Allied Health Professional case studies: Music Therapist

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What is the impact of a Neurologic Music Therapy service on an inpatient acute Stroke Unit?

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INTRODUCTION/BRIEF DESCRIPTION

The UK Stroke pathway has been well developed since the introduction of the National Stroke Strategy in 2007 (Department of Health, 2007). Included in current National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2016) are recommendations that patients have access to a range of Allied Health Professions (AHPs) including Physiotherapy, Occupational Therapy, Speech and Language Therapy and Dietetics. Music Therapy is an AHP that has less presence within the current stroke pathway. Music therapists use music to help their patients achieve therapeutic goals through the development of the musical and therapeutic relationship (British Association for Music Therapy, 2020). Neurologic Music Therapy (NMT) is a neuroscientific model made up of standardised clinical techniques and provides evidence and outcomes to demonstrate its positive impact in patients with neurological impairment in domains such as physical rehabilitation, cognition, speech and communication (Magee, Clark, Tamplin, & Bradt, 2017; Thaut, McIntosh, & Hoemberg, 2015; Thaut & Volker, 2014). In line with the national guidelines for Stroke rehabilitation (NICE, 2013), the NMT intervention targets specific patient rehabilitation goals integrating a multi-disciplinary approach to therapy. More generally, this approach also focuses on patient emotional well-being and psychological needs (NICE, 2013).

The following is an example of how an NMT pilot on an acute NHS stroke unit, which ran in 2015, led to an ongoing service as part of the unit's multidisciplinary team. The service demonstrates how music therapy as an Allied Health Profession, can contribute to the National Clinical Guidelines for Stroke Recommendations (2016) suggesting 45 minutes every day of 'each appropriate therapy', through joint-working and goal-setting (p. xiv).

Context and Aims

Recent research has identified that research advancements into stroke rehabilitation (principally cognitive and physical rehab), could significantly reduce costs of care in the public realm (Stroke Association, 2017). Studies such as this, therefore, add significant value, not only improving quality of life for stroke survivors but offering cost effective, sustainable treatment at acute stages of care.

In 2015, Chiltern Music Therapy was funded by the Buckinghamshire NHS Charitable Trust to provide a pilot NMT service on Wycombe General Hospital's acute stroke unit.

The aims of the pilot project were:

1. To explore accessible provision for further Neurologic Music Therapy on the ward
2. To fit in with general hospital aims of
    - developing their stroke services to patients
    - providing the highest level of rehabilitation care to patients through specialist provisions centred around the patients' care needs
    - developing the skills of the dedicated workforce

METHOD

The music therapy pilot ran for a total of 12 weeks, with one Neurologic Music Therapy practitioner providing a service one day a week. The Speech and Language team manager acted as the liaison between Chiltern Music Therapy and the hospital therapy team, which included speech and language therapy, occupational therapy and physiotherapy. The service was set up on a referral basis, with a member of the therapy team referring patients dependent on patients' needs

and goals. The MDT used morning handover to refer patients to either individual or group NMT. The MDT member and the Music Therapist set session goals using the Goal Attainment Scale (GAS) measurement tool and planned which NMT techniques would be used with the patient in line with the MDT therapy goals. Music therapy sessions were all held with the MDT member who referred the patient. Following the session, a debrief was carried out, during which any assessment tools would be completed and the GAS outcome tool used to generate a score for goal achievement. Patient notes were jointly written.

Outcomes to explore how music therapy would fit in with the wider team and the needs of the patients included keeping a detailed log of patient referrals, gathering details on who referrals were made by and why patients were referred.

