Music and Memory™

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Photo front page by Natalie Baird

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Introduction

The growing population of older adults living with cognitive disorders, including dementia, is well acknowledged in the research literature and by health care policy makers.

Institutional care for this population is often challenging; caregivers are stressed, and many nursing home residents spend the majority of time not engaged in meaningful activity. The need for programs that are engaging, that increase quality of life, and recognize residents' individuality, is recognized as essential.

Music is a universal positive human experience, which has recently been the subject of scientific inquiry demonstrating profound effects on the brain. A growing body of research has attempted to investigate music's effect on memory and the brain, and specifically the effect on behaviours exhibited by those with dementia.

Long-term care (LTC) residents have always found musical activities to be a source of meaningful interaction and pleasure. Newer technology such as iPods enable LTC providers to provide individualized music opportunities easily and inexpensively.

Music and Memory™ is a program that has been adapted in many long-term care facilities. Based on the provision of individualized music to long-term care (LTC) residents, this program is gaining recognition internationally. Recreation Services at Misericordia Health Centre (Winnipeg, Manitoba) has added this program to the ways they provide relationship-based care to residents in its LTC program.

In order to expand the program to more residents, the Recreation Services Manger wished to evaluate the program. A team including the Misericordia Health Centre Clinical Nurse Specialist and University of Manitoba Librarian decided that a consistent method to record observations during music sessions would be a useful first step towards providing quantitative data. We worked with Music and Memory™ facilitators to develop a checklist for recording observations, and designed a research project to test the Checklist.

Although we were unable to test the inter-rater reliability of the Checklist, we analyzed the data we collected. We also conducted and analyzed interviews with those who piloted and used the Checklist.

This document is intended to introduce interested long-term care workers and program managers to the role of music in dementia care, in particular individualized music and the Music and Memory ™ program. It describes the Music and Memory™ Program at

Misericordia Health Centre, the development of the Observational Checklist, and the research project we designed to test the Checklist. The document also includes:

- A brief literature review on music and dementia
- Resources and information on the Music and Memory™ program
- Music and Memory™ implementation at MHC
- Discussion of the issue of capacity to consent
- An analysis of interviews to evaluate the Observational Checklist

Please note that the literature review does not provide an exhaustive review of the literature, but an overview of the topic, with suggestions for more in-depth reading, and a focus on recently published literature.

Acknowledgements:

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“Music is a part of being, and there is no human culture in which it is not highly developed and esteemed. Its very ubiquity may cause it to be trivialized in old songs going through our minds for hours on end, and think nothing of it. But to those who are lost [in some cognitive or neurological issues, such as Alzheimer’s] dementia, the situation is different. Music is no luxury to them, but a necessity, and can have a power beyond anything else to restore them to themselves… at least for a while.”

Oliver Sacks, Musicophilia

Background

Over 10,000 Manitobans live with dementia (Manitoba Bureau of Statistics, 2016). Sixty one percent of Manitobans living in personal care homes have a diagnosis of dementia (Canadian Institute of Health Information, 2013).

Dementia has no cure, and while pharmacological treatments can sometimes help with symptoms, their limited efficacy and potential side effects have lead several health institutions to recommend non-pharmacological approaches. Of particular concern is the use of physical and chemical restraints to control behaviour (British Columbia, Ministry of Health, 2012). Dementia often leads to social and occupational impairment, as well as emotional and sensorimotor deficits, which can result in loss of function, reduced independence and social isolation.

Behavioral and psychological symptoms of dementia (BPSD) are common and affect 80% of LTC residents (Caltic, 2015). These behaviours include agitation, aggression, mood disorders, wandering, and sleep problems. BPSD's are difficult to manage and are a significant source of stress for people with dementia, their families, friends, and institutional caregivers (Gerdner, 2005; Ueda, Suzukamo, Sato, Izumi, 2013; Samson, 2015; Visiontye & Madison, 2013).

Much of the literature on dementia uses the term BPSD, but some writers refer to these behaviours as *responsive*. This expresses the idea that people with dementia behave in response to their environment: that all personal expressions (words, gestures, actions) have meaning; and to understand the meaning of behaviours, you must consider the physical, emotional and environmental elements influencing behaviour (Alzheimer Society Ontario, 2014). In keeping with the philosophy of person-centred care guided by our work, we will refer to BPSD's as *responsive* behaviours in this document from now on.

Passive behaviours are among the most common symptoms of dementia (Sapra, DeYoung, & Kim, 2014). Residents who are withdrawn can become isolated and inactive and are at higher risk for further cognitive and functional decline.

Cohen-Mansfield, Dakheel-Ali, & Marx (2009) wrote that nursing home residents spent the majority of their time not engaged in meaningful activity. This magnifies apathy, boredom, depression and loneliness. Engaging residents is therefore critically important because it leads to an increase of positive emotions, can improve activities of daily living, quality of life, and decrease responsive behaviours. Because of these negative

outcomes of passive behaviour and lack of engagement, a need to find interventions and activities that engage passive residents is necessary (Kolonowski & Buettner, 2008).

Recreational activities in LTC are one of the most important determinants of a resident's quality of life and well-being. Carefully tailored activities can provide a needed source of meaning, competence, social connection, and pleasure for residents (Haitsma et. al., 2016).

The Alzheimer Society of Canada has identified activity and recreation as one of the key elements for person centred care (2014). The Society encourages LTC recreation programs to "engage each resident in stimulating and meaningful activities, tailoring recreational plans to the person's interests, preferences and abilities. A resident's participation and engagement in group or one-on-one activities can be an important way to support independence, a sense of accomplishment and a sense of self."

Music and the Brain

"Whenever humans come together for any reason, music is there," writes Daniel Levitin (2007) …."weddings, funerals, graduation from college, men marching off to war, stadium sporting events, a night on the town, prayer, a romantic dinner, mothers rocking their infants to sleep and college students studying with music as a background….".

> ***"When words fail, music speaks."***
> *Hans Christian Andersen*

Throughout the history of literature and philosophy, authors have written much about the importance of music. For example, Henry Wadsworth Longfellow wrote, "Music is the universal language of mankind". Hans Christian Andersen said, "Where words fail, music speaks". Recently, music has also become the subject of scientific inquiry for its complex and intriguing effects on the human brain. Oliver Sacks and Daniel Leviton are among those who have written about the cognitive neuroscience of music, telling remarkable stories of how music has healed the brain.

Read More about Music and the Brain

Leviton, Daniel (2007). *This is your brain on music: the science of a human obsession*. New York: Plume.

Sacks, Oliver (2007. *Musicophilia: tales of music and the brain*. New York: Knopf.

Blog post about these books and more:
https://www.brainpickings.org/2011/03/21/must-read-books-music-emotion-brain/

For a scholarly article on the psychology of music listening:
Schäfer, T., Sedlmeier, P., Städtler, C., & Huron, D. (2013). The psychological functions of music listening. *Frontiers in Psychology*, *4,* 511.
http://doi.org/10.3389/fpsyg.2013.00511.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3741536/

Music Therapy References and Resources:
Institute for Music and Neurologic Function Website
http://musictherapy.imnf.org/research-education/category/references-and-resources

Research on Music and Dementia

A large body of literature has also emerged on the neuroscience of dementia and music. The relationship between music and memory in people with dementia is particularly noteworthy. Researchers have found that people with dementia, even in the later stages, respond to music in positive ways. They found that people with dementia will remember familiar music even when their memory for verbal information is impaired (Cuddy, Sikka, & Vanstone, 2015; Gerdner, 2010). Music can also be both stimulating for passive residents, (Holmes, Knights, Dean, Hodkinson, & Hopkins, 2006), as well as calming, soothing and relaxing. Furthermore, it can stimulate well-being, and enable the recall of life experiences and emotions (Vink, Birks, Bruinsma, & Scholten, 2004; Gerdner, 2010).

Benefits of Music

- Calming
- Soothing
- Relaxing
- Stimulating
- Stimulates well-being
- Facilitates reminiscence

> *"Music can also evoke worlds very different from the personal, remembered worlds of events, people, places we have known."*
> Oliver Sachs, Musicophilia

A growing body of research exists on the use of music to alleviate responsive behaviours in dementia. Some of the research looks at all types of musical interventions, such as live music presentation, group music, music making, or listening to familiar music; while others focus on one intervention or a comparison of two or more interventions, (including non-musical interventions). Many studies examine the use of music for specific behaviours, such as agitation (Raglio, 2012). Although many types of health care workers use music with people with dementia in a range of contexts and with all types of health care workers, much of the literature looks at music therapy as a specific psychological intervention.

Music therapy is defined as "the skillful use of music and musical elements by an accredited music therapist to promote, maintain and restore mental, physical, emotional and spiritual health" (Canadian Association of Music Therapy, 1994). The

American Music Therapy Association (AMTA) clearly states that not all therapeutic music interventions are music therapy:

> "These examples of therapeutic music are noteworthy, but are not clinical music therapy: A person with Alzheimer's listening to an iPod with headphones of his/her favorite songs" (Bumanis, 2014).

The AMTA created a Working Group in response to the popularity of Music and Memory™. The Working Group website includes many excellent resources, including a factsheet explaining the difference between clinical music therapy and Music and Memory™.

