Life satisfaction of musicians with focal dystonia

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Background
Little is known about the effects of musicians’ dystonia (MD) on patients’ life satisfaction.

Aims
To assess general life satisfaction in patients with MD with regard to their health and jobs, in relation to the duration and course of the condition.

Methods
We asked patients with MD and a group of healthy musicians (controls) to complete a life satisfaction questionnaire. We analysed responses from those who had to change their profession and those who did not, and we assessed life satisfaction scores in relation to the duration and the course of the condition.

Results
Of the 642 patients contacted, 295 responded (46%). We excluded 52 amateur musicians and analysed a sample of 243 patients with MD. We contacted an unknown number of healthy musicians and 57 responded. We found no differences in life satisfaction between patients and controls or between patients who had to change their profession and those who did not and no correlations between life satisfaction and the duration or the course of the disease.

Conclusions
Musicians find a way to cope with dystonia, irrespective of the course of the disease or a change of profession. Patients should be made aware of self-regulatory mechanisms and the probability of being able to cope and be supported in selecting their goals and achieving them.

Key words
Coping; hedonic treadmill; life satisfaction; movement disorders; musicians’ dystonia; quality of life; subjective satisfaction paradox; task-specificity.

Introduction
Musicians’ dystonia (MD) is a task-specific movement disorder that leads to involuntary cramping of an affected limb. It severely impairs the ability to execute highly trained movements that are needed in playing an instrument. MD affects ~1% of professional musicians and in many cases leads to the end of a career [1–3]. Its aetiology is multifactorial and related to several internal factors (e.g. anxiety, perfectionism, heredity, gender and deficits in inhibitory mechanisms) and external ones including musical genre as well as temporospatial and sensorimotor constraints, such as the complexity of movements in playing specific instruments [1]. Most professional musicians start playing their instruments before adolescence and practice >10000h by the age of 20 [4]. Therefore, apart from the immediate impact on musicians’ professional careers, dystonia may affect their general life satisfaction (GLS), especially for those who have to change profession as a result of the disorder. Interestingly, little is known about the impact of dystonia on musicians’ life satisfaction.

An accepted model of personal well-being is the ‘hedonic treadmill’ theory, according to which people tend to adapt to life events and return to a set point [5,6]. However, other studies have shown that a shift in the set point may occur due to disabilities or unemployment [7,8] and that young and middle-aged adults invest most of their thinking and actions in their jobs, friends or families [9]. As dystonia typically starts when patients are in their mid-30s [1], it might be expected to have a significant impact on life satisfaction.

The aim of this study was to investigate the following hypotheses: (1) GLS, and specifically the subscales ‘health’ and ‘job’, differ between MD patients and (a) the general population and (b) healthy musicians (HMs); (2) MD patients who have to change their profession because of MD have lower GLS scores, in general and on the health and job subscales and (3) GLS scores in
general and on the ‘health’ and ‘job’ subscales are associated with the duration and the course of dystonia.

Methods

We randomly selected patients diagnosed with focal dystonia from the database of a neurological outpatient clinic at the Institute of Music Physiology and Musicians’ Medicine, which specializes in the diagnosis and treatment of disorders related to music-making, and which supported the project. We contacted patients by mail. We recruited HMs as controls from professional orchestras, music-universities and freelancers via an open invitation, which we sent by e-mail to the respective administrative offices, so the number of HMs contacted was unknown.

To assess GLS, we chose the standardized Questionnaire on Life Satisfaction (Fragebogen zur Lebenszufriedenheit in German) [10]. This was validated in 2000 by a representative sample of the general population. Possible age and gender differences between individuals are thus normalized to stanine values (i.e. standard nine values that place a person’s relative position in comparison to the general population according to his/her age and gender [10]), allowing comparisons of different age and gender groups. The GLS has 10 subscales: ‘health’, ‘job’, ‘financial situation’, ‘spare time’, ‘marriage/partnership’, ‘relation to one’s children’, ‘one’s own self’, ‘sexuality’, ‘friends/relatives’ and ‘own apartment’, the last of which refers to satisfaction with accommodation. Rating is based on a self-assessment on a 7-point Likert scale (1 = very dissatisfied, 7 = very satisfied). Stanine values between 4 and 6, which represent 54% of the general population, were considered to be an ‘average’ GLS. Values between 1 and 3 (23%) and 7 and 9 (23%) represent a GLS ‘below’ and ‘above average’, respectively. For the calculation of the GLS score, data from seven subscales were required, including those from ‘sexuality’. Due to many missing values in this specific subscale for HMs, the GLS could not be calculated for this group. Therefore, no direct comparisons between HMs and MD patients were conducted.

