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

Brandon Pilot Phase Three (B3) Report: Processes and Outcomes

ACKNOWLEDGEMENTS

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1. Introduction

A growing body of research suggests that arts-based programs such as music, dance, and painting can improve the lives of older people. Much of the research on dance has focused on measuring outcomes in terms of preventing falls and improving balance, mood, cognition (Coubard et al., 2011) and physical functioning (Abreu et al., 2013; Alpert et al., 2009; Blankevoort et al., 2010). Much less is known about how dance programs might improve social inclusion for older adults. In this internal research report, we begin by discussing how we have conceptualized and examined the use of a dance program, Baycrest NBS *Sharing Dance Seniors*, to improve social inclusion for older adults, and we then highlight processes and outcomes, challenges, recommendations, and next steps in research and program development.

1.1 Understanding social inclusion of people with dementia living in the community

Social inclusion refers to the ability of people to fully participate in relationships and activities. Older adults can face a range of barriers to full and meaningful participation in their communities. For example, local factors such as social relations, access to services, financial resources, transportation and mobility, and safety and security as well as broader influences such as economic forces, community development, and individual life-course trajectories influence older adults' opportunities to participate (Walsh et al., 2012). Moreover, older adults living with dementia may face additional barriers to social inclusion because of social attitudes, policies, and practices in their surrounding environments (Herron et al., 2019). As previously stated, a growing body of research suggests that arts-based programs can improve the lives of older people, as well as people living with dementia and their carers; however, little is known about how these programs might address social inclusion specifically. The concept of social inclusion recognizes that participation is not just an individual choice; people and organizations shape programs, practices, policies, and attitudes to more fully include those who experience exclusion (Funk, 2015). We need to know more about what types of programs can enhance the social inclusion and well-being of older adults.

The purpose of the project is to examine the potential of an innovative dance program, Baycrest NBS *Sharing Dance Seniors*, to improve the social inclusion of older adults. The program was developed as a joint venture between Baycrest Health Sciences and Canada's National Ballet School (NBS). The research was based

out of Trent University in collaboration with Brandon University, University of Manitoba, and University of Toronto. The research team used multiple methods to examine the experiences of older adults participating in the program as well as assess the effectiveness of delivering the program through a video-streamed group model, and the challenges of expanding and sustaining the program.

1.2 Overview of Brandon Pilot Study (Phase Three)

The Brandon Pilot Study is part of a four-year study "Improving social inclusion for people with dementia and carers through sharing dance", involving research at study sites in Brandon and the Westman region as well as in the Peterborough Region in Ontario (see Figure 1) in four phases (Skinner et al, 2018). Table one outlines the timeline for the Brandon project expansion as well as previous research exploring the experiences of older adults in Peterborough, Ontario during the Peterborough Pilot Study. Full details of the research methods are published in the study protocol (see Skinner et al., 2018) and can be found on the project website, along with project reports on findings from each of the project phases at www.sdseniorsresearch.ca.

Table 1: Pilot project timeline

Phases *Peterborough pilot *Brandon pilot	Year One: 2017-2018												Year Two: 2018-2019												Year Three: 2019-2020											
	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D
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P2: Community care expansion									█	█	█																									
B1: Alzheimer Society dress rehearsal													█	█	█																					
P3: Expansion to institutional sites																█	█	█																		
B2: Expansion to community sites																						█	█													
B3: Expansion to institutional sites																											█	█								
B4: Expansion to Household sites																																				
P4: Expansion to Household sites																																				

