Evidence Brief #319

SUMMARY of SYMPOSIUM

Caring for Older Adults, Health, Wellness and Person-Centred Care
Prince George, British Columbia, November 7-8, 2019
Contents

Executive Summary .................................................................................................................. 3
I. Aim of Symposium .............................................................................................................. 3
II. Goals ................................................................................................................................. 3
III. Central Messages ............................................................................................................. 3
IV. Summary .......................................................................................................................... 3
V. Methods ............................................................................................................................. 4
VI. Results ............................................................................................................................. 4
VII. Discussion ....................................................................................................................... 12

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Executive Summary

I. Aim of Symposium
The Aim of the Symposium was to have dialogue with patients, care givers, policy- and decision-makers, clinicians, and other stakeholders about “Caring for Older Adults: Health, Wellness, and Person-Centre Care” and to “make sense” of actions that might ensue.

II. Goals
- Emphasize healthy aging, including how to maintain it and avoid frailty in older adults;
- Combine the knowledge base about frailty and dementia, together with local and regional knowledge, to better understand and improve practice and policy for older adults;
- Advance understanding of frailty—through avoidance and amelioration—at the level of caregiver, patient, and health care professional.

III. Central Messages
1. Build the North for the North.
2. Always focus action on all aspects of the Quadruple Aim.
3. First and foremost, promote upstream prevention of frailty and dementia.
4. Detect, assess, and intervene earlier for frailty and dementia.
5. Language and labels matter to people, especially considering stigma of frailty and dementia.
6. Support a paradigm shift in messaging, education, and advocacy for frailty and dementia.
7. Place of care matters (where, how, and with whom).
8. Improve communication and information sharing across the whole interdisciplinary team, including patient and family, from home to hospital.
10. Diversity in risk tolerance influences care decisions.
11. Northern BC needs more resources—including human, financial, and technological—to better address frailty and dementia.

IV. Summary
Providing health and social care in Northern BC is complex and challenging for a number of reasons, including geography and culture. Meeting these challenges requires unique and creative solutions, both upstream and downstream. Prevention and management of dementia and frailty necessitates multi-pronged solutions “for the North, by the North”. This includes interventions in homes, communities, and institutions to provide the right care, at the right time, in the right place. Some interventions may require additional resources—human, technological, and financial—though opportunities and solutions also lie in innovative, and more appropriate, use of available resources. Going forward, a high level of inter-sectoral and inter-disciplinary collaboration, cooperation, and communication between all stakeholders will be critical to ensure equitable access to services and care for those living in Northern BC.
V. Methods

Using case study methodology, we undertook a thematic analysis of notes provided by writing partners embedded in discussions that took place at each of nine roundtables (Day 1), workshops (Day 2), and the panel discussions at the end of both days. Case study methodology relies on multiple sources of evidence to add breadth and depth to data collection, which assists in bringing richness of data together through triangulation. The “case” in this instance was the Symposium, as informed by the participants.

We asked discussants to focus on three questions:

- Q1: What are the central messages that we have heard?
- Q2: What is the relevance of these messages to rural and remote service delivery and care?
- Q3: What are the specific actions that might ensue in Northern BC?

We analyzed the participants’ responses thematically to generate descriptive themes as they emerged from the data. This analysis included familiarization by immersion in the data, identifying a thematic framework to guide coding, iteratively refining the codebook, indexing and charting the data, and mapping. Themes were generated from the data through open (unrestricted) coding to create a template of codes. Two consultants to AHSN, including one from the North, generated themes, then collaboratively reconciled and revised the coding. The codebook was iteratively refined throughout the coding process as new concepts became apparent, until no additional codes emerged. We used line-by-line coding and constant comparative methods to curate the data and understand key themes around aging and frailty in Northern BC. Validation procedures included triangulating to corroborate or refine our findings, seeking disconfirming evidence, and researcher reflexivity, though not member checking, as this was deemed impractical in this circumstance.

VI. Results

**Day 1 (round tables): Frailty and Dementia in Canada: What does this mean for us?**

Participants reflected on the morning sessions offered by Elder Darlene McIntosh of the Lheidli T’enneh Nation, Charles Jago (Board Chair, AHSN), John Muscedere (Scientific Director, CFN), and David Hogan (Expert Panel Member, CAHS). We synthesized and interpreted notes provided by our writing partners at each of 9 moderated roundtables.

Q1: What are the central messages that we heard about frailty and dementia in Northern BC?

