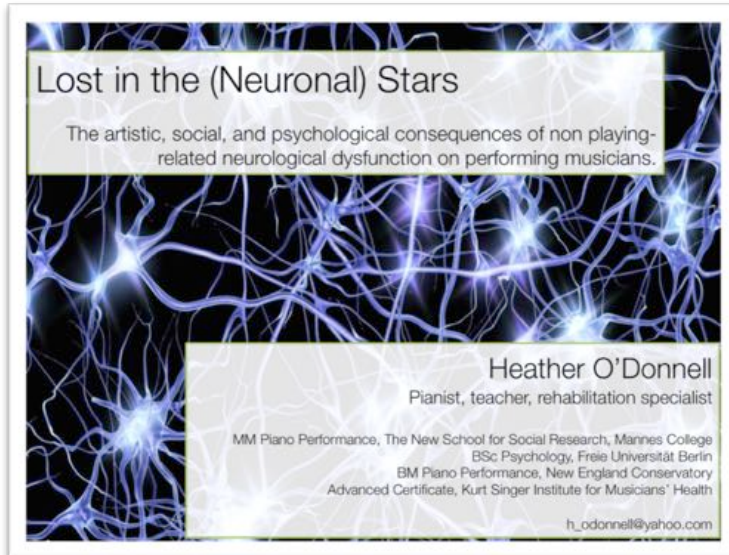


Presentation- International Symposium of the Performing Arts Medical Association

Weill Cornell Medical Center, New York, July 7 – 10, 2016



The title of this presentation (based on Kurt Weill's 1949 song *Lost in the Stars*) may seem a bit sentimental for a medical conference, but I would like to infuse the presentation with an emotional weight that in some way reflects the depth of suffering experienced by musicians who see their life's work disintegrate as a result of a movement disorder

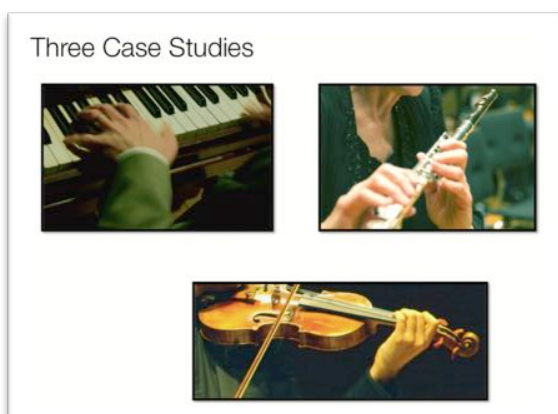
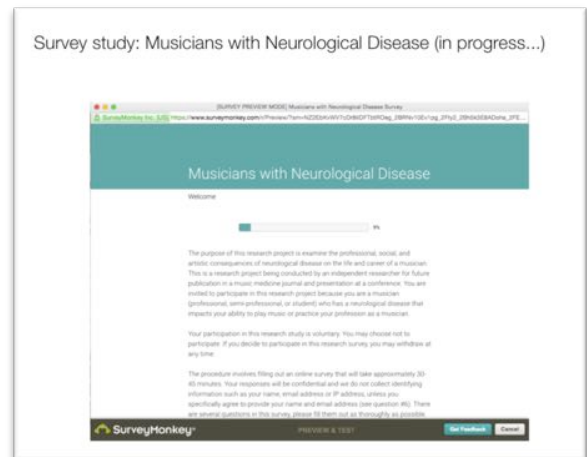
arising from dysfunction at the level of central or peripheral nervous systems.

The musicians who fall into this category are a highly heterogeneous group, including those with diseases such as Parkinson's, MS, or other disorders arising from axonal demyelination, autoimmune dysfunction, or cerebellar or basal ganglia degeneration. It can also include aging-related movement disorders (for example tremor, neuropathy), and traumatic events such as stroke or accident. These are unfortunately underrepresented groups in music-medicine research and literature. There are very few epidemiological studies on these types of cohorts .

Their lack of visibility in the literature is often mistaken for a low prevalence of movement disorders arising from neurological dysfunction, disorders that exert a severe impact on the career of the musician. Additional hindrances to the visibility of these kinds of cases may be that musicians tend to be fearful of disclosure (wanting to prevent or minimize the adverse professional consequences of disclosure), they also tend to act autonomously in managing the professional effects of their acquired disabilities, and they may be less likely than those with playing-related musculoskeletal disorders to seek out help from professionals specialized in

working with musicians. To put it simply, they become invisible to the people who could track and treat them most effectively.

These observations come from interviews I've conducted with musicians for non-academic articles on musicians' disabilities. I am at the beginning stages of developing a qualitative and exploratory study to begin to better understand these types of musicians. My hope is to eventually use this research for advocacy and for participating in the developing of multi-disciplinary institutions that could assist these musicians in maintaining their professional careers, or if necessary transitioning into new careers. Ideally, these institutions could provide various forms of support – somato- and psychotherapeutic,



music-pedagogical (such as retraining and refining playing technique), social, and financial. Let's continue onto 3 very short retrospective case studies. Famous cases such as the cellist Jacquelyn Du Pre's struggle with MS and conductor James Levine's struggle with Parkinson's Disease have already been well documented, and though these examples are not always handled with sensitivity and fairness, I'll

leave them in favor of less-famous musicians who are in turn more vulnerable to loss of income, working status, and who possess limited resources to manage their illnesses.