Raglio et. al. (2015) also distinguishes between types of music intervention: "A trained music therapist who interacts directly with the individual provides active MT, whereas LtM (individualized listening to music) is based on self-administered music that the individual or caregiver chooses and does not involve any kind of direct relationship with the therapist." However, Raglio acknowledges that the literature sometimes includes approaches other than music therapy, and that the specific therapeutic approach being investigated is sometimes unclear.

Still, the literature on music therapy has relevance to the variety of situations where music is used with people with dementia. Studies from "non-music" therapy disciplines have also demonstrated outcomes in association with the use of music (Gallagher, 2011).

Several researchers have taken evidence-based approaches to music and dementia, applying empirical approaches to their research while others have analyzed the existing literature through meta-analysis and systematic reviews, including the Gold Standard of systematic reviews, a Cochrane review.

Raglio is one of many researchers who have contributed a significant body of work on music and dementia. In 2012, he published an extensive review of the literature with recommendations for practice from the Italian Psychogeriatric Association. In 2015, he published a study comparing active music therapy with individualized listening.

Other recent studies on the use of music in dementia include:

- Sanchez et al. (2016) did a randomized controlled trial comparing multisensory stimulation with individualized music with people with severe dementia.
- Särkämö et. al. (2016) compared scores in the Cornell-Brown Scale for Quality of Life in Dementia for residents participating in music singing and music listening

- Hsu et. al. (2015) studied a five-month music therapy programme including weekly individual active music therapy for people with dementia in care homes and a weekly post-therapy video presentation for their carers.

Read More About Music and Dementia

Baird, A. & Samson, S. (2015). Music and dementia. *Progress in Brain Research, v. 217*, pp. 207-35.

Clair, A.A. (2016) Music therapy in clinical practice for those with dementia. In J. Edwards (Ed.), *Handbook of Music Therapy*. Oxford University Press.

Gerder, L. & Remington, R. (2010). Therapetuic effect of music on people with dementia. IN Ames, D., Burns, A. *Dementia*, 4th. Ed., CRC Press.

Raglio, A. Music therapy in dementia IN *Dementia: non pharmacological therapies*. Access for free at: https://www.novapublishers.com/catalog/product_info.php?products_id=18952

Systematic reviews and meta-analysis are tools researchers use to critically evaluate and gather research. These reviews synthesize the results of related studies by using strategies that reduce study biases and determine whether studies are suitable for integration into evidence-based practice.

The Cochrane Review is considered the gold standard of systematic reviews. In 2004, Vink, Bruinsma, & Scholtern conducted a Cochrane review looking at 10 research studies.

The following are more examples of systematic reviews and meta-analyses of the literature on individualized music and dementia.

- Vink et. al. (2013) analyzed the effects of music therapy in the treatment of behavioural, social, cognitive and emotional problems of older people with dementia, in relation to the type of music therapy intervention.
- Ueda, Suzukamo, Sato, & Izumi (2013) broadened the scope of the review to include controlled trials in their systematic review and meta-analysis, and found that music therapy is effective for the management of BPSDs.
- Vasionyte & Madison (2013) carried out a meta-analysis to consider the effects of music therapy on affective, behavioural, cognitive and physiological problems) on different types of interventions and different outcome measures, namely affective, behavioural, cognitive and physiological.
- Chang (2015) claimed to conduct the first study to evaluate the effectiveness of all randomized controlled trials of music therapy intervention over the last 15 years for people with dementia.

Most of this work concludes that there is inconsistent and poor empirical evidence for the use of music and dementia because of poor methodological quality of the research studies examined (including small sample sizes, etc.). Because of these issues, we can make limited conclusions about music's effect on dementia (Vasionyte & Madison, 2013: McDermott, 2012). Still, the potential for music as a way of dealing with responsive behaviours in dementia continues to motivate researchers.

Evidence-Based Practice Definitions

Evidence-based Practice
Clinical decision making based on the use of best evidence, clinical expertise, and patients' values.

Meta-analysis
A type of systematic review that includes the statistical combination of at least two studies to produce a single estimate of the effect of an intervention or an outcome.

Systematic Review
A critical analysis, using a rigorous methodology of original research, identified by a comprehensive search of the literature.

Controlled trial
A clinical study in which one group of participants receives an experimental drug while the other receives either a placebo or an approved-'gold standard' therapy

Randomised Controlled Trial
Method used in evidence-based clinical trials whereby a group of patients is randomised into an experiment group and a control group. Using randomization is one way in which any possibility of selection bias in a trial is minimized.

Cochrane Reviews
Cochrane Reviews are systematic reviews of primary research in human health care and health policy, and are internationally recognized as the highest standard in evidence-based health care resources. They investigate the effects of interventions for prevention, treatment, and rehabilitation. They also assess the accuracy of a diagnostic test for a given condition in a specific patient group and setting. They are published online in the Cochrane Library.

Individualized Music and Dementia

While musical entertainment has long been a staple of recreation programs in LTC, new opportunities and programs for incorporating music, are in harmony with person-centered care. Personalized music playlists can be selected and created using inexpensive MP3 players like iPods, and computer programs like iTunes. The Music and Memory™ program uses these technologies to provide individualized music sessions to residents in LTC. This brief review of the literature focuses on individualized music and dementia:

Individualized music is also called:

- Personalized music
- Individualized listening to music
- Receptive music therapy

Linda Gerdner (see References) has written extensively since the early 90's about individualized music and dementia, looking primarily at its effect on agitation. She defines individualised music as "music that has been integrated into the person's life and is based on personal preference (selected according to the preferences of the patient, or identified by asking himself or herself or relatives or caregivers" (1993). Gerdner theorizes that when people with dementia are exposed to a selection of music that they perceive as pleasant and familiar, this may override potentially confusing environmental stimuli and replace them with familiar and soothing sounds (1997). Her years of work and research led to the development of the evidence-based protocol "Individualized music for elders in dementia" (2010). Recognizing that non-professionals and family members may wish to participate in music sessions with people with dementia, she also compiled a guide for consumers to supplement the evidence-based protocol.

Individualized Music

… "is music that has been integrated into the person's life and is based on personal preference" (Gerdner, 1993).

…"is selected according to the preferences of the patient, identified by asking himself or herself or relatives or caregivers. Most studies use individualised music purposefully for arousing memories, one important ingredient in reminiscence therapy commonly used for the treatment of dementia patients" (Ashida, 2000). Quoted by Vasionyte: musical intervention and dementia: a meta analysis.

Music, Quality of Life, and Person-Centred Care

> *"Music should be not be viewed as a tool to fix a behavioural problem, but rather a person-centered approach designed to improve the quality of life of people with dementia."*
> Orrie McDermott

Despite the potential that music holds for alleviating responsive behaviours, some researchers question whether an empirical, scientific approach is the best way to determine music's effect on dementia. McDermott (2013) suggests that randomized controlled trials are not the most suitable research design for psychosocial interventions such as music therapy. Randomized controlled trials require procedures such as double blinding which are not always practical or ethical. She believes that the use of music poses few risks, particularly in comparison to medications, and furthermore, that music should be not be viewed as a tool to fix a behavioural problem. She sees music therapy as a person-centered approach designed to improve the quality of life of people with dementia, and that one of the most important goals of music therapy is relationship-building (McDermott, 2014).

> *"We might say that music therapy is a tool of access – access to memory of music and access to a past social self."*
> Steve Matthews

Recognizing this, McDermott et. al. (2013) used a narrative synthesis approach to determine evidence for music's effectiveness. A narrative synthesis is an approach to the systematic review and synthesis of findings from multiple studies that relies mostly on the use of words and text to summarise and explain the findings. By analyzing the themes uncovered in the literature, she found that "music taps into an individual's sense of self in relation to their personal preferences and life history, and it goes beyond the idea of music as a tool to fix a behavioural problem (e.g. agitation) suggesting that it is part of a "wider appreciation of life" (McDermott, 2014).

After analyzing focus groups and interviews with care home residents and their families, day clients, and music therapists, McDermott, Orell, & Rider (2015) also found:

- Music instantly caught the attention of residents and they responded to familiar music
- Music mentally stimulated and engaged participants
- Residents and clients found the experience of listening to music emotionally meaningful
- Song lyrics were linked to personal history and personal and cultural identity
- Music listening built relationships
- Music listening led to immediate and short term effects on mood

Person-centred care is based on the work pioneered in the 1990s by Thomas Kitwood. Kitwood advocated for engaging with the experience of people with dementia and strongly emphasized the quality and sensitivity of the interpersonal process between the person with dementia and carer (McDermott et. al., 2014).

LTC organizations throughout the world have embraced the philosophy of person-centred care. Alzheimer's Canada (2016) advocates for person-centred care with people with dementia, stating:

"Person-centred care recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect, and to participate fully in their environment".

Manitoba's Alzheimer Framework (2014) also states, "all care and services will be provided through a person-centered approach with a focus on respect for the individual".

For more resources on Person Centred Care see the following from the J. W. Crane Memorial Library:

Person-centred care in long term and continuing care: a selected list

The Long Term Care Program at Misericordia Health Centre, a faith-based health centre based in Winnipeg, Manitoba, follows the philosophy of relationship-based care. Misericordia's Long-Term Care program includes a 100-bed personal care home, along with 128 interim-care beds. Central to the philosophy of relationship-centred care is the need to form authentic human relationships with the patient/resident/client. The person-centred approach guides care at Misericordia Health Centre. Life Enrichment Grants from the Misericordia Health Centre Foundation aim to provide quality of life experiences for residents.

These philosophies of care led the Misericordia Health Centre Recreation Manager to explore the potential of Music and Memory™.