Additionally, we asked MD patients (i) whether they had changed their profession due to dystonia, (ii) about the course of the disease and (iii) about the duration of dystonia since its onset (see Supplementary data available at Occupational Medicine Online). The variable ‘course of the disease’ was rated using a 6-point scale (‘no symptoms’, ‘major improvement’, ‘moderate improvement’, ‘minor improvement’, ‘unchanged symptoms’ and ‘deterioration’).

To test hypothesis (1a), we performed a chi-square test to compare the stanine distributions of GLS subscales ‘health’ and ‘job’ in MD patients and the general population (3 × 2 cross tabulation). To test hypothesis (1b), we performed a one-sided Wilcoxon rank sum test for the mean stanine values of GLS between MD patients and HMs, assuming a lower mean value for MD patients. For hypothesis (2), we performed a two-sided Wilcoxon rank sum test of the mean stanine values of the GLS and for subscales ‘health’ and ‘job’, respectively, between those MD patients who had changed their professions and those who had not. For hypothesis (3), we conducted two one-sided Spearman correlation tests.

We also tested the contribution of each subscale of GLS in MD patients and HMs because physical impairment may affect how people invest their thoughts and actions, which is related to subjective well-being [11].

The study was approved by the ethics committee of the Hanover Medical School and all participants gave written informed consent.

Results

Of the 642 MD patients contacted, 295 responded (response rate 46%). We excluded 52 amateur musicians (18%) so the study group consisted of 243 MD patients (age: 48 ± 10 years [M ± SD], 77% male). Fifty (21%) had changed their jobs. Fifty-seven healthy professional musicians (age: 37 ± 10 years, 54% male) responded. As the denominator for this group was unknown, we could not calculate the response rate. Details of participants’ characteristics are given in Table 1A and B.

The significant age (W = 10 609, P < 0.001) and gender (χ²(1) = 32.8, P < 0.001) differences between MD patients and HMs were eliminated by the use of the standardized norm values of the GLS questionnaire (see previous section).

We found no significant difference between the distribution of below average, average and above average GLS scores in MD patients and the general population (χ²(2) = 0.8, P > 0.05) (Figure 1), or for the ‘job’ (χ²(2) = 0.9, P > 0.05) and ‘health’ (χ²(2) = 3.3, P > 0.05) subscales, respectively. The Wilcoxon rank sum test comparison of mean stanine values for the ‘job’ and the ‘health’ subscales between MD patients and HMs revealed no significant difference (‘job’, W = 7574, P > 0.05 and ‘health’, W = 7302, P > 0.05) (Figure 2). Additionally, there were no differences in the mean stanine scores between MD patients who changed professions (21%) and those who did not for total GLS (W = 4464.5, P > 0.05), and ‘job’ (W = 4189.5, P > 0.05) and ‘health’ (W = 4908, P > 0.05) subscales (Figure 3).

Among MD patients there were no correlations between GLS and the course of dystonia (r = −0.03, P > 0.05) or its duration (r = −0.06, P > 0.05). Similarly, no correlations were found between ‘job’ subscale score and the course of dystonia (r = −0.08, P > 0.05) or its duration (r = 0.2, P > 0.05) or between ‘health’ subscale scores and the course (r = 0.008, P > 0.05) or the duration of dystonia (r = 0.04, P > 0.05). The other subscales revealed mean stanine scores for MD patients and HMs within the ‘average’ range (between 4 and 6) (Table 2).
Our findings suggest that musicians suffering from focal dystonia are not less satisfied with life in general or with their health and jobs than are unaffected musicians and the general population. Furthermore, neither GLS or job satisfaction or health is associated with the duration of dystonia or the course of the disease. Although these findings disprove our study hypotheses, they are interesting and have important implications for MD patients. Given the rarity of MD among professional musicians, this is the largest sample used to investigate GLS in MD patients. Different recruitment methods between patients and controls, the poor response rate of patients and an unknown response rate in controls are limitations of the study, particularly as we collected no information about non-responders. However, our sample was representative of the dystonic population with regard to gender distribution, age at the onset of dystonia and age of beginning to play the instrument\[1\]. Also the GLS questionnaire may not be specific enough to detect differences in the life satisfaction of MD patients. A validated questionnaire specifically for MD patients might therefore be needed. However, our questionnaire contained the subscales 'job' and 'health', which allowed a comparison of the satisfaction level of these scales with control groups (i.e. HMs).

