

# The Soundtrack of Life: Developing, Implementing, and Sustaining Quality Personalized Music Listening Programs for Persons with Mid-Late Stage Dementia

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# Overview of Presentation

- Presenter introductions.
- Importance of quality music programs for persons living with dementia (PLWD).
- Music in LTC Contexts: Some facts, assumptions, & possibilities
- The Soundtrack of Life Pilot Project
  - Background
  - Process
  - Selected Results
- Potential Implications, Moving Forward, & Resources

# Presenter Introductions

- Wendy Foster
- Laurel Young
- How this all started?

# Why is today's topic important? (1)

- 46 million living with dementia worldwide.
- Predicted this number will double by 2030 & triple by 2050.
- Persons 65+ have a mean survival rate of 4-8 years after diagnosis—some live as long as 20 years.
- More years often spent in the most severe stage of the disease—on average, 40% of the total number of years.
- *Dementia is one of the biggest global public health and social care challenges facing people today and in the future.*

# Why is today's topic important? (2)

- While waiting for a cure, Alzheimer societies/dementia care strategy plans are focusing on risk reduction (brain health promotion) and improving QoL for PLWD & their loved ones.
- Alzheimer's Disease International and the WHO support “the realization of the full potential for living well with dementia” (2015 World Alzheimer Report).
- Today's focus: How music [listening] programs must be realized within a best practices framework.

# Why is music important? (1)

## Neuroscience research indicates that:

- Areas of the brain related to musical functioning are often fully/partially preserved in PLWD. Musical perception, sensibility, emotion, & memory may even be heightened after other forms of memory have disappeared.
- Procedural music memory often spared; new music learning can occur in musicians & non-musicians.
- **Hypotheses:**
  - The brain may have a memory system for music that is wholly/partially unaffected by most dementias which may be functionally & physiologically distinct from other domains.
  - Engaging PLWD in personalized music experiences that maintain/heighten preserved music functions is important because maintenance of musical health may be crucial in the realization of their full potential for living well.

# Why is music important? (2)

- For many PLWD, music can be a bridge through which they are able to connect with their environment, engage in relationships with others, and maintain connection with their sense of identity/self.

## Questions

- Is optimal musical health for PLWD being promoted through quality [recorded] music [listening] experiences that occur within a best practices framework?
- Are we using knowledge about music or preconceived notions/assumptions about music to guide music [listening] practices in dementia care?

# Music in Canadian Long Term Care Contexts

- **Survey of directors 50 Canadian LTC homes** (Foster & Bartell, 2016)
  - All felt that music was beneficial for residents BUT had different perceptions of how it was beneficial.
  - Only 24% believed that music could have adverse affects.
  - Found incongruence among facilities with regard to type, consistency, and quality of music services being offered.
  - Leadership & staff participants had limited knowledge as to what a full scope of “music care practices” could involve (i.e., beyond listening to recorded music and entertainment).
- **Strengthening Palliative Approaches in LTC** (Kaasalainen, Sussman et al.)
  - Focus groups & interviews: Residents, family, staff members of 4 LTC sites (ON).
  - Reviewed references to music in staff interview transcripts.
  - Music perceived positively. Different/no perspectives offered on why music might be used for PLWD who are in the final stages of life.
  - Some expressed uncertainty about choosing/using recorded music.

# Music in Canadian Long Term Care Contexts

- **1975: Music therapy established as a profession in Canada.**
  - Long history of music therapists working in dementia care.
  - 520+ Accredited Music Therapists (MTAs)—many work in LTC; unable to realize full scope of practice.
  - Lack of integration of music practices (MT/other music practices) into the interprofessional care plans of PLWD (Young, 2013; Foster & Bartell, 2016).
- **Music and Memory©**
  - 259 Canadian organizations & LTC facilities certified (17? in Quebec).
  - From website: Training includes three 90-minute webinars on *“best practices for how to set up a system for providing a personalized playlist for those in your care.”*

# Deconstructing Henry



(“Alive Inside” <http://www.youtube.com/watch?v=NKDXuCE7LeQ>)

# Points to Consider

- Clip speaks to the power of music to potentially reach PLWD.
- Appears that the “right music” was chosen for Henry. What was he listening to?
- Religious music? Cab Calloway? Never recorded: “I’ll be home for Christmas.”
- Sacks: *“Music brings people who are out of it, back into it.”* When did Henry exhibit the most obvious signs that he was alert and/or expressing himself?
- During iPod music: Animated facial expression, vocalizing, moving arms.
- After iPod music: Responded verbally after being prompted by a question. Sustained conversation. Twice, he initiated a new musical response (singing song lyrics).
- Do the above points really matter? Henry had a positive response— isn’t that enough?

