NAV-CARE
Navigating Life and Aging with Chronic Illness
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Nav-CARE
Making Connections, Making a Difference

- Nav-CARE helps people living with serious illness find services and resources in their community.

- Highly trained, resourceful and compassionate volunteer navigators help to create connections and improve quality of life.

- The goal is to improve the lives of people living with serious illness by providing specially trained volunteers to build community connections, access to services and resources, all while providing caring, consistent and emotional support.
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Objectives

- To provide a background to the challenges older adults are experiencing as they live with serious chronic illness.
- To share the development of Nav-CARE.
- To provide evaluation data from Nav-CARE.
- To consider factors relevant to Nav-CARE implementation.
Adults Living with Serious Chronic Illness

- Lack of early supportive care.
- Lack of knowledge of resources.
- Loneliness and isolation.
- Multiple complex decisions.
- Heavy symptom burden.

Did you know? One in five seniors report that they experience emotional distress and have difficulty coping day-to-day.¹ Loneliness and social isolation are significant predictors of healthcare utilization.
Nav-CARE Target Population

McGregor D, Porterfield P. Identification of Patients Who May Benefit from Palliative Care. [PowerPoint]. General Practice Services Committee Practice Support Program; 2009.
Nav-CARE Clients: Quality of Life Issues

- Loneliness or social isolation.
- Recent loss.
- Mobility or sensory challenges.
- Multiple concurrent life changes.
- Increasing disengagement.
- Coping with multiple decisions.
- Difficulty finding/accessing information or resources.

Perceived need
Nav-CARE Opportunities

- Provide Early Support
- Capitalize on Volunteer Philanthropy
- Optimize Available Resources
- Build Social Capital for Individuals and Communities
An Upstream Role for Volunteers Within Hospice

- Bereavement Volunteers
- Hospice Volunteers
- Nav-CARE Volunteers
Extend the Reach of Community-Based Organizations
Nav-CARE: Development to Date

- 2014-2015: One-year feasibility pilot in a rural community in BC.
- Partnership between UBC and the U of A.
Navigation Competencies for the Care of Older Rural Adults at the End of Life

- Report available online:
  http://www.nurs.ualberta.ca/livingwithhope/library

Dr. Wendy Duggleby
2016-2018: Knowledge Translation

What are the barriers/facilitators in different contexts?

Implementation and evaluation in six community-based hospices with non-cancer and cancer population.

Implementation and evaluation in three community-based hospices with advanced cancer population.

Toolkit for implementation and scale out.
2016-2018: Knowledge Translation
2017-2020: Scale Out

Building Robust Evidence

Scale out to 10 additional community-based hospice societies. Both urban and rural

Adapt to 4 additional contexts

Newfoundland: Dr. Gail Wideman, Memorial University

Policy
2017-2020: Scale Out
Nav-CARE: Program Description
Nav-CARE Implementation

Volunteers visit clients in home to provide navigation support.

Training
- Evidence-based education
- Ongoing mentorship by nurse navigator

Community-based
- Advisory Committee oversight
- Healthcare partner
- Community Resource Guide

Evaluation
- Clients
- Volunteers
- Stakeholders
Available Resources

- Implementation Manual
- Curriculum
- Toolkit "Brand"
- Evaluative Tools
- Community Resource Template
Educational Competencies for Volunteers

1. Provide client/family assessment (e.g., understand quality of life priorities).
2. Advocate for client/family (e.g., assist client and family to make wishes known).
3. Facilitate community connections (e.g., assist client/family to connect with networks).
4. Facilitate access to services and resources (e.g., computer assistance).
5. Promote active engagement (e.g., build capacity toward desired level of engagement).
6. Visit clients in home to provide navigation support.
Nav-C.A.R.E.
Examples of Volunteer Activities to Connect, Access, Resource and Engage
Connecting to Others

- Building rapport through social conversations.
- Identifying and building social connections.
- Facilitating discussions around illness, coping, and overall life impact.
Accessing Available Services and Resources

- Strategies to work with healthcare providers (e.g., identifying priority problems, planning conversations, attending visits as a ‘second ear’).
- Mobility options to support access (e.g., airline options).
- Transportation services.
**Resourcing According to Need**

- Healthcare (e.g., chronic illness self-help groups and services).
- Home support services (e.g., equipment loan cupboard, meals on wheels).
- Available living options in the community (e.g., rentals that accept pets).
- Life changes (e.g., downsizing possessions).
- Comfort adaptations (e.g., replacing old shoes).
- Seniors resources (e.g., ombudsman, office of senior’s advocate, senior’s centre, adult day program).
- Policy changes/services that affect seniors (e.g., information about changes to MSP premiums for low-income earner).
Engaging with Life

- Renewing old hobbies (coloring leading to art classes, games).
- Seniors activity planning.
- Advance care planning (e.g., funeral home visits, writing out things that they want healthcare providers to know).
- Facilitation of plan for client’s volunteer work (e.g., helping refugees moving into the community).
- Strategies for preparing for stressful events (e.g., renewing driver’s license).
Nav-CARE: Evaluation to Date
Evaluation Data

- **Adults and Family**
  - Qualitative interviews.
  - Quality-of-Life
  - Engagement questionnaire

- **Volunteers**
  - Self-efficacy and satisfaction questionnaires.
  - Qualitative interviews.
  - Coaching teleconferences monthly
  - Quality-of-Life

- **Organizational Stakeholders**
  - Qualitative interviews & questionnaire at 2 time-points.
  - Implementation teleconferences monthly.

