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*“Mijn geheugen staat in notenschrift te lezen,
elke herinnering kent zijn eigen lied,
elke goede, elke slechte periode,
onlosmakelijk verbonden met muziek”*

Jan Rot (1957 - Uit: Mijn Geheugen, theatershow “Rot is liefde” 1993)

Music therapy in patients with Huntington’s disease

a case report

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Abstract

This chapter reports about 2 patients with Huntington's Disease who benefit greatly from music therapy while they are struggling with behavioral and emotional problems, due to the advanced stage of the disease. Huntington's disease (HD) is an inherited neuropsychiatric disease with progressive neural degeneration of the basal ganglia and gradual atrophy of the frontal and temporal cortex. Symptoms are progressive and include motor, emotional and cognitive disturbance. There is as yet no cure for HD, nor can its progress be reversed or slowed down. All treatment is aimed at improving quality of life.

Music therapy is a non-pharmacological intervention to improve communication skills, reducing behavioral problems and thus leading to a better quality of life in patients with HD. There is little knowledge on how music therapy may contribute to improve the QoL in HD. This case report provides greater insight into how to treat patients with HD, especially in the advanced stage of the disease.

Keywords: Huntington's disease, quality of life, music therapy, case report

Case reports

Huntington's disease (HD) is an inherited neuropsychiatric disease with progressive neural degeneration of the basal ganglia and gradual atrophy of frontal and temporal cortex [1]. Symptoms are progressive and include motor, emotional and cognitive disturbance. Despite the increase in number of therapeutic trials over the last 20 years, there is as yet no cure for HD, nor can its progress be reversed or slowed down [2,3].

Many of the patients present with language abilities that are inadequate to enable them to fully or sensitively express their feelings verbally. Dysarthria, dyspraxia, or aphasia result in poor articulation of words or difficulties in expressing language [4]. While speech itself is severely impaired, the thinking process of persons with HD, especially in the later stages, is often severely delayed. Also, poor insight, lack of awareness and denial, all due to cognitive decline associated with HD, imply that it is extremely difficult to create a coherent and meaningful therapeutic relationship. In addition, persons presenting with rigid thought processes may have difficulty considering alternative viewpoints, solutions, or situations. Finally, many of the patients have a low self-awareness due to the use of psychotropic medication [1,2,3,4]. As long as there is no cure for HD, the emphasis of many of the treatments is on improving quality of life [3]. One of these non-pharmaceutical treatments offered to patients with HD in long-term care facilities is music therapy [5].

The American Music Therapy Association (AMTA) defines music therapy as follows: "Music therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program" [6].

Music therapy uses music experiences and patient-therapist relationships in order to effect therapeutic change. Music therapists are part of the multidisciplinary team and participate in interdisciplinary treatment planning, ongoing evaluation, and follow-up [6]. They assess emotional well-being, physical health, social functioning, communication abilities, and cognitive skills through musical responses. Music therapists design music sessions for individuals and groups based on client needs using music improvisation, receptive music listening, song writing, lyric discussion, music and imagery, music performance, and learning through music [7].

Applying music therapy to persons with Huntington's disease is challenging, especially in the later stages of the disease, because of the aforementioned deficiencies. The following two case

reports illustrate the finding that music therapy can be successfully applied in persons with HD to help them with self-expression. The first report tells the story of a person with HD in whom music turns out to be the trigger for him to open up and show the man that he really is, as opposed to the patient with severe behavioral problems whom nurses are afraid to approach. The second report tells the story of another person with HD, whose lack of verbal communication hinders him from showing remorse towards a caregiver whom he has physically abused. Through therapeutic song-writing, he is offered the opportunity to rewrite the lyrics of a familiar song, personalizing it to his own experience.

