All Together-Compassion Communities: Developing Dementia-Inclusive Spaces for Community Access, Participation, and Engagement (DemSCAPE)
Date: Dec 6, 2023

AGENDA ITEM	DISCUSSION
Overview	**Facilitator**: **Melody Jobse**, Community Engagement Lead **BC Centre for Palliative Care (BCCPC)** **Presenter: Cari Randa-Beaulieu** Project Manager, **DemSCAPE, Simon Fraser University**
What is Neighbourhood Built Environment?	• Cari invited participants to contribute to a Jamboard to brainstorm ideas about dementia inclusive neighbourhood principles. Familiar, Accessible, Comfortable, Distinct, Legible, Safe are foundational principles from research.
Cari's Presentation	Learning Objectives: 1) Understand the importance of neighbourhood built environment for mobility and participation of people living with dementia 2) Apply innovative community-base participatory research methods with people living with dementia 3) Access and share public engagement tools for dialogue and challenging stigma surrounding living with dementia in the community **Intro** • DemSCAPE is a 3 year study funded by the Dementia Strategic Fund Awareness Raising Initiatives program of the Public Health Agency of Canada and the Alzheimer's Society Research Program • DemSCAPE is a collaboration between researchers at SFU, UBC and UNBC • The co-investigators are researchers in the fields of gerontology, nursing, urban planning and social work with the support of an interinstitutional interdisciplinary team

Background

- 69% of older adults living with dementia are under the age of 80. 58% of those over 80 live in the community
- Neighbourhood Built Environment has a key role in out-of-home activity of people living with dementia (PLWD) and can hinder or facilitate:
  - mobility and physical activity
  - social participation
  - orientation and wayfinding
  - access to services and social networks
- Research on the built environment and dementia inclusive planning is quite sparse still emphasizing need for research-based principles to help support people living with dementia maintain community connections and independence as long as possible – leading to DemSCAPE project Objectives

DemSCAPE project Objectives

- Identify neighbourhood destinations that people living with dementia visit and changes in the patterns of those visits over time
- Identify neighbourhood built environmental features that affect their outdoor mobility, engagement, and social participation
- DemSCAPE is the first project in Canadian focusing on this area

Project Participants

32 community-dwelling persons living with mild to moderate dementia or mild cognitive impairment and their care partners, if applicable. Participated June-Dec 2022

- Metro Vancouver: 26 participants
  - 11 individuals
  - 15 dyads
- Prince George: 6 participants/dyads

Project team members did walk-along interviews with participants and took video recordings

Analysis:

- Analysis of interview transcripts
- Video analysis of walk-along interview footage

- Survey questionnaire data

Preliminary Findings:

Outdoor walking experience is influenced by: Physical Aspects, Cognitive Aspects, Social Aspects, Psychosocial & Emotional aspects and Temporal Aspects

1) Physical Environment Facilities or Hinders walking experience by things such as terrain, ambident conditions, sidewalk condition, places to rest, access features, crossings
2) Experiencing Familiarity With and Understanding Neighbourhood Environment include taking familiar routes, knowledge of neighbourhood layout and identifying streets (ave and streets with same name/number can be very confusing)
3) Environment Promotes Orientation and Wayfinding includes streets with good sightlines to assist with navigating, landmarks such as amenities and artwork. Features can overlap and be beneficial for different aspects
4) Positive Social Interaction and Social Support is fostered when community members have dementia awareness and sensitivity so people living with dementia feel comfortable access direct and indirect support from others.
   - Participants recognize importance of connection (saying hello, smiling) for themselves and others and hopes that is reciprocated if they do need to ask for support.
   - All participants looked at sharing their lived experience as a way to make a difference in their community

3 main knowledge mobilization resources created from findings
1) Dementia-inclusive Planning and Design Guidelines – for decision-makers and city planners
2) Environmental Audit Tool – for advocacy orgs and people living with dementia to audit their neighbourhood and identify intervention projects
3) Short Video – increase awareness and understand issues

Knowledge Mobilization Plan
- Continuing collaborations with Richmond and Burnaby to conduct screenings and group discussions, municipal planner focus group discussions to tailor planning to their cities, surveys to community members
- Vernon - co-developing and evaluating stigma-reduction training for city staff

