



Improving Social Inclusion for Canadians with Dementia and Carers through Sharing Dance

**Research Project
Synthesis Report
2021**

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Lozinski Centre for Community Dance
Centre Lozinski pour la danse communautaire

Executive Summary

Improving social inclusion for Canadians with dementia and their carers through Sharing Dance

The goal of this study was to investigate the potential to improve social inclusion of people living with dementia and their carers through the expansion of the Baycrest NBS Sharing Dance Seniors program.

Sharing Dance Seniors is a joint venture between **Canada's National Ballet School** (NBS) and **Baycrest Health Sciences** to make dance accessible to older adults with a range of physical and cognitive abilities, including people living with dementia. Dance sessions were delivered remotely for participants in institutional and community settings with on-site facilitator support. The development and expansion of the program was funded by the Public Health Agency of Canada and in collaboration with long-term care homes and community support agencies.

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The four year study (2017-2021) involved pilot studies in non-metropolitan regions of two Canadian provinces, Peterborough, Ontario (seven communities) and Brandon (Westman) Manitoba (six communities).

Brandon
Manitoba

Peterborough
Ontario

There were in total **289 participants** involved in the study, including **98 people living with dementia**, **32 carers**, and **16 volunteers**.

The collaborative research team included **two co-principal investigators** out of **six university researchers**, and **seven research assistants** in collaboration with **six professional dance instructors, 16 community administrators, and 16 program facilitators.**

The pilot studies involved three phases of observations, diaries, focus groups and interviews with Sharing Dance Seniors program participants (people living with dementia, carers, coordinators, instructors and volunteers,) as well as critical reflections among research investigators and knowledge users. Qualitative data were analyzed to understand the experiences, effectiveness and challenges of the dance program to inform whether and how it enhances social inclusion and quality of life for older people living with dementia and carers.

Our results captured the experiences of participants in the Sharing Dance program. In Peterborough pilots, we discovered that the program provided benefits and social interaction for participants (see P2 Report) and that instruction needed to take diverse abilities into consideration (see P2 Report). In Brandon Pilots, participants living with dementia enjoyed getting out, being creative, and expressing themselves in relation to others, while the program provided opportunities for understanding and talking about dementia (see B2 Report). Family carers, volunteers, and personal care staff appreciated new ways to interact with people living with dementia (see B3 Report).



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Preface

Older adults, including people living with dementia, can experience barriers to meaningful participation in social life across a range of settings. Accessible, innovative and creative programs are essential to supporting social inclusion and enriching the lives of older adults wherever they live. This synthesis report is the culmination of a nationally funded, four-year research project that aimed to understand the potential of Canada's National Ballet School's innovative Sharing Dance Older Adults program, particularly in relation to improving social inclusion of older people living with dementia and carers. The report brings together the perspectives of older adults, family carers, and health and social care providers to highlight processes and outcomes related to social inclusion as well as identify challenges and recommendations for improving social inclusion and advancing future research.

The report offers a summary of findings over the course of the research project with references and links to previous reports and publications, tracing the evolution of our collaborative research and the Sharing Dance program. We encourage readers to follow the links to all of the previous reports and to explore the project website where they will find more details about the work, the team, and participants and supporting partners.

The research in this report was born out of a shared view that bringing together diverse approaches and perspectives would yield a more comprehensive understanding of the importance and impact of the arts for older adults and communities. Working with Canada's National Ballet School has been an incredible opportunity and a great example of how interdisciplinary and multi-sectoral collaboration can address the complex needs of individuals, build community capacity, and respond to national demands.

As co-principal investigators, we are grateful to all of our co-investigators, collaborators, and partners for their dedication, imagination, and adaptability throughout this project. We thank the Alzheimer Society of Peterborough, Kawartha Lakes, Northumberland & Haliburton for their advice and feedback in the early stages of the research and the Alzheimer Society of Manitoba in Brandon for working closely with the research team throughout many adaptations of the Sharing Dance program. We are grateful for the support of Community Care Peterborough, Prairie Oasis Community Centre, Minnedosa 50 + Activity Centre, Minnedosa Personal Care Home, Carberry Plains Personal Care Home, Country Meadows

Personal Care Home, Prairie Oasis Community Centre, Bayside Personal Care Home, and Birch Lodge Personal Care Home for hosting Sharing Dance and collaborating to make this research possible. Finally, we thank the older adults for being open to participating in Sharing Dance.