# Other Information to Consider

- Documentary only features positive responses. Not a complete picture upon which to base a model of best practices.
- Scientific evidence cited to support effectiveness of personalized music listening programs delivered via an iPod being applied out of context.
- Neuroscience/music medicine researchers indicate: For PLWD, music can also irritate, escalate negative behaviours, evoke feelings of sadness/ loneliness/anxiety, &/or elicit involuntary responses. Ability to control the sound source also key (Freedman, 2014; Hallam, 2012; Swayne, 2014; Foster & Bartell, 2016; Young, 2013).
- Persons with frontal temporal lobe dementia can experience changes in their music preferences (Geroldi et al., 2000; Mell, Howard, & Miller, 2003; Ridder & Aldridge, 2005).
- Hearing impairments can distort the way that music is processed & heard. 2/3 adults 70+; may even be a predictor of dementia (Lin et al., 2013).

# In summary, we know that...

- ...music functions of the brain often remain intact for many PLWD up to and including the final stages of their disease. This could have implications for how music is used and perceived in dementia care contexts.
- ...personalized music listening programs may be one way in which some PLWD can experience improved quality of life.
- ...there is potential for well-intentioned misapplications of music due to lack of knowledge or assumptions.

*We need more knowledge about the use of personalized listening devices with PLWD so that we can establish sustainable best practice frameworks for music listening programs.*

# The Soundtrack of Life Pilot Project: Examining iPod-Based Personalized Music Listening Programs for Residents Living with Dementia

- Pilot Project supported by the Innovative Practice Development Fund: CSSS Cavendish
- **Co-investigators:** Laurel Young & Wendy Foster
- **Purpose:** Gather information to initiate development of a best practices framework for music listening programs for PLWD in long term care
- **Research Question:** How do individuals with mid to late stage dementia respond to personalized music listening programs delivered via an iPod?

# Method (1)

## Participants

- 3 females, 1 male; ages 70 to 98
- Non-ambulatory, little to no verbal functioning, mid-late stage dementia
- No apparent hearing loss, under stimulated

## Preparation

- Music Therapist (MTA) Research Assistant (RA) conducted a Music Preference Questionnaire with SDMs.
- Based on this info. as well as age & cultural background, created a music listening assessment program for each participant.
- Individualized music listening assessment protocol played for each participant using a CD player. Visible responses noted. Receptivity to ear buds/headphones assessed.
- Two 10-minute personalized music programs compiled for each participant (1 upbeat, 1 low key) & loaded onto an iPod Nano.

# Method (2)

- Each participant had two personalized music listening sessions (one upbeat (morning), one low key (afternoon) delivered via an iPod).

## CAVEAT

- Participants video recorded for: 5 minutes before music listening, 10-minutes of music listening, & 5 minutes after music listening.
- Two RAs independently recorded descriptive observations & completed the Observed Emotion Rating Scale (**OERS**) for each phase (before, during after). Good inter-rater reliability.
- The **OERS** scores along with qualitative descriptive data presented for each case.
- Quantitative data combined to look for trends among participants' **OERS** scores.
- Common/contrasting qualitative themes compiled for group.