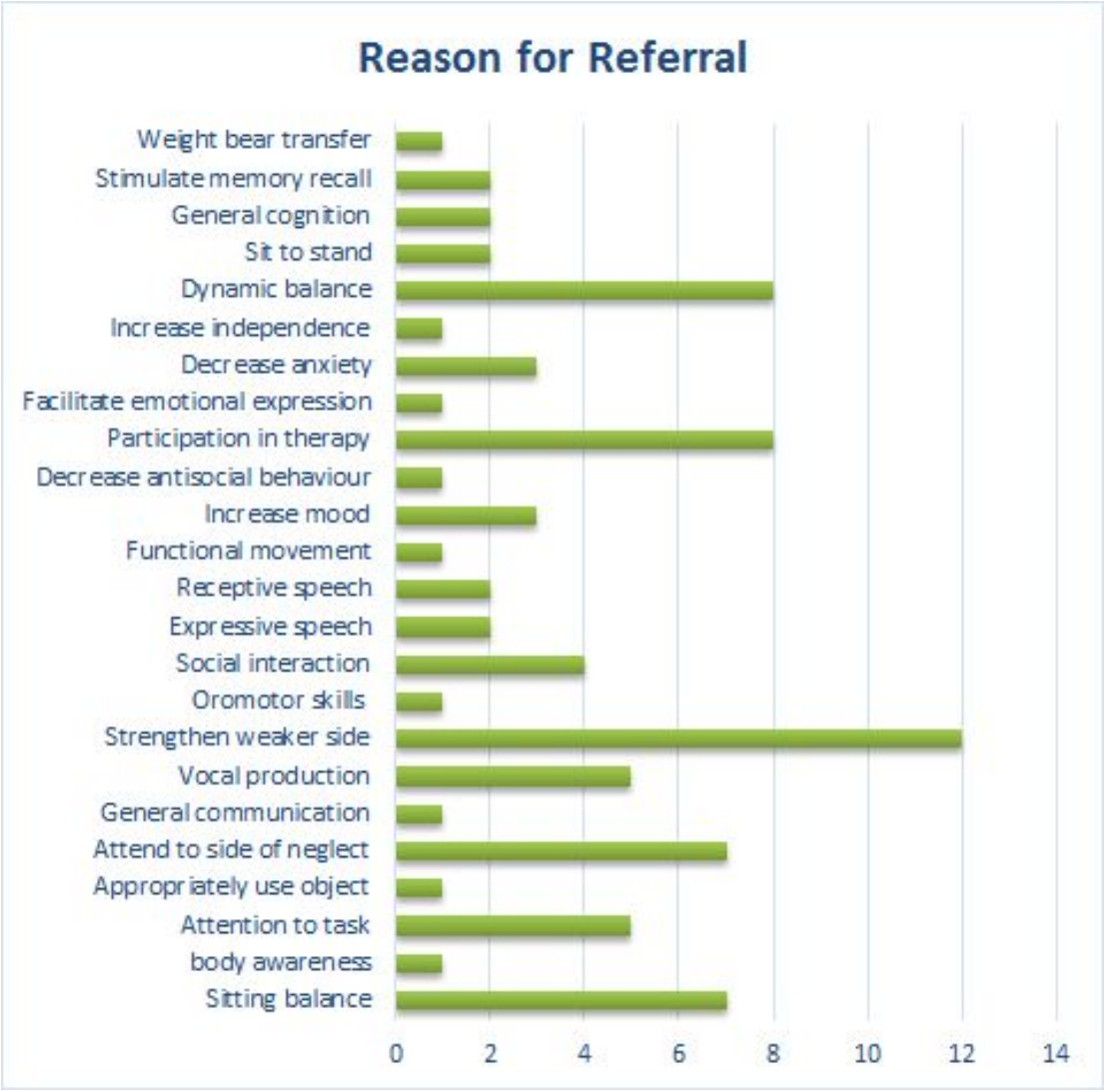
In order to explore the impact on meeting a patient's individual goals, carryover from musical exercises to non-musical exercises at the end of each session were documented. This data was gathered by providing staff with feedback forms (see appendix 1), which included documenting their observations of patient behaviour/performance in therapy and goal attainment, as well as any additional comments about the session. Patients were asked to score their satisfaction level at the end of the session using a visual scale consisting of high visibility animated facial expressions. Mood and anxiety levels were measured at the beginning and end of the session to ascertain Depression Intensity Scale Circles (DISCs) and Anxiety Scale Circles (ASCs) scores. Patients were asked if they would opt to come to music therapy again and to give verbal feedback if appropriate. Patient experience was then collated into quantitative data (satisfaction score, DISC scores) and qualitative data (verbal feedback).

RESULTS/OUTCOMES:

1. Referrals

18 patients either received group or individual NMT over the twelve-week period, with 3-4 sessions occurring on the allocated one-day service per week. Each session lasted approximately 45 minutes, depending on the needs of the patients.

Across the pilot, referrals were roughly equal among the three referring groups, with 32% of referrals coming from Occupational Therapy, 32% from Speech and Language Therapy and 36% from Physiotherapy. Reasons for referral from each discipline can be seen in the following charts below. The varied reasons for referral from each of the Allied Health Professions indicate an understanding that the music therapy service could be utilised to work on the functional goals of the patients in the areas of communication (for example apraxia and aphasia), cognition (i.e. attention and neglect) and physical function (i.e. upper body strength and standing balance). A portion of referrals also noted the inclusion of music therapy sessions for motivation in movement, with the underlying assumption that music may provide an impetus for movement or engagement in therapy.


Reason for Referral
Weight bear transfer
Stimulate memory recall
General cognition
Sit to stand
Dynamic balance
Increase independence
Decrease anxiety
Facilitate emotional expression
Participation in therapy
Decrease antisocial behaviour
Increase mood
Functional movement
Receptive speech
Expressive speech
Social interaction
Oromotor skills
Strengthen weaker side
Vocal production
General communication
Attend to side of neglect
Appropriately use object
Attention to task
body awareness
Sitting balance
0
2
4
6
8
10
12
14

2. Goal Achievement and Carryover

A total of twenty-one written observations were collected by occupational therapy, speech and language therapy and physiotherapy in relation to patients' responses to music therapy sessions as well as their goal achievement.

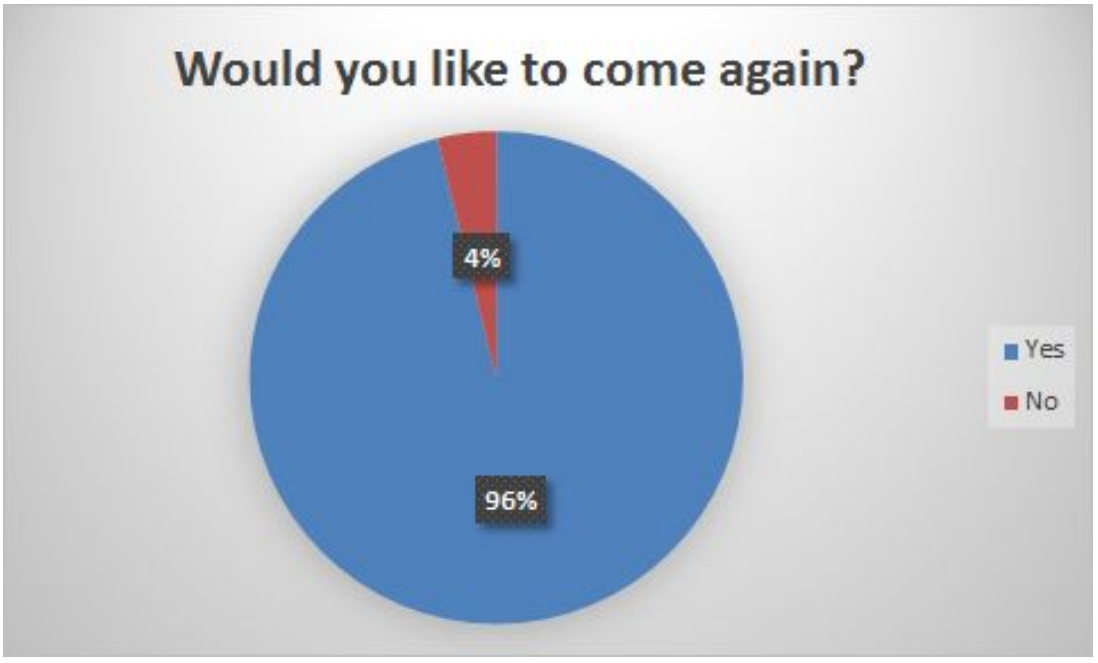
Upon reviewing the content, a number of themes arise. These are engagement, music and motor skills, communication and mood.

