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#### **KEYWORDS**

Music therapy; Matched control group; Self-acceptance; Self-esteem; Depression; Anxiety; Functional scores; Aesthetic

#### Summary

*Introduction:* Neuro-degenerative diseases are, and will remain, an enormous public health problem. Interventions that could delay disease onset even modestly will have a major public health impact. The aim of this study is to see which components of the illness are responsive to change when treated with music therapy in contrast to a group of patients receiving standard medical treatment alone.

Material and methods: Twenty multiple sclerosis patients (14 female, 6 male) were involved in the study, their ages ranging from 29 to 47 years. Ten participants formed the therapy group, and 10 the matched control group matched by age, gender and the standard neurological classification scheme Expanded Disability Status Scale (EDSS). Exclusion criteria were pregnancy and mental disorders requiring medication. Patients in the therapy group received three blocks of music therapy in single sessions over the course of the one-year project (8–10 sessions, respectively). Measurements were taken before therapy began (U1), and subsequently every three months (U2–U4) and within a 6-month follow-up without music therapy (U5) after the last consultation. Test battery included indicators of clinical depression and anxiety (Beck Depression Inventory and Hospital Anxiety and Depression Scale), a self-acceptance scale (SESA) and a life quality assessment (Hamburg Quality of Life Questionnaire in Multiple Sclerosis). In addition, data were collected on cognitive (MSFC) and functional (EDSS) parameters.

*Results:* There was no significant difference between the music-therapy treatment group and the control group. However, the effect size statistics comparing both groups show a medium effect size on the scales measuring self-esteem (d, 0.5423), depression HAD-D (d, 0.63) and anxiety HAD-A (d, 0.63). Significant improvements

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were found for the therapy group over time (U1-U4) in the scale values of selfesteem, depression and anxiety. In the follow-up, scale values for fatigue, anxiety and self-esteem worsen within the group treated with music therapy.

*Discussion:* A therapeutic concept for multiple sclerosis, which includes music therapy, brings an improvement in mood, fatigue and self-acceptance. When music therapy is removed, then scale scores worsen and this appears to intimate that music therapy has an influence.

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### Introduction

Neuro-degenerative diseases are, and will remain, an enormous public health problem. Interventions that could delay disease onset even modestly will have a major public health impact. These diseases are disabling to the sufferers, there is a loss of normal motor functioning, a change in mood, and a gradual loss of cognitive abilities<sup>1,2</sup> including auditory problems<sup>3</sup> and memory changes,<sup>4</sup> and sensory processing.<sup>5</sup> These multifarious problems worsen during the course and stages of the disease.<sup>1</sup> Furthermore, the patient does not suffer alone; these losses have an impact upon family and social life.

Multiple sclerosis is the most frequent inflammable disease of the central nervous system among young adults. It is an autoimmune disease with additional genetic and environmental factors<sup>6</sup> and considered to be one disease in the general class of neurodegenerative diseases. Disease progression differs considerably from patient to patient, so that while we may talk about stages of the diseases there is no typical multiple sclerosis patient but rather a heterogeneous group of patients where generalizations do not really apply.<sup>7</sup> As there are no curative therapeutic interventions, we are reliant upon a palliative intervention.

While medical approaches will undoubtedly focus on a functional strategy for treatment, we cannot ignore that these diseases have implications for the performance and appearance of the person in everyday life. Therefore, we need therapeutic approaches that include aesthetic performance as well as functional performance.<sup>8</sup>

Multiple sclerosis patients show increasing interest in complementary and alternative therapies.<sup>9</sup> One reason is their general disappointment with conventional medicine, since causal treatment is not possible; another is a wish to play a more active role in coping with the disease and a demand for a wider range of therapies to meet psychosocial needs as well. Patients say that by using a complementary medical approach then they take personal responsibility for health, reframe the measures by which therapeutics are evaluated, and adopt a pragmatic approach to living as well as possible in the context of a chronic condition.<sup>10</sup>

Although complementary and alternative medicine approaches are being asked for by patients suffering with multiple sclerosis, only a limited number of studies have explored arts and music therapy recently. O'Callaghan,<sup>11</sup> for example, encourages patients to write songs using expressive elements related to positive feelings for other people, memories of relationships and expressions of the adverse experiences resulting from living with the illnesses.