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Introduction

Background

In 2013, Canada's National Ballet School (NBS) got together with the shared interest of developing dance programs accessible to older adults with varying physical and cognitive abilities, including people living with dementia in long-term care. Since then, NBS and Baycrest have developed dance program accessible to older adults with dementia in long-term care. Further, NBS-Baycrest have developed a training program to train people (dance instructors and recreationist/activationists) to teach these dance programs in their communities.

To enhance accessibility, in 2016, NBS connected with the Trent Centre for Aging & Society (TCAS) at Trent University to consider how the dance program might be shared with older adults who did not live in large urban centres through remote delivery. Further, while the program was initially developed with people living in long-term care, NBS and Baycrest began to consider how the program might be adapted for more independent older adults.

In March-April 2017, using the dance program developed by NBS-Baycrest, a pilot dance was run in partnership with TCAS in the Peterborough, Ontario, one of Canada's most rapidly aging regions. In the three years that followed, NBS-TCAS evaluated the program and different delivery models of it, while conducting research on its benefits, with participation from Baycrest and support from the Public Health Agency of Canada (PHAC). Additionally, in 2017, TCAS was awarded a CIHR operating grant to study the social inclusion aspects of the program, including an expanded pilot in Brandon, Manitoba. The CIHR grant is co-funded by the Alzheimer Society of Canada (ASC) and involves partners at Brandon University; KITE- Toronto Rehabilitation Institute, University Health Network; and University of Manitoba.

This community report provides a compilation of the findings from multiple pilot studies conducted for the CIHR/ASC study, "Improving social inclusion for Canadians with dementia and their carers through Sharing Dance." Results are organized into categories of processes and outcomes, challenges, and recommendations, and will include references and links to the previous reports of individual pilot studies. Please enjoy this final report and for further details and a list of publications and previous reports, visit the website.



“Dance is like another language, it sort of draws people together.”

Sharing Dance Seniors Participant,
Brandon, Manitoba

About the Project

This study examined the potential of dance to improve social inclusion for people living with dementia and their carers. Research suggests that arts-based programs can improve the health of people living with dementia and carers; however, little is known about how these programs might address barriers to social inclusion. Addressing barriers requires the development and evaluation of accessible, non-stigmatizing and affordable programs that facilitate social inclusion across the continuum of institutional, community and household care settings.

GOAL:

To investigate the potential to improve social inclusion for people with dementia and their carers through the expansion of Baycrest NBS Sharing Dance Seniors program

OBJECTIVES:

- 1** Examine the experiences of older people living with dementia and their carers participating in the Sharing Dance program as they relate to understanding the multiple dimensions of social inclusion across the care continuum in urban and rural settings
- 2** Assess the effectiveness of the multi-modal delivery of the Sharing Dance program as it relates to enhancing social inclusion processes and outcomes across the care continuum in urban and rural settings
- 3** Identify the challenges of expanding (scaling-up) the Sharing Dance program as they relate to experiential, programmatic and contextual factors that influence the success or failure of the program as it relates to social inclusion across the care continuum in urban and rural settings

The Team



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About Sharing Dance



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An innovative, community-oriented dance program, Sharing Dance Seniors is a joint venture between Canada's National Ballet School (NBS) and Baycrest Health Sciences. The Sharing Dance Seniors program is unique in Canada and internationally in its aim to make dance accessible to older adults with a range of physical and cognitive abilities, including people living with dementia. The program involves a suite of remotely instructed (streamed) dance sessions to participants in institutional and community settings with on-site facilitators supporting participants. The program was piloted for nation-wide expansion as part of a multi-sectoral strategic partnership with the Public Health Agency of Canada in collaboration with long-term (residential) care homes, regional home care providers, and community support agencies.

About Social Inclusion

Our definition of social inclusion as a multi-dimensional process and outcome draws on a conceptual framework developed at the Irish Centre for Social Gerontology by Walsh and colleagues (2012). This framework suggests that social inclusion is best understood by looking at the dynamic linkages between social relations, access to services, financial resources, transportation and mobility, safety and security, macro-economic forces, place and community characteristics, individual capacities, and life-course trajectories.