Some of the ways individualized music is a person-centred care approach:

- Music may be tailored to the specific interests and life story of people with dementia.
- Central to the philosophy of person centred care, music can provide a way for positive and meaningful interaction between staff and family with the person with dementia.
- People with dementia enjoy music even in the later stages, and this enjoyment contributes to their quality of life.
- Music elicits emotional responses, even when other forms of communication have been lost.
- Music has an elusive, spiritual quality that can allow people to transcend their physical, temporal environment.

> *"When words fail, music provides a way for the person with dementia to connect with others and engage memories and emotions."*
> http://www.alzheimer.ca/en/We-can-help/Resources/Power-of-music

In order to evaluate the Music and Memory™ Program at Misericordia Health Centre, we wanted to find outcomes from the program that followed the person-centred relationship-based care approach.

Outcome Measurement and Music

Evaluation of music therapy is a complex task (McDermott, 2014). Because most of the quantitative studies that look at music therapy focus on the reduction of psychiatric symptoms, many of the tools used to measure these symptoms require training and expertise. These tools include well-established measures such as the Neuropsychiatric Inventory (NPI), Cohen-Mansfield Agitation Inventory, and the Geriatric Depression Scale.

However, tools to measure responses to music exist outside the psychiatric literature. Glynn (1992) developed the "Music Therapy Assessment Tool" which measured behavioural responses of people with Alzheimer's disease exposed to "taped" music. This tool was found to have high inter-rater reliability.

Many researchers agree that an important outcome of music therapy is improved quality of life (Vanstone, Wolf, Poon, & Cuddy, 2010: Vasiontye & Madison, 2013) and that there is a need to develop tools that reflect a holistic picture of therapy outcomes including positive responses of people with dementia (McDermott, 2014). These measures should quantify positive behavioural responses and determine quality of life outcome measures such as positive affect, expressed satisfaction and meaningful interaction with others (Gerdner, 2010). McDermott (2014) also claims that studies driven by an evidence-based approach may be in danger of choosing well-established measures in an attempt to provide trustworthy evidence, yet that may not be the most relevant to the experiences of people with dementia.

The Quality Palliative Care in Long Term Care Alliance developed the Music Interaction Observation Checklist to measure the impact of student led sessions and help guide their observations. Students involved with the program reported they felt they were not having an impact on the residents in long-term care. The tool was adapted by permission from the "Greater Cincinnati Chapter Well-Being Observation Tool", originally created and developed by Kinney & Rentz (2005).

This observational tool is based in Lawton's Conceptual Framework of Well-being. Lawton's Framework is highly influential in the literature on quality of life and dementia. According to Lawton, well-being includes positive and negative affect, and positive affect is related to external, interactive aspects of the person's world (1997). Lawton believed there should be a focus on interventions that contribute to quality of life in contrast with a model of dementia that focuses on memory or cognitive impairment.

The Quality Palliative Care in Long Term Care Alliance Music Observation Checklist divides responses into the following categories:

1. Macro expressions: e.g. tapping fingers, dancing, clapping
2. Micro expressions: e.g. smiling, moving lips to the music
3. Positive Expressions: (pleasure, enjoyment and attention): e.g. verbalizing a sense of pleasure
4. Negative expressions (anger, sadness, agitation): appearing angry during the interaction
5. Social Interaction: e.g. making eye contact

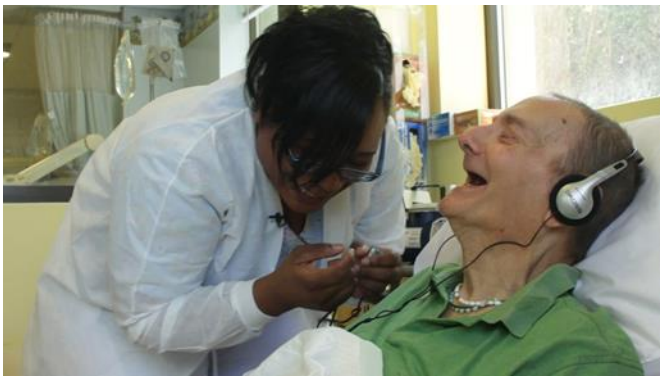
McDermott et al. (2014) developed the music therapy outcome measure (Music in Dementia Assessment Scales or MiDAS), incorporating the values and views of people with dementia based on the categories “resident interest”, “response”, “involvement” and “enjoyment”, and a supplementary checklist of positive and negative reactions. They noted “head turning, longer contact or the changes in the emotional qualities of vocal responses were all considered important indicators of responses when working with people at late stages of dementia.” They created two forms, one for music therapists, and the other for care home staff.

In developing our Checklist, we used elements of these tools in order to develop an easy-to-use checklist. We also attempted to identify behaviours that could be observed objectively. Recognizing that people with dementia and their family caregivers experience stress due to difficulties with communication (Garabedian, 2014), the research team was also inspired by the idea of finding a way to involve family or friends in Music and Memory™ sessions.

Music and Memory ™

The Music and Memory™ Program was created by Dan Cohen, a retired New York based social worker who volunteered at local nursing homes applying his knowledge and technological expertise to benefit others. Recognizing the profound impact that music has on memory and reflecting on his own aging, Dan Cohen began creating personalized musical playlists on iPods for nursing homes residents. In 2008, The Shelley & Donald Rubin Foundation provided funding for the purchase of 200 iPods that Dan Cohen used to test his program on a larger scale in four New York long-term care facilities. Based on the program's success, Dan Cohen created the non-profit organization Music and Memory™ in 2010. To date, hundreds of LTC facilities have implemented Music and Memory™ in facilities throughout the USA, Canada, Europe, and around the world. Specifically, the State of Wisconsin has designated many LTC facilities as Music and Memory™ Certified Care Facilities.

In 2012, the Sundance Film Festival award winning documentary *Alive Inside: A Story of Music and Memory* was released, and has generated much interest in the program.



Still photo from "Alive Inside". Michael Rossato-Bennett, 2012

More about Music and Memory™

Story on Alive Inside and Music and Memory on Democracy Now
http://www.democracynow.org/2014/1/22/alive_inside_how_the_magic_of

On CBC
http://music.cbc.ca/#!/blogs/2014/7/The-memory-key-how-music-is-unlocking-the-minds-of-people-with-Alzheimers

Follow Music and Memory ™ on Social Media

- Alive Inside

On Twitter: https://twitter.com/aliveinsidefilm
On Facebook: https://www.facebook.com/BeAliveInside
Youtube:

- Music and Memory™

Twitter: https://twitter.com/music_n_memory
Facebook: https://www.facebook.com/MusicAndMemory
YouTube

More about the documentary Alive Inside at http://www.aliveinside.us/#land

Watch it on Netflix!

Read a review of the film in the journal Gerontologist 2015, 55(6): 1058-9.

Other Music and Memory™ Programs

Ohio Department of Aging: Music and Memory™
Evaluation Project

Wisconsin Music and Memory™

"To my surprise, the humble intervention rendered amazing results. Residents who were nonverbal began to sing along and even dance. One woman in particular who was 90 years old began dancing—even though she needed her walker to do so. It is hard to express with words the impact of this seemingly simple intervention".

Griser, S. Enjoy. Shuffle. Repeat: Using personalized music playlists to improve the quality of life for people with dementia. Journal of Palliative Medicine, 2016

Other Individualized Music Programs

Alzheimer Society of Toronto iPod Project

In 2013, the Alzheimer Society of Toronto (AST) initiated an iPod project aimed to provide iPods, free of charge, to 10,000 older persons living with Alzheimer's disease and other dementias and their caregivers. The project hoped to engage 10,000 participants as a way of improving communication, cognition and quality of life. AST commissioned the University of Toronto Balance of Care Research and Evaluation group to assess the project's implementation and performance and to demonstrate the impact of the project. The evaluation consisted of semi-structured interviews with stakeholders, including staff, and focus groups with caregivers. An analysis of data on participants and outcomes including responses to the Caregiving Distress Scale and the Cornell Scale for Depression and Dementia is also included.

Read more about the Alzheimer Society of Toronto iPod Project

Science behind the Alzheimer Society iPod Project: http://www.ryerson.ca/content/dam/crncc/knowledge/infocus/factsheets/InFocus-ScienceBehindtheASTiPodProject.pdf

In Focus Backgrounder: http://alz.to/get-help/music-project/

- Contains tools and resources to implement a music project
- Letters for families
- Facility starter kit….
- Ensuring success with residents, a guide for staff

Evaluation of the Alzheimer Society iPod Project Final report: http://www.ryerson.ca/content/dam/crncc/knowledge/relatedreports/balancecare/EvaluationoftheAlzheimerSocietyTorontoIPodProject.pdf

Playlist for Life

www.playlistforlife.org.uk

"Playlist for life" is a Scottish organization that provides awareness, training and support for incorporating music in the care of dementia. They also collaborate with other organizations engaging in research and evaluation.

Creating effective music listening opportunities

www.baycrest.org/care/culture-arts-innovation/therapeutic-arts/music-therapy/creating-effective-music-listening-opportunities/

From Baycrest Health Centre in Toronto Ontario, this brochure is intended for caregivers and all persons interested in learning about developing successful shared music listening opportunities, including how and when to use a personalized playlist, how to creative effective playlists and how to respond to deep emotions that could result from music listening.