In a controlled pilot study Wiens et al.<sup>12</sup> demonstrated a potential strengthening effect of music therapy—with a focus on breathing and speech on the respiratory musculature of multiple sclerosis patients. Respiratory muscle weakness is characteristic of individuals with advanced multiple sclerosis and can result in repeated infections of the lung.

Based on experiences with a music-therapy group of 225 hospital inpatients with multiple sclerosis who participated in a 6-week group musictherapy program,<sup>13</sup> music therapy appeared to offer psychological support, relieve anxiety and depression and possibly help with the difficult process of coping with the disease individually.

Magee,<sup>14–17</sup> also makes use of well-known, precomposed songs and spontaneous improvisation on instruments and their attitudes change from a ''disabled self-concept'' to a more ''able selfconcept''. In a further study,<sup>18</sup> the authors showed improvements in mood state following music therapy, although depression was not directly affected.

Studies into factors governing the quality of life for multiple sclerosis patients are interesting in this context. They reveal that patients and their physicians have different perspectives. Physicians determine quality of life mainly with physical and functional parameters, while patients themselves see psychosocial well-being, emotional stability and ways to cope with multiple sclerosis-induced stress as the most important factors.<sup>19</sup> High levels of depression and anxiety are associated with people with MS who seek complementary approaches, although this may be an underlying factor of chronic illness.  $^{\rm 20}$ 

The aim of this study is to see which components of the illness are responsive to change when treated with music therapy in contrast to a group of patients receiving standard medical treatment alone.

# Patients

Twenty multiple sclerosis patients (14 female, 6 male) were involved in the study, their ages ranging from 29 to 47 years, with episodic, secondary chronic and primary chronic progression and an average disease duration of 11 years.

Ten participants formed the therapy group, and 10 the control group. The groups were comparable in the standard neurological classification scheme Expanded Disability Status Scale (EDSS).<sup>21</sup> The EDSS of both groups was 2.6 on average, which means that the participants were between normal functions (score: 0) and disability that precludes full daily activities (score: 5.5).

Exclusion criteria were pregnancy and mental disorders requiring medication.

All participants were informed of the content and details of the study and gave their written consent to publish the material, especially the video sequences from the music-therapy sessions. The Ethical Committee of University of Witten Herdecke examined the protection of data privacy and the ethical aspects.

Patients were matched by the researcher administering the trial for age, gender, stage of disease and the standard neurological classification scheme EDSS. The basis for the recruitment population was from patients coming for their regular check-ups to the general hospital. A patient was allocated to the treatment group. The next consecutive patient, if matching the previous patient, would be allocated to the control group. If not, that patient would be allocated to the treatment group until the treatment group was complete. Subsequently, 10 matching control patients were allocated.

The patients in the therapy group received three blocks of music therapy in single sessions over the course of the project (8–10 sessions, respectively). Patients in the matched control group were promised music therapy after the waiting period.

The music-therapy approach used for this study is based on the Nordoff Robbins approach.<sup>22</sup> Both patient and therapist are active. Music-making on instruments, or singing, and the music itself that emerges, all are potential possibilities for activity, encounter and experience. Individual themes and musical developments emerged for each individual patient; some wanted to sing and dance, others wanted to be sung to, and others wanted to play an instrument or brought their own instruments with them. There were no expectations of previous musical education. The patients wanted recordings of their sessions and their individual selections were recorded onto compact discs. They played them to their partners or friends or just listened to some pieces and remembered the condition and feelings of the situation.

There was a high degree of willingness on the part of all patients to take part in the study, so that all rounds of interviews were completed, and 85% of all music-therapy sessions took place.