# iPod Listening Session Clips

*Centre intégré  
universitaire de santé  
et de services sociaux  
du Centre-Ouest-  
de-l'île-de-Montréal*

Québec 



Centre de recherche et d'expertise  
en gérontologie sociale

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# Descriptive Observations

- **Pre-listening:**
  - Does not seem engaged with surroundings. Some unintelligible speech. Startled when MTA-RA approaches, then withdraws.
- **During upbeat music listening:**
  - Feet move in response to music. Whole body moves at one point. Unintelligible speech.
- **After listening:**
  - As headphones are removed, participant attempts to interact verbally with the MTA-RA. Speech intelligible.
  - MTA-RA does not build upon the response. Participant lifts hand and head up – says “You want me to cook? What do you want to eat?”
  - MTA-RA continues with only necessary interaction. Participant withdraws.

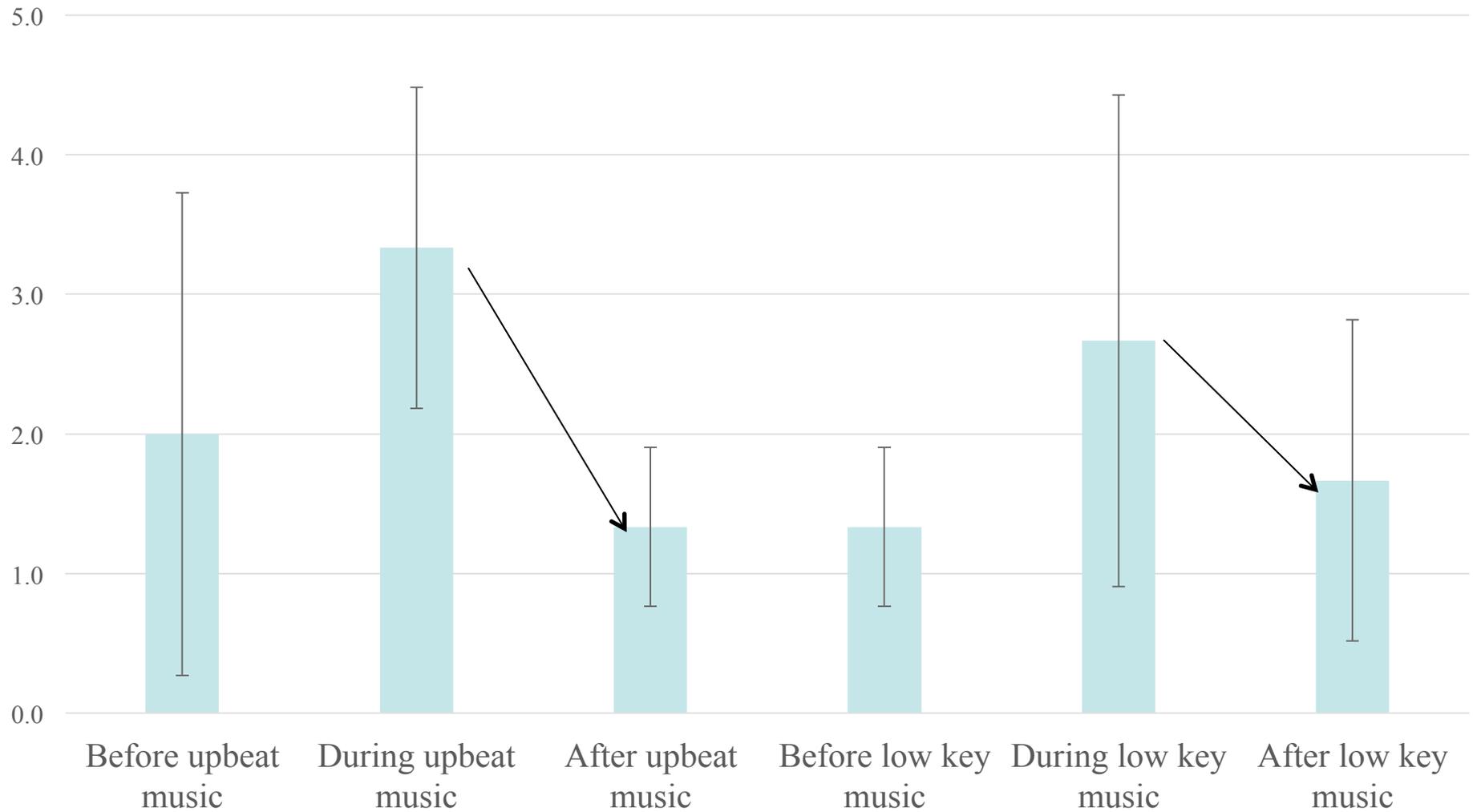
OERS	Before Upbeat Music	During Upbeat Music	After Upbeat Music	Before Low Key Music	During Low Key Music	After Low Key Music
Participant 3						
Pleasure	1	4	1	1	4.5	3
Anger	1	1	1	1	1	1
Anxiety/Fear	2	2.5	1.5	2	2	1
Sadness	1	1	1	1.5	1	1
General Alertness	3.5	2.5	4	3.5	4	3.5

