Evaluating the Impact of Music Therapy for Children with Dementia

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Description

Batten disease, a rare neurodegenerative condition, currently affects around 200 children in the UK. Children experience gradual loss of sight, speech, understanding, memory and mobility, and the disease causes shortened life expectancy. Care pathways for children with this disease, are focused on isolated symptom management, and a more holistic, pre-emptive approach to care, therapy and education is needed. Current research into therapeutic care is limited for this population, yet there is emerging evidence suggesting benefits of music-based interventions. This project aimed to ascertain the benefits of music therapy on the key functional areas of cognition, speech, and movement to improve health outcomes for children affected by Batten disease in the UK.

Context

Principally, healthcare research for children with Batten disease is currently focused on curative pharmacological interventions and the care pathway is largely focused on symptomatic management or palliative care solutions (Augustine, Adams, & Mink, 2013). This means many families and children living with Batten disease, lack consistent support in terms of care and education and many feel they must navigate their own pathway of care when they need help (von Tetzchner, Elmerskog, Tøssebro, & Rokne, 2019). Unpredictable deterioration can create anxiety, psychological distress and trauma for affected children and their families, yet formal recommendations for wellbeing activities are non-existent for this population.

Emerging research has demonstrated the positive influence of pre-emptive education strategies and the significant impact that music can have on a child's wellbeing (von Tetzchner et al., 2019). Incorporating pre-emptive teaching into a child's education and therapy curriculum could help anticipate difficulties or challenges experienced later in a child's life (for example introducing Braille skills, cane and orientation skills, speech activities or independent mobility aids). As yet, research into music and wellbeing activities are non-existent, and this project, therefore, aimed to address this gap in knowledge in order to guide families and professionals supporting children with the disease.

Method

The three-year project observed children with Batten disease in weekly music therapy sessions. Drawing upon assessment measures from both the clinical and music therapy domains, the project explored how functional skills in music therapy could change over time in comparison to standard clinical assessments, in order to improve wider health outcomes for affected children. Data used in this project formed part of a larger study looking into the impact of music for individuals with Batten disease, where ethical approval was granted by the University of Roehampton Ethics board in 2016 (Ockelford et al., 2019).

Participants

Twelve children with Batten disease (aged between 3 to 18 years) took part in the research, and from the fourteen variants of Batten disease presently known, the children represented five different types. Ten music therapists and one music teacher were involved in the delivery of music therapy and music lessons over the three years.

Intervention

Children received weekly music therapy sessions over the course of three years primarily in an education setting. Sessions focused on a suggested practical framework to facilitate speech and language, cognition, creativity, movement and wellbeing. The team of researchers made observation visits once every school term and practitioners also sent session videos at quarterly intervals each year for additional analysis.

Assessment Measures

The standardised Hamburg Clinical Rating Scale for Batten disease (Kohlshutter, Laabs, & Albani, 1988) was used every 12 months to record speech, movement and cognition. In addition, a new bespoke music therapy assessment tool (Chiltern Music Therapy Outcome Measure (CMTOM), Atkinson, 2018 [see appendix 1]) was used to analyse each video recording of children's sessions. To demonstrate validity of the CMTOM measure in the study, validation exercises were carried out to determine appropriateness, relevance, and feasibility of the measure for music therapy sessions. Results from the validation exercise indicated positive results with regards to the reliability (Intraclass Correlation Co-efficiency) and face validity (practitioner questionnaires).

Outcomes

The Impact of Music Therapy

Clinical Assessment

In all areas of the Hamburg Clinical Scale, average mean scores showed consistent deterioration in the areas of cognition, communication, and mobility. As can be seen in Figure 1, average mean scores ranged 0.4 – 2, and plot lines show a downward deterioration across all domains.

