



Brandon Pilot Phase One Report: Process and Outcomes

ACKNOWLEDGEMENTS

The Improving Social Inclusion for Canadians with Dementia and Carers through Sharing Dance project is funded by the Canadian Institute of Health Research (CIHR) and the Alzheimer Society of Canada and based out of Trent University. All photographs in the report were provided by Dr. Mark Skinner. The authors of the report are:

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April 2018

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1. Introduction

A growing body of research suggests that arts-based health interventions, such as music, dance, and painting, can improve the lives of people living with dementia. Much of this research has focused on measuring the impact of arts-based programs in terms of improving balance, mood, cognition (Coubard et al., 2011), and physical functioning (Abreu et al., 2013; Alpert et al., 2009; Blankevoort et al., 2010). However, little is known about how these programs might improve social inclusion for people living with dementia and their carers. In this internal research report, we begin by discussing why social inclusion is so important for people living with dementia as well as the significance of this research project. We highlight best practices, challenges, recommendations, and next steps for research and program development.

1.1 Social inclusion, dementia, and community living

Social inclusion generally refers to the ability of a group to fully participate in relationships, activities, and environments (Wilton et al., 2018). It is a process and an outcome that emphasizes eliminating barriers such as lack of resources, rights, and goods and services required to participate in social life (Warburton et al., 2013). Many different forces such as access to services, transportation and mobility, safety and security, community development decisions, and policies within organizations and communities, and across regions and countries contribute to inclusion or exclusion (Funk, 2015; Walsh et al., 2012).

For people living with dementia and their carers, experiences of exclusion are often influenced by the physical conditions (e.g., a lack of public transportation and other infrastructure) and social conditions (e.g., stigma) in which people live. Negative stereotypes that assume people with dementia are incapable of growing and developing, and making meaningful contributions to their own lives and the lives of others create social exclusion and marginalization, deter help-seeking, diminish dignity, and threaten well-being and quality of life. Internalized stigma creates concern for making a mistake and fear of embarrassment, which in turn can cause people living with dementia and their carers to withdraw from social situations to avoid stigma. Developing sustainable and scalable interventions to improve social inclusion for people with dementia and their carers is thus essential to supporting Canadians with dementia to live well.

The purpose of the project is to examine the potential of an innovative dance program, Sharing Dance, to improve the social inclusion of people living with dementia. The Sharing Dance 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 people living with dementia participating in the program, the effectiveness of delivering the program through a video-streaming group model, and the challenges of expanding and sustaining the program.

1.2 Brandon pilot overview

The Brandon pilot study is part of a four-year study involving research at two study sites: Peterborough, Ontario, and Brandon, Manitoba (Skinner et al., 2018). Both of these pilot sites are involved in a single site dress rehearsal of the program (referred to as P1 and B1) as well as a broader expansion phase to other community sites (P2 and B2) and institutional settings (P3 and B3). It is also an objective of the project to explore the delivery of Sharing Dance in the home. Table one outlines the timeline for the Brandon project expansion as well as subsequent research exploring the experiences of older adults in Peterborough, Ontario. The phases are unified by an identical method of data collection and program evaluation.

Table 1: Timeline for the Sharing Dance project expansion

*Peterborough pilot *Brandon pilot	Year One: 2017-2018												Year Two: 2018-2019											
	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D
P1: Community care dress rehearsal (Chemung site)																								
P2: Community care dress expansion (five sites)																								
B1: Alzheimer Society dress rehearsal																								
P3: Expansion to institutional sites (TBA)																								
B2: Expansion to community sites																								
B3: Expansion to institutional sites (TBA)																								

A project planning meeting was held at Brandon University in October 2018 to clarify research objectives, to discuss past successes, best practices, and lessons learned from the ongoing pilot in Peterborough (P1 and P2), and to give all those involved in the project an opportunity to participate in a dance demonstration. Additionally, and perhaps most importantly, this meeting also served as a platform for group discussions and problem solving to inform the first phase of the Brandon pilot.