1=never; 2 = less than 16 secs; 3 = 16-59 secs; 4 = 1-5 mins; 5 = 5+ minutes

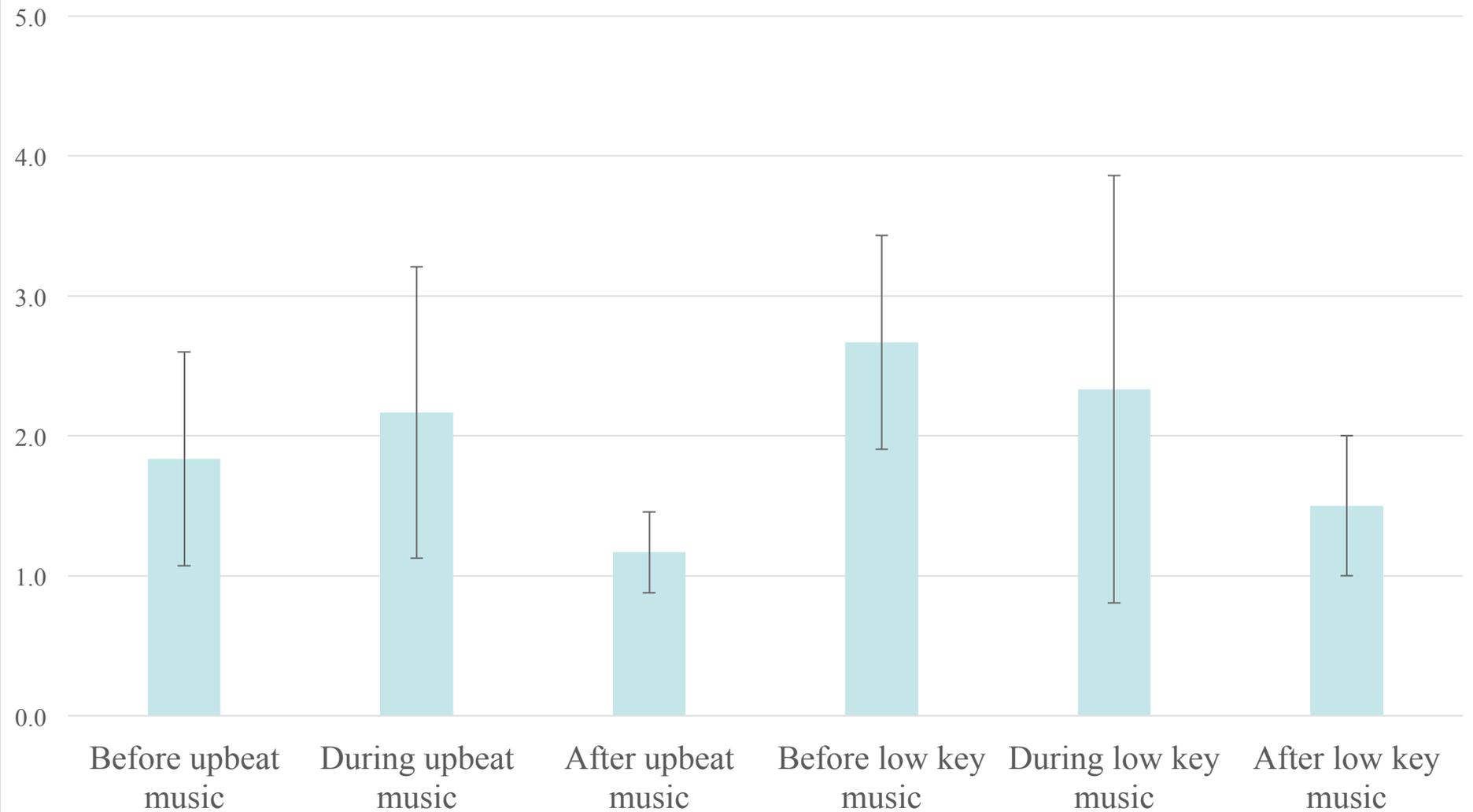
# Other Selected Group Results

- Pilot study had limitations so results must be interpreted with caution. However, they do yield interesting information that warrants follow up.
- No statistically significant differences in mean (average) OERS scores (all 5 areas) before, during, or after music. No statistically significant difference between mean OERS scores in the upbeat music listening condition versus the low key music listening condition.
- However, a trend analysis (used for small sample sizes), yielded some interesting tendencies in the data.