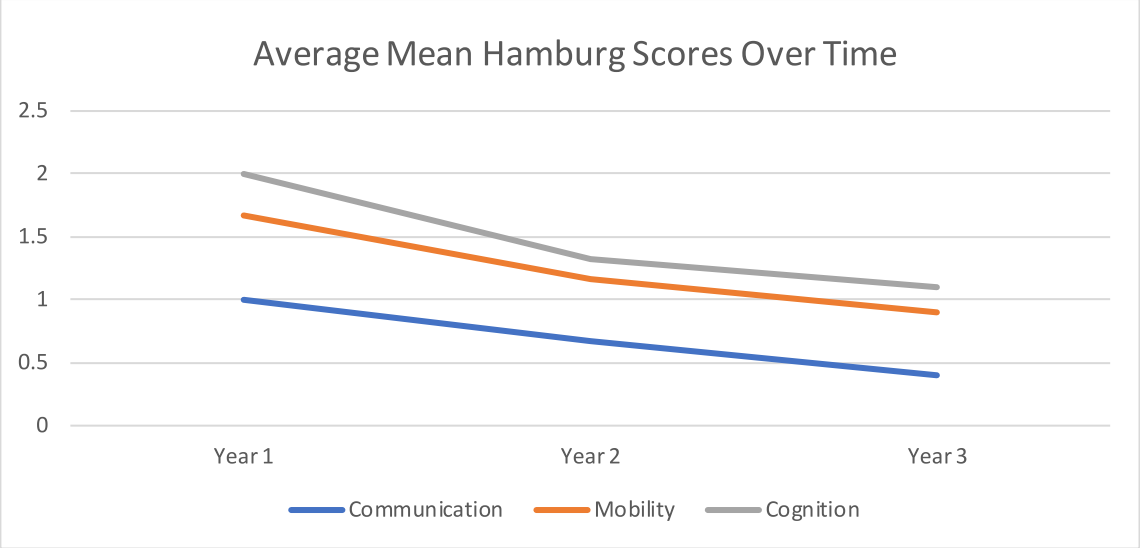

Figure 1: Average Hamburg Scale mean scores for communication, cognition and mobility across 3 years.

Music Therapy Assessment

By contrast, average mean CMTOM scores showed a different picture. As can be seen in Figure 2, the graph demonstrates a smaller range of scores (1.47-2.83) and a plateau effect occurring in the mid stages of the three-year project (time points 3-13). It was observed that there was a period in music therapy sessions, where children's average mean scores remained stable, and skills were seemingly maintained.

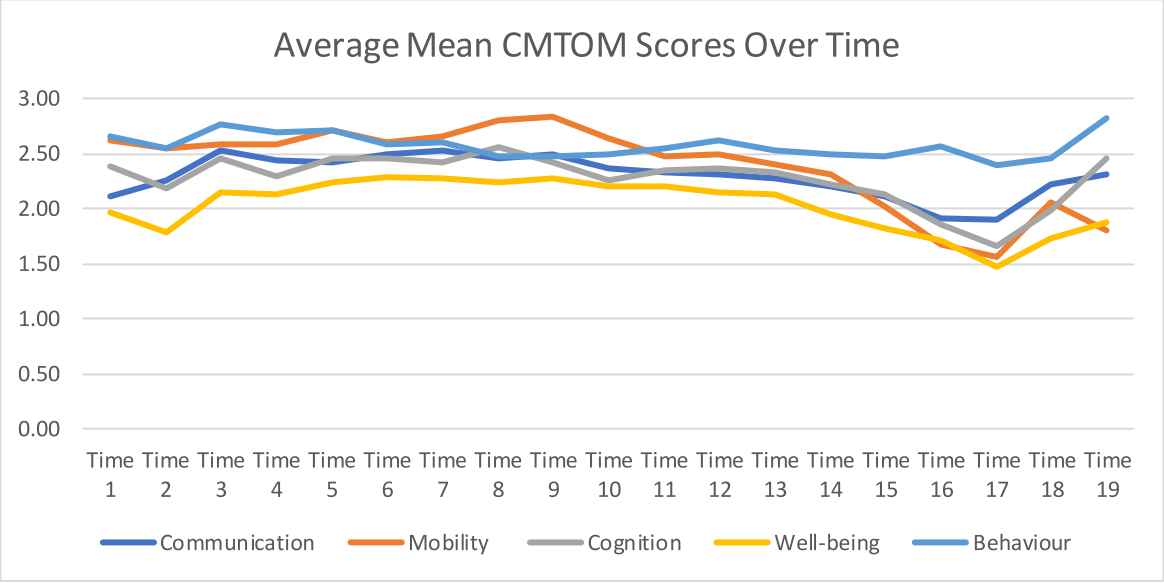

Figure 2: Average CMTOM mean scores in communication, behaviour, emotional wellbeing, cognition and mobility across 3 years.

