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Musicians' social representations of health and illness: A qualitative case study about focal dystonia

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Abstract. Musicians are artists who use the entire body when playing their instruments. Since over-practicing may lead to physical problems, musicians might encounter focal dystonia, a hand's motor disorder. The cause seems to be the brain's confusion between afferent and efferent information transfer provoking a disharmony with the instrument. Although focal dystonia may have serious consequences for a musician's career, it is unclear how musicians perceive this trouble.
This case study describes two musicians with focal dystonia. Qualitative research was used to study their social representations of health and illness. The results show the central role of the hand during music playing, the passion for music and the understanding for focal dystonia as "brain panic". Therapists should account for those specific features inherent to this population in order to better help them in their quest for art through music. Giving a voice to musicians may improve their quality of care.

Keywords: Physical therapy, performing artists, rehabilitation

1. Introduction

The art of playing music evolves in a particular environment: the artistic environment. A musician is above all an artist. Artists are particularly sensitive and emotional people whose work and career are at the center of their lives [1]. Within the musical world, emotions, sensitivity and perfectionism are combined with irregular schedules, competition, pressure and stress [2]. This context mirrors the particular work environment of musicians. This journal with the aim to provide research on work-related prevention, assessment and rehabilitation is right at the heart of the questioning of this article.

Playing an instrument requires a high level of performance of the body, and a musician's performance can be compared to an athlete's. Musicians use their body many hours a day, however, they are neither always conscious of the importance of physical demands of their work nor aware of how to deal with physical problems when they arise [2]. In addition to that, pain is not always considered important enough as it is often associated with a slow-down from public performance [3]. These considerations may lead to playing-related musculoskeletal disorders (PRMD) [4]. One of those disorders is focal dystonia.

2. Focal dystonia

Focal dystonia – a task-specific movement disorder – is defined as [5] "a muscular incoordination or loss of voluntary motor control of extensively trained movements" (p. 144).

Both neurophysiologic and psychological aspects have to be considered in the development of focal

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dystonia. Results of magnetoencephalography or somatosensory evoked potential technology have shown that focal dystonia is linked to dysfunctional plasticity neuronal networks [5]. In the cerebral cortex, afferent and efferent receptive fields of adjacent finger representations are blurring [6].

Several characteristics of the loss of motor control can be distinguished: it is painless, task specific and most of the time concentrated on the hand while performing a complex task. It does not occur during the acquisition of skills but when motor programs have already been acquired [7]. The symptoms appear gradually and reach their peak at the high point of the musicians' professional career. It affects approximately 1% of professional musicians, and there are some known risk factors such as male gender, positive family history and predisposition, favoring the development of focal dystonia [8]. In addition to those risk factors, some intrinsic – need for control, perfectionism, anxiety, local pain and intensified somatosensory input – and extrinsic factors – spatial and temporal sensorimotor constraints as well as social constraints – might have a somatosensory or sensorimotor influence [5].

Great interest is also put on the psychological dimension of the problem. As an example, Robert Schumann's developed a writer's cramp, a task-specific loss of voluntary control of his right middle finger in 1831. This trouble forced him almost completely to give up playing the piano. Physicians at that time already mentioned psychogenic conditions [6]. Studies about the personality of musicians show that psychological traits in musicians with focal dystonia differ from those of healthy musicians [9]. As music is considered a "language of emotions", playing an instrument requires specific affective conditions associated with precise fine motor skills. This link between a continuous search for high performance and the involvement of strong emotions may lead to a dystonic pattern. A tendency toward perfectionism and anxiety was found to be often present by musicians developing this kind of trouble [5].

3. Social representation of health and illness

Focal dystonia is suffering from marginal recognition due to a lack of knowledge in the medical world and a low prevalence in the musical world. It is extremely important to focus on this possibly devastating phenomenon for a musician's career. Even though a quantitative approach can provide insights into frequency and prevalence of this trouble, it is not able to take into account musicians' point of view.

Social representations theory provides a useful framework for this purpose. Moscovici [10] argues that collective representations determine the individual's behaviour. Collective representations are a system of beliefs, ideas and practices that are shared in a group and establish a specific conduct for this group. Therefore, a group's representation has a direct influence on the cognitive functioning of each subject of this group.

In the same way, health representation is an interpretation giving sense to illness, health and body. The social representations of health (or in this case, specifically focal dystonia) can be understood as the connection subjects (musicians) make between the medical world and their own world using their own words [11]. It is argued that cognitive mechanisms of social representations provide a useful approach to study health [12].