1. **Always focus action on all aspects of the Quadruple Aim.**
   - Actions should aim to enhance patient experience; improve population health; reduce costs; and improve the work life of healthcare providers including clinicians and staff.
2. **Build the North for the North.**
   - One size does not fit all. Solutions and care plans to prevent dementia and frailty should be tailored for Northerners, including those with specific needs, such as women and Indigenous peoples.

3. **Northern BC needs more resources— including human, financial, and technological—to better address frailty and dementia.**
   - Increase human resources, including specialist geriatricians, but also generalist physicians, RNs, LPNs, OT, PT, and other allied care providers with advanced training in geriatrics.
   - Increase public funding for frailty- and dementia-related services delivered at home, in communities, and in institutions.
   - Evaluate, scale-up, and publicly fund appropriate technology to support people with frailty and dementia.

4. **Language and labels matter to people, especially around stigma of frailty and dementia.**
   - Design and implement a plan to help de-stigmatize language, including “frailty”, “older adult”, “senior”.

5. **First and foremost, promote prevention of frailty and dementia.**
   - Frailty is not inevitable, and prevention requires a “whole life course” approach.
   - The AVOID Frailty strategy is a positive approach and should be scaled-up and spread. Consider adding “S” for “sleep”, as in “AVOIDS”.
   - Prevention should focus on hearing loss—the greatest remediable risk factor for dementia—, social determinants of health, and enhancing social relationships.

6. **Detect, assess, and intervene earlier for frailty and dementia.**
   - Early screening is critical, but currently sub-optimal. Develop strategies to clarify standards and improve case finding.
   - Subsequent to earlier screening, assessment should lead to more in-depth evaluation when warranted.

7. **Support a paradigm shift in messaging, education, and advocacy for frailty and dementia.**
   - Frailty can occur at any age.
   - The goal of aging is to add life to years, not years to life.
   - Recognize the bilateral relationship between frailty and dementia.
   - Develop strategies to improve health literacy to support informed choices.

8. **Overcome obstacles to build multi-disciplinary, team-based care, rather than geriatric specialists alone.**
   - Promote person-focused rather than disease-focused care, enabled by cross-disciplinary teams.
9. Place of care matters (where, how, and with whom).
   - Support patient choices when possible.
   - Increase alternatives to institutionalization and hospitalization.
   - Where residential care is appropriate and desired, balance quality of life with risk. We have the right to live at risk. There is no expiry date on civil liberties. Our job is to support the choices of older adults, not to mitigate risk to zero.
   - Enable better home care supports, including programs and services, for those who choose to remain at home.
   - Lower eligibility for Choice in Supports for Independent Living (CSIL) to support self-directed options for home support. Don’t be “penny wise but pound foolish” (i.e. stingy with small sums and extravagant with large sums)
   - Reduce emergency/acute care bounce-backs by improving access to housing, home support, and informal caregivers.

10. Improve communication and information sharing across the whole interdisciplinary team, including patient and family, from home to hospital
   - Resolve privacy issues.
   - Promote Shared Care.
   - Create, constantly update, and share an inventory/catalogue with information about resources, services, devices to support patients.
   - Implement patient navigators as part of team to connect systems with patients, and patients with systems.

Q2: What is the relevance of these messages to rural and remote service delivery and care for frailty and dementia in Northern BC?

1. Care-seeking is not always consistent with a Northern culture of rugged individualism.
   - There is a tension between autonomy vs. dependence that may affect care-seeking behaviour.

2. There is a persistent lack of access in the North.
   - Lack of access to primary care
   - Lack of services to execute care plans
   - Lack of home supports, including specialized home-care equipment
   - Lack of co-located services and housing
   - Lack of communication technology, such that telephones are still vital
   - Lack of access to trusting relationships with caregivers
   - Lack of publicly funded community-based services, especially for Indigenous peoples
   - Lack of culturally safe community-based accommodations for patients who must travel far in advance of procedures (e.g. colonoscopy prep cannot arrive by bus)
   - Lack of innovations to stretch resources in light of perpetual resource constraints
3. **Team-based assessments and care are essential in the North.**
   - Co-train patient-centered generalists, across professions and disciplines, in the care of older adults.
   - Investigate and implement technologies that enable teams.

Q3: What are the **specific actions** that might ensue related to frailty and dementia in Northern BC?

1. **Talk less, act more.**

2. **Fund more.**
   - Subsidize costs of implementing technology.
   - Subsidize home- and community-care.
   - Subsidize transportation.
   - Subsidize informal caregivers to reduce reliance on volunteers.
   - Regionalize support programs (strengthen and rely on resources in nearby outlying communities to support more remote communities).
   - Reconcile pay differences between community workers and hospital employees.