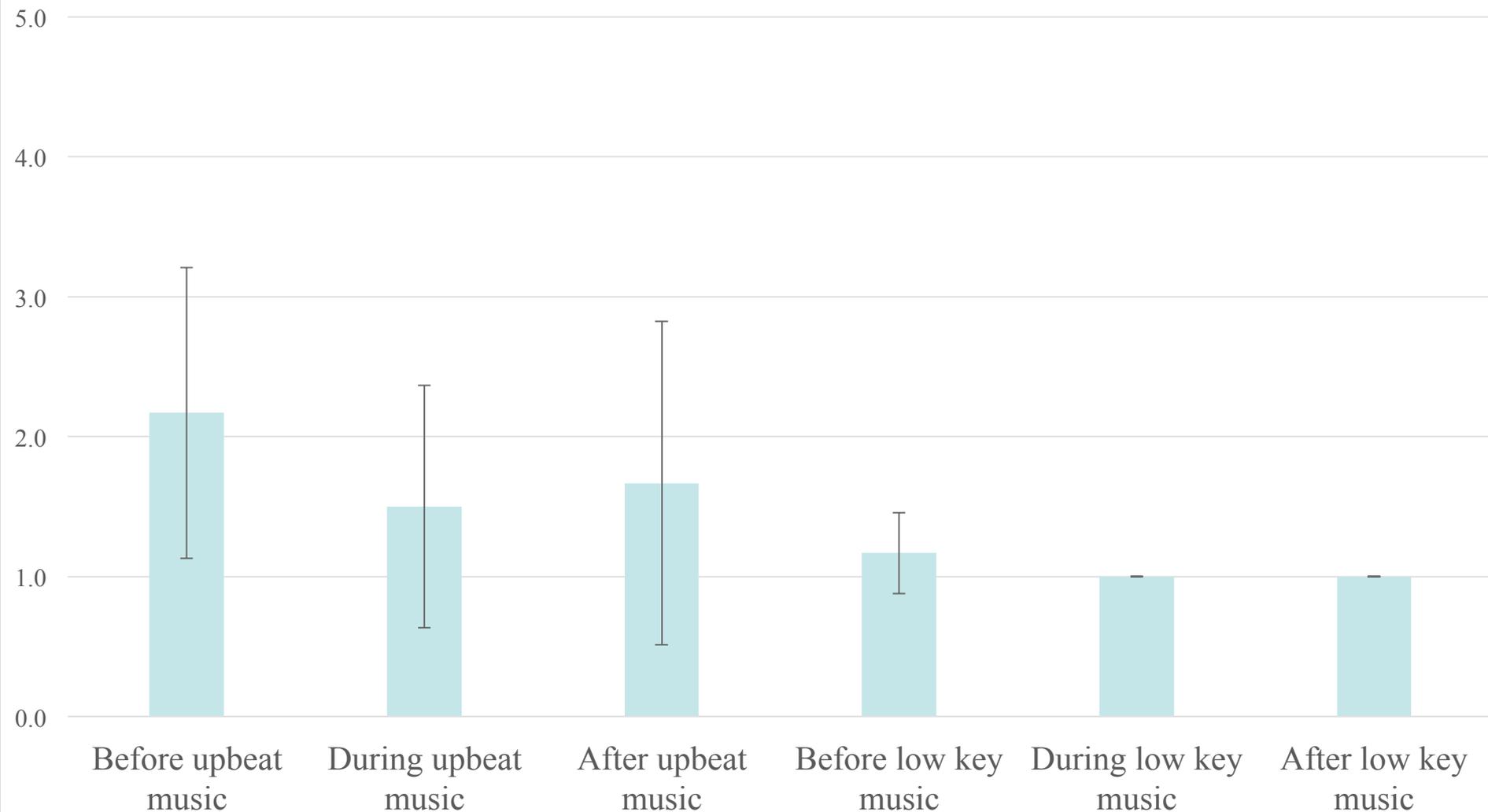
# Means for Pleasure



# Means for Anxiety/Fear



# Means for Sadness



# Other Results/Observations

- Signs of anger not observed so no statistical analysis performed.
- Combined, general alertness group scores remained relatively stable within each music condition & did not vary between music conditions. However, the standard deviation statistics indicate individual variability in this area.
- All participants exhibited responses to the music (vocal, verbal, physical, emotional, etc.). Some responses indicated engagement with the music; some responses may have been involuntary.
- Some incongruence in observed responses to music (e.g., singing along with a furrowed brow). Difficult to interpret.
- Issues with iPod Nano & headphone wires.
- Participants often tried to initiate interaction with the MTA-RA (during/after music). Withdrew when [what appeared to be] their desire for interaction was not fulfilled.

# Potential Implications

- Use of preferred music is important but structural elements of the music may also be important to consider when compiling & choosing personalized music listening programs (e.g., some different responses to upbeat preferred versus low key preferred music).
- The personalized music program chosen should consider the individual's needs at that particular time (e.g., sun downing). There needs to be a selection of personalized programs from which to choose.
- Personalized music listening may serve as a primer for meaningful interaction with others (during and/or immediately after music listening).
- Music listening may be more beneficial as a shared experience rather than a private one (e.g., free field listening). Regardless, the person should not be left unmonitored while listening to music.
- The less wires, the better.
- Ability to monitor & adjust the music as needed could greatly enhance the quality of the music listening experience, which in turn could maximize the benefits.