4. Musicians' point of view: Two case studies

In light of this framework we will now focus on two interviews with professional musicians suffering from focal dystonia. The objective of the interviews was to explore the meaning the musicians give to their practice and to gain insight into the social representation of health and illness. It was also important to understand what the musicians really needed and expected from health professionals.

A case study approach is a systematic research tool [13] and can become a valuable tool for health services research [14]. According to Yin [14] the strength of a case study lies in its "intense focus on a single phenomenon within its real-life context" (p. 1211). Like any other research design, scientific rigour criteria are very important and have been taken into consideration in this case study.

Reflexivity – one of the stated criteria – can be defined as "the sensitivity to the ways in which the researcher's presence (. . .) has contributed to the data collected and their own a priori assumptions have shaped the data analysis" [15, p. 188]. This should be done continuously in order to enhance credibility of the data [14]. Yin [14] proposes the following procedure: to define the case, to use multiple sources of evidence (triangulation), to follow specific steps during data collection and to separate his own interpretations from the case study evidence. Triangulation as a test of validity is a contested criterion [15]. However, a second opinion might be useful to detect *a priori* assumptions of

Table 1
Two semi-structured interviews were conducted with professional musicians

	Sex	Age	Instrument	Profession	Physical trouble
Interview I	male	26 years old	piano	teacher – concert artist	Focal dystonia (Right hand)
Interview II	male	27 years old	electric guitar		

the researchers [15]. Therefore, a second researcher – physical therapist with a musical background – was involved throughout the study to discuss certain aspects and to confront her opinion with the other researcher's. Specific steps were then followed during data collection.After each interview, the researcher took a moment to reflect and revisit her framework and data collection. In this way each case becomes a "pilot" case for the following one.

Validity of the findings may be reached through the use of an interview guide [14,15]. The interview guide was previously tested and adapted after two interviews with professional pianists. Such a logical model can accomplish the generalization from case studies through hypotheses or theories about the cases [14].

4.1. Recruiting and data collection

The musicians were recruited through the treating physical therapist and gave their consent to be referred to the first author (AZ). Inclusion criteria were professional musicians with a history of focal dystonia. The presence of symptoms meant that the participants had received treatment and therefore had opinions about the medical approach and treatment options. Only professional musicians were considered for this study because it was felt that physical difficulties with performance would be more significant for these musicians. Musicians who met these inclusions criteria were then contacted by phone by the interviewer (first author) and invited to participate in an interview with her.

Two interviews were conducted with a 26-year old piano teacher (interview I) and a 27-year old electric guitar teacher (interview II). Both were male with a diagnosis of focal dystonia and both played at a professional level Table 1. At this time, physical therapy treatment was not required anymore as symptoms were absent.

Each interview lasted about an hour and was conducted with French musicians who had to have mastered the language sufficiently in order to express themselves freely. It was done in a non-medical environment in order to provide a neutral setting. The interviewer presented herself as a physiotherapist and a musician. The aims of the case study and the ethical aspects (e.g. voluntary participation, confidentiality) of the research were explained and the musician was then free to accept or refuse the interview. Interviews were audio-recorded.

Semi-structured interviews with open questions focusing on the topic of research were used Table 2. The table represents a check-list describing all the dimensions to be considered (professional, sociological, social, psychological and medical). As the questions do not have to be asked one after each other, the interviewer followed the themes proposed by the subject. Immediately after the interview, the researcher wrote down her reflections about the interaction. This process helped to clarify the researcher's role and feelings that could possibly influence the data analysis. Reflexivity is one criterion to enhance quality in qualitative research [16, 17]. The tape recordings were transcribed verbatim and shared with another experienced qualitative researcher.

4.2. Data analysis

Transcriptions were then analysed using thematic analysis permitting the emergency of key themes [18]. Each interview was first analysed separately. Categories found in each transcript were then compared to those in the other transcripts. This was an inductive process and did not rely on pre-established categories. Apart from this analysis directly deriving from the interview data, the researcher added the description of the interview's context, her personal impressions and her musician's self-evaluation.

Ethical aspects were important to assure musicians' anonymity and data confidentiality. Data were made anonymous during the transcription process and recordings were destroyed after use. For this article, participant's quotes were translated into English.

5. Findings

There are three main themes that emerged from the data: 1) Body as the first instrument, 2) Music as a way of living, and 3) Focal dystonia as "brain panic".

