

Music Therapy and Motor Neurone Disease: a case study

Translation of paper published in the Swiss journal Palliative –CH 2010

Abstract

Music therapy is a small profession, but work in palliative care settings in the UK is increasing steadily. Hospice patients have predominantly cancer related illnesses, but other terminal conditions including motor neurone disease (MND) are cared for. Empirical and qualitative music therapy research in palliative care highlights benefits for both physical and emotional needs such as: relaxation and physical comfort; emotional awareness, expression and catharsis; joy, pleasure and spirituality and the reduction of pain and fatigue. However, no research was found related to music therapy and MND patients.

Many factors came together to allow a qualitative single case study research project to take place. Namely the exploration of the music therapy experience of an MND patient who was in an established and on-going collaborative music therapy relationship, which began 2½ years before the research started. The patient was in his fifties and had a slow progressive form of MND, which meant that the research had a realistic chance of completion. Harry (pseudonym), an African scientist and researcher who had recently relocated to the UK, had already shown an out of the ordinary ability to articulate and reflect about his music therapy experience. These insights were enhanced through being filtered through another cultural perspective and communicated in a third language.

Approval to carry out the study was sought for and given by: the ethics committees of the University of the West of England, the local National Health Service (NHS), and the hospice where the work took place. Ethical implications that were considered in detail included issues around coercion, anonymity and the health of the participant.

The methodology used was that of a single exploratory case study. Three types of data: verbal, musical and visual, were collected over a bounded 12-week period. Reflective, unstructured discussions were recorded at the start and end of the research process. A musical improvisation was filmed, jointly viewed and then discussed. A frame-by-frame description of the movements seen and a written analysis of the music itself were also undertaken. An archive recording of a song-writing process was reviewed and discussed. The data were analysed using thematic analysis and thick description and integrated to form an account of Harry's experience of music therapy.

Four interlinked themes were extracted: the start of music therapy; the experience of improvisation and songwriting; and the value of the therapeutic context. The findings suggested that he experienced music therapy as holistic, non-coercive, collaborative and non-hierarchical. He felt that it offered an opportunity for integration of mind and body that developed and preserved function. Music therapy was also experienced as an alternative to psychological or psychotherapeutic intervention providing opportunities for self-expression through

different aspects of the therapy, which enabled him both to process and communicate his experience of MND.

The research makes a significant contribution towards the development of knowledge and understanding about the potential for music therapy with MND patients, suggesting it could have an important place within a multidisciplinary approach. Further research is indicated, particularly looking at the effect of music therapy and preservation of movement in MND.

Lings, J. (2010). Musiktherapie und Amytrophe Lateralsklerose/ Ein Erfahrungsbericht. Palliative-Ch. No 2. Sommer 2010

Music Therapy and Motor Neurone Disease: One Man's Experience

Background

Harry (not his real name) was in his mid 50's when we met. An African by birth, he had recently moved to the UK from Europe. He had suffered from a slow progressive form of motor neurone disease (MND) for more than 10 years and was living alone, working full time as a scientist and researcher. He had paresis in his legs, and his hands and arms were weak. His voice was quiet and he had started to seek out ways to amplify it in noisy settings. He used an electric wheelchair for mobility.

His first realisation that his vague symptoms amounted to something serious was when playing with his children he could not turn a cartwheel. For a fit sportsman with a judo black belt this was unexpected. However, confirmation of an MND diagnosis took six years. In those years, his worsening condition had been instrumental in the break up of his marriage and among the many other losses was active involvement in playing music. He described being given the diagnosis as catastrophic, removing any remaining hopes of recovery. He considered ending his life.

Still in full time work after diagnosis his employer offered the possibility of relocation to the UK. He viewed this as the moment to leave his old life behind and start afresh with a new identity as a disabled person.

His referral for music therapy came from a hospice community nurse after a time in hospital. His ability to walk had been lost and he was in a low mood, struggling to adapt. Music therapy is often difficult to explain (O'Kelly & Koffman, 2007) and Harry's impression was that it would be a passive experience for him, akin to reflexology or aromatherapy. He was both busy and unconvinced, and it took two months of cancellations and missed appointments before he came to his first music therapy session. This was just less than five years ago. Since then the music therapy relationship has continued, fortnightly, and he has attended more than 80 sessions, interrupted only by illness, his demanding work schedule and when weather conditions stop him driving his chair to the hospice.