# Moving Forward

- Music technology offers expanded opportunities for use of music in dementia care. However, it must be used in knowledgeable ways in order for initiatives to be ethical, effective, and sustainable.
- Professional “music care” leadership, staff/volunteer training, clear (yet realistic) organization of initiatives, and accountability are needed.
- The importance and role of music in dementia care needs to be better understood & re-defined. “Buy in” from LTC staff, leadership, other stakeholders is key or best practice initiatives will not be sustainable.
- Personalized music listening devices (such as iPods) are not appropriate for every PLWD and are only the “tip of the iceberg” when it comes to what a full range of best music practices in dementia care could entail.

*As a society, we must do more than simply control or treat the textbook symptoms of dementia.*

*We have a moral obligation to support the unique identity that still exists within each person and to help them & their families to fulfill their full potential for living well in the face of this disease.*

*Provision of music services that are realized within a best practices framework is an integral part of this mission.*

# Information & Resources

- Clements-Cortes, A., Pearson, C., & Chang, K. (2015). Creating Effective Music Listening Opportunities. Toronto, Ontario: Baycrest.  
[www.baycrest.org/care/culture-arts-innovation/therapeutic-arts/music-therapy/creating-effective-music-listening-opportunities](http://www.baycrest.org/care/culture-arts-innovation/therapeutic-arts/music-therapy/creating-effective-music-listening-opportunities) (English & French)
- <http://www.musicotherapieaqm.org/media/2015/Appareils.pdf>
- <http://www.musicotherapieaqm.org/media/2015/Personallistening.pdf>
- [http://www.musicotherapieaqm.org/media/2015/Music\\_Therapy\\_For\\_Individuals\\_with\\_Alzheimerand\\_Other\\_Dementias.pdf](http://www.musicotherapieaqm.org/media/2015/Music_Therapy_For_Individuals_with_Alzheimerand_Other_Dementias.pdf)
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