2.1 Engagement

An overarching positive outcome of the project saw a high level of engagement observed across the participant group in all disciplines. Specifically, engagement and attention was markedly higher in comparison to other previous therapy interventions (Physio, SALT, OT). In some cases, a higher level of engagement was seen in relation to previous therapy sessions. For example,

> "patient engaged in music therapy very well, demonstrated ability to use her left and to the rhythm of the beat. Patient previously has disengaged/got sleepy when using her left hand in activities such as cards. Dominoes." (OT)
>
> "This particular patient has been struggling to access traditional therapy. In this session he exceeded his goal" (OT)
>
> "It has encouraged patients to join in when other techniques have failed". (OT)
>
> "significantly improved sustained attention to task and patient's ability to engage in the task" (OT)

Patients were asked if they would like to come again. Of those asked,



2.2 Music and Motor Skills

The notion of music acting as an impetus for movement was noted in terms of rehabilitation in the both upper and lower limbs.

- "Initially requiring increased prompts to follow tasks and to attend to left side but with music was able to start following the task independently. Increased bilateral integration of upper limb when initially not engaging his left arm" (OT)
- We have been struggling with this patient and they are highly distractible. The minute the music started the patient moved to the rhythm and he walked across the gym with a significantly improved gait pattern. (PT)
- The sessions definitely made a difference to the patient's use of left hand. Although prompts were needed on some activities the rhythm encouraged the patient to use her left hand. (OT)

2.3 Communication

Goals met in the area of speech and communication were also described including automatic speech and fluency.

- "The patients I have been with have enjoyed the sessions, but we have also seen positive effects on their participation/attention/communication e.g. vocalizing/automatic speech" (SLT)
- The patient was able to make verbal choices with songs which he is struggling with previously) making choices) (SLT)
- Able to sing when talking is difficult due to dysfluency" (SLT)

2.4 Mood

While mood was not listed as a reason for referral, the particularly positive response in terms of patient's mood was described by staff. The effect of stroke on mood, including depression and anxiety has been documented (Robinson and Jorge 2016, Burton et al 2013) and the NICE (2016) Guidelines for Stroke include recommendations for psychological care. Staff responses in terms of mood included the following:

- The session had a positive impact on mood – patient was engaged, participated and attended'
- We saw the patient at bedside and patients in the bay commented positively about the music- lifted the move. Other patients keen to join in/have future sessions.'"
- Patients were engaging in session and with music therapist, it improved mood and motivation.

In addition, the responses to the DISCs showed a mean average change across participants from 3.4, "Fine" to 1.9, "Great" between the start and end of sessions.

Note: A lower score shows improvement in mood.

2.5 Additional outcomes

Staff responses also described taking on techniques used in music therapy and carrying on with these between sessions. This points to the aim of developing workforce skills, in this case through the use of shared practice.

- "We have been able to use the singing in our session which has been very helpful" (SLT)
- "SALT to compile list of favourite music and also use song in their SaLT sessions" (SLT)
- "We will continue to use the techniques to ensure generalization" (PT)
- "Patient was motivated by music; going to use in other therapy rehabilitation" (PT)

Word cloud showing some of the qualitative comments and data gathered in responses:

In summary, staff perception concluded that music therapy provided focus and motivation to help achieve goals across a range of areas including physical/ motor, cognition, speech and communication, and emotional wellbeing. Feedback gathered from the project suggests that Neurologic Music Therapy, alongside other AHP's and approaches, has the ability to positively impact on outcomes for stroke patients.

In 2017 The Stroke Association published projected costs of stroke over the next 20 years on The NHS, social care, informal care and lost productivity. Within this report they identified that research into 5 key areas, including cognitive and physical rehabilitation, would have a significant reduction on the financial burden of cost. In their 2019-2024 research strategy they identified one of their key goals as funding research into effective new ways to support stroke survivors and their families after stroke. It is hoped pilots such as this can contribute to the wide body of research

within stroke rehabilitation and contribute to reducing financial burden and improving quality of life for stroke survivors.

LEARNING POINTS:

Upon completion of the pilot, a number of recommendations followed. First, the full day service was recommended to include the creation and handover of music therapy Home Programmes with staff and family members in order to enable patients to continue and maintain their rehabilitation once they have been discharged from the Stroke Unit. This was also important for carryover between sessions when the music therapist was not present.

It was also recommended that the Music Therapist attends team or department meetings as well as links in closely with one key member of staff within each therapy team: Speech and Language, Occupational Therapy and Physiotherapy, to ensure that the referral system is managed and implemented as effectively as possible.

Finally, further music therapy service pilots on stroke units would benefit from a standardised outcome to use alongside qualitative feedback in order to quantify outcomes, or to be included where standardised measures are used.

As well as providing services in Neurologic Music Therapy for patients, an innovative program led by CMT, entitled the iPod Pharmacy has also been implemented on the ward (as well as in other services provided by the organisation). The iPod Pharmacy is an initiative which takes unwanted MP3 players, cleans and loads them with a selection of tailored music to help stimulate, soothe and engage patients. For this particular patient population, research has suggested that music listening may improve mood for patients in the acute stages of stroke (Särkämö et al., 2008).