Music Therapy

Although Music therapy is a comparatively new profession, emerging in the 1950's, it is now well-established, recognised, researched and increasingly evidence-based profession (Aigen, 2008). Its place in palliative care began to emerge in the 1980's with pioneers such as Susan Munro (1984) beginning to write about their work. In UK the numbers of music therapists employed in adult hospices is still small (22 in 2005), but is increasing steadily (O'Kelly & Koffman, 2007).

At the hospice where I work, music therapy is viewed by the team as having the potential to support patients with perceived psychological needs, offering an alternative avenue for expression through the use of both music and words. There are many definitions of music therapy but central to it is both music and a relationship. The therapist works with the patient towards appropriate

and often multi-faceted therapeutic aims to 'support and encourage physical, mental, social, emotional and spiritual well-being' (Bunt & Hoskyns, 2002, p.11).

The techniques that I draw on to work with patients may be active or passive. Music is such a versatile and flexible medium that it can facilitate appropriate and meaningful ways to meet and accompany someone in their illness, however unwell or disabled they are. For Harry improvisation, songwriting and verbal reflection have been central to our work together.

Improvisation offers the opportunity for expression where communication might be intense but words can be bypassed (Pavlicevic, 2000; Wigram, 2004). Instruments are available that do not need particular skills in order to play, such as drums and other tuned and untuned percussion. Through joint playing a musical dialogue can be established which has many parallels with verbal therapies e.g. reflecting back, mirroring and matching. Songwriting offers the possibility of expression in words and music. In a collaborative process songs can be written where the words and much, or indeed all of the music are the patient's. The created song, often sung by the patient, can be recorded and has the potential to be shared with others (Baker & Wigram, 2005; O' Callaghan, 1994).

Many music therapists in palliative care settings often work with non-cancer related patients. Published case vignettes of work with MND patients describe positive outcomes in terms of offering new insights, hope, meaning and direction (Forrest, 2002 & 2005. Petering, 2005). However, despite extensive searches I was unable to locate any published research about work with MND patients.

The research project

In an early music therapy session Harry made a remark, which was surprising to me, namely that it was the one place in his life that his mind and body could work together without fighting. Harry encouraged me to research this experience. An opportunity to follow this up came about and the University of the West of England and the local National Health Service (NHS) ethics committees gave permission for an exploratory qualitative single case study research project (Yin, 2003; Stake, 1995). Ethical considerations for undertaking this type of research were very carefully considered and safeguards put in place to ensure that Harry was not feeling coerced, and his health needs not compromised.

A period of 12 weeks was set aside in our (at that time) weekly music therapy sessions, to collect three types of data: verbal, musical and visual. This included unstructured discussion at the start and end of the research, a video recording of an improvisation, followed by joint viewing and discussions. There was also a review of an archive recording of the first songwriting process. The different types of data allowed: different viewpoints to be brought together; triangulation of the material (ensuring rigour and trustworthiness); and facilitation of the building of thick description (Geertz, 1973), which was the aim of the research.

Research Findings

The research findings were linked to four themes: the start of the therapy process; the experiences of both improvisation and songwriting; and an overarching theme referring to the whole therapeutic context.

The Start of Music Therapy

Harry described himself as 'ignorant' about music therapy and his expectations were of being a passive recipient. However, in the first session he found that despite physical weakness in his hands and arms, it was possible for him to play the metallophone.



This chromatic instrument, similar to a xylophone, has two rows of metal bars, played with two beaters and is closely related to an African balofon, an 'essential' instrument in Harry's culture. The effect of this discovery was seminal:

'You go from the point where you say I can't play music and I can't play anything else ... and you come from a session where you discover you can play.'

It turned around his experience from 'can't' to 'can'. He could re-engage with active music making and express his own culture. It marked the beginning of a collaborative relationship where he felt he was viewed holistically, not just as an MND patient, but as a fellow musician.

The word 'can't' is a feature in the lives of people living with an illness with multiple experiences of being able to do less and less. Resilience and hope are built on experiences that feature the word 'can' (Munroe and Oliviere, 2007).

