven days a week with your family, your loved ones or whatever. And so, just to give them a chance to go out and breath and do something else for a couple hours. That was important. (Volunteer Navigator)

To me, it adds a richness to my life to meet other people, to journey with them. I know it sounds trite but it's the truth for me...and even though one of my clients died, I found the whole process of being the volunteer navigator and being involved with the family as, well—it was very powerful for me. (Volunteer Navigator)



Implementation

Nav-CARE is designed to be adaptable to any community, no matter how big or small and how rural or urban. Our research suggests the following components are necessary for successful implementation:

A community-based organization that provides volunteer services to adults and has:

- strong connections in the community
- organizational capacity to train, manage and support volunteers
- access to experienced volunteers
- ability to identify potential clients through community engagement
- a coordinator who is a strong champion of the program
- an individual willing to take the Nav-CARE training and serve as a trainer for future volunteer training
- linkages to health networks and healthcare personnel

Prior to taking on the Nav-CARE program it is important for the organization to determine if Nav-CARE is a good fit with their overall strategic directives, if they have champions that can carry the project forward, and if they have sufficient organizational capacity to implement and sustain a new program of this nature.



Keys to Success: The Team

The Volunteer Coordinator

The Volunteer Coordinator oversees the Nav-CARE program for the organization. The coordinator is responsible for building the profile of Nav-CARE in the community, recruiting and mentoring volunteers, and identifying and screening potential clients. The coordinator is the central strength and dynamism of the program. In every community, the Volunteer Coordinator role proved critical to the success of the program. It was found that ensuring they have ample and dedicated time to commit to volunteer support and client recruitment is essential to their success.

Volunteer Navigators



Volunteer Navigators are individuals who have at least one year of related volunteer experience and who take the Nav-CARE training. Nav-CARE study sites found that it was easy to find volunteers and it was ideal to launch the Nav-CARE program with three to four volunteers. Having early success with fewer people supported the sustainability of Nav-CARE programs.

Volunteer Navigators involved in the research project reported that, although they were highly satisfied with the initial training, they required ongoing education and emotional support to ensure they could sustain the emotional intensity of the role. Navigators found they benefited from structured ongoing learning on topics such as self-care, boundaries and transition support. Additionally, the opportunity for volunteers to debrief with the Volunteer Coordinator as well as in a group setting with other navigators was integral in feeling supported in the navigator work.

The Healthcare Champion

The Healthcare Champion is a healthcare professional located in the community who works with the Volunteer Coordinator to recruit clients. This role of an active health care partner who can create linkages between Nav-CARE and other health systems is mandatory for success. In some Nav-CARE study sites, the Healthcare Champions were a social worker, a nurse or a family physician. It is essential that the person be passionate, committed and have the ability to recruit clients. If this role is not effective and client recruitment is hampered, the program is not sustainable.

Barrier to Success: Client Recruitment

Client recruitment posed a significant barrier to implementing the Nav-CARE program. In conjunction with relationship-building strategies, study sites were encouraged to use a combination of tactics for client recruitment. These efforts included ongoing public advertising, community talks and word of mouth using specially-designed program materials provided by Nav-CARE. This was best done by the Volunteer Coordinator. However, during the study period a number of challenges being faced by hospice societies often meant that their efforts were diluted.

Even when all the strategies were in place, communities still faced barriers to recruitment. Participants in the study identified two significant barriers to recruitment: The public perception of hospice palliative care and resistance or lack of engagement from healthcare professionals. All Nav-CARE study sites were hospice societies. The public perception of hospice societies and palliative care influenced the ability to recruit clients who did not see themselves as ‘hospice clients.’ Hospice and palliative care is often mistakenly associated with imminent death, as opposed to living and dying well. Therefore, careful strategizing about how to navigate the public perception of hospice and palliative care is advised.

Many study participants felt that healthcare providers in their community would easily be the primary means of client recruitment. However, they soon discovered that healthcare providers did not typically refer clients. Research participants reported that some healthcare professionals felt Nav-CARE was duplicating other services and that others working in home-care settings did not see the value of the volunteer and felt this role should be for paid employees.

The research indicated that the Healthcare Champion role is crucial to creating Nav-CARE buy-in by the health care community. It was reported that in addition to forming relationships with health care professionals in leadership roles, family doctors, home care institutions, home care nurses and allied health practitioners such as physiotherapists or acupuncturist could be helpful for referring potential clients.



A Healthcare Champion role is required to engage referring medical professionals.

Study sites were also mindful about carefully balancing recruitment with their capacity. Nav-CARE sites were concerned that healthcare providers would send too many clients and their resources would be overwhelmed. Finding sustainable ways to match these willing volunteers with clients who require their services remains an ongoing challenge to be solved.

Evaluation

Nav-CARE is an evidence-informed navigation program. To ensure the program is meeting its objectives, evaluation data is gathered from navigators, clients, family members and select community and organizational stakeholders. The evaluation results allow Nav-CARE researchers to continually gain insight into the impact of the program and ways to improve execution and delivery. The gathering of data is a shared responsibility between Nav-CARE and participating organizations. Results are shared with the organization that participate.

Sustainability

After the research period, the goal was to have Nav-CARE be sustainable in each community. At the conclusion of the research period, of the eight participating communities, six sites were committed to growing their Nav-CARE program, two sites continued to support clients, but did not intend on recruiting further clients (thus bringing their program to a close). The organizations that were successful with Nav-CARE had the capacity to implement and support the program over the long term. The Nav-CARE founders are hopeful that Nav-CARE will be part of a movement towards increasing the awareness, organizational capacity and resource base of hospice organizations.

Conclusion

Based upon the evaluation data from the eight sites included in this report, Nav-CARE is a promising program that has the potential to improve the quality of life of seniors and their families living in the community with advanced chronic illness. Nav-CARE is currently being implemented and evaluated in additional sites across Canada, and with funding from the Max Bell Foundation, with the goal of building further evidence of its impact.

The Nav-CARE volunteer navigation model was profiled in the Best Brains Exchange Report on Innovative Approaches and Pathways Used to Integrate Home and Community Care with Primary Health Care for Elderly Persons in Rural Canada funded by the Canada Research of Health Institute and Health Canada. The report is available at www.cihr-irsc.gc.ca/e/documents/kt-bbe-report-2018-en.pdf. Nav-CARE also received an innovation award from the Canadian Foundation for Healthcare Improvement.



If you are interested in starting Nav-CARE in your organization,
contact the founders: barb.pesut@ubc.ca or wendy.duggleby@ualberta.ca
For more information visit www.nav-care.ca

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