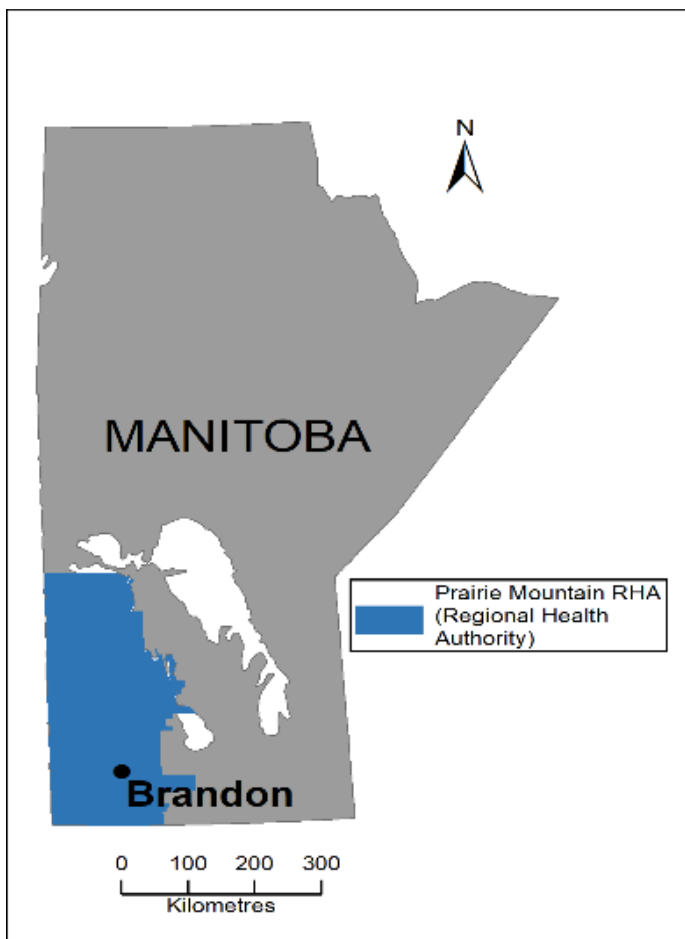


Figure 1: Brandon and the Prairie Mountain Health Region

In January 2018, Brandon University, NBS, and the Alzheimer Society worked collaboratively to test the first 'live to tape' group session of the Sharing Dance program for people living with dementia in the community. The program took place at the Alzheimer Society office in Brandon, Manitoba. The 8-week program ran from January 2018 to March 2018 and was scheduled to coincide with the Alzheimer Society's existing support group for people living with dementia. The Sharing Dance program ran for one hour and was immediately followed by a snack break and their usual support group. There were seven participants in the program. Participants in the program were people living with dementia already attending a regular support group, and they resided in Brandon or surrounding communities. The class itself consisted of an in-class facilitator who focused on engaging with the participants, and

an on-screen instructor who lead the session, and one Alzheimer Society employee who was always present to assist with facilitation, with another Alzheimer Society employee available as needed.

helping to modify movements as necessary. In addition, there was

an on-screen instructor who lead the session, and one Alzheimer Society employee who was always present to assist with facilitation, with another Alzheimer Society employee available as needed.

1.3 Method of evaluation

This report is a summary of the data collected in phase one of the Brandon Pilot (B1). Each phase of data collection (i.e., B1 to B3) involves four sources of information: observations, diaries, focus groups, and interviews (Skinner et al., 2018). The primary sources of information for this report are weekly observations by two research assistants, weekly diaries kept by participants, and focus groups with participants and staff/facilitators. In total, 16 observations were analyzed, 15 diary entries were collected from three participants, five entries were collected from three carers, three pre and post program interviews were conducted with people with dementia and carers together, and two focus groups were conducted. 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 the participants. The diaries included participant descriptions of what happened in the dance session each week as well as participant evaluations of their favourite elements of the program, any challenges they encountered, how they felt during the program, and anything else the individual felt was important to record that week. Immediately following their dance session each week, the participants would work with the research assistants to enter this information into their diaries. Two weeks after the program had finished, one focus group was conducted with participants and an Alzheimer Society staff member, and another focus group was conducted with carers. The focus groups facilitated exploration of what participants, staff, and carers liked best, what they liked least, what they saw as the most challenging part of the program, how the mode of delivery influenced the program's success, and what changes could improve the program. The project also included follow up interviews with participants who completed the diaries to explore their reflections regarding their experiences with the program. The facilitator interview data is not included in this report.

2. Best practices

2.1 Positive view of the program

People living with dementia (hereafter referred to as participants) indicated that they had a positive experience with the program. When asked what they thought about the program, participants said it was a good program, that they enjoyed it and looked forward to going every week. One carer expressed that he "appreciated bringing... [his spouse] here, she loved it". Other carers noted that because their spouses were generally happy and fond of the Alzheimer Society support group meetings, it was difficult for them to assess what difference the dance program made for their spouse.

"All of it. I like the music. I liked M (facilitator), she's amazing. I enjoyed everything about it. I enjoyed it."

