

Moving to Breathe, Breathing to Move:

A study on the benefits of singing and dancing exercise programs for people with neuromuscular conditions.

Project Background

With support from a Muscular Dystrophy Canada seed grant and a grant from MITACS, we ran a 15-week singing and dancing program for adults with neuromuscular conditions. Both singing and dancing have been shown to improve physical health, mental health, breathing capacities, and quality of life for a range of people with and without disabilities.¹ These are also activities that can be adapted easily around each individual's abilities. Little was known about how these activities could be modified for, and used to support, people with neuromuscular conditions.

Project Description

We hired expert instructors to teach 90-minute singing and dancing programs once-per-week for 15 weeks. Adults with a range of neuromuscular conditions were recruited to participate through the MDC Edmonton Chapter, and two medical facilities. 9 people participated in some part of the program. Some of these opted out of the research measures, and others did not attend regularly, meaning we have limited data. Breathing tests, quality of life questionnaires, and qualitative interviews were completed before and after the program. During the program we used special vests (Hexoskins) to track breathing, asked people about how tired they felt, how we could improve the program, and we also made a video together, which can be found at: <http://www.mediainmotion.ca/projects/moving-to-breathe-breathing-to-move>

Results: Program Benefits and Risks

- **Breathing:** This program did not negatively affect anyone's breathing measures. One participant showed a clinically significant improvement in their breathing.²
- **Quality of Life:** Participants reported quality life improvements of between 9% & 19%.³ They reported that muscle weakness had 16-21% less negative impact on QOL. For one, swallowing had 26% less impact on QOL after the program. They also noted shifts in the impact of their condition on fatigue, pain, activities, relationships, and body image.
- **Participant Experiences:** All participants said the social connection was the most meaningful part of the program. In particular, they loved sharing experiences with others who had neuromuscular conditions. They wanted to grow the program to include youth.
- Participants said that their breathing muscles felt tired, especially after singing, and so we took regular breaks. All said this kind of tired felt pleasurable and safe, and they recovered easily. Three people said that learning new singing skills, and practicing them made their singing and speaking feel stronger.
- Equipment barriers made dancing feel more tiring and less independent for one person.

¹ Clark, I., & Harding, K. (2012). Psychosocial outcomes of active singing interventions for therapeutic purposes: a systematic review of the literature. *Nordic Journal of Music Therapy*, 21(1): 80-98; Clift, S. (2012). Creative arts as a public health resource: moving from practice-based research to evidence-based practice. *Perspectives in Public Health*, 132(3), 120-127; Graham, S. (2002). Dance: a transformative occupation. *Journal of Occupational Science*, 9(3), 128-134.

² This participant had baseline spirometry (FVC and FEV1) measures below 20% predicted. A minimal clinically important difference (MCID) in ventilation outcomes was established from previous literature on individuals with chronic obstructive pulmonary disease.

³ Based on standardized scores on the Individualized Neuromuscular Quality of Life Questionnaire 2.0

- Dancing helped some participants learn wheelchair skills, learn about how body language works with their mobility tool, and feel more connected to other people. For most, it felt like meaningful physical activity that was less tiring than singing.

Learnings About Running Singing and Dancing Programs

General:

- Singing and dancing could be run as separate programs, but our program worked best when alternating between the two every 20-30 minutes. Dancing helped rest breathing muscles but kept bodies warm, engaged, and active.
- Experienced instructors or facilitators who are skilled in adaptation is crucial.
- Timing and space: Late mornings enable many who get fatigued in afternoons, and support those with small children, but hard for those at work or at school. Continuing care facilities were more accessible for those living there, but represented a psychological barriers for those who feared this stage in their disease progression.
- Due to range of neuromuscular conditions, program should include adaptation for wheelchair accessibility, limited hand and arm motion, as well as vision and hearing impairments. microphones and large print documents are useful.
- Social connection, mutual learning, and NMD mentorship were most meaningful aspects for participants. This could be optimized by offering program across all ages.

Singing:

- Plan for breaks every 30 minutes, and use slower pace songs to offer breathing space.
- Large print, repetition, and use of familiar songs helps those with sensory impairments.
- Learning about singing technique may help support breath, speech, and swallowing.
- This program works best with at least 12 people, to support multi-part harmonies.

Dancing:

- improvisation may work better than choreography given range of impairments (ex. Playing with spatial relationships, shapes, timing, sensation, and connection).
- Descriptions of movement help for those with visual impairments.
- Can use to support mobility skills and body language.
- May help to partner with equipment provider, to try tools that offer more mobility.
- Crowded spaces can reduce movement possibilities for those using wheelchairs.

Authors

Peers, D., Jones, K., Richman--Eisenstat, J., Acharya, H., Eales, L., Toth, A., Acton, K.

Collaborators & Sponsors

Muscular Dystrophy Canada (Special thanks to Fraser Hall); Mitacs Accelerate Program; Capital Care Norwood; Alberta Health Services (Kaye Neuromuscular Clinic).