Music Interaction: Quality Palliative Care in Long Term Care Alliance

http://www.palliativealliance.ca/assets/files/Alliance_Reources/Psychosocial_Care/Music_Interaction_-_Final.pdf

Manual created based on work of students who listened to music with residents in an Ontario LTC facility. Provides tips on preparation, conducting, and debriefing from music interaction sessions. Also includes a Music Interaction Observation Checklist.

Department of Health, New York State

http://www.health.ny.gov/diseases/conditions/dementia/edge/forms/index.htm#indivmusic_forms

Person-centred sample care plans, assessments for individualized music, etc.

Music and Memory™ at Misericordia Health Centre:

Misericordia Health Centre, located in Winnipeg, Manitoba is a faith-based health centre providing a diverse range of health care programs, including Misericordia Place, a 100-bed personal care home, and a 108-bed interim care unit. In 2012, Ellen Locke, Manager of Recreation Services at Misericordia Health Centre submitted a proposal to the Misericordia Health Centre Foundation Life Enrichment Program.

The Misericordia Foundation Life Enrichment Program provided funding for training and equipment including:

- laptop computer
- 15 iPod shuffles
- 25 pairs of headphones
- 10 headphone splitters
- a pair of small speakers
- $100 iTunes card

Dan Cohen trained three staff members via webinar at a cost of $1000. After completion of the training in 2013, Misericordia Health Centre became a certified Music and Memory™ facility.

The Music and Memory™ organization donated 15 iPods once the training was completed and ten more were purchased through other donations. To obtain additional donations of gently used iPods or MP3 players, Recreation staff posted notices around Misericordia Health Centre, published a story in *Life@Miz* (Misericordia Health Centre's newsletter), and created a post on the Misericordia Health Centre intranet and Facebook page and on personal Facebook pages. A *Winnipeg Free Press* article on the program in June 2015 elicited several phone calls, questions, visits, and nine more iPod donations. Continuous efforts are made to procure more iPods and mp3 players.

In 2013, *The Ladies of the Street*, a local women's choir, held a fundraising event that raised $6000.

A music library containing music from around the wold was purchased with these funds on Dan Cohen's recommendation.

James Cohen, a drummer in a local band, also donated $5000 to the MAM program at MHC.

Currently Misericordia Health Centre provides 12 hours of Music and Memory™ sessions per week. Recreation Services aims to expand the number of trained individuals to deliver more Music and Memory™ hours to residents as well as increase the number of participating residents.

Optimal Music and Memory™ delivery times are sought for each resident and after 4-5 refusals; they are excluded from the program. Observers fill out the Observational Checklist during and after each session (See Page 31).

Staff Training

Dan Cohen trained the Recreation Services Manager, along with one staff member and two paid student facilitators via Webinar. A Recreation Services Staff member and one student facilitator designed a two-day training session for new facilitators and volunteers.

Training sessions are held in the Misericordia Health Centre computer lab. Training begins with a brief orientation to Music and Memory™ program. Trainees watch "Henry's Story" from the Music and Memory™ website, as well as an internal video of a Misericordia Health Centre resident. Training includes observing Music and Memory™ sessions as well as the following:

- Brief description of equipment used including iPods
- How to download music
- Accessing the program laptop
- Resident referral and criteria for choosing residents
- Communicating with residents during a session, including resident refusals to participate in a session
- Communicating with families
- Filling in the Observational Checklist

Referrals

Referrals come from nurses, staff, families, physicians and musicians who perform on site. They fill out a formal referral document reviewed by Recreation staff.

Criteria for referral:

- Must show an interest and find meaning in music

- Must have potential for using music to communicate
- Be at risk for social Isolation, agitation, wandering or signs of emotional distress

While residents do not necessarily have a diagnosis of dementia, the majority of the participants have some form of cognitive impairment.

Setting up Profiles

Once the resident has shown interest in Music and Memory ™ and a trial run has been done, facilitators create a file about the resident.

Information in the file includes:

- Preferred musical genres, artists, and songs
- Resident name and unit

Facilitators use a musical preference sheet from Music and Memory™ to document types of music and specific songs that are meaningful for the resident. However, the referral document is used only for new residents, patients, or clients.

Other methods for determining musical preferences include:

- Residents are observed in choir and at musical events on their units
- Interviewing residents and family members

If the family is unavailable, or the resident is unable to identify their preferences, facilitators determine preferences by playing songs from a playlist and observing the resident's reactions.

Setting up iPods

Recreation Staff purchased a dedicated Music and Memory™ laptop computer with grant funds. iTunes was configured on the laptop. Volunteers began downloading the music library from the Music and Memory ™ program. Based on the resident's musical preferences, the iPod is loaded with music from a playlist created in iTunes for the resident. If a requested song is not in the current music library, the song(s) are purchased on iTunes using program funding.

Facilitators add or remove music from the resident's playlist depending on resident reaction. If a resident or family member requests songs, or if a resident responds to a song during choir or live musical entertainment, facilitators add this music to their playlist. If a song gets no reaction or a negative reaction, facilitators remove it from their playlist.

When residents leave the Interim Care Program, families receive a list of the songs of their playlist.

Music and Memory™ Session Process

Each session begins with the Music and Memory™ facilitators approaching the participant and simply asking if they would like to listen to their playlist alone or with a facilitator. The participant can decline, or stop the session at any point.

Files, Sheets and Forms

All sensitive data and completed Observational Checklists sheets are locked in a secure location on site. Access to less sensitive data (including blank Observational Checklists), is available at the Recreation Department.

> *"One of our residents had a stroke: she was left with aphasia and could only verbalize the same four or five phrases, yet she could sing every word to every song she listened to. All the frustration of not being able to communicate seemed to disappear when she listened to her music. Her agitation was gone, she was able to smile and her body (shoulders) was in a relaxed state rather than tense."*
>
> Ellen Locke, Recreation Services Manager, Misericordia Health Centre

Evaluation

We identified three elements that would be useful in evaluating the Music and Memory™ Program.

1. Impact on residents

2. Cost
3. Staff time

We hoped that by providing an easy-to-use tool to record responses to music, we could begin to evaluate the program with qualitative data.

Cost:

The costs of implementing Music and Memory™ at Misericordia Health Centre are not high. The minimal costs associated with individualized music in LTC are also reported in the literature. “Staff and family have reported that individualized music requires minimal time expenditure, and the elder’s positive response to the intervention has served as a facilitator for implementation” (Raglio, Gerdner, 2005).

Supply costs are minimal. Responses to requests for iPods at Misericordia Health Centre have been good.

Staff Time:

The grant from the Misericordia Health Centre Foundation provides 4-6 hours per week of facilitator time.

When there are no facilitators available, it is difficult for Misericordia Health Centre recreation staff to fit Music and Memory™ sessions into their schedules.

Staff time was also identified in the Alzheimer Society of Toronto as an issue. “Staff reported inconsistent use of iPods because they were not always able to spare staff to help persons use their iPods” (Williams, A.P., Pecham, A., Rudoler, D., Tam, T., & Watkins, J., 2014).

More about Music and Memory™ at Misericordia Health Centre

- For a short video on the Music and Memory ™ program at MHC go to: https://www.youtube.com/watch?v=J_PqRkjzDuM
- WRHA Inspire: news and information for staff working in the Winnipeg Health Region
  - http://www.wrha.mb.ca/extranet/inspire/2015/160420_Music_of_the_heart.php
- Winnipeg Free Press article: http://www.winnipegfreepress.com/local/The-power-of-music-brings-back-long-lost-memories-309950661.html
- CBC Radio interview: http://www.greenplanetmonitor.net/podcast/music-in-my-head/

Research Project

The Misericordia Health Centre Manager of Recreation Services asked the Clinical Nurse Specialist and the University of Manitoba librarian located at Misericordia Health Centre to suggest approaches to evaluate the Music and Memory™ program. She hoped to provide Misericordia Health Centre Management and the Misericordia Health Centre Foundation with program outcomes to increase resources for Music and Memory™.

While Music and Memory™ program facilitators were keeping narrative notes after each session, we identified the need to quickly, easily, and efficiently document resident responses. We hoped that the Checklist could be used by both trained Music and Memory™ facilitators and other Misericordia Health Centre staff, volunteers, and resident's families or friends. Quantitative data documenting responses to the sessions could potentially be used as part of an ongoing evaluation of the program and would supplement the qualitative comments facilitators were already collecting.

Because Music and Memory™ is a person-centred recreation intervention with the goal of enhancing quality of life for Misericordia Health Centre residents, we felt that simple, observable responses to music are a significant reaction for people with dementia. If listening to music elicits a smile, or humming along to a favourite tune, these reactions contribute to resident quality of life.

We conducted an environment scan of the literature on individualized music in dementia, and consulted with Music and Memory™ facilitators at Misericordia Health Centre to develop a checklist of observable behaviours before, during, and immediately after the Music and Memory™ sessions. Facilitators piloted the checklist for a month. We obtained University of Manitoba Research Ethics and Misericordia Research Committee approval in order to conduct an inter-rater reliability study of the checklist. We also obtained ethics approval to interview those who were using the checklist in order to obtain more evaluative information. Unfortunately, issues with obtaining consent coupled with staffing issues at the Recreation Department meant that we were unable to complete an inter-rater reliability study.

Please see the Appendix for the Research Protocol.