The community and institutional expansion for phase three of the Brandon Pilot (B3) was held at six sites in the Westman Region of Manitoba including: the Prairie Oasis Community Centre in Brandon; the Minnedosa 50+ Activity Centre in Minnedosa; the Country Meadows Personal Care Home in Neepawa; the Carberry Plains Personal Care Home in Carberry, the Birch Lodge Personal Care Home in Hamiota; and the Bayside Personal Care Home in Killarney, (See Figure 2) from April 2019 to June 2019. Brandon University and NBS worked collaboratively to implement phase three using videostreaming at set times for each location.
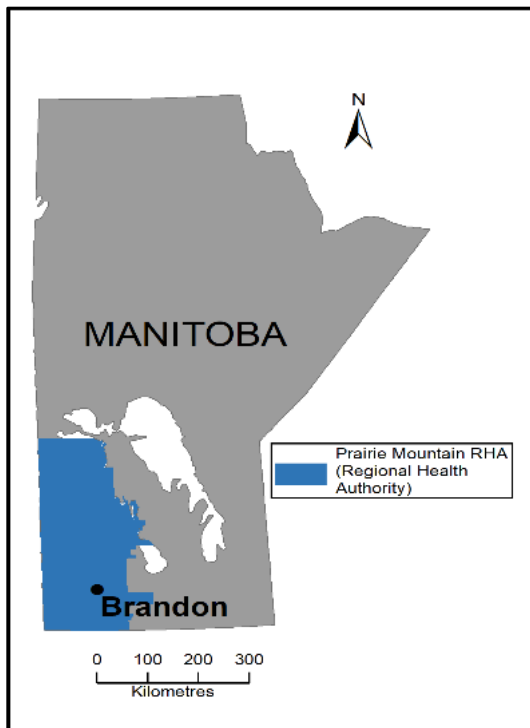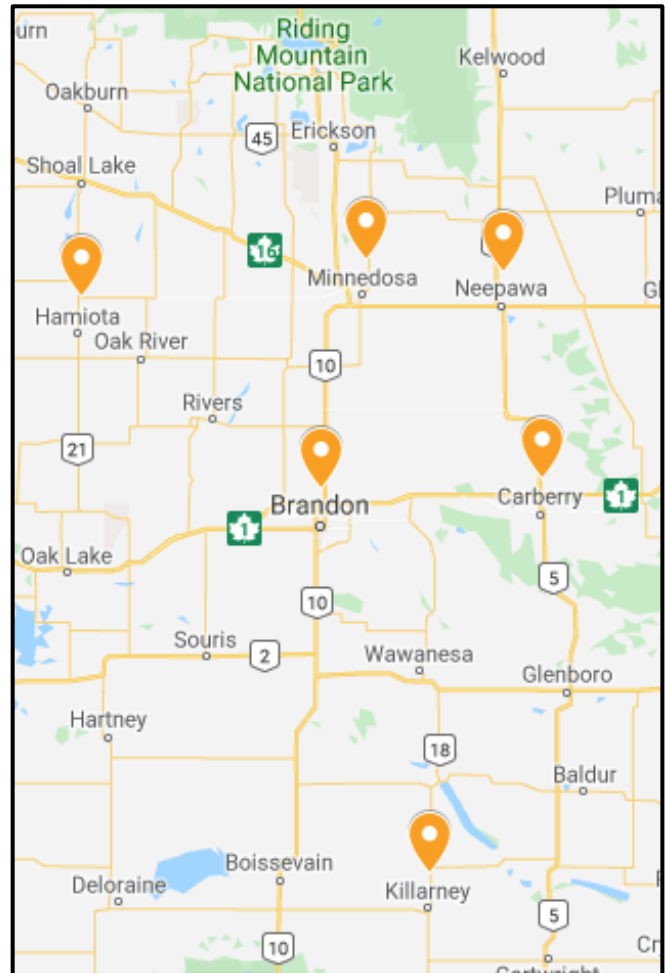

Figure 1: Westman Region

Figure 2: B3 Site locations included Brandon, Minnedosa, Neepawa, Carberry, Hamiota, and Killarney.

1.3 Method of evaluation

Each phase of data collection involves four sources of information: observations, diaries, focus groups, and interviews (Skinner et al., 2018). Detailed This report is a summary of the data collected in phase three of the Brandon Pilot Study (B3).

Observations

Weekly observations were recorded in writing at each of the program sites by a research associate. Thirty-nine observations in total were analyzed (see Table 2). The observations included weekly descriptive notes about the physical setting, participants' actions and interactions, the sequence of activities and responses to the dance instructors on screen, and communication between the onsite facilitator and participants. The number of sessions differed at the Carberry site due to two holiday Mondays; at the Hamiota site due to Wi-Fi connectivity in the second week; and at the Neepawa site because all paperwork was done in advance of the first session; otherwise all observations began during the second week. In addition, with the permission of all participants, video recordings of each session were taken in Neepawa, Hamiota, and Carberry sites.