Results perhaps indicate that a child's skills, within the context of music therapy, deteriorate to a lesser extent than skills measured in a clinical context. The marginal declines and periods of maintained skills in the CMTOM (when compared with sharp declines on the Hamburg scale) suggest that the impact of music therapy could help slow the decline of skills and offer periods of stability. Moreover, marked differences in the rate of deterioration on the Hamburg Clinical rating scale and CMTOM, suggest that a wider understanding of the child's abilities and capacities, can be picked up in a music therapy assessment framework in comparison to the standard clinical test. It could be suggested that without music therapy input or music-based assessment, children affected by Batten disease could be perceivably deteriorating faster over time, which could significantly impact the approach to their care and education.

Practical Activities

Observations from the session videos, highlighted key musical activities found to be of benefit to the children. As reported in the full research study (Ockelford et al., 2019) particular activities were found to help support language, memory and wellbeing.

Music to support language

Drawing on the principles of Neurologic Music Therapy (Thaut, 2014), music and language activities focused on scaffolding language in song, rhythm or melody. For example, key meaningful phrases (such as family members' names, preferences, or activities) were formed into meaningful, memorable melodies and songs to help support memory retrieval. Previous parent accounts also support this finding:

> "Music was very important – she enjoyed listening and singing. Long after her speech went she was still able to sing or mouth the words to 'Happy birthday'" (von Tetzchner et al., 2019: 348).

> "…lyrics came out clearly, even though her speech was so little, stuttering and slow" (von Tetzchner et al., 2019: 348).

Techniques of Music Speech Stimulation (MUSTIM) and Rhythmic Speech Cueing (RSC) were used to help children complete their sentences with prompts or pace their speech with a metronome tempo. To encourage carryover, further research would investigate the carryover of such techniques and whether they could be introduced by teachers or other allied healthcare professionals.

Music and memory activities

Music, songs and melodies were also used to support recall and memory retrieval. Particularly when children were showing symptoms of memory loss or confusion, often music was used to help orient the child i.e., songs for activities throughout the day, or songs for each day of the week etc. This concept was also demonstrated in previous parent feedback:

> "Music is used every day. He has special songs to fall asleep to; different songs have been used in different situations (pee song, wake up song, be together song)" (von Tetzchner et al., 2019: 353).

Additionally, practitioners in the research created memory books for children based on experiences, memories, or key pieces of information (i.e. family members). These were multi-sensory in nature drawing upon braille, audio clips, tactile objects and accompanying musical recordings. Professionals reflected on the positive impact of memory books:

> "This fully interdisciplinary approach involving music, English, braille, and art was motivating for her and as her disease progresses further, the book will be there to aid her in remembering her favourite songs, through listening to her own voice and by feeling the tactile materials that she has so carefully chosen" (Ockelford et al., 2019:32)

Despite early visual deterioration, sessions also utilised the child's unimpaired hearing to support choice-making or to indicate preferences. By presenting different instruments in different auditory fields, children were encouraged to use gesture to indicate preferences. With pre-emptive teaching, instruments could be extended to sounds or voice notes, to represent activities, place, or people in order to develop independent choice-making for children for longer. Although further research is needed with regards to these activities, they could be translatable to allied health or education or home contexts to support independent choice-making and enhance quality of life for affected children.

Music and wellbeing

Generally, music was found to help support relaxation, stimulation and comfort, and previous parent feedback supported this concept:

> "[Music] really calms him down, and he gets so upset when we try to turn it off…… It really calms him down when he's agitated or in pain" (Ockelford et al., 2019: 33).

> "We usually use music to create a calm, relaxing environment … but a fast song with a strong beat will usually get her to open her eyes." (Ockelford et al., 2019: 33).

Using music to support wellbeing is one area particularly transferable to other areas of education, therapy and care, and the simple act of interactive music listening alongside family members of professionals, could significantly enhance wellbeing for children affected by Batten disease.

Key learning points

Findings from this initial research project unearthed many learning points which could have a positive impact on the future care and therapy for children affected by Batten disease. They are summarised as follows:

- There is seemingly a positive impact of the long-term music therapy for a child's speech, cognition, mobility, and wellbeing.
- Current standard clinical assessment measures for children affected by Batten disease could be limiting and misrepresentative.
- Activities such as memory books, using music to support key phrases, songs for activities, auditory choice-making and music for relaxation received positive feedback from parents and staff.
- Music activities could be transferable to other therapy, care, allied health settings or education contexts to provide a holistic joined-up approach to healthcare and education.