Adapted from: Walsh, K., O'Shea, E., & Scharf, T. (2012) Social Exclusion and Ageing in Diverse Rural Communities. Irish Centre for Social Gerontology, Galway



"I felt able to enjoy the movement without fear of agonizing pain by moving something too abruptly or harshly... No pain, no gain type exercise is not for me!"

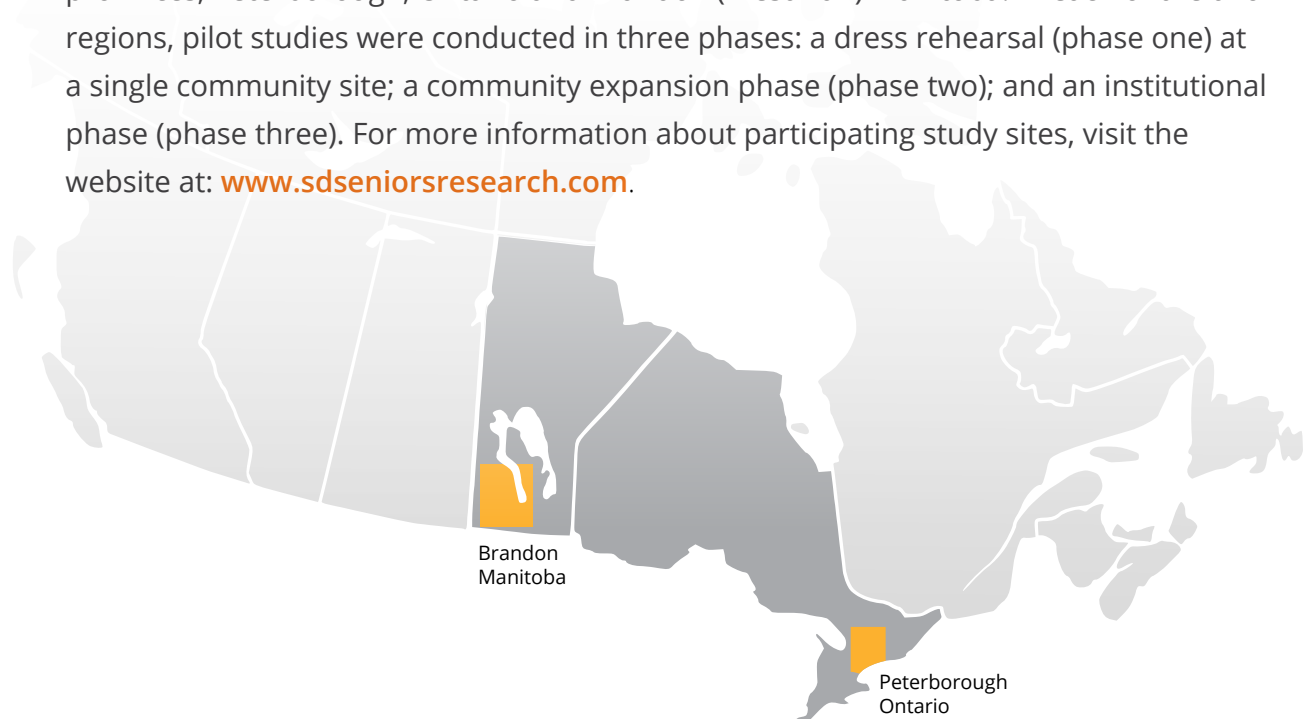
Sharing Dance Seniors Participant,
Brandon, Manitoba

Research Design

This study was a qualitative sequential pilot study of the innovative Baycrest NBS Sharing Dance Seniors program in non-metropolitan regions of two Canadian provinces, Peterborough, Ontario and Brandon (Westman) Manitoba. It focused on the remotely-instructed delivery of the program in care facilities and community centres. The study involved five phases of observations, diaries, focus groups and interviews with program participants, people living with dementia, carers, coordinators, instructors and volunteers as well as critical reflections among research investigators and knowledge users. Thematic analyses of the qualitative data produced new knowledge about the experiences, effectiveness and challenges of the dance program that informed our understanding of whether and in what ways it increases social inclusion and quality of life for older people living with dementia and their carers. For more information, see the [study protocol paper](http://www.sdseniorsresearch.com) at www.sdseniorsresearch.com.