The pilot was mentioned in the Royal College of Physicians quarterly Sentinel Stroke National Audit Programme (SSNAP), where it gave the Stroke service an 'A' overall rating – placing it among the top 7% of stroke services in England, Wales and Northern Ireland. The music therapy service on the unit continues to evaluate and present its progress and challenges across nationwide platforms such as the Live Music Now conference at the Royal Society of Medicine in 2015, and the UK Stroke Forum Conferences in 2017 and 2018.

REFERENCES:

Burton, C. A. C., Murray, J., Holmes, J., Astin, F., Greenwood, D., & Knapp, P. (2013). Frequency of anxiety after stroke: a systematic review and meta-analysis of observational studies. *International Journal of Stroke*, *8*(7), 545-559.

Department of Health. (2007). National Stroke Strategy. Retrieved from https://webarchive.nationalarchives.gov.uk/20130104224925/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081059.pdf

Intercollegiate Stroke Working Party. (2016). National clinical guideline for stroke. *National Clinical Guideline for Stroke*. http://doi.org/10.3354/meps314001

Magee, W. L., Clark, I., Tamplin, J., & Bradt, J. (2017). Music interventions for acquired brain injury. *Cochrane Database of Systematic Reviews*. http://doi.org/10.1002/14651858.CD006787.pub3

National Institute of Health Care and Excellence (2013) *Stroke Rehabilitation in Adults*. Retrieved from https://www.nice.org.uk/guidance/cg162/resources/stroke-rehabilitation-in-adults-pdf-35109688408261

NHS Buckinghamshire Healthcare Trust (2015, October 12). S*troke service 'A' Team celebrates earning highest score in independent audit.* Retrieved from https://www.buckshealthcare.nhs.uk/About/stroke-service-a-team.htm

Robinson, R. G., & Jorge, R. E. (2016). Post-stroke depression: a review. *American Journal of Psychiatry*, *173*(3), 221-231

Särkämö, T., Tervaniemi, M., Laitinen, S., Forsblom, A., Soinila, S., Mikkonen, M., ... Hietanen, M. (2008). Music listening enhances cognitive recovery and mood after middle cerebral artery stroke. *Brain*, *131*(3), 866–876. http://doi.org/10.1093/brain/awn013

Stroke Association. (2017). Current , future and avoidable costs of stroke in the UK. https://www.stroke.org.uk/sites/default/files/costs_of_stroke_in_the_uk_report_-executive_summary_part_2.pdf.

Stroke Association. (2019). Research Strategy 2019-2024 https://www.stroke.org.uk/sites/default/files/jn_1819.316_-_research_strategy_web.pdf

Thaut, M. H., McIntosh, G. C., & Hoemberg, V. (2015). Neurobiological foundations of neurologic music therapy: Rhythmic entrainment and the motor system. *Frontiers in Psychology*. http://doi.org/10.3389/fpsyg.2015.01185

Thaut, M. H., & Volker, H. (2014). *Handbook of neurologic music therapy*. *Oxford University Press*.

APPENDIX 1. STAFF FEEDBACK SHEET

Music Therapy Feedback

Why did you refer your patient for MT	
What aims did you have for your patient and were they met	
Do you think the MT service should continue – why?	
What improvements could be made to the MT service?	

APPENDIX 2. AUDIT SHEET

Buckinghamshire Healthcare NHS
NHS Trust

Referral/Audit Record
Chiltern Music Therapy

Admission Date:
Diagnosis:

Hand Dominance [R] [L]
Affected Side [R] [L]

Date of Referral:
Vision:
Glasses [YES] [NO]
Heminopia:[R] [L]
Hearing: Aids?

Current Physical Status

i.e Walking: -Sitting Balance: Transfer Standing Balance: Current diet / fluids:

Current Communication
[Expressive] [Receptive] [Dysarthria] **Comments:**----------

---

Current Cognitive skills:
Following Directions: Independently [ ] Hand over Hand Guidance [ ] Physical prompt [ ] Verbal prompt [ ] Both [ ]
Inattention / Neglect: [Left] [Right]
Memory: Immediate Recall [ ] Delayed Recall [ ] Long term Recall [ ] Other: ----------
Attention to task: Focused [ ] Sustained [ ] Divided [ ] Selective [ ]

Comments:----------

Current Phsychological Status

History of Depression and/or Anxiety: [YES] [NO] ----------

Mood: Recent ASC/DISC Scores **Date:**----------

Behaviour: ----------i.e Impulsivity, Agression etc

Reason for Referral: **CIRCLE KEY AREAS: [COMMUNICATION] [BEHAVIOUR] [PHYSICAL] [COGNITIVE]**

Include any relevant /current goals you have set.

Would this person be suitable for [Group] [Individual] sessions. OR [Both]

The following section to be completed by Music therapist /Key Therapist:

Date(s) of sessions attended	**Goals set during session(s)**

Music Therapy Techniques Used

Physical
RAS [ ]
*Cadence:*_____ *Velocity*:_____Stride Length:_____
TIMP [ ] *Metronome Marking [ ]*
PSE [ ]*Metronome Marking [ ]*

Other:_____
_____
_____

Speech
MIT [ ] MUSTIM [ ] VIT [ ] TS [ ]
OMREX [ ] SYCOM [ ]
RSC[ ] *Metronome Marking* [ ]

Other:_____
_____
_____
_____

Cognition
MMT [ ] MSOT [ ] MNT [ ]
APT [ ] MACT [ ] AMMT [ ]
MEFT [ ]

Other;_____
_____
_____

Emotional Well-Being
Music Assisted Relaxation [ ] Song writing [ ] Music Listening [ ] Lyric Analysis [ ]
Improvisation [ ]

