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Music therapy in Huntington's disease

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Citation

Bruggen-Rufi, C. H. M. van. (2018, January 11). *Music therapy in Huntington's disease*. Retrieved from <https://hdl.handle.net/1887/58922>

Version: Not Applicable (or Unknown)

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Cover Page



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Title: Music therapy in Huntington's disease

Issue Date: 2018-01-11

*“One good thing about music, when it hits you,
you feel no pain”*

Bob Marley (1945 – 1981.) Uit: “Trenchtown rock”

**The effect of music therapy for patients
with Huntington’s disease**

A systematic literature review

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*Journal of literature and art studies. David Publishing (2015),
Vol.5, No.1, 30-40. DOI: 10.17265/2159-5836/2015.01.005m*

Abstract

Huntington's disease is a progressive, neurodegenerative, autosomal dominant disease characterized by motor- and psychiatric disturbances, and cognitive decline. Since there is no cure, all treatment is aimed at improving quality of life (QoL). One form of non-drug therapy which is barely recognized, is music therapy. The literature on its use and effect in patients with Huntington's disease is limited. We therefore performed a detailed literature survey in order to delineate the different types of music therapy interventions and their aims. Music therapy studies were included when targeting: (1) motor disturbances; (2) cognitive disturbances; (3) psychiatric disturbances; and (4) emotional/social disturbances. A total of eight studies that met these criteria were analyzed. We found that music therapy interventions vary throughout the different stages of the disease and are not yet applied optimally. Not the stage of the disease but the individual treatment goals seem to be more determinative for the music therapy indications. In conclusion, precise aims and methods in relation to the stage of the disease are not well determined. There is a need for systematic study of this treatment option.

Introduction

Huntington's disease (HD) is a rare neurodegenerative disorder of the central nervous system. It is a progressive, autosomal dominant disease, characterized by a triad of symptoms and signs, consisting of: (1) motor disturbances: chorea and hypokinesia; (2) cognitive decline; and (3) psychiatric disturbances: depression and behavioral changes (Roos, 2010). The prevalence of HD ranges from 1 : 143 in Venezuela to 1 : 10.000.000 in the black population of South Africa. In the Caucasian population the prevalence is estimated to be between 5 and 10 per 100,000 (Al-Jader, Harper, Krawczak, & Palmer, 2001).

The disease can be roughly divided into three stages: the early, the middle, and the late stage. As the disease progresses, the dependability of the patient increases. Admission to a long term care facility (LTCCF) is unavoidable in most cases.

To date, there is no drug to cure or delay the onset of the disease. The majority of drugs is prescribed to treat the motor and psychiatric signs. Besides medication, many other non-drug interventions are available such as physiotherapy, occupational therapy, speech therapy, dietitian advice, psychological support, social worker help, and music therapy. All treatment must be individually tailored, as the symptoms and signs are different for each person and change over time. The intention of all forms of treatment is to improve quality of life (Roos, 2010).

The term quality of life reflects the overall status of a combination of factors: a person's health, symptoms, and level of physical and social functioning. Functional and cognitive impairment are significantly correlated with the patient's QoL (EHDN website¹; Ready, Mathews, Leserman & Paulsen, 2008). Health-related quality of life (HrQoL) is defined as follows: "The optimum levels of physical role and social functioning, including relationships and perceptions of health, fitness, life satisfaction and well-being" (Bowling, 1995).

Ho, Gilbert, Mason, Goodman, and Barker (2009) conclude that depressive mood and functional ability are critically linked to health-related QoL in HD. In a previous study, Helder, Kaptein, Kempen van, Houwelingen van, and Roos (2001) conclude that physical and psychosocial symptoms have a great impact on the patient's well-being.

1 European Huntington's Disease Network (EHDN), working group Quality of Life. Retrieved from <http://www.euro-hd.net/html/network/groups/qual>. Last accessed December 23rd, 2013.

In 2011, the European Huntington's Disease Network (EHDN) Quality of Life Working Group initiated a qualitative research study on the impact of HD across the entire disease spectrum (Ho & Hocaoglu, 2011). The outcome provides important implications for the management and development of interventions throughout all stages. The physical/functional theme peaked throughout the different stages, indicating that these issues were raised more frequently over the course of the disease. There were no significant changes between stages for the emotional and social themes. The cognitive impairments only featured in the early and middle stages. In the advanced late stage, the cognitive theme hardly featured any more, probably due to the degree of cognitive impairment which affects insight at this stage (Ho & Hocaoglu, 2011). Also, in the late stages, the physical impairments become more and more evident which makes determination of the cognitive, emotional and social themes extremely difficult.