# **Methods**

A matched control trial was implemented using a battery of indices before therapy began (U1), and subsequently every three months (U2–U4) and within a 6-month follow-up without music therapy (U5) after the last consultation.

The test battery included the following instruments.

# Indicators of clinical depression and anxiety (Beck Depression Inventory and Hospital Anxiety and Depression Scale)

The Beck Depression Inventory (BDI) is an established and reliable questionnaire for assessing the severity of depression and offers an instrument suitable to compare this study with other clinical studies.<sup>23</sup> Patients with multiple sclerosis are considered to be impaired in identifying emotional states from prosodic cues,<sup>24</sup> so it makes sense to use such an inventory.

The Hospital Anxiety and Depression Scale (HAD) is a self-administered, bidimensional instrument developed to screen for clinically significant depression and anxiety in medical populations. Somatic items are excluded to avoid the confounding effect of physical illness. While it is recognised that patients with multiple sclerosis have a high lifetime risk for major depression, less is known about affective instability and how symptoms like irritability, sadness and tearfulness affect a subject's overall degree of psychological distress.<sup>25</sup> Clinically significant anxiety, either with or without depression, was endorsed by 25% of patients, three times the rate for depression.<sup>26</sup>

### Scale for self-acceptance (SESA)

The Scale for the Evaluation of Self-Acceptance (SESA) is a 35-question scale translated from an original scale that assesses the acceptance of self and others.<sup>27</sup> Social support, and coping behaviours, are important for persons afflicted with multiple sclerosis. A healthy conception of oneself is central to coping effectively with the day-to-day stresses of modern living. The onset of any neurological disease, with either actual visible deficits or potential future disability, threatens the integrity of that concept.<sup>28</sup>

# Hamburg Quality of Life Questionnaire in Multiple Sclerosis

The Hamburg Quality of Life Questionnaire in Multiple Sclerosis (HAQUAMS) is a diseasespecific quality of life instrument for MS. There are 38 items about physical, psychological and social functions and questions about symptoms, progression of the disease and general impairment.<sup>29</sup>

People suffering with multiple sclerosis identify depression and social function as important components of quality of life and including preferences for health states and treatment alternatives in the decision to initiate treatment for individual patients is seen as an important treatment consideration.<sup>30</sup>

In addition, data were collected on cognitive (MSFC) and functional (EDSS) parameters. The EDSS describes the state of disability of an MS-patient and ranges from 0 (normal) to 10 (death due to MS). It is a classification scheme that insures all participants in clinical trials are in the same class, type or phase of MS.<sup>21</sup> It is also used by neurologists to follow the progression of MS disability and evaluate treatment results. Because of its strong emphasis on ambulation, the EDSS is insensitive to changes in other neurological functions and to cognitive dysfunction in MS. The Multiple Sclerosis Functional Composite (MSFC) is a multidimensional instrument to assess disability of MS-patients. It has three parts, testing the function of legs and walking-ability, the functions of arms and hands and the cognitive functions.<sup>31</sup> The IFSS is a scale that assesses incapacity and fatigue.

For an evaluation of the efficiency and sustained success of music therapy, Wilcoxon-test statistics of outcome-measures differences from U1 to U4 between the groups were applied to show significant differences.

# Results

Fig. 1 shows the development of the outcomemeasures in the course of time with therapy from U1 to U4 and up to U5 in the follow-up. At the start of the study (U1) there was no significant difference between therapy group and control group on the varying scale measures.