Pilot Studies

The pilot studies involved multiple sites in non-metropolitan regions of two Canadian provinces, Peterborough, Ontario and Brandon (Westman) Manitoba. In each of the two regions, pilot studies were conducted in three phases: a dress rehearsal (phase one) at a single community site; a community expansion phase (phase two); and an institutional phase (phase three). For more information about participating study sites, visit the website at: www.sdseniorsresearch.com.



Methods

OBSERVATIONS

Observations included detailed descriptions of the actions, expressions, and interactions of participants in the program to inform our analysis of multiple dimensions of social inclusion, particularly those related to social relations, mobility, and safety. For example, observations focus on the degree and nature of social interaction as well as safety (e.g., comfort with dance moves, fellow participants and the facilitator).

DIARIES

Participant diaries explore the lived experiences of engagement with the program as they relate to processes and outcomes of social inclusion. People living with dementia and carers record their personal experiences throughout the program in a weekly semi-structured journal using written, oral and/or video communication (paper booklets and iPads).

FOCUS GROUPS

Focus groups with program participants and carers as well as with program coordinators, instructors and volunteers were conducted regarding the effectiveness of the program delivery and the challenges of implementing the program. This allows for an examination of the breadth of experiential, programmatic and contextual factors that influence the effectiveness of the program to improve social inclusion.

INTERVIEWS

Interviews with program participants and carers as well as with program coordinators, and volunteers explored the effectiveness of the multi-modal program delivery to identify the challenges of implementing the program. Semi-structured interview questions explored in greater depth issues and connections among the multiple dimensions of social inclusion that emerged from the focus group discussions.

REFLECTIONS

Critical reflections among the research investigators and knowledge users served to identify opportunities and promising practices for expanding the program in various types of community and collaborative settings. In-depth reflections regarding the challenges and opportunities experienced and/or observed by the research team (comprising the investigators, knowledge user collaborators from NBS, and research personnel) were recorded as part of weekly one-hour meetings to build a reflective dataset as the program expanded through the pilot phases.

DATA ANALYSIS

Sequential and iterative qualitative data analysis was conducted during the multi-phased data collection to support the refinement of research instruments as well as communication of preliminary findings with community partners. Management and analysis of all phases of the study were supported by Nvivo 11 software. Thematic content analysis of text-based observations as well as diaries informed the focus group discussions of the effectiveness and challenges of the Sharing Dance Seniors program. Building on the observational and diary phases, thematic analyses of focus group transcripts informed the in-depth inquiry of emergent social inclusion themes in interviews. Thematic analysis of the recorded researcher and knowledge user reflections provided the foundation for narratives of promising practices relating to the development and implementation of the research design as well as the implementation and expansion of the dance program. These analyses informed a series of knowledge exchange reports ([See Pilot Study Reports](#)) and community and academic presentations for each phase of the pilot studies that were disseminated to participants, community leaders and knowledge users.



Peterborough Pilot

The Peterborough pilot study took place at multiple study sites (seven total) in the Peterborough region in three phases.

PHASE ONE (P1)

Dress Rehearsal

In April 2017, Trent University, NBS, and Community Care worked collaboratively to test the first streamed group session of the Baycrest NBS Sharing Dance Seniors program for active seniors over eight weeks (P1). The “dress rehearsal” took place at the Chemung office in Ennismore, ON. A project planning meeting was held at Trent University in July 2017 to discuss the outcomes of the dress rehearsal and plan the expansion of the program (P2) in September 2017.

PHASE TWO (P2)