DemSCPAE Video	**Knowledge Mobilization Video** Purposes of video: • To educate on the role of Built Environment as an essential component of Dementia-Friendly and Inclusive Communities • To challenge stereotypes of what it means to be a person living with dementia in Canadian neighbourhoods • To inspire action that includes people living with dementia in municipal decision-making and planning purposes Video developed with 3 key stakeholders in mind 1) Organizations such as Public Health Agency of Canada, Health Canada as well as non-governmental orgs 2) Municipal planners, urban designers, educators 3) People living with dementia, their care partners and the general public to inspire hope, optimism and engagement Cari invited attendees to share DemSCAPE resources with their networks: • Digital version of DemSCAPE photo exhibit on website: www.sfu.ca/demscape • Demscape social media accounts: DemSCAPE (@DemSCAPEbc) / X (twitter.com), DemSCAPE (@demscapebc) • Instagram photos and videos, DemScape | Vancouver BC | Facebook • Cari's contact: demscape@sfu.ca 8 minute video: Dementia-inclusive Streets and Community Access, Participation and Engagement (DemSCAPE) - YouTube
Discussion questions	Participants discussed the following in breakout rooms following viewing the 8-minute video: 1. Thinking back to the video, Esther, Lynn, and Neils encountered different challenges in their neighbourhood built environments (streets, sidewalks, public spaces, transit, housing, etc.). Were there any specific areas of challenge you related to from your personal or professional experience? 2. Are there any strategies in your neighbourhood/municipality that work well?

	3. What would you like to see change in your neighbourhood?
Q&A and discussion wrap-up	**Reflections**

Reflections

- Impactful hearing the stories of the those living with dementia and the challenges they can face walking around their neighbourhoods – cognitive and physical. Looking for a way to find home – lights and wayfaring signs on bus stops would be beneficial for everyone
- Importance of having someone to champion this in the community whether through a disability resource centre or an individual in the community and how much can be accomplished when someone is leading the way
  - **Cari**: DemSCPAE project in the stage of bringing research into practice and with partnerships in Burbnavy and Richmond we are working with municipal planners and getting connected in Brunaby with ACCESS committee (community representatives with visible and invisible disabilities) to work on the ground up dissemination of this work and key champions in making changes
- **Q: Resources for people in smaller/remote communities for safe activities to do, is there a registry/way to connect?**
  - **Cari:** Smaller communities face different challenges. In partnership with UNBC that was a challenge in recruitment as there are less community-based services for those living with dementia. Each community is different. Often times the local Alzheimer Society chapter is a key resource, as well Neighbourhood Houses
  - Hospice organizations are often a great network for connection and resources. Ex. Prince George Hospice has an amazing network and may be able to connect for support in smaller Norther communities outside of Prince George

- My group spoke about setting up safe/supportive environments for folks if/when they get lost, and what that might look like. I.e., how do you set up a safety net without potentially increasing vulnerability by "outing" someone as having a cognitive impairment and available to be taken advantage of? We wondered if smaller communities are actually better set up for this than urban centres?
  - Larger communities it may be harder to work through the hoops and smaller communities may have more capacity and energy to develop necessary structures
  - Individual comfort level – depending on the individual and where they are at in their dementia journey they may not want their dementia diagnosis known to neighbours, family, etc. Isn't a

	prescriptive way to do this but agree that smaller communities may naturally be structured to provide that support in a more person-centered way. Would be good to learn more • In smaller communities things like transit may rare. Having that makes a big difference. In smaller communities people are more willing to stop and help if they see someone in need (ex. Ride home) • Challenging to go through volunteer training – the amount of training, mostly all online, health authority approval sometimes needed, additional insurance you may need on vehicle if you volunteer to drive. Additional challenges when you want to help can make a barrier to getting volunteers back where we need
Additional Resources and connect	• Cari's contact: demscape@sfu.ca • BC Centre for Palliative Care: Compassionate Communities Resources • Keep in touch with BCCPC's work in this space of Compassionate Communities: Subscribe to CentrePoint