Misericordia Health Centre Music and Memory Observational Checklist

Date:	
Resident Code:	**Unit:**
Observer Code:	**Observer Status: ☐ Facilitator ☐ Family ☐ Volunteer ☐ Staff**
Time Started:	**Time Ended:**
Location of session:	**Activity prior to session (eating, bathing, etc.):**
✓ **Check all or any of the below**	**Comments**
Pre Session	
	Asleep
	Drowsy/falling asleep
	Alert
	Calling out
	Restless
	Physically responsive behavior (hitting, kicking)
	Uninterested/unresponsive
	Interested/responsive
	Other
During Session	
	Falls asleep
	Drowsy
	Alert
	Body/Facial
	Makes eye contact
	Closes eyes
	Moves body to music (taps fingers, toes, sways)
	Smiles
	Frowns
	Pulls off headphones
	Restless/tries to leave
	Physically responsive behaviour
	Verbal
	Humming/singing
	Talks
	Requests songs
	Cries
	Laughs
	Expresses gratitude/pleasure
	Calls out
	Other
Immediately Post-Session	
	Asleep
	Drowsy/falling asleep
	Alert
	Calling Out
	Restless
	Physically responsive behavior
	Uninterested/unresponsive
	Interested/responsive
	Other

Capacity to Consent and Dementia

The ethical issues involved with determining capacity for consent in people living with dementia in a study provided obstacles to our research. Claire Garabedian (2014), a Scottish PHD candidate, echoed our experience.

> *"Despite my assertions regarding the importance of including people from this growing segment of society, the very low risk involved, the very high chances for benefit, and the potential benefits that findings from this study might have for people within similar populations (Adults with incapacity Act http://www.legislation.gov.uk/asp/2000/4/part/5: 51.4), I was only granted permission to include people able to provide direct informed consent."*

Canadian legislation regarding capacity to consent is also problematic. In Canada, the legal frameworks governing research involving adults incapable of providing informed consent are beset by gaps and ambiguities…federal laws and policies relevant to the regulation of research involving decisionally incapable adults interact in complex ways with provincial or state laws (Wildeman, 2013).

In order to conduct the inter-rater reliability study for the Observational Checklist, we needed to obtain consent from the residents, patients, and clients. According to Manitoba law (Health Care Directives Act, 1992), if a person is not capable of providing consent, their substitute decision makers cannot enroll them in a research study unless the person has indicated in their Health Care Directive.

> "Unless a directive expressly provides otherwise, a proxy cannot consent to:
> (a) medical treatment for the primary purpose of research;
> (b) sterilization that is not medically necessary for the protection of the maker's health; or
> (c) the removal of tissue from the maker's body, while living,
> (i) for transplantation to another person, or
> (ii) for the purpose of medical education or medical research.

None of the Misericordia Health Centre residents enrolled in the Music and Memory™ program had indicated this in their Health Care Directive.

However, "dementia does not deem a person incapable of making an informed choice" (McKeown, J. 2010), and so we developed a process to obtain consent from residents who had potential capacity for consent according to Manitoba law.

> "A person has capacity to make health care decisions if he or she is able to understand the information that is relevant to making a decision and

able to appreciate the reasonably foreseeable consequences of a decision or lack of decision".

We outlined our consent process in the application to the University of Manitoba Bannatyne Campus Research Ethics Board. Unfortunately, none of the residents enrolled in Music and Memory™ were identified as being potentially capable of providing consent, and were not approached.

Although we were unable to conduct our inter-rater reliability study, it is important to emphasize that these obstacles should not deter researchers from pursuing this important subject. The two quotes below express the opinion of many dementia researchers.

"the importance of providing opportunities for people who are most often disregarded for inclusion in research, whose 'voice' is seldom heard, and who are least likely to benefit from more standard forms of care home entertainments and activities, cannot be overstated. And there is no better opportunity than in a study such as this, where there is virtually no risk of harm and every possibility of benefit for those who take part" (Garabedian, 2014).

"The move to person-centered care has resulted in growing acknowledgment that people with dementia have rights, including the rights for their experiences to be explored through research" (McKeown, 2010).

The consent process we developed is described below.

Consent Process:

Residents enrolled in Music and Memory™ who potentially have capacity to consent will be identified by Misericordia Health Centre Unit Managers. A package with letters and the consent form will be sent to these residents requesting their participation, with a copy sent to their family or substitute decision makers.

Residents will be contacted in person by the study coordinator to find out if they are potentially interested and would like to set-up a meeting. The study coordinator will set-up a meeting with the resident, a Misericordia Health Centre social worker, family member or substitute decision-maker. At the meeting, the study coordinator will explain the study in plain language. They will ask the resident whether they would like time to consider their decision and if necessary, leave a copy of the letter to participants and the consent form. If residents are ready to consider consent at that time, their capacity to consent will be assessed by their responses to open-ended questions determining: their understanding of what will be asked of them during the study; whether they understand that they are not required to participate in the study

to receive Music and Memory ™: and whether they understand that their care will be not be affected if they choose not to participate.

Consent Process

Resident Name:		**Unit:**
Visit dates:		
Meeting dates:		
Meeting participants:		
Questions:	Possible responses (do not supply answer)	Resident response
Why do you think we're doing this research project?	• To test a checklist • To learn more how Music and Memory affects those who take part	
What will happen with your Music and Memory™ sessions if you don't want to be in the study?	• Won't change • Nothing will happen	
What will happen with your care at Misericordia Health Centre if you don't want to be in the study?	• Won't change • Nothing will happen	
If you change your mind about being in the research project, what can you do?	• Tell the person doing Music and Memory, family member or substitute decision maker.	

Observational Checklist Data

We analyzed the data collected by the Observational Checklists from December to April 2016 from residents who had more than one Music and Memory™ session. Although we were unable to investigate whether the Observational Checklist has inter-rater reliability, we decided to look at the data collected during the time we had originally designated for our research project. We are unable to share specific results due to our inability to obtain consent from residents.

We also examined comments captured in the Observational Checklist. We found some interesting patterns in the data and the comments. However, more data, preferably from a validated version of the Checklist, should be collected before meaningful conclusions can be drawn.

Participating in Music and Memory™ may reduce some responsive behaviours, and stimulate positive behaviours. Many positive responses were observed. Many of these positive responses are communicative, and support the theory that music can be an alternate way of communicating and maintaining relationships with others.

The observed positive responses suggest that participants' quality of life may be improved during and immediately after the Music and Memory™ sessions.

We were also pleasantly surprised to observe many expressions of gratitude during the Music and Memory™ session and immediately post-session. For those whose opportunities for enjoyment are limited, this seems significant. It also suggests that participants were grateful to have the opportunity for personal interaction the sessions provided.

Although the Observational Checklist documents only one specific behaviour related to reminiscing: requesting songs, several incidents of participants requesting songs were recorded.

Many residents actively participated in the sessions and sang along to the music.

Many of the memories elicited emotional responses such as crying and laughter. More incidents of laughter were reported than crying. However, the emotions of sadness and happiness, and their observable reactions of crying or laughter are sometimes inextricably linked.

These are preliminary findings but suggest that a validated checklist could be a useful tool for evaluating Music and Memory™ programs.

Observer Interviews

Semi-structured Interviews were conducted with six Music and Memory™ facilitators who used the Observational Checklist. These were recorded and transcribed.

1. Did you feel comfortable using the tool during the Music and Memory™ Session?

All interviewees found the tool easy to use and felt comfortable using it. Other comments made were that it was straightforward, clearly laid out and comprehensive.

2. Did it enhance or interfere with the Music and Memory™ session?

Five out of six interviewees reported that they preferred to use the tool following the session and one specifically commented that they felt it made the resident uncomfortable. Another felt it took the focus off the resident if it was filled out during the session. However, the interviewee who used it during the session reported that the resident was simply curious about what they were filling out. One interviewee commented that she felt that a difficulty of filling it out after the session was that she might forget some of the residents' responses, and in the future she would fill out the Checklist immediately following the session.

3. Did the tool record most of the responses you observed during the Music and Memory™ session?

All interviewees reported that the tool recorded most responses. All reported that they felt having a "Comments" section was important. They used this section to record what people said during the session, to record memories or stories that emerged during the session.

4. What would you change, if anything, about the tool?

Two interviewees thought a section for songs requested would be useful.

Two interviewees reported that they felt that the post-session section was not useful, because they often left the resident immediately following the session.

Two interviewees commented again that they felt the tool was easy to use, foolproof, and they liked using it.

Discussion

Misericordia Health Centre Music and Memory facilitators found the Observational Checklist to be an easy-to use tool for gathering responses.

Most felt more comfortable filling out the tool after the session because they felt it took away from the resident's experience. In a trade-off between data accuracy and resident experience, it was felt that the resident's experience should take precedence. Facilitators can decide whether to fill out the Checklist during the session or immediately afterward.

Although some of the interviewees felt the "Immediately Post-Session" section of the Checklist was redundant, once the data was reviewed, it was determined that this information was useful.

We modified the Observational Checklist to include "songs requested" in the Comments section at the bottom of the page.

The Observational Checklist is now an official Misericordia Health Centre form.

Conclusion

Individualized music listening opportunities for people with dementia appear to be a powerful person-centred intervention.

As LTC providers and researchers continue to explore the potential of this intervention, the need to gather qualitative and quantitative data on its effectiveness is crucial.

Our project was a beginning step to evaluate the Music and Memory™ program implemented at Misericordia Health Centre.