Diaries

Diaries were kept by interested participants, facilitators, and volunteers and included participant descriptions of what happened in the dance program each week, as well as participant evaluations of their experience of the best part of the program, any challenges the participants encountered, how they felt during the program, and anything else the participants felt was important to record that week. In B3, a total of five diaries were collected from five participants (see Table 2).

Focus Groups

Focus groups were conducted in all six study sites. The focus groups were used to deepen understanding about what participants and facilitators liked best, what they liked least, what they felt was the most challenging part of the program, how the mode of delivery influenced the program's success, and what possible changes might be made to the program. Six focus groups were conducted (see Table 2).

Interviews

The project also included interviews with a variety of participants to explore their individual evaluations of the program. Seven pre-session interviews (including three personal care home participants living with dementia) were conducted. Thirty six post-session interviews were conducted with four carers, six facilitators, three administrators, three volunteers, one staff, and six community participants (see Table 2).

Table 2. Summary of participants in data collected at each site

Data Collection Method	Brandon	Neepawa	Minnedosa	Killarney	Hamiota	Carberry
Weekly Observations	10	21	17	15	41	13
Diaries	0	1	0	0	4	0
Focus Groups	7	19	12	13	13	11
Interviews	4	6	6	6	7	7
Video Taken*	0	8	0	0	7	6

* Total number of video recordings per site

2. Processes and Outcomes

2.1 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." (Staff)

"I just think it brought everybody together ... more as a family and a group."(Staff)

One volunteer noted, "It was nice to get out … It's nice to be part of something bigger," and according to a staff member, "It was good to be needed. Like we were part of this, you know … everybody needs to be needed, right?"

A facilitator described how she saw the staff and volunteers get involved:

… they looked happy, they looked like they were involved, part of something bigger than what they usually are – we all like to be included in something like that, they all jumped on board and felt like they were part of something big. Things like that give you a sense of purpose and I saw that in them. I also saw volunteers that work regularly and they juggled their shift so they could be here (Facilitator).

Getting out was considered both a benefit and a challenge that manifested differently in community vs. institutional settings. In the community setting, there were a few who drove an hour each way to get to the program and talked about how, "it was worth it – and I would do it again" (Carer). In the institutional setting – many talked about getting out of their rooms being a challenge for them, for carers and support staff, and that the Sharing Dance Seniors program provided added motivation.

A related theme that was discussed among participants was the idea of connecting to the greater world beyond participants' immediate surroundings. For residents in a personal care home, there was an added benefit of exposure to the outside community through the volunteers and personal carers who joined the program. "I got to see people from the community and I liked that." (Older Adult Resident Participant) Residents in the small town settings also expressed appreciation for being chosen to participate in the program. "Small towns need something like this to … sort of put us back on the map." (Older Adult Resident Participant)

2.2 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."

"Quite often, caregivers say when they come in for a visit they have to carry the conversation ... for this they just had to sit back and be a part of something" (Facilitator).

From the perspective of the administration in the institutional setting, administrators also commented on their observations of family interactions that resulted from hosting the program.

"To be able to provide that to them and to be able to include their families and caregivers was so satisfying. ... It was so fulfilling to see them enjoying themselves and have their caregivers there – it's something they can do with their family – they're always a little uneasy when they're visiting, 'what can we do?' – this is something they can do together." (Administrator)

The following example from the observations illustrates some of the subtle ways in which carers and people living with dementia interact with one another and the instructor, supporting equal participation and social interaction.

… One participant's daughter is here with her participating in the program… During the narrative sequence of going fishing, they both respond to the on-screen instructor's direction to search the room, shielding their eyes from the imaginary sun. She and her daughter search towards each other and catch each other's eyes. They stop and smile at each other. (Field note, Week 7)

Facilitators expressed that, "the extra staff and companions and volunteers made it more interactive and engaged everybody," and that, "the neat thing [was] to see the residents interact with the volunteers and the staff."