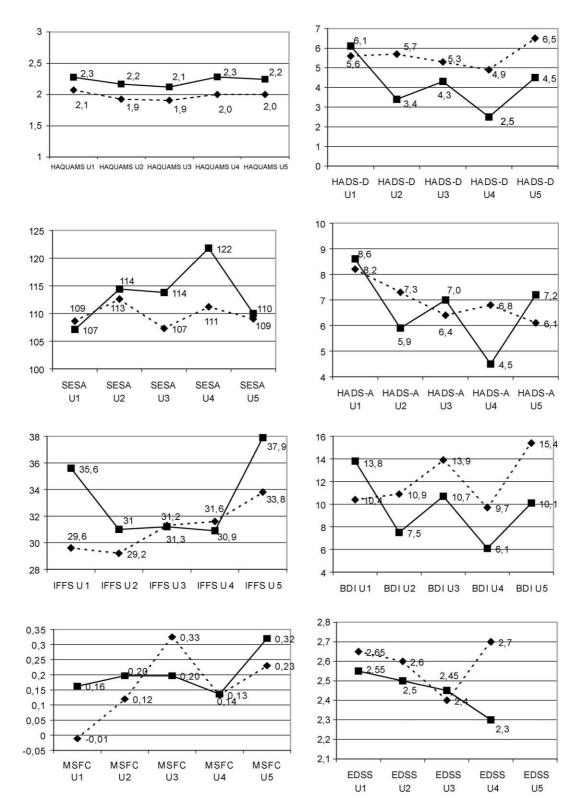
Significant improvements were found within the therapy group over time (U1-U4) in the scale values of SESA (p = 0.012) for depression (BDI, p=0.036; HADS-D, p=0.035) and anxiety (HADS-D subscale anxiety, p = 0.13). Significant differences were found for the control group in regard to the subscale anxiety (HADS-A, p = 0.031), while the values for depression and self-acceptance did not show any significant differences over time (U1–U4). No differences were found for the functional and physiological values (MSFC, EDSS) and guality of life (HAQUAMS). The latter is probably because the HAQUAMs quality of life is mainly assessed from statements of physical well-being and mobility thus reflecting scores on the functional scales. However, there was no significant difference in the improvement from U1 to U4 between the musictherapy treatment group and the control group (see Table 1), although effect size statistics comparing both groups show a medium effect size on the scales measuring self-esteem (d, 0.5423), depression HAD-D (d, 0.63) and anxiety HAD-A (d, 0.63). In the follow-up, scale values for fatigue, anxiety and selfesteem worsen within the group treated with music therapy.

The use of *p*-values and effect size are used as guides in this study as to what may be interesting as hypotheses for further studies, or if further studies are warranted. They are intended as *exploratory* statistics rather than confirmatory. This is a pilot study and there are considerable limitations both in terms of the sample size and a bias in terms of matching in that there was no random allocation to the treatment group.

Considering the correlations between the scale scores differences between T1 and T4, we found correlations between the HAD depression index and self-acceptance, and depression on the BDI and HAD anxiety and depression (see Table 2). We could, therefore, reduce our battery of tests to the Hospital Anxiety and Depression scale in any future trial.

# Discussion

This study tried to identify factors to be influenced with a music therapeutic approach in treat-



**Figure 1** Outcome measures over time. U1–U4: treatment phase, U5: follow-up. Dashed line: control-group, full-line: music-therapy group. BDI: Beck Depression Inventory, HADS-A: Hospital Anxiety and Depression Scale—anxiety, HADS-D: Hospital Anxiety and Depression Scale—depression, SESA: Scale for self-acceptance (SESA), HAQUAMS: Hamburg Quality of Life Questionnaire in Multiple Sclerosis, EDSS describes the state of disability, MSFC: Multiple Sclerosis Functional Composite, IFFS: Incapacity and Fatigue Scale, MSFC: Multiple Sclerosis Functional Composite.