### Table 1. Subject- and music-related data

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>(A) Subject-related data</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td>47.6 (9.9)</td>
<td>36.5 (10.0)</td>
</tr>
<tr>
<td><strong>Age at dystonia onset (years)</strong></td>
<td>34.6 (9.3)</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Duration of dystonia (years)</strong></td>
<td>7.6 (4.2)</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Time until diagnosis (years)</strong></td>
<td>5.5 (6.3)</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Gender, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>55 (23)</td>
<td>31 (54)</td>
</tr>
<tr>
<td>Male</td>
<td>188 (77)</td>
<td>26 (46)</td>
</tr>
<tr>
<td><strong>Kind of dystonia, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand</td>
<td>176 (72)</td>
<td>NA</td>
</tr>
<tr>
<td>Embouchure</td>
<td>59 (24)</td>
<td>NA</td>
</tr>
<tr>
<td>Other</td>
<td>8 (3)</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Job change, n (%)</strong></td>
<td>50 (21)</td>
<td>NA</td>
</tr>
<tr>
<td><strong>(B) Music-related data</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age when starting the instrument</strong></td>
<td>9 (3.1)</td>
<td>8.5 (3.9)</td>
</tr>
<tr>
<td><strong>Instrumental group, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keyboard</td>
<td>64 (26)</td>
<td>29 (51)</td>
</tr>
<tr>
<td>Woodwind</td>
<td>58 (24)</td>
<td>7 (12)</td>
</tr>
<tr>
<td>Brass</td>
<td>51 (21)</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Plucked</td>
<td>35 (14)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>String</td>
<td>31 (12)</td>
<td>18 (32)</td>
</tr>
<tr>
<td>Percussion</td>
<td>4 (2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Singing</td>
<td>0 (0)</td>
<td>1 (2)</td>
</tr>
<tr>
<td><strong>Music style, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Classical</td>
<td>214 (88)</td>
<td>56 (98)</td>
</tr>
<tr>
<td>Jazz/Rock/Pop</td>
<td>27 (11)</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Blasmusik*</td>
<td>2 (1)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

NA, not applicable; SD, standard deviation.

\*Traditional German wind music.

### Discussion

Our findings suggest that musicians suffering from focal dystonia are not less satisfied with life in general or with their health and jobs than are unaffected musicians and the general population. Furthermore, neither GLS or job satisfaction or health is associated with the duration of dystonia or the course of the disease. Although these findings disprove our study hypotheses, they are interesting and have important implications for MD patients.

Given the rarity of MD among professional musicians, this is the largest sample used to investigate GLS in MD patients. Different recruitment methods between patients and controls, the poor response rate of patients and an unknown response rate in controls are limitations of the study, particularly as we collected no information about non-responders. However, our sample was representative of the dystonic population with regard to gender distribution, age at the onset of dystonia and age of beginning to play the instrument\[1\]. Also the GLS questionnaire may not be specific enough to detect differences in the life satisfaction of MD patients. A validated questionnaire specifically for MD patients might therefore be needed. However, our questionnaire contained the subscales 'job' and 'health', which allowed a comparison of the satisfaction level of these scales with control groups (i.e. HMs).
Another limitation is that no detailed analysis of the stage of the disorder could be obtained, as MD develops differently between individuals and fluctuates over time, depending on the different ways patients are able to cope with the disorder. Our findings suggest that different mechanisms help patients cope with MD. The subjective satisfaction paradox describes the phenomenon that objectively, adverse events in a person’s life apparently have little or no impact on GLS, as long as a minimum of existential needs are secured [12,13]. One explanation for the paradox may be the long duration of dystonia (7.6 ± 4.2 years [M ± SD]). Previous studies suggested that subjective well-being is influenced only by events in the preceding 3 months [14]. This is in accordance with the concept of the hedonic treadmill [5,6]. Other studies investigating patients with spinal cord injuries showed that only 3 weeks after the trauma, happiness was the strongest emotion felt by 58% of patients, and 8 weeks later, positive emotions prevailed over negative emotions [12,15,16]. Therefore, it is likely that many MD patients find a way to cope with their situations in a way that allows them to regain an average satisfaction level not only with regard to GLS but, more importantly, to their jobs and their health as well.