"It opened our eyes to the importance of music and dance and how to get staff and volunteers more involved and work better as a team." (Administrator)

Overall, participants in the program interacted in new and creative ways, which helped to facilitate diverse forms of interaction among different groups.

2.3 Opportunities for creative expression

"When you moved in time to the music – you felt that you could really do those moves and then you put a little art into it. It [makes you want] to try… to be graceful." (Older Adult Community Participant)

Participants expressed that they had many opportunities to be creative in how they moved either due to the narrative nature of the imaginary sequences or because of the ability to express their individuality. A volunteer described how she, "thought it was very creative, starting the fire, putting the logs on – [during] the ones that were like a story."

"I thought we were creative for the whole time … we were picking flowers and drinking coffee and … that seaweed when everybody's arms are doing different things." (Facilitator)

"… even though we were all doing the same thing it was all different … Some people moved their arms differently and some people moved their legs differently … some have them more down, some have them up, some have them straight, some have them bent, we're all individuals and you can see that – I enjoyed that. (Older Adult Community Participant)

2.4 Use of humour

"And laughing. In our group there was lots of laughing throughout the eight-week program. Lots of little jokes going on … we're all sitting there laughing together." (Facilitator)

Laughter and the use of humour were also common themes in descriptions of participants experiences as a way to diffuse anxiety about getting the moves correct or the possibility of being intimidated by having to dance in a certain way. Participants, volunteers and facilitators agreed that humour helped with acceptance of their abilities in the program, as one older adult participant from a personal care home said, "We were all making mistakes and I think that [humour] helped us."

The following observation demonstrates how two residents at a personal care home shared an opportunity to laugh together as a result of moving along with the program: *Fred gets mixed up following the moves on the "one - two - three strikes you're out." He turns to Ruth and the two share a laugh and a nod in shared understanding. (Field notes, Week Two)*

As a form of creativity, some used humour within the program to enhance moments as they were articulated in the imaginary narrative scenarios. *"Florence stopped fishing when I told her that she had to clean what she caught." (Laughter from the group) (Field notes, Week 3)*

Overall, humour was a prominent theme in the B3 Pilot, as participants demonstrated and talked about how they could share moments of laughter together in their relationships and as a larger group.

2.5 Memories through music and dance

Participants shared how they experienced memories brought about by the program's music, movement and activities. One older adult participant from a personal care home described how the wilderness expedition narrative took him back to his past, "Because I used to fish …" and another said that the songs "…brought back good memories for me of when my kids were young."

Some reminisced about going to dances when they were younger or about dancing with their spouses, and they also went back to memories of their own childhood or of moments they shared with their children.

"… and of course, when I was dancing, there was lots of different kinds of music. Yeah …the music is a part of you. Music has always been a part of me. My mom used to take me into the choir with her when I was just…" (Older Adult Resident Participant)

One of the staff members observed that participants would embody their memories through their own style of movement. "Everybody was kind of dancing their own interpretation whether [they] were fishing or riding their bikes the way they remembered fishing, or riding their bike.) (Staff)

The carefully selected music and dance instruction made the program activities familiar, safe, and consistent with past activities even if they could no longer do these activities outside of the program.

3.0 Challenges

3.1 What is dance?

One of the challenges for the uptake of the program was the way that people interpret the concept of dance differently. There were potential participants who did not want to participate in the program because they were concerned that they would not be able to "keep up" or that they couldn't do "ballet – they didn't seem to think we were maybe dainty enough," (Older Adult Community Participant) or that they weren't able to dance anymore. One older adult community participant talked about a friend who decided not to participate in the program. "He didn't come because someone said to him, 'Are you going to the Sharing Dance' and [he said], 'I don't dance anymore'…" One explanation for this was how important dance was to older adults at a different time in their lives.