The following cases include three musicians who had an acquired neurological disease that struck in their late 30s or early 40s, so, in the middle of their professional careers. Two of the cases will be anonymous, and, in the spirit of openness and full-disclosure, I can tell you that the other is myself. I'll use the opportunity of presenting my case to give you an introduction into my history and my work.

I'm a classical pianist and was active as a performer for 15 years until 2010, when I stopped playing professionally and began concentrating on studying neurological dysfunction and its effects on musicians. These two right hands shown in a similar position are from me and were taken within the time span of 8

Three Case Studies

43 year old female pianist

auto-immune disease resulting in various playing-related disorders (dystonia, median nerve-entrapment syndrome, tenosynovitis)

recovery of c. 80% of function through instrumental retraining, diet, reduction of playing time and stress reduction



years. In 2008 at the age of 35, I was diagnosed with an autoimmune disease after having had symptoms since childhood. The pianistic problems that arose from this, or were compounded by this, included many common instrument-related injuries including median nerve entrapment syndrome (also known as carpal tunnel), tenosynovitis (more commonly called tendonitis), and dystonia. I like to say that I was a walking and talking compendium of pianistic ailments. It was nearly always assumed by doctors and other practitioners that these ailments arose from misuse or overuse of the instrument. I was in contact with a variety of medical and therapeutic professionals (several of whom had a specialization in music medicine), including physiotherapists, osteopaths, neurologists, orthopedists, kinesiologists, nutritionists, practitioners of Alexander technique and Feldenkrais method, as well as with pianists who specialized in injury rehabilitation. I also worked with a psychotherapist on the recommendation of several of the above-mentioned practitioners in order to explore possible psychosomatic sources for these mysterious afflictions. This care was mostly provided in Germany, where I lived and worked until last year.

The symptoms that most affected my playing included pain in various fingers, weakness and a sense of incoordination in the hands and fingers, and typical trigger point sensitivities (such as the "lateral epicondyle"). There was a lack of structural integrity in various parts of my body, for

example the right shoulder sagged visibly lower than the left, the hands had lost structure and appeared to be “wasting away” as you can see in this picture on the palmar side, and it was impossible to maintain the structural bridge of knuckles when coming in contact with the instrument. Since the autoimmune disease was diagnosed and treated, most of the symptoms have subsided. A few symptoms – namely, chronic pain, weakness, and incoordination - have proven to be the most difficult to resolve.


I would describe my recovery from the worst period before the diagnosis until now at a very subjective level of having regained 80% of my previous function. This was insufficient for maintaining a performance career, and I have since shifted to teaching, working with injured pianists and also with amateur musicians suffering from stroke, TBI and other disabilities, and conducting research in order to eventually better assist other musicians encountering similar difficulties.

Three Case Studies

45 year old female flutist

Bell's Palsy, resulted in sudden and complete paralysis on left side of face

recovery of 95% of instrumental function attributed to Botox injections in platysma muscle, pain management through facial massage, stress management techniques



The second case involves a flutist who experienced a sudden-onset and complete paralysis on the left side of her face, with disruptions in hearing and balance, this was diagnosed as Bell's Palsy, one that also affected vision. In addition to several rounds of Botox injections in the platysma, she underwent a program of neuromuscular re-education which began

with basic facial movements and progressed to flute playing. Her subjective assessment of her recovery after 6 years is at 95%. She experiences chronic pain and needs to manage stress levels in order to alleviate symptoms. Social and professional consequences included a complete loss of income for the 2 years following the paralysis, the loss of work permit in the country she was living in, and dependency on her family for financial support. She experienced painful social ostracization in the music communities she was active in, which she felt was directly related to the disclosure of her illness. Nowadays she performs occasionally, and researches issues related

to performance practice.

The third case involves a violinist with multiple sclerosis in which the symptoms emerged very rapidly and severely over the course of two months, beginning with pain behind the left ear, and spreading to an almost complete paralysis in which he reported that only his eyes, ears, nose, mouth and brain continued to function.

His long recovery involved intensive physiotherapy, first of all with activities such as re-learning to walk, moving onto to finer movements that eventually involved violin playing. He spent a lot of time with mental practice when he was unable to physically work at the instrument. He describes visualization of movements, and the training of a positive psychological outlook (achieved through meditation, and psychotherapeutic work) to be key components in his recovery. His subjective rating of his recovery is also at 95%, enough to resume professional orchestral duties, but making it necessary for him to choose projects carefully, watching stress levels and signs of over-exertion. He is fortunate to live in a country with strong social programs for disabilities and worker's rights, and therefore was able to navigate his illness without it endangering his professional existence.