In the attempt to meet the needs of the individual, the challenge is to find adequate responses and to develop relevant and effective therapeutic strategies (Gilbertson, 2005; Aldridge, 2005). One form of non-drug therapy which is barely recognized, is music therapy. Music therapy recognizes individual needs and can be adapted to meet them. Over the past decades, music therapy is developed for patients with neurodegenerative diseases, recognizing the individual needs of the patients (Cohen-Mansfield, 2000).

What is Music Therapy?

The American Music Therapy Association (AMTA)² 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”.

Music therapists 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. Finally, they are part of the multidisciplinary team and thus participate in interdisciplinary treatment planning, ongoing evaluation, and follow-up (AMTA website).

History of Music Therapy

The first use of music in relation to illness can be traced back to ancient Egypt. More systematic studies on the effects of music on physiological processes such as cardiac output, respiration, pulse rate, and blood pressure were first carried out at end of the 19th century. Nowadays music is provided for relaxation purposes and pain relief (Bradt & Dileo, 2009).

The 20th century discipline began after the First World War when musicians went to Veteran hospitals around the country to play for the thousands of veterans suffering from physical and emotional traumas. It was soon evident that the hospital musicians required some prior training before entering the facility and so the first music therapy degree programme was initiated in 1943 in the United States. In 1998, the American Music Therapy Association (AMTA) united the National Association for Music Therapy (founded in 1950) and the American Association for Music Therapy (founded in 1971) (AMTA website).

During the last decades, new MRI techniques have made it possible to visualize the brain while playing or listening to music (Peretz & Zatorre, 2009). Studies have revealed that each musical parameter (e.g., rhythm, melody, harmony, pitch) seems to engage a broad network of brain regions (Patel, 2008). Processing the musical structure appears to trigger networks in the prefrontal and the interior frontal cortex, superior temporal poles and the cerebellum. When the music is emotionally meaningful to the listener, activity extends to the ventral tegmental area, the accumbens nucleus and the hypothalamus (Levitin, 2009).

It has been revealed that music and motor control share specific neural circuits. This has led to the assumption that music could improve movement problems in patients with Parkinson's disease and Huntington's disease (Thaut & McIntosh, 2010). Also, music has been shown to activate distinct neural pathways in the brain associated with emotion, such as the insula and cingulate cortex, hypothalamus, hippocampus, amygdala, and prefrontal cortex (Juslin & Sloboda, 2010). It has, therefore, been suggested that many more patients with dementia and other age-related conditions, developmental and learning disabilities, substance abuse problems, brain injuries, physical disabilities, and acute and chronic pain, could benefit from this treatment (Magee & Davidson, 2008; Schmid & Aldridge, 2004; Thaut, 2005).

There is evidence that rhythmic auditory stimulation improves gait in patients with Parkinson's Disease (PD) (Thaut et al., 1996). Pacchetti et al. (2000) showed in a randomized controlled, single-blinded study beneficial effects of music therapy on affective and behavioral functions in PD patients.

² American Music Therapy Association [homepage on the Internet. Retrieved from: <http://www.musictherapy.org>. Last accessed December 23rd, 2013].

Based on the insights mentioned above one can assume that music therapy could be a suitable non-drug intervention for HD. We, therefore, reviewed the literature to find out the different techniques, the primary outcome measures, and assessments used in music therapy in HD.

Methodology

A systematic literature search was conducted for any related publication, published between 1950 and 2014, in the following databases: Medline/PubMed; Embase, Cinahl, PsychINFO/PsycIndex, and Web of Science. The following terms were included: music, music therapy, in combination with the terms Huntington and Huntington's disease.

Furthermore, (hand)searches were carried out in specific music(therapy) databases, such as:

- CAIRSS (Computer-Assisted Information Retrieval Service System), a bibliographic database of music research literature, including national and international Music Therapy journals;
- The Center for Biomedical Research in Music (CBRM);
- The digital database of the Music Therapy Neurology Network (MTNN);
- The Nordoff Robins Music Therapy Research Program.