Although we were unable to determine inter-rater reliability of the Observational Checklist, Recreation Services will be using the tool to gather quantitative data on responses during Music and Memory™ sessions. This data will provide Misericordia Health Centre staff and administrators with a better picture of how residents, patients and clients benefit from Music and Memory™. As an easy-to-use tool, the Observational Checklist also has the potential for use by families and other visitors.

We hope this document will be a useful starting point or guide to your exploration of music and memory.

Appendix

Research Project Protocol

Research question:

Will an observational tool to record responses during an individualized music session (Music and Memory ™) have reliability among a diverse group of raters, including staff, volunteers, and Music and Memory™ facilitators?

Background information and literature review:

In 2012, the Manager of Recreation Services at MHC applied to the MHC Foundation Life Enrichment Program for funds to support a pilot of the Music and Memory™ Program (https://musicandmemory.org/). Music and Memory™ was introduced in New York by Social Worker Dan Cohen. Looking for a personalized intervention that would suit the needs of people with dementia residing in a long term care facility, he decided to try using iPods loaded with music identified as meaningful to the individual.

The Music and Memory™ Project at Misericordia Health Centre is coordinated by the Recreation Department. Trained paid facilitators work with residents from Misericordia Health Centre Interim Care Unit or Misericordia Place personal care home, compiling individualized playlists for the resident. They are present with them while they listen to their music, and take narrative notes on their responses to the music during the sessions. Some staff and volunteers have also been trained to conduct Music and Memory™ sessions. Music and Memory™ training consists of a minimum of 3 2-hour long sessions.

To maintain funding and to create more opportunities for more residents to participate in Music and Memory ™, the Recreation Department would like to undergo an evaluation of the program. In order to consistently and efficiently document responses to the music, one component of an evaluation would be the adoption of an easy-to-use checklist. This checklist would provide data on the effect of the music on residents. Although considerable literature on the effect of music on outcomes among institutionalized elderly with cognitive challenges (decreased depression, anxiety, and agitation) exists (Gerdner, 2000; Sung & Chang, 2010 ;), trained professional staff must be available to document changes in mental health status in standardized instruments. Ideally, a tool that could be used by students, volunteers, or family members/substitute decision makers would provide useful data for undergoing an evaluation of the program, as well as expanding the program's scope.

In consultation with the Head of Recreation Services at MHC; the MHC Clinical Nurse Specialist, Music and Memory ™ facilitators at Misericordia Health Centre, University of Manitoba PHD candidate Linda Wolfe, and MHC long term care managers, a checklist of observable behaviours before, during and after Music and Memory™ was developed in Winter/Spring 2015. This pilot study will investigate the suitability of the checklist to be used by Music and Memory ™ facilitators, as well as Misericordia Health Centre staff and volunteers, by testing the checklist's inter-rater reliability. Focus groups and interviews will also be conducted with observers/raters to gather additional data on its usability.

Gerdner, L.A. (2000). Effects of individualized versus classical 'relaxation' music on the frequency of agitation in elderly persons with Alzheimer's disease and related disorders. *International Psychogeriatrics, 12*(1), 49–65.

Sung, H.C., Chang, A.M., & Lee, W.L. (2010). A preferred music listening intervention to reduce anxiety in older adults with dementia in nursing homes. *Journal of Clinical Nursing 19*(7-8), 1056–1064.

Study design:

Two observers/raters will independently and without consultation with one another, record responses using the observation tool during a Music and Memory™ session with long-term care residents. Observers will remain as unobtrusive as possible during the session.

Up to twenty sessions will be observed using different combinations of types of observers/raters. The observation tool records resident's responses before, during and immediately after the music session. Percent agreement between observers will be measured. Basic demographic information for observers (type of observer; training in Music and Memory™; highest level of education) will be gathered.

Focus groups or individual interviews, depending on the availability of the participants, will be conducted no longer than one month following the completion of the session. These interviews will provide more information on the usability of the tool. Interviews or focus groups will be audio recorded. Only observers/raters will participate in the focus groups or interviews. A list of predetermined questions will guide the interviews or focus groups.

Research Methods:

Subject selection and inclusion criteria:

Residents of Misericordia Health Centre Long Term Care Program enrolled in the Music and Memory ™ program will be recruited to be observed. The Music and Memory ™ program currently has 17 participants.

Misericordia Health Centre staff and volunteers trained in Music and Memory ™ and in Music and Memory ™ facilitators will be recruited to be observers.

Recruitment:

The Principal Investigator and Co-Investigator will present an information session on the study at a Misericordia Health Centre Long-Term Care Program Family Night. The presentation will include the objectives of the study; how the study will be carried out; and emphasize that study participation is voluntary and will not affect the quality of residents' care. The Principal Investigator and Co-Investigator will also present a similar information session at Misericordia Health Centre Long-Term Care staff meetings.

Misericordia Health Centre staff will distribute a package to residents and their family members or substitute decision currently participating in the Music and Memory ™ program. The package will include: a letter explaining the research study and asking for their voluntary participation, and consent forms. Should fewer than five residents be recruited, a follow-up letter will be distributed to residents and their families.

The Study Coordinator will distribute packages to Misericordia Health Centre staff and volunteers trained in Music and Memory ™ and to Music and Memory ™ facilitators containing: a letter explaining the research study and asking for their voluntary participation; and consent forms.

Observers/raters who indicate interest in participating in a focus group or interview will be contacted for a follow-up interview or participation in a focus group.

Data collection:

Up to twenty sessions will be observed using different combinations of types of observers, depending on the success of recruitment of observed and observers.

Two observers/raters will independently and without consultation with each other, record observations using the checklist during an individualized music session with long-term care residents. Basic information for observers (type of observer; training in Music and Memory; highest level of education) will be gathered.

Less than a month following the rating sessions, raters will be interviewed individually or in a focus group to gather their experiences with using the tool. These interviews will provide more information on the suitability of the tool. Interviews or focus groups will be audio recorded. No identifying personal information will be recorded. Basic information for observers (type of observer; training in Music and Memory; highest level of education) will be documented on the sound recordings.

Residents and or their families or substitute decision makers will not participate in interviews or focus groups.

Data analysis:

Percent agreement between observers will be calculated. Percent agreement among and between types of raters will also be analyzed.

Focus groups or interviews will be transcribed and a thematic content analysis of qualitative responses will be performed.

Time frame: September 2015 – August 2016.

Protection of human rights/consent/privacy:

University of Manitoba Bannatyne Campus Ethics Board approval is being sought. Areas covered by this include:

Consent:

Participants in the study may have dementia. If so, family members or designated decision maker will give consent on behalf of the resident. According to Manitoba laws, substitute decision makers are only permitted to enroll a person for whom they have decision making powers in a research project, only if the participant signed a Health Care Directive permitting the substitute decision maker to enroll them in a research project. Because no potential participants have signed such a Health Care Directive, a modified consent process has been developed. Residents enrolled in Music and Memory who potentially have capacity to make decisions related to participating in research will be identified by Misericordia Health Centre Unit Mangers. A package with letters and the consent form will be sent to these residents requesting their participation, with a copy sent to their family or substitute decision makers.

Residents will be contacted in person by the study coordinator to find out if they are potentially interested and would like to set-up a meeting. The study coordinator will set-up a meeting with the resident, a Misericordia Health Centre social worker, family

member or substitute decision-maker. At the meeting, the study coordinator will explain the study in plain language. They will ask the resident whether they would like time to consider their decision and if necessary, leave a copy of the letter to participants and the consent form. If residents are ready to consider consent at that time, their capacity to consent will be assessed by their responses to open-ended questions determining: their understanding of what will be asked of them during the study; whether they understand that they are not required to participate in the study to receive Music and Memory ™: and whether they understand that their care will be not be affected if they choose not to participate.

If residents are able to demonstrate their understanding by providing correct responses to all four questions, they will be asked to fill out an informed consent form. If residents wish to take additional time to make a decision or to fill out the informed consent form, an additional meeting will be set-up with the above participants. Dates of these meetings, participants at the meetings, and responses to the questions will be documented on the *Assessment for Determining Capacity to Consent* form. During this process, forms will be stored in a locked cabinet in the Information Office at Misericordia Place and will be attached to the participant consent forms when the process is complete. If the resident does not demonstrate capacity, the Assessment forms will be destroyed.

The Assessment for Determining Capacity to Consent asks the following questions:

1. Why do you think we're doing this research project?
2. What will happen with your Music and Memory™ sessions if you don't want to be part of the study?
3. What will happen with your care at Misericordia Health Centre if you don't want to be in the study?
4. If you change your mind about being in the research project, what can you do?

All participants will be required to fill out informed consent forms and return in a sealed envelope to the Information office at Misericordia Health Centre where they will be put in a locked filing cabinet.

Informed consent forms will be kept in a sealed envelope in the Information Office at Misericordia Health Centre in a locked filing cabinet. Participants may contact the study coordinator for assistance or questions about the consent form.

Before the focus group or interview, participants will be asked to read a general description of the interview/focus group and asked to agree or not agree to give their informed consent to use their responses in our research study. Their names and all personal information will be excluded from any future items relating to this study.

No compensation will be offered to participants.

Assent:

For each session, residents will be asked by Music and Memory ™ facilitators whether they are interested in participating in a Music and Memory ™ session. This procedure is followed for each Music and Memory session. If they agree, they will then be asked by the facilitator if they agree to the session being observed for the study. If the resident declines, they will still receive their Music and Memory ™ session with the Music and Memory facilitator, but the session will not be included as part of the study.