3. **Shrink the digital divide.**
   - Connect small communities to enable virtual frailty teams and ensure timely payments for income assistance and disability programs.
   - Implement or scale-up technology for home health monitoring.

4. **Design buildings and spaces for older adults**
   - Hospitals and health care facilities need senior- and dementia-friendly areas.
   - All facilities should encourage patient movement to prevent frailty.

5. **Educate older adults and their loved ones.**
   - Teach caregivers the art of advocating for loved ones.
   - Connect new pensioners to services and screenings, such as AVOID.
   - Design and implement awareness campaigns on health, social issues, fitness, and reducing stigma.

6. **Improve access to care.**
   - Promote culturally appropriate advanced care planning.
   - Increase adult day care and respite programs closer to home.
   - Improve safe transportation to care for those living in more geographically remote areas.
   - Implement FP/NP/OT/PT team house calls, in-person or via phone/web-based apps.
   - Enable the Medical Home Model.
   - Bend rules in reimbursement for distance.
   - Implement mobile health units where appropriate.
7. Improve recruitment and retention strategies for care providers.
   - Work with College of Physicians and Surgeons of BC (CPSBC) to credential internationally trained professionals for Northern practice.
   - Offer nurses full-time employment rather than casual hire positions.
   - Rely more on advanced-practice RNs.
   - Publicly-fund home-care aides.
   - Reconcile wage gaps that incentivize private- over public-pay PT and OT, which limits their availability in Northern Health Authority.

Day 1 (panel): What this work means for Northern BC?
In “making sense” of what we heard during the panel discussion on current research, there was one overarching “guiding principle” about frailty and dementia: Don’t leave the North behind, or equity will only get worse. It is essential to find ways to enable equitable access to appropriate care for residents of Northern BC. Beyond that, 7 themes emerged from the panelists and audience participants:

1. Knowledge Translation is critical but lacking.
   - There’s not enough KT across the Canada between jurisdictions, or with other countries.
   - Gather knowledge, evaluate it, summarize it, but, most critically, share it.

2. Language matters around “frailty”.
   - Clearly define “frailty” by coming to consensus on a working definition.
   - Be mindful of stigma around the word “frailty”, as it promotes negative self-perception and may lead to further decline.
   - Consider alternative language that invites people to participate in “additional supports that could help you”.

3. Build, leverage, and support multi-disciplinary teams in all care settings.
   - Place patients at the centre of the team, in the driver’s seat, along with family.
   - Use navigators and coaches trained in working with older adults to assist and follow-up with patients to guide their health and social care.
   - Support primary care providers with the best education they can have, so they are equipped with tools to assess, and leverage, community-based resources and primary care networks.

4. Increase opportunities to assess frailty.
   - Take advantage of windows of opportunity to assess for frailty, such as upon admission to ED and at discharge from hospital.
   - Use standardized common assessment forms and tests for frailty.

5. Improve appropriateness and location of care.
   - Right care, right time, right place
   - Care must be culturally safe, especially in the North.
   - Adapt interventions to rural/remote/northern communities to ensure models fit community needs and preferences.
• Increase “social prescribing” to refer people to a range of local, non-clinical services, recognizing that people are not just patients.
• Build an inventory/catalogue of resources and supports for providers and patient navigators to improve their knowledge about what services are available.
• Support enablement at home, rather than funneling people into facilities.

6. Promote and enable prevention.
• More proactive, less reactive and strengthen upstream early education, rather than downstream reactivity where we wait until something bad happens.
• Implement “anticipatory guidance” to educate family caregivers, before they become caregivers, to relieve the stress of caring for someone in functional decline.

7. Challenge policy- and decision-makers to always consider the North.
• Continually “poke” colleagues to remind them that the rest of Canada exists, beyond urban areas.
• In all decisions, consider how this would work in rural/remote/northern Canada.

Day 2 (workshops): Older Adults in Northern BC

1. Healthy Aging (Anne Pousette)

Q1: What are the central messages that we heard?

1. Design, implement, and fund upstream opportunities to access health and social care
   • Navigation supports for older adults will enhance learning and optimize earlier timing of care.
   • Strength-based approaches engage patients better than deficit-based approaches.
   • Design and implement strategies to help access basic supports that enable health: dental care, vision care, food security, transportation, housing, income security.
   • Investigate and prioritize opportunities to support intergenerational community-based activities that enhance social connections.
   • Resource and work with municipal governments and other community stakeholders to optimize actions that support healthy aging.