- Parents, families, and caregivers could integrate the music activities outlined here, to enrich interactions in the home environment.
- Future research would aim to develop a systematic and consistent approach to music therapy sessions (i.e., sessions would be delivered by the same practitioner or follow a set protocol).
- Follow on validation exercises would aim to strengthen the validity and appropriateness of the CMTOM for other neurodegenerative patient groups.
- Introducing music-based activities earlier on (before skills are lost) could support children's memory, communication, and wellbeing for longer.
- Ongoing research is needed to explore the impact of specific music-based language exercises for affected children.

Findings from the research will be shared with other allied health care settings, parent advocacy services, and music therapy learning communities in order to improve approaches to education and therapy for affected children. Findings may also be relevant for other paediatric and palliative care settings, other rare or neurodegenerative conditions, and dementia care sectors.

Further research will focus on creating and developing a music therapy program for affected children that is transferable to other healthcare and education settings. Research in this area ultimately aims to provide families, health professionals and educators with music-based activities to enhance wellbeing, increase quality of life, and improve health outcomes for children with Batten disease.

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Appendix 1 - Chiltern Music Therapy Assessment Tool

The CMTOM was used to assess and monitor developments and changes in relation to music-based skills within the clinical areas of speech, cognition, movement. The CMTOM was by CMT practitioners, with the aim of capturing behaviours and skills in a music therapy session. The matrix is intended for multiple populations, but specifically enables skills to be tracked over time, so that it can be used with neurodegenerative populations. The use of the matrix provided an opportunity for more in-depth and regular analysis of each child within sessions and captured a detailed picture of musical skills (i.e. singing abilities), beyond that which was captured using the Hamburg Scale.

Observations			
	DATE		**DATE**
0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4 = consistently	**Score**		**Score**
1. Communication & Social interaction		**4. Emotional Expression**	
Appropriate eye contact OR tracking of visual stimuli		Verbal expression of mood	
Appropriate use of gesture		Physical expression of mood	
Vocalisation (any sound)		Musical expression of mood	
Verbalisation (use of speech)		Choice of instrument / art material / object / preference	
Singing		Use of voice/ sound making tools for expressing self	
Awareness of others		Able to tolerate sound(s), art form, types of media used	
Ability to interact non-verbally / verbally		Insight into difficulties & strengths	
Interaction with staff		Ability to explore and discover	
Ability to Initiate interactions		Shows capacity to improvise / free play	
Behaviour / music to therapist appropriate?		Can differentiate between real and imagined	
Notice, tolerate, accept, aware of others		Has enthusiasm, shows pleasure, fun, enjoyment	
Ability to participate / join in			
Sharing emotions, thoughts and ideas		**5. Sense of Self**	
Being able to think about others - show empathy		Ability to participate, initiate, choose, lead	
		Shows appropriate level of self confidence	

2. Behaviour		Is resourceful, decisive and can work autonomously / independently	
Trigger observed to changed behaviour?		Demonstrates appropriate levels of assertiveness	
Any verbal aggression noted			
Any physical aggression		**6. Cognition**	
Behavioural response to musical components noted?		Follows verbal instructions	
Ability to express / control self in an appropriate way		Makes choices	
Expression of feelings of distress, agitation, anxiety		Ability to attend to task	
Expression of feelings of depression, trauma, loss, bereavement		Recognition or carry over of previous material	
		Engages appropriately with instruments	
3. Physical Presentation		Any memory recall noted? (rhythmic recall etc.)	
Active movement noted?		Sustains attention	
Core/trunk stability noted?		Shows interest and is inquisitive	
Head and neck stability noted?			
Use of weaker limbs noted?			
Bilateral (both hands) coordination noted?			
Hand-eye coordination noted?			
Ability to cross mid-line - movement R-L or L-R			
Fluency of gait movements?			
Ability to grip in RH			
Ability to grip in LH			
Individual finger movements noted for use with piano, assistive or music technology?			
Oral motor control noted?			
Breath control and regular respiration noted?			

Hand-over-hand or facilitated movement needed to participate in music making?	