Benefits and Harms:

Music can elicit powerful human emotions. Observers may be exposed to emotional responses elicited in residents. These may be potentially upsetting.

There may or may not be direct benefits to participants. We hope study results will benefit participants in the Music and Memory™ program in the future, and Misericordia Health Centre staff and decision makers.

Privacy and Confidentiality:

The observational tool will not contain resident names. No information will be collected on residents. The tool will code only Resident1, Resident2, etc.

Observers/raters will also be coded but not linked back to individual names, only to information such as Type of observer; level of education; and training in to Music and Memory ™.

Focus groups or interviews will be recorded on password protected devices. Recordings will be deleted once they are transcribed. No identifying information will be collected on transcriptions.

Significance and feasibility of the study:

This pilot study will potentially provide useful information on the reliability and usability of the observational tool to use in its development and improvement. If found reliable and usable, data gathered by the tool may potentially be used for seeking

funding or expansion of the program. If the tool is found to be reliable among a diverse group of observers, then more observers will be potentially available to participate in sessions.

Privacy and Confidentiality:

The observational tool will not contain resident names. No personal information will be collected on residents. The tool will code only Resident1, Resident2, etc. Observers will also be coded but not linked back to individual names, only to information such as Type of observer; level of education; training in Music and Memory™.

There will be no personal information collected other than the above (type of observer; level of education; training in Music and Memory™) for interviews or focus group participants.

Personal health information will not be collected. Observational data sheets will be locked on the unit or in a locked cabinet in the Principal Investigators locked office. Data from these sheets and from focus groups and interviews will be entered onto a password protected computer that will not be connected to a computer network or the internet. Data will be backed up onto a password protected hard drive. Focus groups or interviews will be stored on the Principal Investigator's password protected device. Transcriptions of these interviews will contain no identifying information.

Once all data has been entered in a computer spreadsheet with no identifying information, observational sheets will be shredded. Recordings of focus groups and interviews will be deleted once transcribed.

Conflict of Interest:

There are no conflicts of interest, personal or financial associated with this study.

References

Alive inside: Reprise. (2015). *Gerontologist, 55*(6), 1058-1059..

Alzheimers Canada (2016). *Culture change towards person-centred care*. http://www.alzheimer.ca/en/We-can-help/Resources/For-health-care-professionals/culture-change-towards-person-centred-care.

Alzheimers Canada (2014). *PC PEARLS*. http://www.alzheimer.ca/~/media/Files/national/Culture-change/PCPEARLS_5_e.pdf

Alzheimers Society Ontario (2014). *Examples of responsive behaviours*. http://www.alzheimer.ca/en/on/We-can-help/Resources/Shifting-Focus/Examples-of-responsive-behaviour.

Alzheimer Society Toronto. *Evaluation of the Alzheimer Society iPod Project Final report*. http://www.ryerson.ca/content/dam/crncc/knowledge/relatedreports/balancecare/EvaluationoftheAlzheimerSocietyTorontoIPodProject.pdf

Ashida, S. (2000). The effect of reminiscence music therapy sessions on changes in depressive symptoms in elderly persons with dementia. *Journal of Music Therapy, 37*(3), 170-182.

Baird, A., & Samson, S. (2015). *Music and dementia. Progress in Brain Research*.

Beer, L. E. (2016). The role of the music therapist in training caregivers of people who have advanced dementia. *Nordic Journal of Music Therapy*, 1-15.

Bravo, G., Dubois, M., Wildeman, S. M., Graham, J. E., Cohen, C. A., Painter, K., et al. (2010). Research with decisionally incapacitated older adults: Practices of canadian research ethics boards. *IRB Ethics and Human Research, 32*(6), 1-8.

Bravo, G., Wildeman, S., Dubois, M. -., Kim, S. Y., Cohen, C., Graham, J., et al. (2013). Substitute consent practices in the face of uncertainty: A survey of canadian researchers in aging. *International Psychogeriatrics, 25*(11), 1821-1830.

British Columbia. Ministry of Health (2012). *Best practice guideline for accommodating and managing behavioural and psychological symptoms of dementia in residential care: a person-centred interdisciplinary approach*. http://www.health.gov.bc.ca/library/publications/year/2012/bpsd-guideline.pdf.

Brotons, M., & Marti, P. (2003). Music therapy with alzheimer's patients and their family caregivers: A pilot project. *Journal of Music Therapy, 40*(2), 138-150.

Bumanis, A (2014). *Setting the record straight: what music therapy is and is not*. American Music Therapy Association.

http://www.musictherapy.org/atherapistmta_press_release_on_music_therapy_-_jan_2014/

Burack, O. R., Jefferson, P., & Libow, L. S. (2002). Individualized music: A route to improving the quality of life for long-term care residents. *Activities, Adaptation and Aging, 27*(1), 63-76.

Cacchione, P. Z. (2011). People with dementia: Capacity to consent to research participation. *Clinical Nursing Research, 20*(3), 223-227.

Garabedian, C.E. (2014). 'I'd rather have music!': the effects of live and recorded music for people with dementia living in care homes, and their carers. Thesis submitted for the degree of Doctor of Philosophy University of Stirling. http://dspace.stir.ac.uk/bitstream/1893/21757/3/POSTVIVA%20THESIS%2013%20FINAL%20May%202015.pdf

Canadian Institute for Health Information. (2013). *When a nursing home is home: how do Canadian nursing homes measure up to quality?* Ottawa: CIHI. https://secure.cihi.ca/free_products/CCRS_QualityinLongTermCare_EN.pdf.

Caltic A. (2015). Nonpharmacological management of behavioral and psychological symptoms of dementia in long-term care residents. *Annals of Long Term Care, 23*(11). http://www.annalsoflongtermcare.com/article/nonpharmacologic-management-behavioral-and-psychological-symptoms-dementia-long-term-care. Accessed June 15, 2016.

Center for Research on Aging and Health (201?). Quality Palliative Care in Long-Term Care Alliance. *Music interaction*. http://www.palliativealliance.ca/assets/files/Alliance_Reources/Psychosocial_Care/Music_Interaction_-_Final.pdf.

Chang, Y. , Chu, H., Yang, C., Tsai, J. , Chung, M. , Liao, Y. , Chou, K. (2015). The efficacy of music therapy for people with dementia: A meta-analysis of randomised controlled trials. *Journal of Clinical Nursing, 24*(23-24).

Clark, M. E., Lipe, A. W., & Bilbrey, M. (1998). Use of music to decrease aggressive behaviors in people with dementia. *Journal of Gerontological Nursing, 24*(7), 10-17.

Cohen-Mansfield, J., Dakheel-Ali, M., & Marx, M. S. (2009). Engagement in persons with dementia: The concept and its measurement. *American Journal of Geriatric Psychiatry, 17*(4), 299-307.

Cuddy, L. L., Sikka, R., & Vanstone, A. (2015). Preservation of musical memory and engagement in healthy aging and alzheimer's disease. *Annals of the New York Academy of Sciences, 1337*: 223-31.

DeLauro, R. (2013). Music and memory. elders with dementia find hope in a song. *Social Work Today, 13*(1), 18.

Dubois, M., Bravo, G., Graham, J., Wildeman, S., Cohen, C., Painter, K., et al. (2011). Comfort with proxy consent to research involving decisionally impaired older adults: Do type of proxy and risk-benefit profile matter? *International Psychogeriatrics, 23*(9), 1479-1488.

Ellis, D. A. (2015). Life regained: An interview with Michael Rossato-Bennett on alive inside (2014). *Film International, 12*(4), 123-126.

Fu, M., Lin, S., & Belza, B. (2012). Music to heal by. *Journal of Gerontological Nursing, 38*(8), 3-4.

Gallagher, M. (2011). Evaluating a protocol to train hospice staff in administering individualized music. *International Journal of Palliative Nursing, 17*(4), 195-201.

Gerdner, L. A. (2005). Use of individualized music by trained staff and family: Translating research into practice. *Journal of Gerontological Nursing, 31*(6), 22-30; quiz 55-56.

Gerdner, L. A. (2015). Ethnicity is an inherent criterion for assessment of individualized music for persons with Alzheimer's disease. *Clinical Gerontologist, 38*(2), 179-186.

Gerdner, L. A. (2010). Individualized music for elders with dementia. *Journal of Gerontological Nursing, 36*(6), 7-9.

Gerdner, L. A., Raglio, A., Filippi, S., Bellandi, D., & Stramba-Badiale, M. (2014). Effects of individualized versus classical "relaxation" music on the frequency of agitation in elderly persons with alzheimer's disease and related disorders. *International Psychogeriatrics, 12*; 9(1), 49; 1669-65; 1676.

Gold, K. (2014). But does it do any good? measuring the impact of music therapy on people with advanced dementia: (innovative practice). *Dementia, 13*(2), 258-264.

Health Care Directives Act, 1992, CCSM, CH27. https://web2.gov.mb.ca/laws/statutes/ccsm/h027e.php

Holmes, C., Knights, A., Dean, C., Hodkinson, S., & Hopkins, V. (2006). Keep music live: Music and the alleviation of apathy in dementia subjects. *International Psychogeriatrics, 18*(4), 623-630.