Other:_____
_____
_____
___

Instruments:

Keyboard [ ] Guitar [ ] Percussion {] ***Specify:*** _____
_____
Other [ ] ***Specify:***_____
_____
Placement of instruments [N/A]
_____
_____

Repertoire

Chiltern Music Therapy Assessment
OUTCOME MEASURES RECORD

Buckinghamshire Healthcare NHS
NHS Trust

Date:

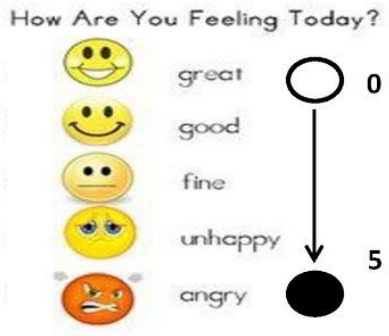
Goals Achieved were at : [ ]

Much Better outcome this is scored at: +2
Better than expected outcome this is scored at: +1
Expected level outcome this is scored at: 0
Worse than expected outcome this is scored at: -1
Much worse than expected outcome this is scored at: -2

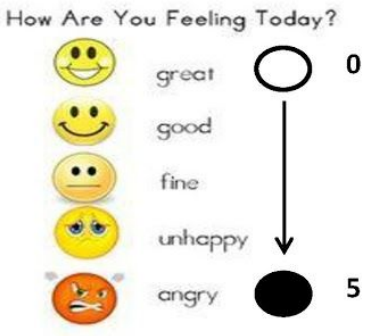
Verbal feedback from Client: ----------

Satisfaction Post session:
How helpful or enjoying has this session been to you today?

Feeling Before Session: ASC & DISC



Feeling After session: ASC & DISC



Would you like to come again? [Yes] [No] Why:----------

Therapist Printed Name: **Signature:** **Designation:** **Date**

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.

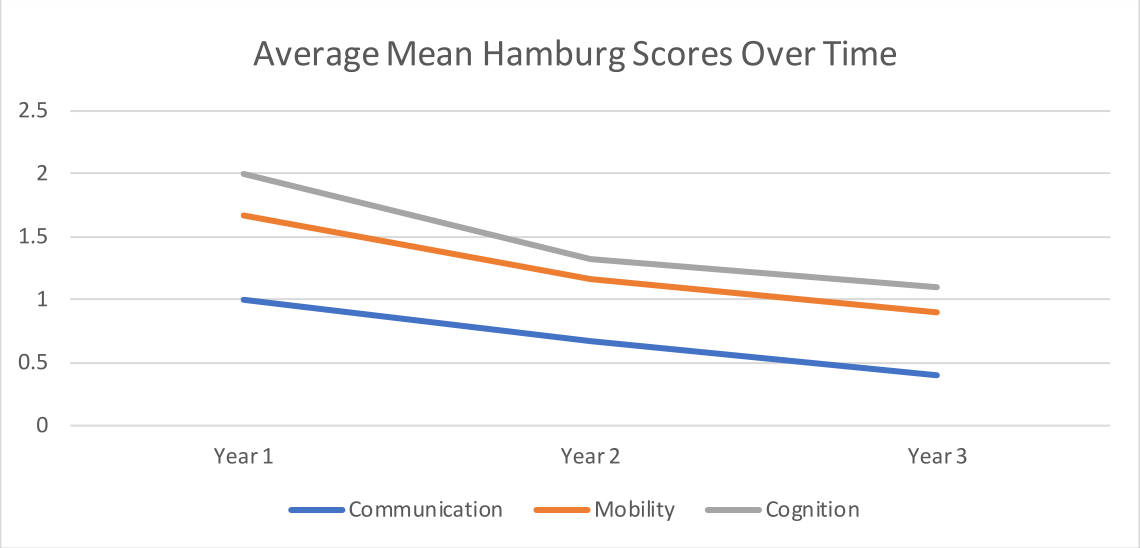

Figure 1: Average Hamburg Scale mean scores for communication, cognition and mobility across 3 years.

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.

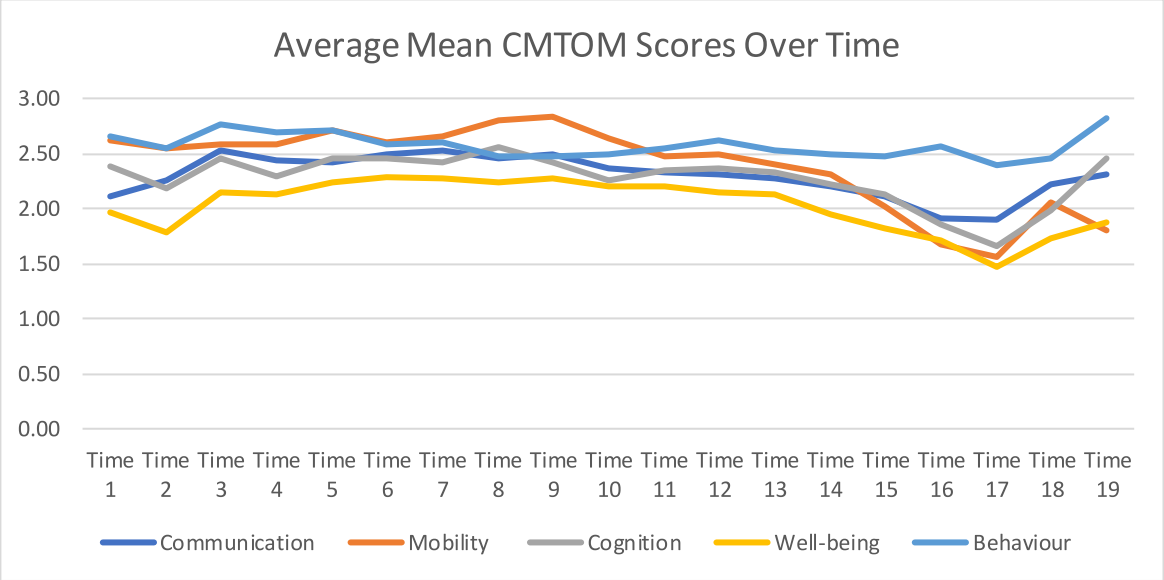

Figure 2: Average CMTOM mean scores in communication, behaviour, emotional wellbeing, cognition and mobility across 3 years.