Also, specific music therapy journals were (hand)searched including the Journal of Music Therapy and Music Therapy Perspectives, as well as reviewing reference lists of the relevant publications. Finally, conference proceedings and dissertation abstracts were reviewed.

The following inclusion criteria were used:

- Participants had to be formally diagnosed as having Huntington's disease;
- Music therapy had to be involved, targeting any of the following symptoms and signs that play a role in the quality of life of patients suffering from HD: (1) motor disturbances; (2) cognitive disturbances; (3) psychiatric disturbances; and (4) emotional/social disturbances.

The references used in this article were purposefully limited to publications that focused specifically on music therapy. All music therapy references in relation to Huntington's disease were retrieved and reviewed (see Figure 1).

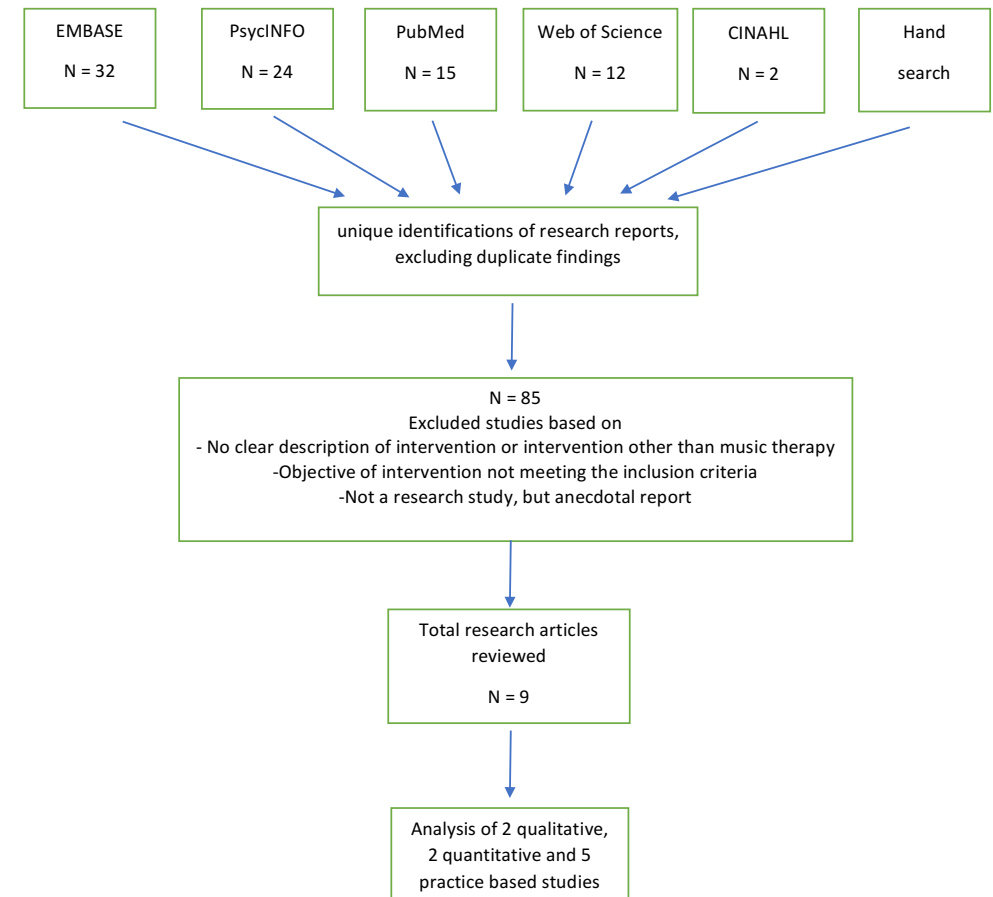


Figure 1. Flow chart search string (last search May 13th, 2014).

Results

The literature contains many case reports suggesting that music therapy may have an effect on the function of people with neurodegenerative diseases. The majority of these articles describe the development of music therapy practice, illustrated by single case studies, clinical reports, and descriptions of methodology. The reported benefits of music therapy for neurodegenerative diseases in general are summarized in Table 1 (Aldridge, 2005).