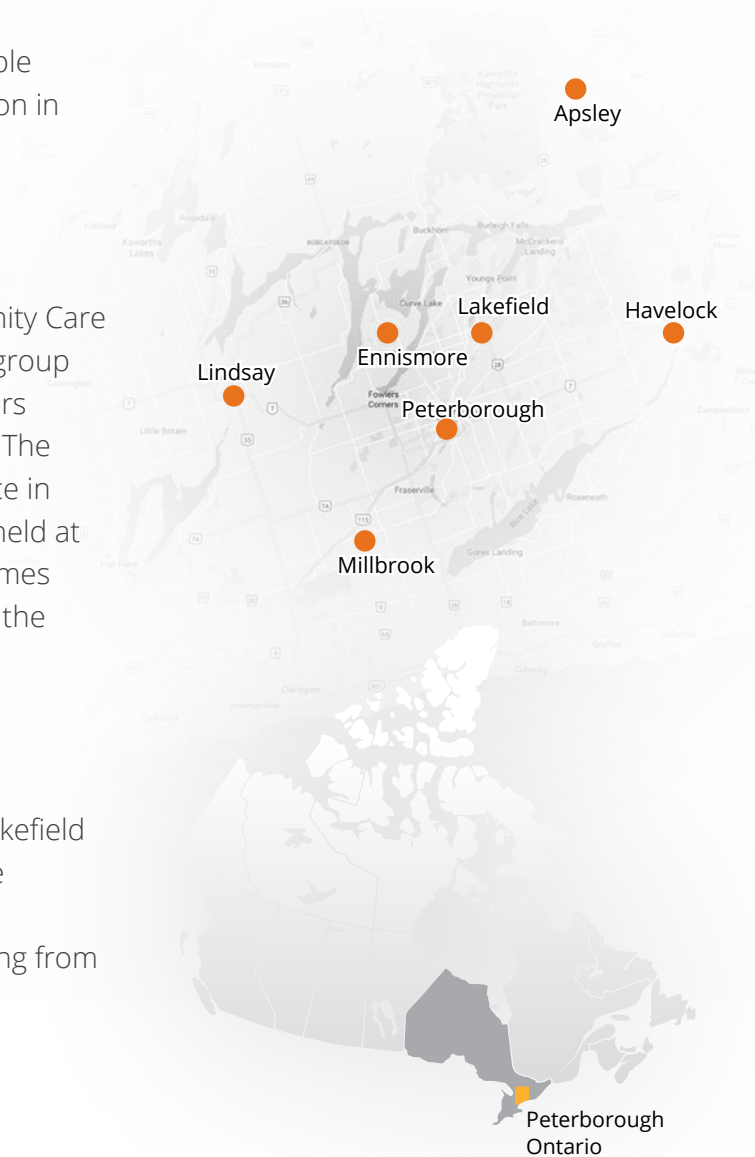
Community Expansion

Branch offices in Apsley, Ennismore, Havelock, Lakefield and Millbrook participated in the community care expansion, which took place from September to November for one hour every Wednesday morning from March to May, 2018.

PHASE THREE (P3)

Institutional Settings

P3 was implemented at branch offices in Apsley, Ennismore, Lakefield, and Millbrook, with the expansion to one institutional setting at William Place Retirement Residence in Lindsay (see Figure 2.) Table one outlines the timeline for the Peterborough project expansion as well as subsequent research exploring the experiences of older people with dementia and carers in Brandon, Manitoba. After the dress rehearsal (P1), subsequent phases were unified by a consistent method of data collection and program evaluation.



Brandon Pilot

The Brandon pilot study involves research at multiple study sites (six total) in the Westman region in four phases.