Person A

A 64-year-old man in the late stage of Huntington disease was admitted to the long-term care facility. Because of severe behavioral problems, aggression, agitation and sexual disinhibition, he was treated with psychotropic drugs, the main side-effect being that he slept most of the day. Despite the medication, the negative behavior towards the nursing staff continued. Furthermore, female nurses inadvertently triggered inappropriate sexual behavior. This resulted in a situation where most female nurses became afraid to approach him. His daily care was always carried out by at least two nurses, preferably one of them male. He could no longer express himself verbally, and so during his outbursts he would scream loudly and his involuntary movements would get worse.

One of the few personal items he brought with him, was his guitar. A phone call to his daughter revealed that in his younger years, he had been a pretty good “rock-and-roll” guitarist. According to his daughter, music had always been his one and only outlet. Taking all these facts into account, it was decided to start with music therapy to see if music could be the trigger for him to open up and express himself, with the aim of improving his behavior.

During my first visit, he was sitting in a wheelchair. Abiding by the instructions from the caregivers on the ward, the door of his room was left open for reasons of safety. Apart from greeting him and introducing myself, I did not talk much with him for the remainder of this first session that only lasted 15 minutes. I played my guitar and sang some songs that I thought would please him. Over the next few weeks, I slowly increased the duration of my visit and my guitar playing, and he seemed to get used to me gradually. I based my song-choices on the information I had about him: his age, the city where he was brought up, and knowing a little bit about his musical taste. As expected, there was no verbal reaction, but he seemed to calm down somewhat, showing fewer unwanted movements (chorea) and listening attentively to the songs.

I continued this procedure for the next three sessions, building trust and trying to create a safe environment. During the 4th session he requested a song that I had played for him in one of the previous sessions by mentioning the title of the song verbally. From that moment on I started a conversation about music. This first conversation, although very laborious, was the turning point in our therapy-sessions. He actually initiated talking about his love for music, and he started singing along with the lyrics that he was familiar with: I left out some words in the lyrics and he filled in the blanks. Obviously he was enjoying the sessions. After each song we talked about the lyrics, the artists, and the times when this particular song was a top-chart hit. We continued like this in weekly sessions.

A couple of weeks later I decided to involve his own guitar in the session. I placed the guitar on his lap, and he held it tight against his chest. Although he could not play it himself anymore, I could see that he enjoyed just holding the instrument. When at the end of the session I returned the guitar to its case, I noticed a small piece of paper inside. Although it was almost illegible, the title of a song had been noted. It was a fairly obscure instrumental piece for the guitar, but I happened to know it well. During the next session I started to play this particular song; he lit up and started to cry. From that moment on he would ask me to play this particular song every session.

In the meantime, I decided to compile a CD with all the familiar songs that we played together. I advised the nursing staff to play this CD whenever he was getting agitated, or during stressful moments of the day (like bathing).

I also videotaped him during the music therapy sessions to show my colleagues the “other side” of this person. This video footage brought about major changes in how the nurses on the ward would look at him. From that moment on, he was no longer the patient that nurses were afraid to take care of, nor was he the patient who was always alone in his room, isolated from the rest of the residents. He became involved in community events on the ward. Whenever it got too crowded for him, or whenever he showed signs of being too stressed, the nurses took him back to his room and left him to listen to a compilation CD of one of his favorite artists from “way back when”.

When he passed away two years later, his daughter asked me to play a couple of his favorite songs during the funeral ceremony and people could watch the video footage of him singing along.

The next case report describes another person in the advanced stage of Huntington's Disease. For him, the song-writing method has proven beneficial on previous occasions. Song-writing in music therapy is a method whereby the therapeutic intervention consists of the process and product of writing a song with the client. Baker and Wigram [8] present a provisional definition: 'The process of creating, notating and/or recording lyrics and music by the client and therapist within a therapeutic relationship to address psychosocial, emotional, cognitive and communication needs of the client' (Baker and Wigram, 2005, p.16).