2.2 The resonance of music

During the focus groups, most participants identified the music as the most enjoyable aspect of the program. This was also evident during observations as the research assistants reported participants singing along with familiar songs. The music was also the main aspect that participants remembered. One participant explained "I would wake up singing it", while another explained that

"When I asked her about it, she'd say oh my bonnie lies over the ocean, or take me out to the ball game, that's all she'd say [...]my bonnie lies over the ocean, J was all over the house singing it."

"some of the songs I remember from a kid...I enjoyed singing that and hearing that and thinking, 'oh yeah I remember hearing that a long time ago.'" During the focus group, the participants reenacted the movements they made to the saloon music and laughed at one another. It is significant that even two weeks after the program had ended, the music and movement resonated with people living with dementia. In addition, some carers commented that the music had a calming effect.

2.3 Familiar space and familiar relationships

Carers and participants suggested that familiarity with the Alzheimer Society office and other Alzheimer Society clients was a critical component of the success of the program. One carer explained "... that's the biggest thing. Most of them have been here together for so long that they know each other now, and it's not like they're strangers". The importance of having a previous relationship with others was also emphasized throughout participants' post-class diaries. One participant shared, "when I found out that I had dementia, I didn't want to go see the doctor. So I enjoy getting out with other people that are in the same group. I know everybody is different and has different issues, but it's nice to be with people who sort of get it." The location and shared experiences created an enabling space for people living with dementia. One person living with dementia who joined the group half-way through the program also expressed a sense of acceptance in this environment.

I think it is very hard for him to be out in public, which we are a lot. We go to hockey games, we do a lot of that. But I think you're always covering. You're always careful. Everyone we know, knows. We have spread the word so that everyone knows. But here, the guard is down. You're just you. And nobody cares.

One participant shared, "when I found out that I had dementia, I didn't want to go see the doctor. So I enjoy getting out with other people that are in the same group. I know everybody is different and has different issues, but it's nice to be with people who sort of get it." The location and shared experiences created an enabling space for people living with dementia. One person living with dementia who joined the group half-way through the program also expressed a sense of acceptance in this environment.

The comradery that developed between participants was also commented on. Laughter and joking with one another were common in research assistants' observations of the weekly interactions between participants. One participant explained that the banter among the group was special saying, "you know that's the thing, when you're around people, you gotta get to know them before you can really start to say anything as a joke or anything. Because some people take things serious." The comradery between participants increased over the 8-week program. Participants "loosened up" to the dance and joked around more. One carer made note of this: "I would say as a group, we would all be leaving together everybody was really more chatty, engaged with each other. Did you not find that during the sharing dance weeks? Did you find that? I sure did. I just seemed to notice that they were leaving together and chatting a little more."

2.4 On-screen instructor and in-class facilitator

Having an on-screen instructor and in-class facilitator proved beneficial for the program. The majority of participants reported that both forms of instruction were beneficial and they had no problem following the screen. Participants were engaged with the on-screen instructor. They enjoyed the 'call-outs' and one person said, "oh yeah she knew who I was." participants also remarked on how the on-screen instructor would remind them to do only the movements that they felt comfortable doing. They thought this was valuable instruction. During the observations, it was clear that participants were focused on the television screen. Participants would answer questions asked by the on-screen instructor and sing along when prompted.

Not surprisingly, the participants liked the interaction with the in-class facilitator as well. Some seemed to prefer the in-class facilitator. One participant commented, "I think I watched M [in-class facilitator] more [than the screen]. I loved watching her." The in-class facilitator engaged participants and provided additional opportunities for personal support and connection. One participant described the in-class facilitator saying, "...with her ability to do things. How she works with people. She's so good with that and just, you know. She'd definitely be checking to see if you're doing okay and if you're looking and that." Additionally, some participants suggested that having the in-class facilitator leading modified movements made it easier to avoid straining oneself. One participant observed, "She was kind of watching us and like if anybody had some issues like you have with your shoulder or whatever. She would say how to do it a different way, that wouldn't affect your... you could still do the movements and it wouldn't hurt you." As such, the in-class facilitator added to the overall sense of safety that participants felt with the program.

2.5 Respite for carers

Using the program as respite time was the biggest benefit for carers. They were happy with the scheduling, as it provided them with more time to do errands or visit, without interfering with other activities because Wednesdays at the Alzheimer Society was their partner's support group meeting. One carer explained, "We would have been coming for group, so it was a great time for us... I am really grateful that they slotted it in at that time because it wasn't changing something." Carers had more time not only to run errands, but they could socialize as well. Some carers would go as a group for coffee, visit family or friends, or have time for themselves to sit and read.