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.

Bibliography

Atkinson, R., (2018) Chiltern Music Therapy Observation Matrix [CMTOM], Unpublished

Augustine, E. F., Adams, H. R., & Mink, J. W. (2013). Clinical trials in rare disease: Challenges and opportunities. *Journal of Child Neurology*, *28*(9), 1142–1150. https://doi.org/10.1177/0883073813495959

Kohlshutter, A., Laabs, R., & Albani, M. (1988). Hamburg Scale Article 1988 Kohlschütter Juvenile NCL.pdf. *Acta Paediatrica, International Journal of Paediatrics*, (77), 867–872.

Ockelford, A., Atkinson, R., & Herman, K. (2019). The Potential Role of Music to Enhance the Lives of Children and Young People with Neuronal Ceroid Lipofuscinosis (Batten Disease). *The Amber Trust*.

Thaut, M. (2014). *Handbook of Neurologic Music Therapy*. (M. Thaut & V. Hoemburg, Eds.) (1st ed.). Retrieved from https://books.google.co.uk/books?hl=en&lr=&id=5Gb0AwAAQBAJ&oi=fnd&pg=PP1&dq=thaut+2014&ots=IAjxHwLyl2&sig=YaNZOjgSNlA94i_4-d1CRWHclMo#v=onepage&q=thaut 2014&f=false

von Tetzchner, S., Elmerskog, B., Tøssebro, A. G., & Rokne, S. (2019). *Juvenile Neuronal Ceroid Lipofuscinosis , Childhood Dementia and Education*. (S. von Tetzchner, B. Elmerskog, A. G. Tøssebro, & S. Rokne, Eds.) (1st ed.). Melhus, Norway: Snøfugl forlag.

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?	

Title: Improving Access to Music Therapy for Children and Young People - An Arts Therapies at Cambridgeshire and Peterborough Foundation Trust (CPFT) and Head to Toe Charity Initiative

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Description

The Youth Music Project was an initiative that aimed to address health inequalities by delivering music therapy across children's community mental health. Prior to this pilot project, music Therapy was limited to inpatient settings in Cambridgeshire and Peterborough, neglecting its potential for early intervention. Music Therapists within CPFT's Arts Therapies Service worked with CAMHS community teams to implement music therapy within CAMHS and assess the outcomes.

The project aims were to:

- Assess the impact of children and young people accessing music therapy in the community with both physical and mental health needs
- Pilot an effective delivery model to provide community-based music therapy to children and young people
- Improve communication and joint working with families and clinical community NHS teams
- Provide education on music therapy via continuous professional development (CPD) to relevant clinical teams

- Collaboratively set psychological goals to be met through music therapy
- Evaluate the project using a Patient Reported Experience Measure for children and young people and to collect feedback from families, carers and clinicians

Context

Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) is a health and social care organisation providing services in inpatient, community and primary care settings. The population served is just under 1 million across a diverse geography across Peterborough and Cambridgeshire. The Arts Therapies Service is one of the specialist services within CPFT, which includes music therapy, and provides input for tier 4 children and young person's inpatient settings within CPFT. Central funding for music therapy has not been able to stretch to cover music therapy for CAMHS and Paediatrics in addition to the inpatient settings. However there continues to be a need for music therapy across community settings. A pilot partnership was set up involving the Trust's Head to Toe Charity, Arts Therapies Service and CAMHS and Paediatrics services. This was supported by the charity Youth Music and using public funding from the National Lottery through Arts Council England. The Arts Therapies Professional Lead had oversight to ensure equitable access across services.

Literature and research have shown the effectiveness of music therapy for children and young people with a variety of mental, emotional and behavioural problems, improving self-esteem and communication and reducing anxiety and depression (Porter *et al.* 2017; Belski *et al.* 2022). Music therapy is a treatment for trauma that is understood to be experienced bodily at a preconscious, non-verbal level (Perry, 2014). Perry (2014) states that we need "*patterned, repetitive, rhythmic somatosensory activity,*" to treat developmental trauma and that music therapy can provide this. There is also a body of evidence, cited by Stegemann *et al.* (2019) for the effectiveness of music therapy in paediatric physical healthcare, including physical illness and disability, as well as neurological issues.

There is a lack of literature assessing the effectiveness of music therapy for children in community settings. However, the need for psychological intervention at an early stage has been cited (Worrall Davies *et al.* 2004; Vusio *et al.* 2020). In CPFT, music therapy was only accessible in inpatient units making access to early intervention and its potential benefits impossible. The Youth Music Project was

established to address the health inequalities that existed due to children and young people being unable to access music therapy in a community setting.

Method

Funding for the project was provided by CPFT's official charity, Head to Toe, supported through Youth Music's Trailblazer Fund. The overall purpose of the project was to address the inequality of the availability of music therapy to children and young people within Cambridgeshire and Peterborough.

Three music therapists provided the equivalent of two days per week of time to support the delivery of music therapy across Cambridgeshire and Peterborough. Each music therapist was assigned NHS community teams across different geographical areas to ensure equitable access.