Personality characteristics play an important role in coping with MD [17]. Coping, according to Lazarus and Folkman [18], consists of ‘constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person’. It is a dynamic and process-oriented phenomenon [19]. The moment the diagnosis is given may be important for the coping process because early symptoms are often misinterpreted as a lack of technical skill or misdiagnosed by physicians [1]. The consequences are insecurity and frustration, helplessness, self-blame and fear of losing one’s job. Furthermore, many musicians are ashamed of not being able to perform at their ‘normal’ level [20] and try to hide the symptoms from friends and family.
colleagues. Therefore, a diagnosis of MD may be a relief for many patients because it not only clarifies 'what happened' from the patient’s view but also allows for specific therapeutic options, giving the patient the feeling that something can be done. The coping process then comprises person-related variables such as personality, on the one hand, and social relations with colleagues, friends, family and physicians, on the other. Thus, coping strategies differ between individuals and, according to Schüßler [21], occur in steps with the goal of achieving a new life equilibrium.

One self-regulatory mechanism to prevent the loss of one’s well-being in difficult situations is the comparison of one’s situation with that of others who are worse off (downward comparison) [12,13,22]. It is assumed that people with higher life satisfaction tend to apply downward comparisons [12]. For instance, it is known that breast cancer patients assessed their well-being as higher after surgery and that they considered their situations as better than those of women in comparable situations. Another self-regulatory mechanism, changing personal demands, may also contribute to individual well-being [13]. For example, it was found that an increase in income did not lead to an increase in subjective well-being [23], which was interpreted as the result of a shift in demand. Both of these mechanisms, a downward comparison and the shift in a person’s demands, interact. Thus, it is conceivable that the protracted experience of dystonia has led patients to reappraise their situation and helped them to adjust their professional goals and demands. Interestingly, a recent study of MD patients suggested that their subjective evaluation of dystonic symptoms after 4 years of retraining therapy was more positive than objective measures [24]. This may be the result of personal readjustment, which does not have to be a conscious process [13]. Moreover, it is known that health impairment may shift the focus of a person’s thoughts and actions and that this is related to subjective well-being [11]. However, we did not find any difference in any of the subscales of the GLS questionnaire, which suggests that none of the measured aspects compensated for another.

In this context, the model of selective optimization and compensation (SOC) [25], as explained in Staudinger’s study [13], is noteworthy. It proposes that for achieving or regaining self-satisfaction, the proactive selection of alternatives plays a role. This may mean a job change. However, for musicians, selection may also mean a new repertoire that poses fewer difficulties. Next, an optimization of the resources available and a compensation for the loss of means no longer available are necessary for achieving the selected goals [13]. Because we found no difference between those patients who had to change their profession and those who continued to play music on a professional level, one may assume that, according to the SOC model, no matter which way was chosen and how the dystonia developed over time, both groups were successful. They first succeeded in selecting new parameters in which to invest and second in optimizing their resources in order to achieve the selected target. Furthermore, those musicians who did not change professions in particular were able successfully to compensate for those technical skills no longer available.

We expected an inverse relationship between GLS and severity of dystonic symptoms and an improvement of GLS with increasing duration of dystonia (in years). Our unexpected findings have consequences for clinical practice. First, it is important to discuss self-regulatory mechanisms and the high probability of being able to cope with the situation, irrespective of the course of the disease. Subjective well-being can be created and modified proactively [13] and a set of coping strategies is related to the level of well-being [11]. Therefore, it may be more important to support patients in proactively selecting their goals and helping them to achieve them than advising a change of job. In order to address different aspects of coping mechanisms in MD patients, we need more longitudinal, rather than cross-sectional, studies.

### Key points
- In this study, life satisfaction did not differ between musicians suffering from musicians’ dystonia and healthy musicians.
- Our findings imply that musicians find a way to cope with dystonia, irrespective of the course of the disease.
- We suggest that physicians should support musicians suffering from dystonia in proactively selecting their goals and help them to optimize their means to achieve them.

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University of Music, Drama and Media Hanover, Germany.

### Conflicts of interest
None declared.

### References