"Especially among the older participants, the word dance may have been a little more intimidating than 'let's just go exercise or listen to the music, moving with the music.' That was such a big part of their life. They went to dances all the time. There were square dances, there were waltzes, … you know, a whole different image comes to mind, I think, when you say the word dance, as opposed to what this is. Right? It's moving to music, it's not necessarily a dance." (Older Adult Community Participant)

For some, the idea of dance created self-consciousness that hampered their ability to let down their guard and enjoy what the program had to offer. One older adult participant from a personal care home explained that they adjusted to this over time. "It took a couple of weeks, because the first couple I felt like I was up front and everyone was watching me, so…" A facilitator suggested that participants were focused on getting movements and "steps" to the dances correct, so it took them a little while to warm up because, "we forget what it's like to be silly. Right?"

3.2 Technology and communications

Consistent with previous pilots, technology and communications remain 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.

One older adult participant from a personal care home joked about how they liked the glitching during a focus group.

P: I liked the glitching.
I: You liked the glitching?
P: Gives you a break. Freeze frame.
(Focus Group Participant)

The capacity for sharing information about the program was different at each site. At one personal care home, a facilitator explained that recruiting participants was a challenge because "It's difficult, to get that amount of information out to people. Our resident council is not well attended and when the open house happened, there were no family members at our information session." At another site, this was not a problem. "The open house beforehand was a great idea – there was a few families who did come and got to see, ask questions…" (Facilitator). This illustrates how the unique aspects of place can either enhance or create barriers to communication of opportunities for participation for people in some programs. Facilitators also commented that they would like more reciprocity in communications with NBS upon completion of feedback forms after each session, noting that "they [weren't] sure if it was being received."

3.3 Appreciation of the delivery model

Due to the nature of the on-screen instruction and the success of the program, there were many participants and facilitators in both the community and institutional settings who requested a copy of a DVD to be able to do the program at their convenience. There were also volunteers and community participants who were interested in adapting the program and operating it on their own in different settings. While this would enable participants to follow the movements to music when it is convenient for them, they would be excluded from the "real-time" or current connection to instructors on a week-to-week basis, the opportunity for the personalized aspects of the program, and from hearing about other communities connecting to the larger world beyond their own institutions.

4.0 Recommendations

4.1 Marketing Communications

To address some of the challenges noted above regarding how people define dance and what the name of the program may suggest to different people:

- Consider adjusting promotional materials to include in-depth descriptions with sample photos and videos available, emphasizing the benefits of social activity and creativity, along with physical movement and exercise.

- Further develop open-houses and information sessions or opportunities for demonstrations of the program: participants and facilitators indicated that seeing the video at open-house events was helpful for understanding what the program entailed so that they could describe it to each other and to others who may be interested in participating.

- To address the challenge of appreciating the digital delivery model over the purchasing of a DVD, consider articulating and elaborating on the benefits of practicing the program in "real-time" with others to maximize the unique aspects of the Sharing Dance Seniors program in its remote mode of delivery.

- Consider engaging participants interested in adapting the program for their own uses as volunteers or in facilitator training programs of the future.

4.2 Recommended adjustments to online facilitator training module

The online facilitator training module was a useful tool for facilitators at each site to become oriented with what would be expected of them in their role. Many of the challenges faced during the program are handled by the facilitator. Based on facilitators' comments and recommendations, the following are suggestions to embellish the facilitator training module:

- Prepare facilitators for inevitable technical difficulties by managing expectations and providing a back-up plan (eg. a pre-recorded session for download to have on hand).
- Ensure reciprocity of feedback forms, letting facilitators know that their

comments and feedback has been received when they send it after each class.
- Include tips for facilitators to enable and model creativity i.e. permit "silliness".
- Reinforce the importance of the chair set-up so that participants can see each other to interact during the program (i.e., everyone sees everyone, rather than making some individuals feel singled out in a front row).
- Increase recommended set-up time to half an hour, with assistance.

5.0 Next steps

The expansion of the dance program to home settings in Brandon and the Westman Region is currently being discussed. The process and outcomes of these overlapping phases will help us to improve our understanding of how the Baycrest NBS *Sharing Dance Seniors program can enhance social inclusion* for a broad range of older adults with different abilities in different settings.

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The research team meets at Canada's National Ballet School in Toronto, Ontario. From left: Rachel Bar, Pia Kontos, Rachel Herron, An Kosurko, Alisa Grigorovich, Mark Skinner, Verena Menec