PHASE ONE (B1) Dress Rehearsal

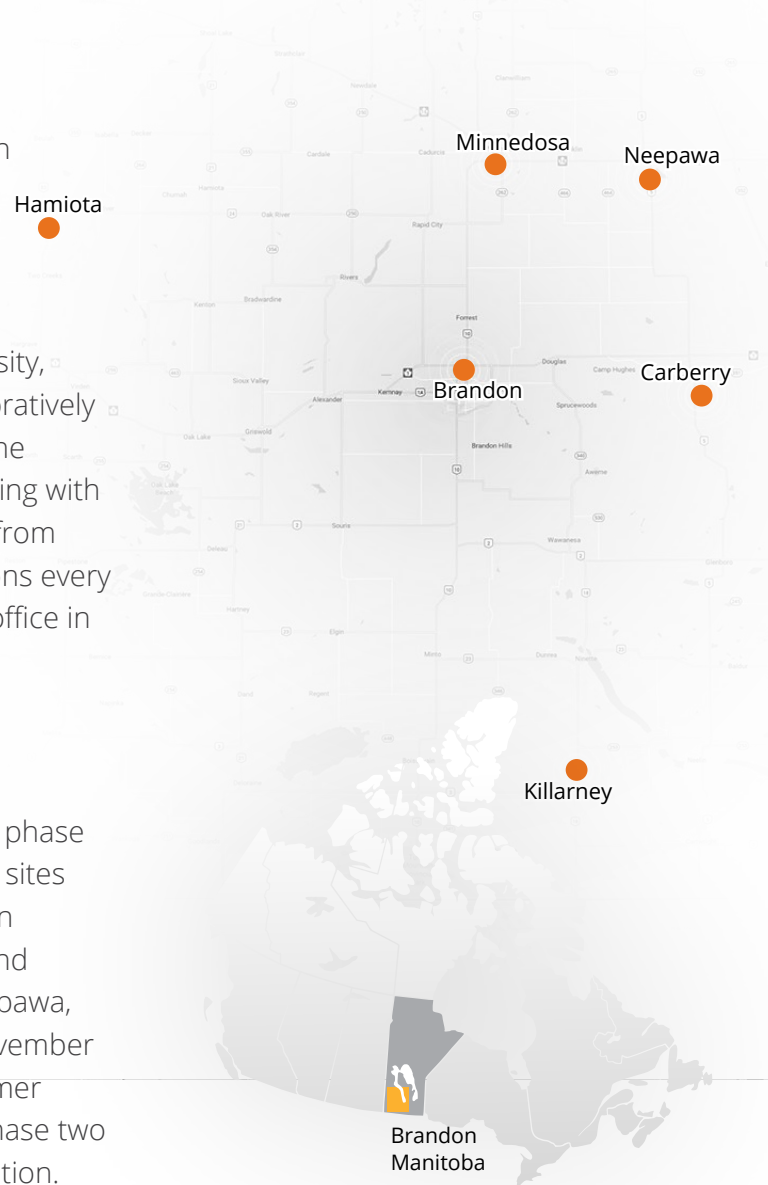
In phase one, in January 2018, Brandon University, NBS, and the Alzheimer Society worked collaboratively to test the first videostream group session of the Sharing Dance Seniors program with people living with dementia. The eight week program, which ran from January-March 2018, entailed 45-minute sessions every Wednesday morning at the Alzheimer Society office in Brandon, MB.

PHASE TWO (B2) Community Expansion

The community and institutional expansion for phase two of the Brandon Pilot (B2) was held at three sites including the Prairie Oasis Community Centre in Brandon, the Minnedosa 50+ Activity Centre, and Country Meadows Personal Care Home in Neepawa, MB (See Figure 2) from September 2018 to November 2018. Brandon University, NBS, and the Alzheimer Society worked collaboratively to implement phase two using videostreaming at set times for each location.

PHASE THREE (B3) Institutional Settings

B3 was implemented in May 2019 at five institutional settings and one community setting at the Prairie Oasis Community Centre in Brandon. Country Meadows Personal Care Home in Neepawa, along with Personal Care Homes in Killarney, Minnedosa, Hamiota, and Carberry were the participating institutions.



Research Participants

There were in total **289 participants** involved in the study, including **98 people living with dementia**, **32 carers**, and **16 volunteers**.

Participants by Research Method:

RESEARCH DESIGN		PETERBOROUGH PILOT STUDY (2017-18)			BRANDON PILOT STUDY (2018-19)		
Program Level		Sharing Dance Seniors (older adults)			Sharing Dance Seniors (including persons with dementia PWD)		
Research Pilot Phase		Dress rehearsal P1 (1 site)	Community settings P2 (5 sites)	Institutional expansion P3 (5 sites)	Dress rehearsal B1 (1 site)	Community settings B2 (3 sites)	Institutional expansion B3 (6 sites)
Methods	Observations - Participants - Carers - Volunteers	23	54	40	16 11 5	46 20 16 9	140 122 11 7
	Diaries - Participants - Carers	23	10	6	20 15 5	23 10 13	1 5
	Focus groups - Participants - Carers - Facilitators - Volunteers	23	26 - 3 5	16 - 3 1	2 5 6 1	3 22 8 10 1	6 39 12 10 5
	Interviews - Participants - Carers - Facilitators - Volunteers	23 23 - - -	16 13 - 2 -	20 17 - 3 -	8 3 3 2 -	25 12 4 8 1	36 19 4 10 3
	Reflections - Investigators - Knowledge users	6 3	6 3	6 3	6 3	6 3	6 3



"It was great for us as staff members as well to be part of the program and to be engaged with residents that closely. Each week you look forward to it. It was great for us staff – for our morale – it just brought us all a little closer I think."

