

A Brief Overview of the Building Trust Research and Knowledge Mobilization Project

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Dr. Sharon Koehn first met the Director of Geriatric services at Fraser Health, Kathleen Friesen, when she attended a 1.5-day symposium on access to services by immigrant older adults organized by Dr. Koehn in 2007. The two stayed in touch and in 2014 teamed up to work on Dr. Koehn's CIHR planning grant that brought together academics and decision-makers to explore issues of interest to the latter, once again concerning access to care by older immigrants.

Ms. Friesen was unequivocal. In her new position as Director of Clinical Programs, Population & Public Health, she wanted to know how the health authority could improve dementia care services for minority older adults, particularly South Asians. After English (77%), Punjabi at 8% was the second most commonly spoken home language by seniors within the region.¹ The team employed the Candidacy Framework to explore the issue in the existing literature and ultimately produced a chapter² for the [e-book](#) generated by this project.

The Candidacy framework for understanding access to care speaks to the patient/client's dynamic and continually negotiated sense of legitimacy in using healthcare,³ which is "subject to multiple influences arising both from people and their social contexts and from macro-level influences on allocation of resources and configuration of services."⁴ Establishing access entails identification of the need for care, finding your way to it, presenting a credible claim for care to service providers who will judge its credibility, and accepting or rejecting offers made. The 'openness' and compatibility of the system and local operating conditions also play a role. The seven dimensions of Candidacy shed light on the roots of inequities in health and health care, by tying seemingly individual behaviors in utilization to socially patterned influences."³ Across the different topics explored by the five teams nationwide, a very clear theme emerged as central to all dimensions of candidacy and hence to the process of gaining access, that of trust.⁵

To further explore access to dementia services in the context of the Fraser Health region, Koehn and colleagues have partnered with Fraser Health, the Alzheimer Society of BC (ASBC), and two immigrant service agencies—PICS and MOSAIC. Their action research project is entitled "Building trust to facilitate access to dementia care for immigrant older adults: the role of the multicultural services sector." The decision to include immigrant-serving agencies as partners was grounded in Koehn's previous research, which established that these agencies play an important role in promoting health and social connection among immigrant older adults.^{6,7} The literature affirms that this is because they understand the multiple barriers and facilitators to access for these populations, but also because they are seen as more trustworthy.⁸⁻¹⁰

With funding from the Alzheimer's Society of Canada,* Koehn's team embarked on a two-phase project that began in Fall 2016 and will conclude in June 2019. In addition to the Punjabi population, they elected to include Korean speakers as a second population of interest. Despite their status as the largest minority language group in some communities within the Fraser Health region,¹¹⁻¹³ Korean speakers have received almost no attention in the Canadian literature on immigrant older adults.¹⁴

In Phase I of the project, Koehn's team studied how people from the Punjabi and Korean-speaking communities in the Fraser Health region of BC understand and experience dementia and access to dementia diagnosis and care (specific to each dimension of the candidacy framework). Interviews with staff from all partner agencies as well as persons with dementia and their family care partners, and focus groups with community members also explored people's perceptions of the trustworthiness of relationships with the people and agencies with which they need to interact in order to either gain or provide access to dementia supports.

Findings are being reported in detail in academic papers and presentations. In brief, however, the team found that cultural views of aging and illness in combination with low levels of education and literacy were sometimes barriers to recognizing behaviours as symptoms of dementia. Limited understanding of dementia in both communities contributed to stigmatization of the disease. Family involvement can add barriers or introduce opportunities and benefits for dementia diagnosis and care, but some participants, especially in the Korean community, indicated that adult children were not always readily available to locate services, and provide much needed transportation and interpretation. Koreans were more likely than Punjabis to have access to computers and seek out information on the internet, but there were fewer services in the community for Korean speakers, compared to those for Punjabis. Participants identified Punjabi temples and Korean churches as important sources of influence through which dementia information can be conveyed.

Interviews with staff surfaced two sets of complimentary knowledge. Health authority and local Alzheimer Society staff told us that they have resources that can facilitate access to dementia information and supports for persons with dementia but have little capacity to address the language and culture-specific needs of the Punjabi and Korean populations. Conversely, PICS and MOSAIC staff have the capacity to connect with and provide culturally responsive health information and navigational support to these populations and to engender trust, but lack knowledge and resources concerning dementia. During our research phase, funds from a Fraser Health project temporarily funded a Punjabi Liaison position and South Asian helpline at the local chapter of ASBC. Subsequently, ASBC has continued to fund a position staffed by a Punjabi speaker that is partially dedicated to building connections with South Asian populations in the region. At the conclusion of Phase I, additional stakeholders attended a forum in which they were engaged in providing feedback on the findings and prioritizing actions moving forward. They identified increasing cultural sensitivity and community connections as important goals for this work.¹⁵

Now in Phase II of the project, Dr. Koehn and her staff have facilitated numerous meetings between the partner agencies to explain the findings of the research, build partnerships, and to work on collaborative strategies to translate the findings into a suite of innovations that can increase access to dementia resources for the target populations. These include the following:

1. **Punjabi-adapted Dementia Friends presentations.** PICS staff, Devinder Chattha and Kamaljeet Bharya, have collaborated with ASBC and Dr. Koehn to adapt the slides used for this workshop to reflect South Asian realities. This involved changing some images, and omitting and adding some slides to reflect specific information needs of Punjabi older adults (e.g. the importance of consulting with a family doctor). PICS staff advised the Punjabi-speaking ASBC liaison (Manprit Chutai) as to the translation of the oral script into words familiar to the older Punjabi audience. Participants were drawn from among PICS clientele and the meeting took place at their headquarters, which is already familiar and accessible to them. These workshops address the finding that dementia is little known

and its symptoms are dismissed as ‘normal aging’ among older Punjabi speakers. The presentation aims to dispel myths about Alzheimer’s disease and other dementias and create a more dementia-friendly community environment.

2. **Dementia-in-the-workplace English language class for newcomers.** Gita Mathew, an EAL (English as an additional language) teacher has designed a three-hour class that will be incorporated into the labour market section of PICS’ English curriculum for newcomers. There is a high demand for entry-level workers in the geriatric care industry in which employees are bound to come into contact with persons with dementia, hence we anticipate that this curriculum will be of interest to newcomers and will help ensure the sustainability of this product for PICS. Our findings indicated that younger family members are often responsible for health resource location and system navigation for their parents; however, newcomers do not have the knowledge of dementia or familiarity with Canadian systems to identify dementia supports effectively. Continued inclusion of this class in the curriculum will maximise exposure of different newcomers to the basics of dementia.
3. **System navigation video in Korean.** To address the dissatisfaction of their visits to the family doctor in Canada, particularly concerning dementia, MOSAIC staff, Darae Lee and Michelle Park, suggested we create a YouTube video to coach older Koreans about the system encounter. Their clients are familiar with and enjoy such videos. Manprit Chutai identified ASBC materials on speaking to your doctor about dementia and the signs of Alzheimer’s Disease as helpful to their content development and system navigation materials from Fraser Health were also included.
4. **Korean Infocard.** MOSAIC staff identified an ASBC resource that would be valuable to their Korean clients: ASBC’s pamphlet on ‘Five Things to Share about Dementia’ and ‘Communication Strategies.’ However, at the time this pamphlet was only available in English. Team members translated the pamphlet into Korean and formatted it as a folded wallet-size business card. These portable infocards include a First Link® number at ASBC, but also the Korean contact at MOSAIC who can help them to navigate the English ASBC resources.

All of the above, except for the Korean infocard, have been piloted with members of the target populations, who completed demographic questions and simple pre-and post exposure evaluations, and the results are promising.

For example, at the first Punjabi-adapted Dementia Friends workshop held on January 22nd, 2019, the 38 participants included almost as many women as men. This number exceeded the number of invitees, indicating keen interest in the topic within the target population. The majority (19) were aged between 61 and 70 and most (17) had a high school education. Three quarters were from India and mainly Punjabi speakers but less than one quarter spoke English. The largest proportion (14) had been in Canada between five and nine years and the majority (23) were Family Class (sponsored) immigrants. More than half knew somebody with dementia but, typically, these were not people close to them.

Prior to the workshop, the majority (18) of the respondents indicated that they knew ‘nothing’ or ‘not much.’ This shifted to a considerable majority (28) feeling that they knew ‘quite a bit’ or ‘a lot’ after the presentation. Similarly, most (17) said they did not know if people could lead meaningful lives with dementia before the presentation, as compared to afterwards when 29 responded that ‘maybe’ or ‘definitely’ they could (with only four saying they did not know). Thirty participants found the presentation to be mostly or completely understandable.

After the Dementia in the Workplace language class, the 7 participants, who spoke either Spanish or Chinese or South Asian languages, indicated that their recognition of signs of dementia and their understanding of what they could do to help a person with dementia had increased. All participants would recommend the class.

A total of 47 Korean adults, 45 of whom were aged 50 or more, reviewed the video. Only one could speak English, despite the fact that most (40) had a post-secondary education and all but 3 (44) had lived in Canada for more than 10 years. Thirty participants knew a person with dementia, ten of them very closely and 2 quite closely. Before watching the video twice, the majority said they either knew very little (27) or nothing (6) about Alzheimer's Disease or other dementias. After viewing, more than half of the group felt they knew quite a bit (21) or a lot (4). The extent to which respondents could name signs of dementia, could recognize that dementia was not a part of normal aging, knew what kinds of questions to expect from their family doctor, knew what questions they should ask their family doctor, understood the kinds of services offered by the health authority and where to go for help with dementia, increased across the board. All participants felt that that the video was very effective in conveying this information. Minor concerns, such as the volume of the music in one section were noted and adjusted before releasing the final version.

To make their research and knowledge mobilization products widely and openly accessible and to provide long-term sustainability for their project partners, Koehn and team will upload these materials onto web pages of the United Way of the Lower Mainland's Healthy Aging CORE website, as well as Koehn's Researchgate page.

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