5-2021

# Living with Focal Task-Specific Dystonia: The Musician’s Perspective

Jill H. Olson Moser
*St. Catherine University*

## Recommended Citation

Olson Moser, Jill H.. (2021). Living with Focal Task-Specific Dystonia: The Musician’s Perspective. Retrieved from Sophia, the St. Catherine University repository website: https://sophia.stkate.edu/ma_osot/32

# Living with Focal Task-Specific Dystonia:
# The Musician's Perspective

Jill H. Olson Moser
St. Catherine University

A thesis submitted in partial fulfillment of the requirements
for the degree of Masters of Arts in Occupational Therapy,
St. Catherine University, St. Paul, Minnesota

May, 2021

Thesis Advisor: Julie Bass, PhD, OTR/L, FAOTA
Thesis Readers: Christine Kim, MD; Darla Coss, OTD, OTR/L, CHT

# St. Catherine University
# Master of Arts in Occupational Therapy

## Certification of Successful Thesis Defense

We, the undersigned, certify that

Jill H. Olson Moser

Student Name

has successfully defended the thesis titled

Living with Focal Task-Specific Dystonia: The Musician's Perspective

Julie D. Bass, PhD, OTR/L, FAOTA May 13, 2021
Thesis Advisor and Chair of Thesis Committee Date

Christine Kim, MD May 13, 2021
Thesis Reader and Member of Thesis Committee Date

Darla Coss, OTD, OTR/L May 13, 2021
Thesis Reader and Member of Thesis Committee Date

---

## Certification of Approval for Final Copy of Thesis

I, the undersigned, approve the final copy of the thesis by

Jill H. Olson Moser
Student Name

Julie D. Bass, PhD, OTR/L, FAOTA May 28, 2021
Thesis Advisor and Chair of Thesis Committee Date

# Acknowledgements

First, I would like to extend my gratitude to the musicians who shared their stories, making this research possible. It is the poignant retelling of their experiences that gives this research heart and relevance.

The commitment and unparalleled mentorship of my advisor, Dr. Julie Bass, have shaped every aspect of this project. Her belief in my vision for this research and her wise and patient guidance into the world of research have inspired new curiosities that will keep me busy for years to come.

Thank you to my readers, Dr. Darla Coss, and Dr. Christine Kim, who generously shared their experience, expertise, and time. They have been invaluable advocates for the promotion and continuation of qualitative research of focal task-specific dystonia in musicians.

Finally, I would like to thank Matt, Walt, and Catherine Moser, who have creatively and lovingly made space in our family for my roles as student and researcher. Their love and their confidence in me have made it possible for me to set my sights high and keep digging into the important work each day.

## Abstract

**Background:** Focal task-specific dystonia, known as musician's dystonia, is a motor disorder that affects approximately 1% of professional musicians. Symptoms of musician's dystonia include the loss of fine motor control and dexterity of repetitive, highly trained movements, which for a professional musician can be career ending. There is limited research on the unique experiences and perspectives of professional musicians with focal task-specific dystonia.
**Methods:** A qualitative approach was chosen to explore the lived experiences of professional musicians with focal task-specific dystonia, specifically a phenomenological research tradition. Eleven musicians fitting the targeted criteria were recruited and interviewed. Four interviews were selected for analysis in this thesis. Each participant completed two online surveys, including the QuickDASH (Disability of Arm, Shoulder, Hand) self-report survey addressing functional limitations related to upper extremity injury. Each musician participated in a semi-structured interview of broad, open-ended questions. Interviews were transcribed and individually analyzed using a modified version of Moustaka's data analysis approach (Cresswell & Poth, 2017). Significant statements were identified, grouped by meaning, and labeled. Grouped statements were then coded to facilitate the identification of emergent themes significant to the individual. Once individual themes were coded, common themes across participants were identified using cross-case analysis.
**Results:** Six primary themes emerged amongst all participants: singularity of identity, practice as primary reaction, secrecy and shame, independent problem solving with trusted support, trauma response, and negative experiences with medical services. The themes illustrate meaningful areas of shared experiences amongst musicians with musician's dystonia, including significant experiences of loss, isolation, and struggle to find adequate support through healthcare.
**Conclusions:** These findings suggest areas in which healthcare providers may improve their support of professional musicians with focal task-specific dystonia. Consistent across all participants were areas of unique strength in abilities of self-assessment, analyses, and modification. These strengths represent an opportunity for healthcare providers to employ a collaborative approach when working with professional musicians with musician's dystonia, in order to provide the best care for this population.

## Table of Contents

# Chapter One: Introduction

Focal task-specific dystonia, or musician's dystonia, is a movement disorder that impairs the control and dexterity of highly trained fine motor tasks. This condition is estimated to develop in approximately 1% of professional musicians (Jabusch et al., 2005; Altenmuller & Jabusch, 2009), for whom the loss of motor control is often career ending. There is currently no cure for focal task-specific dystonia, and the best available treatment options fail to provide consistent relief for most impacted musicians (Betti et al., 2018; Stahl & Frucht, 2016).

The purpose of the present study is to explore the lived experience of focal task-specific dystonia, from the perspective of the musician. Professional musicians begin intense training at an early age, and for many, identity and self-worth are closely tied to their artistic achievement (Frucht, 2009; Guptill, 2012). Disconnection from this role disrupts all areas of the musician's life and participation, and musicians fear negative stigma associated with being injured and unable to play at their highest level (Zaza et al., 1998). The objective of this study was to conduct qualitative interviews to gain insight into musicians' perceptions on the lived experience of focal task-specific dystonia.