Table 2
Extract of the grid used to conduct interviews

Concept	Dimension	Indicator	Questions
Musicians' representations of health and illness	Professional	Reputation. . .	What is the link between your health and your contracts?. . .
	Sociological	Illness' perception. . .	From a general point of view, what does illness lead to somebody?. . .
	Social	Financial aspect. . .	Does your health have an influence on your salary?. . .
	Psychological	Personal value. . .	What do you think about the expression "sound in mind and body"? . . .
	Personal	Dysfunction. . .	Did your body vision change after your physical trouble?. . .
	Medical	Health. . .	Do you have some common goals with your therapist?. . .

Fig. 1. The hand as the mean of expression of musician's passion.

5.1. Body as the first instrument of the musician

The musicians insisted on the central function of the body for playing their instrument.

> *"I'm demanding from my hands the same work like a soccer player is demanding from his legs [. . .] I wonder what distance I'm covering each day on my guitar doing my scales"* (*II p. 17*).

They consider the body as the first instrument of the musician because of the close link between body positions and sound, with sound being every musician's ultimate goal. However, high importance is given to the hand. It is the object of all attention and may influence choices.

> *"Hand health it's the object of all my attention [. . .] I would even say it's the reason influencing my personal and professional choices [. . .] It's the only reason that would drive me to the doctor"* (*II p. 1*).
>
> *"If I have manual work to do I'm gonna wear gloves in order to keep the sensitivity [. . .] I used to like manual work but now I never use a shovel, a pickaxe or a chain saw"* (*II p. 1*).

It is also considered as the means of expression of their passion Fig. 1. This focus can lead to extreme behaviour as mentioned by one of the musicians.

> *"I saw pianists -it was funny- they always have sleeves that are too long, and they keep their hands close to the body"* (*II p. 1*).
>
> *"Some violinists are insuring their hands for millions. . . like a neurotic behaviour"* (*II p. 2*).

These statements are similar to the ones in the literature. The hand's cortical representation is also greater in musicians compared to non-musicians [19]. Most research about musicians' musculoskeletal problems is focused on the upper limb. Disorders of the hand range from 28% (majority of string instruments) to 65% (majority of pianists) in comparison to shoulder and forearm problems [20].

If the hand does not function properly it puts the musician in an uncomfortable position.

> *"I wanted to do an octave, I had to keep my hand open but this became impossible because all fingers in between bent on themselves in such a way that the notes between the 'do' and the 'do' were also played [. . .] It was the right hand [. . .] That was really painful but what was even more tricky was my teacher asking me what I was doing. . . in such a way that I was wondering what my own hand was doing, what I was gonna do, how I was going to play again, how I was going to play music again"* (*I p. 3*).

This partial inability may have an influence on musician's reputations as expressed in the following quote.

> "*So I left my teacher and I chose someone who knew me and who knew I played well because we usually mix focal dystonia and playing abilities. And after this, people thought I had a problem of communication with my music teacher*" (*I p. 4*).
> *"After a while my teacher wondered what he was gonna do with me in his virtuosity class [. . .] the music school told me it was because I wasn't able to organise myself and my work well enough"* (*I p. 10*).

The relationship between the musician and his instrument is quite fusional. Considering this, the hand does have a great importance because it is the link between the musician and his instrument.

5.2. Music as a way of living

For musicians, to play an instrument is much more than a job: it is a need, it is a passion.

> *"I'm kind of addicted to work. If I'm not practicing enough each day I've got the impression of having done nothing and I don't feel good [. . .] for me it would be impossible to stop playing music. . . my life has revolved around music for more than fifteen years"* (*II p. 17*).

They consider themselves as being perfectionist.

> *"I worked for an hour and if I wasn't happy I worked for another hour. I was able to stay hours practicing until I was satisfied"* (*I p. 9*).
> *"My parents knew an orchestra's first violinist who had health problems due to music playing. He interrupted his career to learn to play on the other side. After two years training he came back as first violinist"* (*II p. 19*).

The concepts described above, as well as their artistic sensibility, make musicians susceptible to being highly involved in their work.

> *"We are generally quite sensitive, we tend to have tormented soul. . . so artist's failure. . . .when a musician fails it's an entire world that falls apart"* (*II p. 9*).

Characteristics of a good musician are being involved a lot both emotionally and intellectually while doing their work, and giving music all of their energy and psychic power [21]. It is exactly this point of extreme involvement that can lead to focal dystonia.