Table 1 Benefits of Music Therapy for the Neurodegenerative Diseases

Meets the needs of individual patients and their characteristics
Promotes dialogue and the maintenance of an identity that has a broad repertoire of possibilities
Reintegrates the person within a communicative ecology and prevents isolation
Offers a flexible temporal structure for processing temporal information where timing can be temporarily recovered and practiced
Utilizes gestural abilities, including utterance, binding events together that are indicative of ability
Gestures seen as attempts to regain cognition, not seen as failed abilities
Encourages rhythmical movement
Regulates emotional arousal in terms of expression and inhibition with implications for sufferers and caregivers
Needs can be expressed
Motivates communication and participation without being speech dependent
Attention, arousal, affect and action embodied in musical form

Note. Source: Aldridge, 2005.

When searching for the (MeSH)terms “Huntington’s Disease, Music and Music Therapy” we found a total of 85 references. After omitting the duplicates and the articles not fulfilling the inclusion criteria, nine articles remained: five practice based studies, two quantitative studies and two qualitative studies.

The practice based and quantitative studies were screened on research design (see Table 2). The music therapy goals and interventions described in the reviewed articles were categorized according to the targeted symptoms and signs that play a part in the quality of life of patients suffering from HD, i.e., physical (motor) ($n = 5$), cognitive ($n = 3$), psychiatric goals ($n = 1$), and social/emotional goals ($n = 5$) (see Table 3).

Practice Based Studies

Hoskyns (1982) focused on the effects of music therapy on counteracting anxiety and frustration by encouraging relaxation and group participation, and on reducing choreic movement by use of singing, playing, and listening. The most significant findings were that group singing seemed to be very beneficial and that playing musical instruments increased the choreic movement. Observation indicated a positive change in behavior of the participants, but little long term effect. Observation also suggested that listening to music aids in relaxation.

Rainey Perry (1983) conducted another relevant study in 1983. Over a period of eight months she offered music therapy sessions to small groups (six to eight participants). She developed three types of sessions: (1) music and movement; (2) music and communication/relaxation;

and (3) sing along. She found that small music therapy groups helped maintain and improve functioning in the following areas: participation, communication (both verbal and nonverbal), concentration, memory, relaxation, movement, self-esteem, self-expression, and social interaction.

Magee (1995a, 1995b) focused on different stages of HD and how different music therapy interventions could be shaped to meet the changing needs throughout disease progression. She states that in the early stage the need for active participation in music therapy is desirable, preferably individual sessions. In the mid-stage group, participation is recommended, firstly because participating in a group gives the patient more time to react (and thus less confrontation with his decline), secondly because the other patients in the group can be used as a model for other group members. Finally, in the late stage the use of receptive methods is recommended in group-settings. Active playing of an instrument for as long as possible is encouraged.

Brandt (2000) investigated the effect of performing a favorite song on the involuntary movements of six HD patients in the mid- and late stage. She concluded that there was no significant difference in effect between singing the favorite song and reduction of involuntary movements. Davis and Magee (2001) explored the use of a particular music therapy intervention. They describe a study about the use of structure within musical (active) improvisations with an HD-client. The main goal was to improve the expressive responses and to support interaction by increasing communicative contact through musical parameters.

Quantitative Studies

Grocke-Erdonmez (1976) conducted the first study into HD and music therapy in 7 HD patients. She focused on the stimulation of expressive speech through melodic speech therapy. She did find that several patients were able to sing out words that they had previously had trouble articulation through speech.

Thaut, Millner, Lange, Hurt, and Hoemberg (1999) investigated the rhythmic synchronization ability of 27 HD patients under different conditions and circumstances using the Rhythmic Auditory Stimulation (RAS) techniques. The gait speed of most of the patients could be changed in the direction of the RAS cue. Synchronization of the steps was more difficult for patients in the early stage of the disease. Thaut et al. (1999) concludes that the ability to process auditory stimuli decreases as the disease progresses, due to deterioration of the cognitive abilities.

