

Edmonton West Primary Care Network (EWPCN) – Building Resilience in Caregivers (BRiC) - Final Report

Executive Summary

The purpose of the Edmonton West Primary Care Network (EWPCN) Building Resilience in Caregivers (BRiC) program was to 1) build linkages and connections for the caregivers of individuals impacted by dementia to education, information, and a network of peers; 2) provide a primary-care-led, 11-week program of cognitive stimulation therapy and nutrition program (in-person/group session), for individuals diagnosed with dementia.

The BRiC program was developed by the EWPCN Occupational Therapist and Occupational Therapy Assistant. Participants were identified for a referral to the BRiC program through the Complex Care Transitions Program or through their EWPCN family physician. Participants attended the Westend Seniors Activity Centre (WESAC) once a week for 11 weeks. WESAC is a community hub that fosters a variety of programs and services to support healthy aging and active living. During the program, caregivers learned about how to maintain their health and wellbeing with a variety of team-based health care resources (occupational therapy, behavioral health consultants, exercise specialists, registered nurses, pharmacists, social workers and dietitians). Using a person-centred approach the primary care team met the needs of the caregivers by collaborating on topics of interest they find valuable in helping to develop coping skills and built capacity within caregivers to support people living with dementia in the community. As caregivers took an hour to learn and connect in the community a concurrent Cognitive Stimulation Therapy session was provided to the person living with dementia. All participants met up for lunch to encourage social engagement, reduce feelings of isolation and build community.

Over the course of three years (2020-2022), BRiC reached a total of 49 clients. 35 participated in the caregiving stream both virtually and in person, and 14 in the Cognitive Stimulation Therapy (CST) stream (over the course of three in-person sessions). A total of nine groups completed the program, with one additional group participating in Digital Storytelling in the Fall of 2022. There were eight participants in the Digital Storytelling program (four caregivers, and four clients with dementia). Due to the COVID-19 pandemic, the program shifted its delivery model to virtual (using Zoom) in the spring of 2020. This shift reduced the number of in-person CST sessions for people living with dementia.

Overall, the program met its purpose and participants experienced the following outcomes:

- Caregivers and participants with dementia satisfaction with the program.
- Provision of information on topics of interest to caregivers participating in the program.
- Caregiver connection to community resources and peers.
- Increased caregiver confidence and coping skills.
- 39% of caregivers decreased their caregiver burden score.
- 7/9 participants with dementia maintained or improved their cognitive scores through completion of the cognitive stimulation therapy program.

The program will be integrated into the regular EWPCN programming going forward and will be offered twice a year, with the potential to increase offerings in the future. The program outline, content provided, and the populations served will remain the same. The EWPCN will continue to promote community partnership by offering the BRiC sessions at the West End Seniors Activity Center (WSAC) for the winter session and strengthen the partnership with WSAC by offering the caregiver sessions to WSAC members on a drop-in basis. Finally, the EWPCN will remove transportation barriers to clients



by maintaining a partnership with a community car ride service and providing transportation to the sessions at no cost to the participants.

Objectives/Implementation

The objectives for the multi-year project *Building Resilience in Caregivers (BRiC)* were to:

1. Build linkages and connections for the caregivers of individuals impacted by dementia to education, information and build a network of peers.
2. Provide a primary-care-led, 11-week program of cognitive stimulation therapy and nutrition program (in- person/group session), for individuals diagnosed with dementia.

Based on the literature evaluating similar programming around the world, the outcomes of the project were predicted/hypothesized to be:

1. Maintain cognition of clients with dementia.
2. Improve caregiver quality of life.
3. Decrease caregiver burden, burnout, and social isolation.
4. Increase caregiver supports and networks.
5. Enhance caregiver capacity to care for and support patients with dementia.
6. Increase the EWPCN Complex Care transition program's (formerly known as Frail Elderly Outreach Program) capacity to see more patients outside of the home setting through group programming.

One of the key innovative features of the BRiC project was the execution of the standardized/established Cognitive Stimulation Therapy (CST) programming, which the team at EWPCN understands to be quite a limited offering in western Canada. CST was planned to be offered in-person concurrent to sessions equipping caregivers with information and tools to best support their own health and resiliency.