Each music therapist collaborated with their assigned NHS community team to

- Set up clear and ongoing communication channels
- Promote and educate on the benefits of music therapy
- Develop a leaflet and questionnaire to be given to patients and families
- Produce a clear referral process

Safeguarding was met by ensuring that children and young people had an established care co-ordinator in place who was in close liaison with the relevant music therapist.

Each child or young person was given a leaflet and questionnaire to establish collaborative therapeutic working from the outset. The questionnaire gave young people an idea of what music therapy could involve and asked if they would be interested in any specific medium. The therapist used this to inform their approach. This was intended to empower the child and reduce anxiety by offering an idea of what music therapy may involve. It was hoped that this would also increase engagement.

The music therapists contacted families or carers and collaboratively decided whether group or 1:1 therapy would be beneficial. Six weeks of music therapy was initially provided, subject to review. Goals were established between the

therapist and the patient. Progress was monitored throughout by the therapist, patient, family/carers and the multi-disciplinary team.

Prior to and throughout the project, Music Therapists provided educational and experiential workshops to members of the clinical team with the aim of informing them about the potential benefits of music therapy, to help generate referrals, as well as supporting their own well-being. One team chose to use the workshop to write a song to welcome children to their service in many languages.

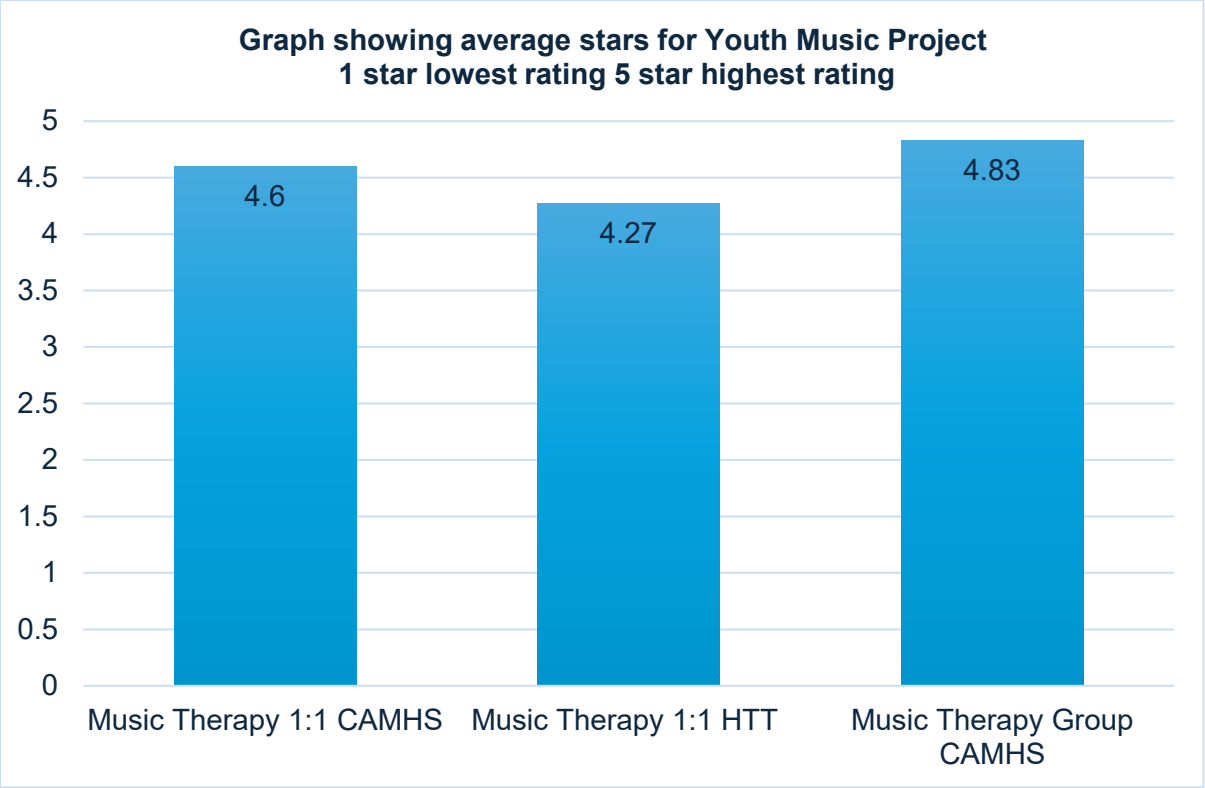
To assess impact, a Patient Reported Experience Measure (PREM) was used after each session. This was a card developed by CPFT Arts Therapists and used throughout the service. The team refer to the "star card". The star card was filled out by children or their carers. The star card had a star rating from 0-5 and optional comments. This rating system had been found to be effective in the CPFT Arts Therapies service and accessible for children and young people. Some NHS community teams used Children's Global Assessment Scale (CGAS) which was collected at baseline and end of treatment. Written and verbal feedback from carers and clinicians was collated, much of which came from discussion with key professionals, post session.

Data was collated to monitor reasons for referral, numbers of referrals and the ethnic and gender diversity of children and young people referred. Data, feedback, impact and adaptions needed were discussed at a monthly steering group.

Outcomes

263 1:1 therapy sessions, 13 group sessions and 12 CPD sessions were delivered and evaluated. Key findings were that there is a need for music therapy in community children's services and that music therapy was particularly effective for children who could or did not engage in other forms of therapy.

The Patient Reported Experience Measure showed that 94.8% of children rated music therapy 5/5 stars. This graph shows the stars given for group and individual music therapy in Core CAMHS and CAMHS Home Treatment Team.