2. Refine the health service physical environment to improve patients’ experiences and outcomes.
   • Patient-unfriendly physical environments discourage care, missing opportunities to assess for frailty and dementia.
   • Prioritize flow in care settings to minimize time sitting or lying on stretchers.

Q2: What is the relevance of these messages to rural and remote service delivery and care?
   • All messages in Q1 are specific to rural and remote service delivery and care.
Q3: What are the specific actions that might ensue in Northern BC.

1. Build partnerships and create inter-disciplinary teams
   - Work with municipal governments to enable multi-sectoral partnerships in support of healthy aging.
   - Implement Healthy Aging Navigators, activated through primary care teams, to facilitate care and improve experiences and outcomes.

2. Actively address ageism in the health sector.
   - Design and implement strategies to intentionally educate the workforce, including mentoring, role modeling, and inputs into post-secondary curricula.

3. AVOID (John Muscedere)
   - No notes provided, as AVOID was discussed elsewhere.

4. Risk: Acceptance, Avoidance, Amelioration (Ray Markham & Fraser Bell)

Q1: What are the central messages that we heard?

1. Perceptions of risk vary across a spectrum
   - Society says risk is bad and the goal is zero risk, but not everyone agrees
   - There is a difference between real risk vs. perceived risk.
   - The balance point is what physicians vs. patients each value.

2. Diversity in risk tolerance influences care decisions
   - How do we optimize care yet still allow people to live at risk they can manage?
   - When patients say “I’m ok” or “Leave me alone” they are sometimes trying to talk about their risk tolerance.

Q2: What is the relevance of these messages to rural and remote service delivery and care?

   - There is a difference between caring for and caring about.
   - How do we reconcile the tension between risk vs. trust, hope vs. fear?
   - Create opportunities in care planning to develop shared understanding of risk, in light of challenging circumstances for patients and insufficient resources to implementing ideal plans.

Q3: What are the specific actions that might ensue in Northern BC.

   - Build understanding of different “mental models” of risk.
   - Engage in “appreciative inquiry” about risk to describe the current state, what’s possible, and what could be.
4. Reality and Promise in BC (Isobel Mackenzie)

Q1: What are the central messages that we heard?

1. Geography matters.
   • The North has unique challenges as compared to other parts of BC.

2. Current policies and guidelines are impacting our ability to support seniors at home.

3. The North could “incubate” innovative projects due to small scale.

Q2: What is the relevance of these messages to rural and remote service delivery and care?

1. Projected demographics show that the North will experience greater challenges relative to other parts of BC.

Q3: What are the specific actions that might ensue in Northern BC.

1. Pilot the following projects:
   • client-direct funding
   • increasing scope of practice for care aides
   • removing co-payments for home support
   • private sector partnerships for market-priced and subsidized independent housing

Day 2 (panel): Reflections on the day’s take home messages (Voices from the North)
These are the “take home” messages we heard through our “voices from the North” panelists.

1. Listen to patient voices.
   • Balance patient voices with family voices and manage conflict where it occurs. Consider whose values, which risk, whose risk, and the risks of independence vs. risks of safety.
   • “Don’t do it to us but do it with us.” How do we embed those conversations into the healthcare system?
   • Healthcare providers are better at caring for people, than caring about them.

2. Language matters and stigma around “frailty” is real.
   • How easily that word slips off the tongue, without realizing the stigma.

3. Distance, communication, and culture are the biggest challenges in the North.
4. **Develop and adapt Northern-specific metrics and care delivery models.**
   - Expand and fund community-based care and care teams.
   - Include everyone along the patients’ journey, across all settings.
   - Consider, for example, “community plans” to collectively keep patients safe
   - Where are the social workers in all of this?

5. **Start Advance Care Planning earlier.**

**VII. Discussion**

These two days of presentation, dialogue, and iterative exchange brought attention to the needs and issues of older adults, including their health, wellness, and the importance of patient-centred care. Messages to rural Canada and the North are clear and actionable.

Where to next?

While this content has relevance to all older adults, it has express meaning and implications for rural and Northern residents and those experiencing frailty and/or dementia. These proceedings are offered as content for consideration, enablement, and implementation where feasible by the Canadian Frailty Network, the Rural Coordination Centre for BC, Emergency Medicine Network, Northern Health, and First Nations Health Authority.