The therapeutic effect is achieved through the client's creation, performance and/or recording of his or her own song. The therapist's role is to facilitate this process, ensuring that the clients create a composition that they feel they can own and that expresses their personal needs, feelings and thoughts. The product is something that the client can revisit, share with others, and that can be evidence of self-expression [8].

Experience tells us that it is better to use only familiar and preferred songs, rather than creating a completely new song. Because of the cognitive decline during the advanced stage, creating a completely new song might be a bridge too far. Also, by using a familiar melody line, any anxiety about the person's musical capacity to perform the work will be minimized. "...And while no song that is created is entirely novel, each song typically tells a story in an original way..."(Marade (2007) in Baker, 2015, p.61, [9].

The case report below resembles that of many persons with HD who present with communication problems, cognitive impairments and rigidity/compulsive behavior.

Person B

A 58-year-old man with Huntington's disease who had been institutionalized for three years in the long-term care facility, was chosen to join a small group of fellow residents at a 4-day summer-camp.

After one day, the physician of the facility received a phone call from one of his caregivers, telling him that the man had completely lost it. He had shown aggressive and agitated behavior and had physically attacked one of the nurses. The reason for this outburst was because he was told not to smoke in his bedroom, and having ignored this, his cigarettes were taken away. He was sent home the next day as his behavior had not improved, despite medication to calm him. Upon arrival in the nursing home, he was still very agitated. The psychologist who met with him did not manage to talk any sense into him. He did not seem to understand that his

behavior was intolerable, nor did he show any remorse for having abused the nurse. He kept screaming and was very upset that he had been sent home.

The physician asked me if I could possibly calm him by playing his favorite music or his self-made songs.

I had known him for over a year by this time; he had been receiving individual music therapy once every week. He is known for not being able to show or express his emotions verbally, although he does have the urge to do so. Music therapy has proven beneficial for him. One of the methods that we often use is analyzing or writing song lyrics to improve communication and expression.

When he came to me, the first thing we did was just listen to some of his old-time favorites while I played along on my guitar. We didn't talk at first, we just enjoyed listening to the music together. After a couple of songs, I started talking about what actually happened. As expected, he could not find the right words to express himself. I then grabbed my guitar and started playing a well-known Dutch song. We talked about the metaphoric meaning of these lyrics, how your thinking gets clearer if you let go of negative and angry feelings. But I also took part of the lyrics literally and "translated" this into how his nicotine-addiction and compulsion for smoking cigarettes had taken over at the summer-camp, the reason why he went completely out of his mind. During our conversation he opened up, and I showed empathy when we started talking about what had happened. At the same time, however, we talked about the fact that his behavior could not be tolerated. He told me that he realized this, and that he was very sorry about what had happened, and that he felt very sorry for the nurse he attacked. He wanted to apologize to her, but he did not know how.

I suggested that we could rewrite this particular song in his own lyrics to express his regrets. He seemed to like this idea. I formatted what he had just said to me into new lyrics, making sure to use exactly the wording that he used, without changing it a bit. My only job was to make his words fit into the cadence of the song so he could sing along.

After a while, he thought the lyrics were "perfect". We sang the song a couple of times, and when he was completely satisfied I suggested that we could record the song. We did so the next day, and I burned the song on several CDs, giving him the opportunity to give one to the nurse whom he had attacked. For him, this was the only way to show his regrets and apologize to her. For the nurse, this was the best way to realize that it was the patient who

had attacked her, but it was the person who had created a song for her to show his regret and bury the hatchet.

The two stories above are examples of persons with HD who benefit from music therapy. As the ability to communicate and express oneself deteriorates over time, music therapy could play an important role in the treatment of persons with HD in all phases of the disease [10]. By providing an additional means of communication, thus enabling the patient to express emotions, "(...) meaning is conveyed through the combination of lyrics and music. Lyrics clearly have a capacity to communicate, in a concrete way, the events that are core to the song. But music can also be key in conveying intended meaning..." (Baker, 2015, p.75 [4]).

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