Table 2 Practice Based and Quantitative Studies, Screened on Design

Author and year of publication	Design	Setting	Participants and HD-stage	Goals	Outcome measure	Outcome results
Erdonmez-Groce, 1976	Clinical observational trial with control group	Clinical setting, individual treatment	N = 2 mid-stage N = 5 late stage	Stimulation of expressive speech	Rating of 3 tests (pre-mid-post) through discussion tapes	No statistical evidence for improvement of expressive speech
Hoskyns, 1982	Observational trial	Holiday Care facility, group treatment	N varied per session, stage of participant varied per session	Counteract anxiety and frustration, group participation, encouraging relaxation, reducing choreic movement		Playing instruments increases choreic movement. Listening to music aids relaxation. Short term positive change in behavior
Rainey Perry, 1983	Observational trial	Clinical setting, group treatment	N = 6-8, middle to late stage	Increase/maintain participation, attention, aware, interaction, providing opportunities for self-expression Increase relaxation, communication Encourage participation		Improvement of participation, communication, concentration, memory, relaxation, movement, self-esteem, self-expression and social interaction
Magee, 1995	Single case study, needs based perspective	Day care facility, individual treatment	N = 1 early stage	Providing emotional outlet and means of expression		Active participation in individual music therapy is recommended
		Clinical setting, group treatment	N = 1 mid-stage	Choice making, improving attention, concentration, encouraging verbalization, stimulate participation, improving social skills, avoiding isolation		Group treatment is recommended, both active and receptive music therapy
		Clinical setting, group treatment	N = 1 late stage	Maintaining attention, making decisions, expression, identity		Receptive music therapy in group setting is recommended
Thaut et al., 1999	Clinical trial	Individual sessions	N = 27 all stages	Velocity modulation and rhythmic synchronization of gait	Baseline setting, pre- and post-test of gait. Statistical analysis (ANOVA)	Gait speed changed using RAS, however synchronization negatively impacted in early stage
Brandt, 2000	Practice based clinical observational trial	Clinical setting, individual treatment	HD mid- and advanced stage, N = 6	Reducing unwanted movements/ stimulating voluntary (wanted) movements	Rating videotapes of 1 session by 2 raters	No significant evidence for reducing while listening to favorite song
Davis & Magee, 2001	Practice based single case study		HD N = 1	Stimulating interaction and communication, organizing responses		Music can offer opportunities for interaction and communication

Table 3 Music Therapy and HD: Referrals and Goals

Physical (motor)	Cognitive (dementia)	Psychiatric (behavior) And psychosocial (emotional)
Encourage relaxation and reduction in choreic movement (Hoskyns, 1982)	Encourage group participation (Hoskyns, 1982)	Counteract anxiety and frustration (Hoskyns, 1982)
Increase/maintain movement, increase relaxation, (Rainey Perry, 1983)	Providing opportunities for self-expression, encouraging participation (Rainey Perry, 1983)	Stimulating communication (Rainey Perry, 1983)
Preservation of vocal abilities, demonstrate and maintaining physical strength (Magee, 1995a, 1995b)	Improvement of memory function, organizing information, musical interaction, initiation (Magee, 1995a, 1995b)	Stimulating active participation, avoiding isolation (Magee, 1995a, 1995b)
Gait improvement (Thaut et al., 1999)	recall of information despite memory function deterioration (Magee, 1995a, 1995b)	Developing relationship, increasing communicative contact (Davis & Magee, 2001)
Modulating velocity (Thaut et al., 1999)	Choice making (Magee, 1995a, 1995b)	Stimulating expressive speech (Grocke-Erdonmez, 1976)
Reducing involuntary movements/stimulating voluntary movements (Brandt, 2000)	Increasing/organizing responses (Magee, 1995a, 1995b)	Preserving expressive and communication skills (Daveson, 2007)
Improvement of physical presentation (Daveson, 2007)	Improving cognitive skills (Davis & Magee, 2007)	Enabling emotional expression (Daveson, 2007) Improving behavior problems (Daveson, 2007)

Qualitative Studies

In two qualitative studies the indication for music therapy is discussed and categorized according to the targeted symptoms and signs that play a part in the quality of life of patients suffering from Huntington's disease. The first study conducted by Daveson (2007) details the findings of an audit of music therapy referrals in a specialist in-patient setting for 16 patients with advanced Huntington's disease. These findings indicated that patients were most likely to be referred due to a need for emotional expression ($n = 10$; 29%), maintenance of communication skills and social relationships ($n = 9$; 26%). Furthermore, 14% of the referrals were due to occupation ($n = 5$), 11% to physical presentation ($n = 4$), 11% to behavior ($n = 4$). Cognitive factors were seldom a reason for referral ($n = 3$; 9%).

The second study (Bruggen van-Rufi, 2010) details the findings of a qualitative study, conducted among different members of the multidisciplinary team ($n = 14$) in a nursing home specialized in HD in The Netherlands. As in the study by Daveson (2007), the aim of the study

was to investigate the music therapy indications in this setting and to compare the findings with the referrals in four other specialized care HD units in The Netherlands.