Hsu, M. H., Flowerdew, R., Parker, M., Fachner, J., & Odell-Miller, H. (2015). Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: A cluster randomised controlled feasibility study. BMC Geriatrics, 15-84. https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-015-0082-4

Jones, C., Sung, B., & Moyle, W. (2015). Assessing engagement in people with dementia: A new approach to assessment using video analysis. *Archives of Psychiatric Nursing, 29*(6), 377-382.

Kinney, J. M., & Rentz, C. A. (2005). Observed well-being among individuals with dementia: Memories in the making©, an art program, versus other structured activity. *American Journal of Alzheimer's Disease and Other Dementias, 20*(4), 220-227.

Kolanowski, A., & Buettner, L. (2008). Prescribing activities that engage passive residents: An innovative method. *Journal of Gerontological Nursing, 34*(1), 13-18.

Lawton, M. P. (1997). Assessing quality of life in alzheimer disease research. *Alzheimer Disease and Associated Disorders, 11(*SUPPL. 6), 91-99.

Lewis, V., Bauer, M., Winbolt, M., Chenco, C., & Hanley, F. (2015). A study of the effectiveness of MP3 players to support family carers of people living with dementia at home. *International Psychogeriatrics, 27*(3), 471-479.

Li, Y., Chen, S., Chou, M., & Huang, T. (2014). The use of music intervention in nursing practice for elderly dementia patients: A systematic review. *Journal of Nursing, 61*(2), 84-94.

Manitoba (2014). Manitoba's framework for Alzheimer's disease and other dementias. https://www.gov.mb.ca/health/documents/alzframework.pdf

Manitoba Bureau of Statistics (2016). Incidence of dementia in Manitoba: 2012-2048. http://www.gov.mb.ca/mbs/reports/pubs/demographic_impacts_2015/mbs_demo_impact_2015_c6_dementia.pdf.

https://web2.gov.mb.ca/laws/statutes/ccsm/h027e.php

Matthews, S. (2015). Dementia and the power of music therapy. *Bioethics, 29*(8), 573-579. doi:10.1111/bioe.12148

McDermott, O., Crellin, N., Ridder, H. M., & Orrell, M. (2013). Music therapy in dementia: A narrative synthesis systematic review. *International Journal of Geriatric Psychiatry, 28*(8), 781-794.

McDermott, O., Orrell, M., & Ridder, H. M. (2014). The importance of music for people with dementia: The perspectives of people with dementia, family carers, staff and music therapists. *Aging and Mental Health, 18*(6), 706-716.

McDermott, O., Orrell, M., & Ridder, H. M. (2015). The development of music in dementia assessment scales (MiDAS). *Nordic Journal of Music Therapy, 24*(3), 232-251.

McDermott, O., Orgeta, V., Ridder, H. M., & Orrell, M. (2014). A preliminary psychometric evaluation of music in dementia assessment scales (MiDAS). *International Psychogeriatrics, 26*(6), 1011-1019.

McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of clinical nursing,19*(13-14), 1935-1943.

Petrovsky, D., Cacchione, P. Z., & George, M. (2015). Review of the effect of music interventions on symptoms of anxiety and depression in older adults with mild dementia. *International Psychogeriatrics, 27*(10):1661-1670.

Raglio, A. (2012). Music therapy in dementia. *Dementia: Non-pharmacological therapies* (pp. 1-14). https://www.novapublishers.com/catalog/product_info.php?products_id=18952

Raglio, A., Bellandi, D., Baiardi, P., Gianotti, M., Ubezio, M. C., & Granieri, E. (2013). Listening to music and active music therapy in behavioral disturbances in dementia: A crossover study. *Journal of the American Geriatrics Society, 61*(4), 645-647.

Raglio, A., Bellandi, D., Baiardi, P., Gianotti, M., Ubezio, M. C., Zanacchi, E., et al. (2015). Effect of active music therapy and individualized listening to music on dementia: A multicenter randomized controlled trial. *Journal of the American Geriatrics Society, 63*(8), 1534-1539.

Raglio, A., Bellelli, G., Mazzola, P., Bellandi, D., Giovagnoli, A. R., Farina, E., et al. (2012). Music, music therapy and dementia: A review of literature and the recommendations of the italian psychogeriatric association. *Maturitas, 72*(4), 305-310.

Raglio, A., Filippi, S., Bellandi, D., & Stramba-Badiale, M. (2014). Global music approach to persons with dementia: Evidence and practice. *Clinical Interventions in Aging, 9*, 1669-1676.

Raglio, A., Fonte, C., Reani, P., Varalta, V., Bellandi, D., & Smania, N. (2016). Active music therapy for persons with dementia and their family caregivers. *International Journal of Geriatric Psychiatry, Jan 14.*

Raglio, A., & Gianelli, M. V. (2009). Music therapy for individuals with dementia: Areas of interventions and research perspectives. *Current Alzheimer Research, 6*(3), 293-301.

Ragneskog, H., Asplund, K., Kihlgren, M., & Norberg, A. (2001). Individualized music played for agitated patients with dementia: Analysis of video-recorded sessions. *International Journal of Nursing Practice, 7*(3), 146-155.

Sakamoto, M., Ando, H., & Tsutou, A. (2013). Comparing the effects of different individualized music interventions for elderly individuals with severe dementia. *International Psychogeriatrics, 25*(5), 775-784.

Samson, S., Clément, S., Narme, P., Schiaratura, L., & Ehrlé, N. (2015). Efficacy of musical interventions in dementia: Methodological requirements of

nonpharmacological trials. *Annals of the New York Academy of Sciences, 1337*:249-255.

Sánchez, A., Maseda, A., Marante-Moar, M. P., De Labra, C., Lorenzo-López, L., & Millán-Calenti, J. C. (2016). Comparing the effects of multisensory stimulation and individualized music sessions on elderly people with severe dementia: A randomized controlled trial. *Journal of Alzheimer's Disease, 52*(1), 303-315.

Sapra, M., DeYoung, N., Kim, Y.K (2014). Apathy in dementia pg. 47-58. IN Tanner, P. *Dementia: Prevalence, risk factors and management strategies*. Nova Science Publishers.

Särkämö, T., Laitinen, S., Numminen, A., Kurki, M., Johnson, J. K., & Rantanen, P. (2016). Pattern of emotional benefits induced by regular singing and music listening in dementia. *Journal of the American Geriatrics Society, 64*(2), 439-440.

Skrivervik, E., Buettner, L. L., & Testad, I. (2012). Care staff experiences of facilitating person-centered care and resident involvement through the use of individualized music in dementia care. *Activities Directors' Quarterly for Alzheimer's and Other Dementia Patients, 13*(4), 33-46.

Slaughter, S., Cole, D., Jennings, E., & Reimer, M. A. (2007). Consent and assent to participate in research from people with dementia. *Nursing Ethics, 14*(1), 27-40.

Sung, H., Chang, A. M., & Abbey, J. (2008). An implementation programme to improve nursing home staff's knowledge of and adherence to an individualized music protocol. *Journal of Clinical Nursing, 17*(19), 2573-2579.

Sung, H., Lee, W., Chang, S., & Smith, G. D. (2011). Exploring nursing staff's attitudes and use of music for older people with dementia in long-term care facilities. *Journal of Clinical Nursing, 20*(11-12), 1776-1783.

Testad, I., Corbett, A., Aarsland, D., Lexow, K. O., Fossey, J., Woods, B., et al. (2014). The value of personalized psychosocial interventions to address behavioral and psychological symptoms in people with dementia living in care home settings: A systematic review. *International Psychogeriatrics, 26*(7), 1083-1098.

Ueda, T., Suzukamo,, Y., Sato, M., Izumi, S. (2013). Effects of music therapy on behavioral and psychological symptoms of dementia: a systematic review and meta-analysis. *Ageing Research Review, 12*(2):628-41.

Van Haitsma, K. et. al. (2016). Honoring nursing home resident preferences for recreational activities to support person-centered care. *Annals of Long-Term Care: Clinical Care and Aging, 16;*24 (2):25-33. http://www.annalsoflongtermcare.com/article/honoring-nursing-home-resident-preferences-recreational-activities-advance-person-centered#sthash.6qTAGYkz.dpuf

Vanstone, A. D., Wolf, M., Poon, T., & Cuddy, L. L. (2015). Measuring engagement with music: Development of an informant-report questionnaire. *Aging and Mental Health, 20*(5): 474-8.

Vasionyte, I., & Madison, G. (2013). Musical intervention for patients with dementia: A meta-analysis. *Journal of Clinical Nursing, 22*(9-10), 1203-1216.

Vink, A. C., Birks, J. S., Bruinsma, M. S., & Scholten, R. J. (2004). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews (Online), (3*).

Vink, A. C., Zuidersma, M., Boersma, F., Jonge, P., Zuidema, S. U., & Slaets, J. P. J. (2013). The effect of music therapy compared with general recreational activities in reducing agitation in people with dementia: A randomised controlled trial. *International Journal of Geriatric Psychiatry, 28*(10), 1031-1038.

Wildeman, S., Dunn, L. B., & Onyemelukwe, C. (2013). Incapacity in canada: Review of laws and policies on research involving decisionally impaired adults. *American Journal of Geriatric Psychiatry, 21*(4), 314-325.

Williams, A.P., Pecham, A., Rudoler, D., Tam, T., & Watkins, J. (2014. Evaluation of the Alzheimer Society iPod Project: Final report. http://www.ryerson.ca/content/dam/crncc/knowledge/relatedreports/balancecare/EvaluationoftheAlzheimerSocietyTorontoIPodProject.pdf