The Experience of Improvisation

The experience of improvisation was multi-layered for Harry. It was a place where MND could be forgotten, where his mind and body worked together, and where physical exercise was a by-product. It was a form of self-expression, being creative in its own right, allowing insight into his feelings. It was also a form of communication and interaction.

He described a three-stage process that happened in improvisation:

‘First the mind, second the body and mind, three the body.’

Watching the six and a half minute improvisation on video, frame by frame, this three-stage process was very clear. At the beginning he stated a theme and his body was quite stiff and the notes chosen were directly in front of him. Then it is clear that he began to loosen up and the music flowed rapidly and rhythmically, he made difficult movements without hesitation (e.g. reaching for a chromatic note at the back of the instrument) his whole upper body moving freely. Finally as fatigue began to set in, his facial expression changed, tremor in his hands was visible and he played fewer notes and brought the piece to an end.

Harry described strategies that he employed without thinking, in order to keep playing. He used his chair to rest his arms and to brace his upper body. He changed his grip on the beaters many times, often holding them asymmetrically, threading the beaters between his fingers, and sticking out his thumbs to balance his hands. He also utilised different parts of his body so that he could relax muscles, using movements from his wrists, forearms or shoulders.





The musical composition itself afforded him ways to keep playing and yet sustain a musical idea. He moved from rapid playing, using the whole range of the instrument, to playing less, using one beater, resting while listening to my responses and playing repeated notes. In the final two minutes, his playing became sparser before a final burst of energy and an ending of two unresolved chords:

‘I know I cannot play all the notes, but those I play will be right on time.’

Harry noticed that he felt that his regular improvising was also affecting his motor function:

‘I think there is something, which is alarming my mind to connect with my armI believe that there has been some progress in maintaining at least my capability to use my arms.’

Which also had the effect of raising self-esteem:

‘And I think that it has helped into finally overcoming this impression of not being able to do anything anymore.’

Thaut (2005) describes research into Parkinson’s disease and stroke damage and argues that rhythm has strong effects on the brain, eliciting, promoting or enhancing movement. It is possible that Harry was experiencing something of these benefits and this aspect would clearly benefit from further research.

Improvisation was also an intellectually satisfying process:

‘You cannot really play music with your body only, you need your mind and its clear that if you were just knocking notes or something like that, ok that’s not music...’

Harry is very clear that this is for him is a highly creative process it is:

‘Like a maieutic It is like giving birth to the mind’.

But it is also highly interactive, where there is give and take between players. He noted feeling the empathy that can be heard and communicated through the musical dialogue without ever needing to be verbalised.

In the music itself Harry’s cultural roots and experience as a bass player are all audible in the rhythmic ideas and jazz influences. But also implied and expressed is something of the bitter-sweet tension that appears to pervade all Harry’s improvisations and songs. The end of the improvisation with unresolved chords expresses this; the disease never goes away, it never gets resolved. This tension appears somewhere in all his music, but becomes explicit in his songs.

The experience of Songwriting

Songwriting is a complex and multi-layered process; involving creating lyrics, melody, harmony and accompaniment. It has been an increasingly major part of the music therapy process for Harry with 11 songs completed. He described these songs as being like ‘milestones’ on his journey, for all are linked by:

‘the way I react to the disease the way I think of it.’

Songwriting was first mooted in an early music therapy session when Harry arrived after his 25 minute wheelchair drive to the hospice too cold to play. He readily accepted the idea of songwriting and ‘Daily Victories’ was written. In the song he expresses his mind-set in dealing with the disease. He recounted in song form some of the unimaginable lengths he had to go to in order to get to work without any help. Although he compared his life with a well person:

You just get up in the morning

He turned away from self-pity and was determined to get on with life:

*Little things you take per se
We have to fight for every day
Daily Victories, daily victories.*

The second song emerged soon after. After an improvisation had a clear melodic idea, I suggested that it might have words. Harry began to sing:

*I can do it by myself..
If you let me try
.....Let me try*

This song, the first to be sung both in English and his own language, encapsulated the dilemmas of someone living with disability. It arose from his new situation, living with an able partner. The song was not 'a revolt' against her, but an awareness that he had to keep pushing against his difficulties where he could, for once he had allowed MND to take over he felt it would do so quickly. Harry gave broad permission for its use and the song has been heard at conferences, presentations and in concert. For him it was:

'really a major song which convinced me of what music therapy can bring me.'