		Music-therapy group, median [25%ile, 75%ile]			Control group, median [25%ile, 75%ile]			Wilcoxon signed rank test, <i>p</i> significance (two-tailed)	
EDSS	2.3 [1.4	2.3 [1.4; 3.5]			2.5 [1.5; 3.6]			0.76	
MSFC	0.23 [-0.21; 0.47]			0.1	0.14 [-0.45; 0.34]			0.61	
IFFS	34.0 24	34.0 [24.3; 45.0]			22.5 [12.8; 47.5]			0.22	
SESA	115 [79;	115 [79; 125]			110 [99; 128]			0.59	
BDI	13.0 [6.	13.0 [6.5; 19.0]			7.0 [3.0; 20.0]			0.33	
HADS-A	9.0 4.8	9.0 [4.8; 11.8]			8.0 [3.75;13.25]			0.54	
HADS-D	5.5 3.8	5.5 3.8; 7.0]			6.0 [1.5; 9.5]			0.84	
HAQUAMS	2.3 [2.1	2.3 [2.1; 2.5]			2.0 [1.8; 2.4]			0.07	
		een intake 1 rank test		of treatm	ent scores				
		EDSS	MSFC	IFSS	SESA	BDI	HADS-A	HADS-D	HAQUAMS
Z		303	507	-1.224	533	972	613	205	-1.837
Asymptotic significance .762 .6 (two-tailed)		.612	.221	.594	.331	.540	.837	.066	

 Table 1
 Wilcoxon signed rank test comparing therapy and matched control group.

BDI: Beck Depression Inventory, HADS-A: Hospital Anxiety and Depression Scale—anxiety, HADS-D: Hospital Anxiety and Depression Scale—depression, SESA: Scale for self-acceptance (SESA), HAQUAMS: Hamburg Quality of Life Questionnaire in Multiple Sclerosis, EDSS describes the state of disability MSFC: Multiple Sclerosis Functional Composite, IFFS: Incapacity and Fatigue Scale, MSFC: Multiple Sclerosis Functional Composite.

ing patients with multiple sclerosis. Music therapy can be considered as a part of a treatment strategy for two reasons. One, it offers a means to improve communicative performance.<sup>18</sup> Second, it promotes the presentation of a self that may be considered as handicapped or degenerating but can be performed as satisfying and whole—and that is a matter of aesthetics.<sup>8,32</sup> We know from the limited, principally anecdotal, music-therapy literature that there are potential benefits from music therapy in terms of enhancing mood and improving self-identity.

While there are numerous projects aimed at finding medical relief for suffering and the treatment of disease, we are reminded that diseaserelated problems influence patient's mental behaviour and this has ramifications for relationships. A major confrontation for those offering treatment, as it is for the patient, is that the problem worsens and there is no cure. This frequently life-long process for patients starting when multiple sclerosis is diagnosed obviously demands a range of therapeutic possibilities which must also consider and encourage a patient's creative abilities.<sup>33</sup> What we need to establish is which of the varying parameters is subject to influence by music therapy, which was the aim of this study.

In this study various outcome-parameters were evaluated for their possible appropriateness for showing effects of music therapy. These were both functional and affective. We included many parameters because although the clinicians involved knew that something positive was happening, there was no clear indication of what this was and how to measure it. Through this study we now have an idea of what changes and from this basis can develop hypotheses for a controlled study.

	correlation of the differences in scales between 11 and 14.						
	SESA	BDI	HAD-A	HAD-D	HAQUAMS		
SESA		-0.37 (0.11)	-0.33 (0.15)	-0.61** (0.04)	0.03 (0.89)		
BDI			0.57** (0.01)	0.49* (0.03)	0.13 (0.59)		
HAD-A				0.41 (0.07)	0.12 (0.62)		
HAD-D					0.01 (0.96)		

 Table 2
 Correlation of the differences in scales between T1 and T4.

Levels of significance are printed in parentheses. BDI: Beck Depression Inventory, HAD-AS: Hospital Anxiety and Depression Scale—anxiety, HAD-D: Hospital Anxiety and Depression Scale—depression, SESA: Scale for self-acceptance (SESA), HAQUAMS: Hamburg Quality of Life Questionnaire in Multiple Sclerosis.

\*\* Correlation is significant at the level 0.01 (two-tailed).

\* Correlation is significant at the level 0.05 (two-tailed).