Staff, Personal Care Home, Manitoba

Results

Processes and Outcomes

In each of the Sharing Dance Seniors pilot studies, we captured the experiences of participants in the Sharing Dance program. In Peterborough pilots, we discovered that the program provided **benefits and social interaction** for participants (see P2 Report) and that **instruction needed to take diverse abilities into consideration** (see P2 Report). In Brandon Pilots, where people living with dementia participated, we found that the program provided **opportunities for understanding and talking about dementia** and that people with dementia had fun and enjoyed participating in the **non-judgemental instruction** (see B2 Report) and that family carers, volunteers, and personal care staff appreciated **new ways to interact with people living with dementia** (see B3 Report).

“She told us to not worry about if you get - because I got mixed up a lot and I could - I did some things that the - I got lost - so I put my feet and did something that with what they were playing, so I - because I’ve got - Alzheimer’s, I get mixed up. But I don’t care, I didn’t do the same thing they they were doing but I kept going and I had fun. I really had fun.” (Participant Living with Dementia, Brandon, Manitoba)

HIGHLIGHTS

Connecting through group movement and music

A majority of participants indicated the strongest aspect of the program was being part of a group “getting out and moving with other people,” using words like “companionship”, “community” and “camaraderie” to describe what they liked best. One participant from P2 explained that her enjoyment of the movement was inseparable from her feeling of “connectedness” with the group: “If I was just doing the physical alone it would be like doing my physio, but it has none of the added benefits of working towards a dance with a group of people.”

Getting out and being part of something “bigger”

“It made me feel that ... I’m part of a bigger world ...” (Older Adult Participant)

Personal care home residents, volunteers, community members, carers, and staff in all sites in Phase Three of the Brandon Pilot expressed that the main benefits of participating in the Sharing Dance Seniors program were getting out and being a part of something – going through the same experience together. ***“Everyone seemed to really participate in the singing ... moving to the music. And even if they weren’t doing the exact same movement, they would move with the rhythm of whatever music was playing.”***

(Personal Care Worker, B2)

Interacting in new ways with carers, staff, and volunteers

“It’s just knowing the importance of interacting with the residents, of having programs like this available, it improves their quality of life, it’s something they enjoyed.”

(Administrator)

Participants expressed that they enjoyed interacting in new ways at an interpersonal level. For carers, it was a nice break from being the centre of the interaction with their loved one in care; from being responsible for keeping the conversation or activity going; or from focusing on the practical tasks of caregiving in daily life. As one facilitator explained, ***“It just gave them a little reason to come out and spend time that didn’t require them to be the centre of the visit.”***

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Results

Challenges

Some of the challenges presented in the pilots were reported as **technical difficulties** (See Reports for P2 and B3) in the digital **mode of delivery** (See P3 Report) and different ideas about what dance is to different people (See B3 Report).

HIGHLIGHTS

Technology and communications

Throughout all pilots, technology and communications remained a constant challenge. Having the appropriate infrastructure and equipment as well as individual attitudes and competencies, continue to influence the capacity and sustainability of the program. Facilitators commonly identified the technical aspect of the program as their ***“least favourite thing: Trying to keep the computer running, having glitches, tech difficulties are the worst things.”*** On the other hand, some participants found that the technological difficulties were bonding moments, where groups were given the opportunity to share moments of both frustration and laughter together.

Stigma

Community and family dynamics and the stigma associated with dementia presented barriers to participation in the community setting. A community administrator described her experience: ***“reaching out to a lot of different members and our board members – as soon as you mention dementia people run and hide, but the ones who did come were successful.”*** ... ***“The people who came from the Personal Care Home – many of them have dementia, so I think that would prevent them from having family bring them to other functions here. We try to include them but there are some families who won’t bring them.”***





"It was great for us as staff members as well to be part of the program and to be engaged with residents that closely. Each week you look forward to it. It was great for us staff – for our morale – it just brought us all a little closer I think."

Staff, Personal Care Home, Manitoba

Results

Promising Practices

The main recommendations involved developing resources and support for facilitators and administrators, recognizing the **key role of local players** in the effective uptake of the program. These resources developed to include marketing and communications tools (See B2 and B3 Reports) and facilitator training (See P3 Report). Another important consideration that emerged in P3 was the need to develop the program to meet diverse abilities, as **older adults represent a wide range of people** (see P3 Report) and that **effective program delivery is adaptive** to their varying interests and abilities to maximize social inclusion (See P3 Report).