A later song contained a profundity in the lines:

'Independent, in dependence'

summing up in just two words his philosophy for coping with his need for help from others.

He also wanted to encourage others through his songs:

*When you are down
It's always time to look up
It's not the time to give up*

Harry was able to articulate in the songs something about how he dealt with his illness. He chose not to talk much about his disease, but was nevertheless living with constant deterioration, requiring continual adaptation. He described coming from a country with endemic 'trouble' and where arts and creativity were strategies used by his culture:

'there is so much trouble there is no trouble and so we sing and dance'.

In effect, through songwriting he has told the story of his illness, with the songs serving as powerful communicators to his family and others. For himself he described it as:

'a relief ... because I can come into a session and express myself with regard to the condition and all the rest'.

At first Harry was uncertain about his singing voice, could he still keep in tune? His first song convinced him. Since then he has sung all his songs. At first I was very aware of Harry's fatigue when recording, feeling it was not possible to do more than a couple of takes. During the research period we were recording a song about his train journey to work with the pleasure of seeing the sunrise on the fields and being able to:

*Feel like any other person
I'm part of the crew, part of the crowd*

We noticed that we could do multiple takes without fatigue, and that he set himself and managed difficult vocal challenges:

'I can feel my voice really strong actually, and the breathing is really up to it'

'The different exercises of the breathing ... are seamlessly done but are very demanding'

During the research he underwent usual breathing tests and was pleased to find that in three years there had been no deterioration.

Singing, health and well-being is being researched with many population groups (Grape et al, 2003; Clift et al, 2008). Singing was rewarding and important for Harry psychologically, emotionally and physiologically. A comparison between recordings of 'Daily Victories' made two years apart, revealed a stronger voice. Harry's voice and energy levels would often be low on arrival after a day's work. After the session his voice would seem noticeably stronger and he often commented on renewed energy, despite having worked hard.

Harry became increasingly directive about the song accompaniments he was looking for, and my job was to try and create musically what he had in mind. This process was fraught with difficulties for me, a classically trained musician, with no written score, trying to hear the subtleties of African rhythmic nuances. Harry spoke of being able to hear a tenth of a beat and told me to:

'be careful ..., it's not harmony a la Bach'

As we articulated these difficulties during the research period he noted that all of us are disabled in some way and he remained remarkably patient as I worked towards the result he wanted.

The Therapeutic Context

Harry described music therapy as being a therapeutic context, bringing together a whole range of helpful aspects in one meaningful context. On a physical level

he could exercise like in physiotherapy or speech therapy without it being dull or coercive, which gave him a sense that:

‘the condition is not always evolving in degradation mode, there are ways to stop it more or less’.

Which in turn gave him a sense of not being completely powerless.

He described frustration with other professionals who did not take a holistic view and saw MND:

‘from a very narrow scope, they don’t listen enough ..to the patient’ commenting, that music therapy cannot exist without listening.

As a deeply reflective man he identified more than once that he did not want the help of a psychologist or psychotherapist, decrying the idea of talking about himself. He also perceived imbalance between patient and therapist in those professional relationships. For Harry both the collaborative nature of the relationship in music therapy and the fact that he could ‘do something’ was important for him. He also noted the psychotherapeutic nature of musical expression where thoughts and feelings are facilitated in unexpected ways it allowed:

‘things to happen and apparently of any drive to constrain it ... they will happen their way not the way you want it.’

He talked of the inevitability of death from MND, but being unwilling to give up. He felt that music therapy helped that resolve, keeping his spirits and morale high and wished he had discovered it earlier in his journey with the disease.

Reflections

Many therapists talk of significant or even ‘critical’ clients who are particularly significant to them in the course of their work (Lee, 1996; Yalom, 1999). Harry has been just such a client whose impact on my professional development and learning has been immense. He has challenged my thinking, assumptions and musical skills at numerous points during the time we have worked together. A single case is not generalisable, however Harry’s hope was that others would be offered the same experience, would not give up on being told there was no effective treatment, and would find something similar for themselves.

As I write this Harry’s health has deteriorated suddenly and sharply and music therapy may have come to an end. His last song is unfinished; his eleventh contains the lines

Fight MND back with your own music.

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