5.3. Focal dystonia as 'brain panic'

The interviewed musicians describe dystonia as 'brain panic'. They consider their problem as a destabilisation of the hand position.

> *"It's small uncontrolled movements. After this the brain panics. When it panics it gives contradictory information and after a while you give a finger the order to move and it's another finger that's moving"* (*I p. 8*).

They link this phenomenon to the right brain function that is responsible for creativity and emotionality.

> *"People with dystonia have a tendency to be "right brained". It's the reason why structure begins to fail, and this state creates a stress in regards to what you can play and it becomes blurred [. . .] I always had an intuitive technique. I never worked my technique I was just playing that's all"* (*I p. 14*).

They expect a treatment that will give them confidence from an accessible and reassuring care provider. Musicians fear that health professionals are unable to detect and treat their health problem.

> *"I wanted to learn something about that so I went to the hospital. I did Rx, I went to a neurologist, I had massages. . . I did a lot of things. Nobody could tell me anything about it"* (*I p. 5*).
> *"A friend had a focal dystonia. His doctor told him to put his hands under warm water!"* (*II p. 7*).
> *"My physical therapist told me she knew musicians who had an operation for focal dystonia. That's very serious because you don't need to get an operation for this!"* (*II p. 17*).

6. Discussion

Our findings show the important links between musicians, their body, their passion and – in case of focal dystonia – their trouble. Taking into account their point of view may give the caregiver the right focus for appropriate care. Our results indicate that treatment goals should address the mobility of the hand – biomechanical part – in order to achieve a better sound – musical part [22], Fig. 2.

A musician seeking help from a caregiver is above all an artist. Giving parts of their body to someone elserequires having confidence in their caregivers. This is the reason why musicians' treatment for their health problems need to achieve an atmosphere to enhance the

Fig. 2. The treatment goal: to improve the mobility of the hand in order to achieve a better sound.

patient'speace of mind [22]. Understanding personality traits might improve care for an artist. Manturzewska studied psychological factors of musicians and concludes that music students are characterised by more egocentricity, need of independence and autonomy than other non-music students [21]. The two interviewed musicians mention at various times the importance of individualized care.

> *"For my job I have some needs. My doctor knows me [. . .] I know he's aware of it and knows how to treat me [. . .] If I'm going to the doctor, it's not "number six hundred twelve what's happening?" I need a human relationship with my doctor"* (*II p. 8*).

Artists are also always looking for recognition and therefore injury is perceived asdevastating. There is a continuous struggle between the search for understanding dystonia and the achievement as a musician.

> *"After all those years of searching to understand, trying to find solutions and work I received my diploma. I was at the top of the class"* (*I p. 11*).

Taking into account those considerations is important in order to provide appropriate treatment. First, the physical part of the treatment should help the musician in recovering a good interaction between afferent and efferent informations. This requires a long work and some improvement for the musician.

> *"I grew up with focal dystonia so know I have to be very patient, rigorous and disciplined because sometimes some old reflexes are coming back to the surface [. . .] I have to work on this. Each order has to be well executed and no movement has to be done without order. That's the way of mastering dystonia: giving orders again and again. So you have to be patient and rigorous. If you had bad habits for many years it's not in one week of work you're gonna adopt good reflexes and erase all the rest. It's a long work"* (*I p. 8*).

The psychological dimension of the treatment should provide the musician the possibility to understand the impact of somatosensorial influence on motoric execution.

> *"The mental aspect also influences your playing, your sound in fact [. . .] so it's important to do psychological work with the therapist. My focal dystonia was an accumulation of both personal and professional things"* (*II p. 3*).

These points show the importance of giving attention to the perceptions of patient-musicians in order to provide appropriate care. Qualitative methods are good tools to understand social representations of health and illness. Eliciting responses from the most involved individuals can be seen as a great source for finding solutions to their health problem. It also helps the musicians in their quest for art through music.

7. Conclusion

Musicians are a group with special needs and – when the brain panics – expect from caregivers to understand their occupation [23]. Focal dystonia is a task specific motor control problem and the caregiver should know the musician, his task and his context. Therefore, it is important for therapists to provide emotional support and global comprehension added to adequate practical care.

Based on the same framework, a further study is now under way investigating social representation in musicians without physical trouble. Those results – based on musicians who found solutions to accomplish their task without developing physical trouble – will permit determine appropriate advices to help injured musicians to recover.

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