In this study, emotion, communication, and self-expression are most often mentioned as treatment goals for music therapists. Goals in cognitive and physical areas are less recognized. Multidisciplinary collaboration is well established in most of the clinics.

Discussion

In this study we reviewed the literature describing the effect of music therapy on improvement of the quality of life of Huntington's disease patients. In doing so we specifically aimed at the effect of music therapy to influence (1) motor disturbances; (2) cognitive disturbances; (3) psychiatric disturbances; and (4) emotional/social disturbances. Furthermore we studied the different music therapy techniques used, the primary outcome measures and assessments used in music therapy with people suffering from Huntington's disease. Subsequently we tried to discover a relation between these issues and the indication for music therapy, the stage of the disease, and the quality of life.

There seems to be a discrepancy between the indication for music therapy and the quality of life issues mentioned by the clients themselves (Ho & Hocaoglu, 2011). On the one hand, conclusions are drawn stating that psychosocial and emotional issues are most often mentioned as being indications for music therapy (Daveson, 2007), while on the other hand, physical and functional problems seem to peak throughout the different stages (Ho & Hocaoglu, 2011). In a later study, the focus was on the role of music in assisting patients to organize their responses. This indication is recognized and supported by the rationale of Davis and Magee (2001). Improvement of motor features during the musical intervention was, however, beyond the scope of their study.

There seems to be no significant change in treatment goals between the different stages as far as the emotional and social themes are concerned, whereas Magee (1995a, 1995b) emphasizes that different goals should be met throughout the different stages. However, Magee bases her conclusions on observational studies in only one patient. Not the stage of the disease but the individual treatment goals seem to be more determinative for the music therapy indications. However, a relation between these two issues is plausible.

Thaut et al. (1999) state that certain goals can no longer be met, most probably because of the decline of cognitive abilities throughout the different stages. This is more obvious when patients are given different instructions. Delval et al. (2009) confirm the difficulties with multi-tasking in people with HD, due to attention deficit.

The sample size of Brandt (2000) was too small ($n = 6$) and the study consisted of only one music therapy session, so no useful conclusions could be drawn. Furthermore, the type of music as well as the manner in which it is offered in the different interventions raises questions (Magee, 1995b; Brandt, 2000): would different music styles, different instruments, different approaches have made the difference? Unfortunately there are no comparative studies of how these factors influence meeting the treatment goals.

The outcome of the two aforementioned qualitative studies confirms the lack of referrals to music therapy due to a cognitive need. Obviously, in contrast with Alzheimer's disease where cognitive decline is the primary outcome measure, this is not an indication for music therapy in Huntington's disease. These findings can be supported by Leng et al. (2003) who identified that therapeutic interventions cannot assist with regaining cognitive abilities throughout HD progression.

The findings of the two qualitative studies (Daveson, 2007; Bruggen van-Rufi, 2010) are in line with the role that has been highlighted within the practice literature: Music therapy can be used to provide a means of self-expression, social interaction, and communication.

Conclusion and recommendation

Music therapy interventions used to improve quality of life for people with HD vary and are not applied optimally. In none of the studies that we reviewed quality of life was the primary outcome. In our opinion, this also has to do with the fact that there is no consensus about which items of quality of life matter most for HD-patients, or at which stage of the disease (Ho et al., 2009; Helder et al., 2001; Ho & Hocaoglu, 2011). Due to the changing needs of the patient, the treatment itself has to be adjusted to the individual needs that are important at that specific moment. Being alert to the patient's signals demands flexibility from all members of the therapeutic team. The aim of the therapy might not be to restore or regain function, but rather to maintain function and provide opportunities for compensatory behavior to be supported, developed, and rehearsed (Thaut et al., 1999). Functional training can be combined with cognitive, emotional, and communicative/relational approaches. In so doing, the music therapist makes a link between medical and psychological treatment. Within music therapy,

the medium of intervention (the music itself) does not have to be changed. In our opinion, therefore, music therapy could be a suitable non-drug intervention for improving the quality of life of those living with HD in every stage.

The majority of articles that examined different music therapy interventions to improve quality of life of people living with HD were derived from observational studies. However, it must be noticed that the studies were often small scaled and the number of music therapy sessions were limited. Therefore we plan a systematic study of the effect of music therapy in HD.

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