"And for me, it was huge. I can't tell you what two hours is. It is priceless."

The importance for carer respite was also noted by participants. They understood the heavy workload carried by their carers. One participant remarked in their diary

that “Whether you’re married or not, you need a break sometimes. Even if it’s a couple hours, so the dancing is good” and another participant commented, “And I think my husband likes it so he can do whatever he wants at home. It’s my outing, and I feel comfortable with people that I’m with.” In addition to connecting with others, time and space alone at home was also a valued outcome of the program for carers.

3.0 Challenges

3.1 Not dance

When asked about the dance program during the focus group, participants were confused since they felt that the program was actually movement or exercise. For example, one participant described, “It’s just a motion thing. If they just say motion instead of a dance, it’s kind of a little misleading [calling it dance].” Over half of the participants stated that the program was not really dance. One carer remarked on this as well, “I think C [spouse] said, well that’s not dancing. And I said well just... think of it as being exercise”. Most participants felt dance was an inaccurate label and some participants expressed disappointment with this because they associated dance with being with a partner.

“Yeah but I guess when you said dance I wanted to dance”

3.2 Diverse abilities

There were some participants who had some trouble with the dance movements because of physical limitations. One participant was hard of hearing. He explained that this was the biggest challenge for him when he was participating in the program, as he could not hear the TV. This also caused some disruptions for other participants, as he would speak out loudly in the middle of the program and make light of the program. His reactions draw attention to the challenges of developing an inclusive program for older adults living with multiple impairments. Two participants have problems with their shoulders, and one of these participants also has back and ligament issues. Strain was visible when the participants tried certain movements (i.e. extending their arms). In these cases, having an in-class facilitator was critical to making appropriate modifications. Another participant added, “My particular type of dementia makes moving around hard sometimes, but I was able to do the dances”.

“I can’t lift my one arm really high because of an old injury and I’ve got a pinched nerved in my back and spine, so I’m having a little trouble doing some because of the pain”

3.3 Small Space

The space was described as too small for dance. One participant explained, "Are you referring to this room? No we need more room if we're going to dance in here." For some, this comment was made in relation to a discussion about wanting to dance with a partner. Some participants wanted their partners to participate in the dance and other participants preferred dancing alone. Overall, the lack of space meant that participants had to adapt some movements and be mindful of where their neighbours were. One carer commented, "One thing that L [spouse] found when he was trying to do his arm exercises there wasn't enough room. The room was too small for the exercises."

3.4 Diary Method

Carers found that the diary method was not very useful for them. As they did not participate in the program, they did not see the value of filling out the diaries themselves. One participant described this challenge, "yeah, and if you wanted my perspective on the dance program, I wasn't there. I wasn't in the room. I didn't see how big it was, I didn't see how many people were there. I didn't know how it worked. So I really didn't have anything to add for that. And my personal life was a little hectic with respite and my own health. So I really put that a little bit low on my priorities." One of the limitations of the program was that carers did not see or share the benefits that people with dementia experienced within the program.

4.0 Recommendations

4.1 Program Expansion

- Revise promotional material to describe the program as 'movements with music.'
- To address diverse abilities in the on-screen delivery of the program, ask participants what they can or feel comfortable doing prior to and during the program. Instructor facilitator should also be present and trained to modify movements.
- The expansion sites will be larger and should address concerns around space.
- If participants are not familiar with each other, focus on building this trust to create enabling space.
- Provide carers with an opportunity to participate in and/or watch the program.

4.2 Research

- Revise the diary instrument to provide better prompts for carers to reflect in their respite time.
- Provide carers with feedback on the program (e.g., end of program summaries).

5.0 Next steps

As the Brandon team has summarized the process and outcomes of this first phase, a third Peterborough pilot has been underway to test best practices from the second phase of the Peterborough project in community and institutional settings. We anticipate the expansion of the dance program to community settings outside of Brandon will take place in the fall 2018 (B2). This will give NBS more time to develop the program and technology for program delivery in rural community settings. It will allow the research team and community partners to assess what each site is capable of supporting, how participants will be recruited, and what type of program these participants will need. A Brandon planning meeting for the expansion process (B2) is the next immediate priority to move forward with this process. The process and outcomes of B1 will help us to improve the program and the research for this next phase and, ultimately for other Canadians with dementia and their carers across Canada.

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