Feedback from young people, families and clinicians about the impact of music therapy sessions was overwhelmingly positive. Collating comments from children, they could be categorised as:

- Having fun
- Learning new music skills
- Learning strategies to support their mental health
- Feeling listened to
- Being able to express their emotions through music
- Completing a composition or song
-

Quotes from children, young people and carers

A child said, *"felt awful coming in, feel less awful leaving…playing music is the way I need help a lot."*

A carer said, *"Delighted at access to music therapy which increased confidence."*

Quotes from staff

"I see diverse mental health presentations and often there is locked trauma or blocked feelings. In music, children and young people can use sound and rhythm to express how they feel…This is the only CAMHS therapy the YP has engaged with, and they have been open to CAMHS for a significant period of time. Talking therapy and art therapy was offered, but erratic engagement".

Young Person Case Example

B was a non-verbal girl with complex neurodisability, gut dystonia and pain. She was referred to have music therapy by the community paediatrics team to use music as a means of communication, self-expression and interaction and soothing. Initially, the focus was assessing response to different musical stimuli and establishing a safe space. Repetition appeared to elicit a strong response to improvised music. Dynamics, tempo and melody played by the therapist, were based on B's vocalisations and movements. Initially, the therapist mirrored B's communication cues, but this progressed to the therapist initiating musical cues to assess response. The following song was used in each session, the words being adapted to B's physical and vocal cues. B would show expectation through facial and limb gestures before laughing at certain points of the song. As the sessions progressed, the therapist gained awareness of B's mood and level of stimulation, responding flexibly to calm or engage. In the therapeutic process, echoing vocalisations, while playing a calming melody and mirroring her breathing appeared to have a positive and soothing effect. This was seen with more relaxed body language, arm movements and facial expressions.

Community practitioners said:
"(*Music therapy) has been the single intervention that has been successful for this specific young person who struggled to make sense of themselves due to adverse experiences"*

"The sessions are truly person centred and have positively impacted not only on the young person but her mother, carers and our staff team. The safe space has given the young person a medium to communicate and express herself and enjoy being in the company of others. It has given her mother space to be a Mum and not a carer and enjoy time with her daughter"

Key learning points

Overall, it was found that children and families highly rated music therapy in community services, finding that it improved mood, anxiety, confidence and connection. Music Therapy also aided young people in transitioning effectively from inpatient to community care. Star cards were an effective way for children to communicate these thoughts. CGAS provided little information due to it not being used by all services and music therapists finding it difficult to complete because they were required to assess a larger area of functioning than they could observe.

It was found that, for some young people, this was the first time they had engaged with therapy, having refused other CAMHS support. Therefore, once they were engaged and music therapists were able to build relationships, young people often requested more than six sessions. The programme was adapted by offering twelve sessions to most young people which impacted on the number of individuals that could be seen. However, those children and young people accessing music therapy took part in an intensive therapeutic programme, allowing more time to build coping strategies and resulting in a stronger relationship with CAMHS' ongoing support.

It was clear that some services were more proactive with making referrals than others. Meetings were held with less active services to understand why this was the case. Often, staff shortages and pressures meant there was not time to make referrals. This disparity led to adaptations, ensuring that music therapist's time was utilised in other services so that young people were reached. Staff engagement sessions and drop-ins were also set up to raise awareness, build relationships and support their teams in understanding the benefits of music therapy. It seemed that having one or two identified 'champions' within the team who can promote the service at team meetings was an effective way of engaging particular services.

Assessment of data showed that most young people engaging in the programme were female, White British and between the ages of 12 – 15. This data, alongside service data, is being reviewed to plan how to reach a wider group of young people from different backgrounds. This may involve promoting the service in particular geographical areas and raising awareness with staff members around ensuring referrals are accessible and reach more isolated groups.

This project has resulted in many benefits for our organisation and community, some in addition to the project's original aims. We have seen an increased awareness and understanding of the power of music therapy. More teams are coming to us with referrals, and this project has directly led to the development of two new projects to support Children in Care and children and young people on CAMHS waiting lists. It has been shown that this project has equipped patients with skills and strategies that will stay with them for life, and we hope that with continued funding we'll be able to reach more of our community.

References

Belski,N.,Abdul-Rahman Z,.Youn E., Balasundaram V.,Diep D. (2021) Review: The effectiveness of musical therapy in improving depression and anxiety symptoms among children and adolescents - a systematic review. *Child Adolescent Mental Health.* 2022 Nov;27(4):369-377.

Perry, B.D. (2014) "Born for Love: The Effects of Empathy on the Developing Brain," *Annual Interpersonal Neurobiology Conference* "How People Change: Relationship & Neuroplasticity in Psychotherapy," UCLA, Los Angeles, March 8, 2013 (unpublished).Available at Perry: Rhythm Regulates the Brain | "Don't Try This Alone" (attachmentdisorderhealing.com)(Accessed 28 April 2024)

Porter S., McConnell T., Mclaughlin K., Lynn F., Cardwell C., Braiden H., Boylan J., Holmes V. (2017) Music therapy for children and adolescents with behavioural and emotional problems: a randomised controlled trial. *The Journal of child Psychology and Psychiatry.* 2017 May;58(5):586-594

Stegemann T., Geretsegger M., Phan Quoc E., Riedl H., Smetana M. (2019) Music Therapy and other Music-Based Interventions in Pediatric HealthCare: An Overview. *Medicines* 6 (1)

Vusio F., Thompson A., Laughton L., Birchwood M. (2020) After the Storm Solar Comes Out: A New Service Model for Children and Adolescent Mental health. *Early Intervention In Psychiatry* 15:3

Worrall-Davies A., Cottrell D., Benson E. (2004) Evaluation of an Early Intervention Tier 2 Child and Adolescent Mental health Service. *Health and Social Care in the Community.* 12:2.

Acknowledgements: Sreeraj Kollurakandy& Emily Corke; Music Therapists. Kimberley Iyemere; CPFT Arts Therapies Professional Lead and Manager. Alex Gordon; Head to Toe. Caroline Stackhouse; CPFT Deputy Director of AHPs.