- **Nav-CARE Costing**
# Findings to Date

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<tr>
<th>Volunteers</th>
<th>Clients</th>
<th>Stakeholders</th>
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| • Highly satisfied with role.  
• Resourceful in navigation support.  
• Good perceived self-efficacy in navigation role. | • Service very important to their care.  
• Tangible benefits that transformed experience of living with serious illness. | • Nav-CARE meeting an important need.  
• Well-designed.  
• Key supports required for sustainability. |
Satisfying and Meaningful Role

- “I think we make it easier for them to go down that path [of illness]”.
- “We are helping people navigate this time of life on an emotional level”.
- “These people really touched me and I got a lot from them as well. I hope I gave them something, but, you know, they became friends and part of my life”.

Unpredictable Nature of the Role

- Clients needs differed.
- Social support as important as ‘navigation’.
- Requires flexibility and adaptability.
- Requires ongoing emotional investment, and hence, support for volunteers in their role over time.
Role Ambiguity

- Role was new.
- Volunteers were unsure about: expectations, contributions to care, and how to measure performance.
- “Sometimes just providing that safe environment for someone to ventilate about their issues – maybe that’s my criteria [for success]”. 
Client and Family Perspectives
Why Nav-CARE is Important: Chronic Illness Experiences

“It causes a feeling of isolation and aloneness. Others treat you differently”.

“So this is a whole new experience now. It is life changing…I am here and I am alone. Am I lonely? Well yes, I guess I probably am”.

“When you’ve been sick for a long time [voice breaking], after a while everything disappears, and all your stability [crying]”.

“It’s just two illnesses fighting here, you know, there’s two sick people. And once in a while you say something you would never say normally and it takes you back again and again. Is this the person I have become?”
Benefits of Person-Centred Care

“She was a great resource and someone to sit back and have coffee with and talk for an hour”.

“It was, ‘how are things going?’ and then I opened up my mouth and we started to talk about what I felt we needed to talk about. It didn’t seem like they were on this or that, or we must talk about this today. It was more fitting of my needs each time”.

“It’s not so much about the medical, it was putting things in context”.
Benefits of Assistance with Making Decisions

- Weighing the various options available related to housing, finances, treatment decisions, transportation, and advance care planning.
- Helping to anticipate and sign-post.
- ‘In the moment information’ rather than too much information at once.

“Everything comes at you so fast and there are so many decisions to make and you’re all sixes and sevens and when your girls [volunteers] come out we can sit and talk about this, and it helps us to understand a little more why they’re [healthcare] doing this or that. And oh, what a difference that makes”.

Benefits of a Social Safety Net

- Safety net amidst the uncertainty of chronic illness.
- Relationship of trust developed that buffered anxiety about crisis points.
- Safely engaging the conversations others were afraid to address.

"I cannot think of the word right now...somebody that defends you. So she was good in clearing that kind of path for me. And taking away some anxiety".
Benefits of a Engagement

“I was surprised by how much it does help the minute she comes in. And later on I said to someone just the other day, ‘You know, I did this and I didn’t realize I could still do it’”.

“Before s/he’s come into my life, like I said, I was just sleeping all the time and not doing anything. I would cancel my doctors appointments. Just not go. And s/he made me see that the doctors appointments were important. And to be honest with them and not to be afraid to ask for things. For help, or whatever”.
Benefits of a Normalization

“It showed us that other people have got the same problems...it gives us an uplifting...I’m sure other people have the same feelings we have...if someone’s there just to put a hand on your shoulder you know you’re going through it with other people”.

“Somebody is looking out for the seniors and trying to find outside of their own little world of experience what is happening with the rest of us”.
Benefits of Social Support

“Cancer is not just the physical thing, it’s an emotional wound. She’s sort of like a placebo in that she’s not going to cure my cancer, but she makes it a lot more livable”.

“It definitely had a quality impact. First of all, to have a conversation with such a pleasant person, right there its positive. So even if there was no value beyond that, we would hope it was a million dollar value, but even if it’s just spare change, it’s very important spare change”.

Implementation Lessons

#1 Barrier: Client Recruitment

- Community champions
- Organizational community capital
- Volunteer Coordinator

Unclear messaging
- Organizational change
- Inadequate volunteer support
Community Readiness
Nav-CARE: Implementation Planning

- Does Nav-CARE fit with the strategic direction of your organization?

- Can you gather a key group of stakeholders who can support the program in your community?

- Do you have a champion who can (1) promote the program in the community (2) mentor and support volunteers (3) connect with key healthcare people and (4) work with UBC in collecting evaluation data?

- Are there ways in which you might like to adapt Nav-CARE to make it more suitable to your organization?
Community Implementation Steps

Community Preparation
- Identify champions to discuss community readiness.
- Presentation to community.
- Tool kit and MOA.

Volunteer Development
- Identify coordinator and volunteers.
- Provide education using train-the-trainer approach.

Implementation
- Recruit clients and provide services.
- Evaluation at 3 time points.
Thank-you!

Questions and Comments?

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