Some commonalities emerge in looking at these kinds of cases. After having received a wide variety of therapeutic interventions, medical, psychological and physiological, musicians must find social solutions to their health crises alone or in a small network of family and close colleagues and friends. They are rather self-sufficient in this regard, an admirable attribute, but one imposed by the lack of an alternative.

I'd like to jump to a sister-profession to look for possible alternatives in handling issues of career transition and transformation. Within dancers' communities, there is an acknowledgement and awareness that dancers will not be able to physically maintain their career for their entire

Three Case Studies

44 year old male violinist

Multiple Sclerosis

recovery of most instrumental function attributed to pharmaceuticals (Rebif, Tecfiera), physiotherapy, diet, personal effort, psychological management techniques, visualization, career management



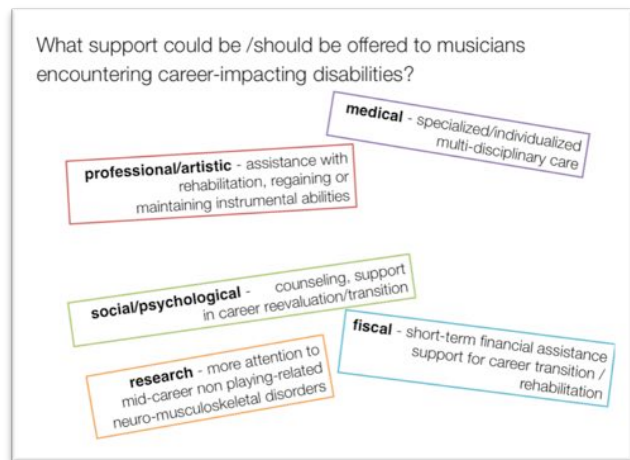


professional lives. Though the transition for dancers into post-performance careers is also fraught with difficulties – including lack of resources, insufficient education outside of dance, and lack of preparedness, there *are* institutions designed to help. There are currently 8 international organizations, in Europe, Asia and North America, devoted to assisting

dancers through career transitions. These institutions provide a mix of services, including career counseling, employment services, scholarships, financial support, mentoring, and workshops. In 2004, a 270-page report was released by the aDvANCE Project which provided results from a comprehensive research project that investigated the process of career transition for dancers in various countries. To my knowledge, there is to this date very little in comparison to these sorts of institutions or research projects in the field of music. I have to make an addendum to this last statement, while I've been here, I've had the pleasure of learning about the New Orleans Musicians' Clinic, and MusiCares, 2 institutions that are indeed addressing the social problems of musicians.

The musicians I have interviewed often spoke of experiencing acute isolation throughout the process of determining the nature of their career transformation and transition. Many musicians, acting out of desperation, turned away from traditional sources of support: medical, psychological or social, instead delving into esoteric or fringe solutions, which promised concrete, definitive, and quick results, not to mention solutions involving self-medication. These "solutions" often put an additional financial strain on the musicians, who were already suffering from the impact of income loss.

The question naturally arises, why there is such a disparity in the field of music and dance in terms of a social acceptance of career transformation/transition, and institutional support to facilitate this.



Let's take a look at some areas where musicians with career-impacting disabilities could be, and I believe should be, supported:

I've listed medical and professional/artistic areas at the top, because I believe these two areas are currently covered most comprehensively. The quality of medical

care offered specifically to musicians has developed and grown exponentially within the last decades, with more and more practitioners specializing in music medicine, and the foundation of centers devoted to multi-disciplinary medical and physiotherapeutic care for musicians.

There are an ever-increasing number of music pedagogues specializing in working with injured musicians. Though their work is often very expensive, and there is no oversight or certification requirement for musicians claiming to work with injury, there are options for instrumental retraining available to injured musicians, albeit at great personal cost. There are also a myriad of somatic education offerings such as body-mapping, Feldenkrais and Alexander, and these can indeed be very helpful, but again at significant cost.

The remaining three areas have relatively little structured systems of support. There are indeed several psychologists who specialize in working with musicians, but these individuals are most often not integrated into larger systems that assist injured musicians such as music-medicine clinics, and again the costs of these kinds of services may be prohibitive. There is negligible support to help musicians financially if they need to spend some time reorganizing their musical careers following injury or disability or transition into new careers. And, as I mentioned before, there is very little research devoted to acquired non playing-related movement disorders, making these types of cases appear to be very rare and therefore of marginal interest to the music-medicine community.

Existing music medicine structures could expand in order to accommodate programs that address the social concerns of musicians with acquired disabilities. Conservatories and other musical institutions could also integrate structures similar to the dancers' transition programs into their educational offerings. Naturally these kinds of assistance would not only be helpful for musicians with disabilities, but also for musicians wanting or needing to reassess their career for any reason.

I hope that this presentation can serve to show some of the difficulties associated with acquired disability, especially in musicians with CNS/PNS illnesses that strongly and adversely affect their musical careers. I am presenting this topic at the PAMA symposium in the hope of connecting with others with similar or related interests in order to exchange, develop research projects, and brainstorm about possibilities for developing structures to adequately assist these kinds of musicians in the future

Where do we stand?
What could we do better?



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