HIGHLIGHTS

Supportive facilitation

Having a facilitator present in the room to complement the on-screen instructor was noted as a helpful aspect of the program's delivery. Participants indicated that they liked having the option to watch the person to clarify what they were doing and that they appreciated comments of support and encouragement in adjusting their movements to individual capabilities.

Engaged facilitators enhanced participant experiences by watching each participant to ensure that the choreography was understood and provided reminders to do what they can, along with encouragement and praise. ***"She would say how to do it in a different way ... you could still do the movements and it wouldn't hurt you."*** (See B1 Report) ***"Not being judged"*** was an important aspect of participating and feeling that one could participate at their own level of ability. As one participant noted ***"I thought [she] was very welcoming and friendly, encouraging without being pushy or judgmental."*** According to participants, facilitators enhanced social inclusion because their ***"engagement in the class exercises makes all the rest of the participants involvement less intimidating ... part of the gang."*** (See P3 Report)

Understanding and talking about dementia

Some participants engaged in conversations about dementia as a direct result of participating in the program. It was a conversation starter for community participants with and about people living with dementia. ***“Their expressions, camaraderie, how they participated opened my eyes that dementia shouldn’t be a word not said.”*** (Participant)

For one facilitator who works with clients at the Alzheimer’s Society, bringing people together out in the community was an opportunity to change perceptions about the ability of persons with dementia to participate. ***“I think opening up the community’s eyes to how this disease effects people – we can still come out and be a part of society and to do activities.”***

One member of the community attested to how their perception of dementia changed as a result of participating in the program. ***“Their expressions, camaraderie, how they participated opened my eyes that dementia shouldn’t be a word not said.”*** (Older Adult Community Participant, B2)

Inclusive instruction for diverse abilities

Participants had concerns about their capabilities to participate in physical and cognitive terms. ***“Well I would wonder at my stamina and wonder the processing speed when I’m 80 compared to when I was 50 in terms of keeping up with the steps – when they get to the left hand I’m still working on my right hand.”***

While some older adults felt ***“it could still be more challenging,”*** many participants appreciated ***“that people are allowed to work at their ability and are encouraged to do what they can, how they can.”*** Instructors, in tandem with facilitators created a ***“do what you can,”*** culture in the class environment by explicitly instructing participants to do movements at their own level of ability, with constant reminders. This allowed one participant to continue to attend classes, knowing that she couldn’t do much due to her state of health at the time: ***“I knew I could go and do as little as I was able and not feel badly.”***

Knowledge Mobilization

The sequential design and iterative approach of this project provided opportunities to reflect, learn, and strengthen our knowledge mobilization strategy throughout.

Mobilization through experiential and embodied learning

Across the project's phases, one knowledge mobilization strategy stood out in its ability to help engage potential knowledge users. Upon first meeting a community's stakeholders, creating the opportunity to get everyone dancing proved to be an effective way to help people understand the project and get excited about it. From site administrators to dance class participants living with dementia, it seemed that the best way to help a diverse group of knowledge users understand Sharing Dance was to have their community dance together. Out of 13 community sites who participated in this project, there were six where we were not able to introduce the project with a dance experience. In most of these communities, there was less engagement overall in the project. This suggests that perhaps the best way to learn, understand and get excited about dance is to dance.

"The best way to understand dance is to dance,"

Rachel Bar, Director, Research and Health,
Canada's National Ballet School | L'École nationale de ballet du Canada]

Knowledge dissemination through dance

Over the course of this research project, we shared presentations at international, national and local conferences and health events featuring academics, professionals and other knowledge users. In addition to introducing participants to the project, dance became a significant component of our knowledge dissemination strategy. Whenever we shared our findings, we would aim to invite participants to join us in a demonstration of the Sharing Dance program, allowing knowledge users to embody the project's learnings and to understand the research through experience.

Moving Forward

The research

This research has inspired further exploration. In the Summer and Fall of 2020, an At-Home delivery model was piloted across Canada to further address accessibility challenges, especially during the COVID-19 pandemic. Upon completion of this report, a project was underway to investigate the possibilities of international expansion.

The Sharing Dance Older Adults Program

After successfully piloting Sharing Dance Seniors in Ontario and Manitoba, the program evolved to Sharing Dance Older Adults and is available through a new app across Canada, providing opportunities for people to dance together in their homes and communities.



Thank you

ACADEMIC PARTNERS



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FUNDERS



PARTNERS & COLLABORATORS