Positive changes are shown in patients' depressed mood, which are also reflected in the self-acceptance scale. Given that patients with a chronic disease are also stigmatised,<sup>34</sup> and this spoiled identity is further exacerbated by the concept of degeneration,<sup>35</sup> then any intervention that improves mood and enhances self-acceptance is valuable in mitigating stigma. We know from the anecdotal literature that music therapy is important for establishing and recreating self identity.<sup>15,32,36</sup> Perhaps we should not simply consider these diseases as neurodegenerative but as dialogue-degenerative diseases, where there is a breakdown in dialogue between the sufferer and the community.

There were no recognizable changes in motor and functional abilities. The form of creative music therapy used here is efficacious for promoting a positive self-identity and relieving the emotional burden on a patient but not for improving functional abilities.

Improvements in patients of the therapy group with regard to relieving anxiety and depression, and above all with regard to improved selfacceptance, are a consequence of the qualitative changes brought about in music-therapy encounters. The change in the subscale anxiety of the HADS-D in both groups may be an indication that regular professional patient care helps reduce depression in multiple sclerosis sufferers. Standard therapeutic practice is that patients only attend for contact with a practitioner or treatment when there is a flare up in symptoms. Being recruited into a trial and being regularly assessed is also perhaps an important variable for therapeutic contact.

There is a worsening of the music-therapy group scale scores at follow-up when music-therapy treatment is withdrawn, particularly with regard to selfesteem. This may be argued as evidence of the temporary effect of music therapy or that music therapy does indeed have an effect and we see how the patient responds when the therapy is withdrawn.

The importance of therapeutic contact is reflected in a qualitative analysis of the data. Two hundred and twenty-six music-therapy sessions were documented on video and evaluated with the help of episodes and generation of categories.<sup>37</sup> What emerged from the qualitative aspects of the study were parameters concerning contact between therapist and patient, coping with the situation, the sharing of musical roles, and an ability to structure time and the possibility to initiate changes in play. These factors reflect the needs of these patients for a deeper personal contact, a recognition of their abilities rather than pathologies, and a possibility for them to exercise their own agency.

#### Qualitative considerations

In a final interview, 9 out of 10 music-therapy participants in the study described how important it was to become personally active in their treatment. All 10 participants reported an immediate improvement in their well-being during sessions. In eight participants, this improved state continued for some time and was confirmed by partners or friends. This is also confirmed by improvements in the self-acceptance and depression scales but not by quality of life scores. Differences over time in the depression scores and self-acceptance scores are highly correlated with each other that may reflect their common conceptual background. Seven participants described an enhanced perception of themselves with an increasing self-confidence over the course of the therapy. They were increasingly able to let themselves be surprised by the music as it emerged and by their own previously undiscovered musical skills. Music and music therapy are experienced by patients as "something moving" that shifts negative thoughts about the disease into the background and offers a means of expression for feelings of security, freedom and pleasure.<sup>38</sup> One participant relates how she met a friend in the University that she had not seen in a long time, after treatment. They talked for a while and it was only on parting that she told her friend that she has multiple sclerosis. This was a shift in her perception of herself as first and foremost "a sick person" to a normal person with other priorities in life.

What is evident from this study is that in assessing music therapy in terms of meeting patients' needs then we cannot simply take a functional approach alone. Multiple sclerosis patients have a variety of needs, some of these are psychosocial and some of these are also aesthetic. An aesthetic therapy offers the opportunity to experience the self not as solely degenerative but also as creative. This is a major turn around in selfunderstanding and is reflected in both self-esteem and an improvement in mood. We are not denying that these patients have a degenerative disease, simply that these patients are not themselves degenerate. In the face of pathology, even in sickness, we have the potential to be active creative agents. Music therapy emphases creative dialogue as an remedy in the face of a dialogic degenerative disease.35

We have used effect sizes here, although modest, to provide a platform for other studies that will no doubt improve on what we have attempted. This exploratory study has indicated the potential benefits of music therapy as an aesthetic intervention concerned with the performance of self in everyday life. At some stage we will also need to consider multi centre trials.

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