Given the context and restrictions that COVID-19 presented, the baseline plan to offer in-person sessions for cognitive stimulation therapy, caregiver support, networking, transportation via Drive Happiness and lunch at West End Seniors Activity Centre, had to pivot after the first session to virtual programming. For the most part, the caregiver components of the programming transitioned seamlessly. The CST component for participants with dementia did have to change substantially given clinicians could not offer direct supervision and program application to the clients; instead, caregivers were given a printed manual and access to software/apps that support CST components within their caregiving relationship. Once the COVID-19 guidance allowed for in-person access to community based programming, the BRiC program delivered the intervention as initially planned, serving both caregivers and persons with mild/moderate dementia at a community setting.

In many ways, the COVID-19 pandemic forced the project to pursue additional innovation given the team's commitment to serving the intended audience; this extra innovation and responsiveness came to life – and continues to evolve – in the delivery of the programming and objectives. For instance, all the caregiver support sessions were converted to audio visual files, and the CST resources were adapted/transformed into individual-oriented manuals to offer the programming virtually. The project team experimented with a few virtual platforms and strategies, from pragmatic calling tele-conference forums, emailing the audiovisual files for self-guided review, live Zoom presentations, and interactive weekly forums between participants and regulated clinicians and/or community-based expert guests.

A key design element of this project was inclusion of digital storytelling methodology to draw out the experience of caregivers supporting dementia, as a tactic to not only gather rich anecdotal data but also to inform future value-add programming within EWPCN. A proportion of the 'graduated' BRiC caregivers were invited to participate in a digital storytelling session delivered by Weasel Tale, a reputable and trained storytelling vendor.

Ultimately, the project team delivered a series of eleven sessions to nine cohorts of participants and finalized the programming with a distinct cohort invited for the digital storytelling component. In the original planning stages, eight cohorts were planned with a maximum of 120 participants (16 per cohort except for cohort 1 operating at half capacity). Unfortunately, due to a variety of factors, the number of participants were much lower than expected with a total of 49. One main reason for this change in plans was due to the COVID-19 pandemic causing an abrupt end to the first cohort in-person session and pivoting to a virtual model for cohorts 2-7. During this time, many of the clients that were referred expressed wanting to be included on a waitlist for when the in-person programming began again. This was a barrier in recruiting clients for virtual programming. During the intake process, EWPCN offered technology options for clients who did not have what was needed to participate virtually including loaning tablets out, providing program material in hard copies as well as digital copies and providing 1:1 sessions with clients for coaching on how to utilize virtual platforms like Zoom etc. Once in-person sessions were able to take place, cohorts 8 and 9 included clients who were added to the waitlist throughout the pandemic. It was observed that there was a progression of dementia since the initial intake and almost to a point that cognitive stimulation therapy would not be appropriate for these clients. This further solidified the importance of not delaying programming any further as a future consideration. Another consideration was related to COVID-19 restrictions and mandates for meeting together in a group. This did not allow for full capacity and is another factor in reduced numbers from the original plan. An additional noteworthy observation is that there was no known COVID-19 transmission between participants and/or staff members during in person sessions from February 2022-July 2022.

Impact

The evaluation sought to answer:

- Is the program working as anticipated?
- How does the program impact clients and caregivers? Does it build resilience, decrease caregiver burden, and increase caregiver capacity?

Data Sources included: caregiver surveys, Quality of Life tool, Zarit Burden Interview, Observation, Informal feedback, and the Saint Louis University Mental Status (SLUMS).

Did the program work the way it was intended:

- The program met 100% of caregiver's expectations.
- 100% of participants felt the program connected them to community resources.
- Clients felt it was easy to participate using virtual technology.
- 97% of participants will access WESAC or community resources.
- 87% of participants felt more connected to/built relationships with other caregivers.

How did the program impact caregivers:

- Increased caregiver knowledge and awareness of resources.
- Increased caregiver's coping skills and confidence.
- Items with largest number of caregivers reducing burden scores:

- Feeling afraid of what the future holds for their relative.
- Feeling they should be doing more for their relative.
- Feeling unsure about what to do about their relative.
- Feeling their social life has suffered due to caring for their relative.

How did the program impact clients:

- Limited ability to engage clients in evaluation due to shift in programming/virtual delivery.
- 9 patients completed evaluation tools:
 - SLUMS scores
 - 7/9 patients maintained or significantly improved score – maintaining or improving cognition.
 - Patient survey
 - All participants enjoyed program; improved mood, increased social connection.
 - 8/9 patients would like to attend other day/group programs.