The body of literature on focal task-specific dystonia in musicians is limited, with the existing literature centering largely around epidemiologic studies, research on pathophysiology, and case reports from practitioners who are experienced in treating musicians (Guptill, 2008). Absent from the research is an account from the musician's perspective, which could identify the priorities for supporting this population. This research aims to capture this unique perspective.

# Chapter Two: Literature Review

Professional musicians are artists who begin intense, specialized training at an early age. For many successful professionals, being a musician has been a singular career goal since childhood. Year-round training, under the pressure of live performance and highly repetitive technical demands make musicians susceptible to musculoskeletal injury, as well as the less understood movement disorder, focal task-specific dystonia. This review of the literature on focal task-specific dystonia in musicians will explore what is currently known, as well as identifying gaps in our understanding of this condition amongst professional musicians.

## Focal Task-Specific Dystonia and Musician's Dystonia

Focal dystonia is a movement disorder that impairs motor control and dexterity of a highly trained fine-motor task. One type of focal dystonia impacts musicians, whose profession demands a high degree of dexterity and ingrained fine-motor movements (Altenmuller, 2009; Betti et al., 2018; Conti et al., 2008). This type of dystonia, often referred to as focal task-specific dystonia or musician's dystonia, is triggered by repetitive motions specific to playing a musical instrument (Aranguiz et al., 2013).

The literature on focal task-specific dystonia among musicians cites two main phenotypes; hand dystonia and embouchure dystonia (Stahl & Frucht, 2016). Hand dystonia is characterized by involuntary flexion or extension of isolated fingers that are responsible for repetitive and complex movements (Betti et al., 2018; Frucht, 2009). Hand dystonia can occur in players of all instruments including bowed and plucked string instrumentalists such as violinists, cellists, and guitarists, as well as pianists, woodwind and brass instrumentalists.

Woodwind and brass players are also vulnerable to embouchure dystonia. Embouchure describes the interplay between the facial muscles and the positioning of the lips, teeth, and tongue to play woodwind and brass instruments, and is responsible for the production of pitch, tone and articulation (Stahl & Frucht, 2016). Embouchure dystonia can affect the coordination of the facial muscles, as well as cervical muscles and breathing (Altenmuller & Jabusch, 2009).

The effect of musician's dystonia on the loss of dexterity is isolated to specific fine motor movements, such as placing a finger on a piano key, extending a finger after plucking a guitar string, or positioning the lips to buzz air into a trumpet. While the presentation of musician's dystonia is different for each person, research reveals patterns among different instrument groups. In most cases, the hand associated with the more strenuous work, more complexity, and higher demand for precision is the hand affected with dystonia (Altenmuller & Jabusch, 2009; Stahl & Frucht, 2016). In pianists and guitar players, the right hand is typically the affected side. In violinists, the left hand is more often impacted (Conti et al., 2008).

Musician's dystonia typically begins gradually and manifests as a lack of muscular coordination, and loss of voluntary control of the fingers (Altenmuller & Jabusch, 2009; Frucht, 2009; Sadnicka et al., 2016). The affected movements are highly trained and practiced, and prior to the onset of symptoms, feel effortless to the musician (Altenmuller & Jabusch, 2009). In hand dystonia, the initial presentation of these symptoms is often subtle, present in isolated fingers, and can be imperceptible upon medical examination (Sadnicka et al., 2016). Over time symptoms may progress from an isolated finger to include the involvement of adjacent fingers, gradually becoming more difficult for the musician to overcome (Altenmuller & Jabusch, 2009).

Embouchure dystonia frequently begins in only one pitch range, leaving other areas of playing unaffected (Steinmetz et al., 2013). Impairment can present as embouchure tremors, involuntary lip movements such as curling, or jaw clamping (Stahl & Frucht, 2016). Over time the limitations expand across a larger pitch register, further limiting the repertoire that a musician can successfully perform, and can include a combination of symptoms (Steinmetz et al., 2013).

Symptoms of musician's dystonia may periodically flare up or decrease, but once the motor interruption begins, remission is rare. Over time musician's dystonia may also grow to be more easily triggered. In acute stages, dystonic movements may even be triggered away from the instrument and while at rest (Conti et al., 2008; Sadnicka et al., 2016).

## Epidemiology and Diagnosis

Some sources estimated that 1% of all musicians are affected by musician's dystonia (Jabusch et al., 2005; Altenmuller & Jabusch, 2009). Other accounts predict that 1% of musicians experience the termination of their career due to musician's dystonia (Betti et al., 2018). There are, however, indications in the literature that these numbers may not capture the true prevalence of affected musicians. Conti et al. (2008) noted the difficulty of capturing definitive epidemiological data on focal task-specific dystonia due to its uncommon nature and the need for longitudinal studies on a large sample size. Betti et al. (2018) highlighted the importance of developing tools for gathering objective, reliable diagnosis, attuned to the highly variable symptomatology of focal dystonia.

The diagnosis of musician's dystonia may be delayed or underreported for several reasons. Musician's dystonia can be difficult to diagnose, and diagnosis often occurs after months or years of self-management, unsuccessful therapy, or incorrect diagnosis (Conti et al., 2008). During this time some musicians lose confidence in their healthcare providers and turn to trusted supports, such as former teachers for guidance (Frucht, 2009), but many teachers are ill equipped to understand the needs of musicians with motor loss. Professional musicians may also deny or ignore their playing difficulties or use personalized modifications and practice techniques to manage independently for as long as possible, delaying diagnosis (Zaza et al., 1998).

Due to a lack of widespread practitioner understanding of musician's dystonia, and the difficulty of diagnosing this condition, musicians may spend years visiting different health care providers before receiving an accurate diagnosis of focal dystonia (Conti et al., 2008). It is important to recognize that many musicians work in self-employment without financial security. Many have insufficient insurance, and limited access to healthcare (Guptill, 2011). This lack of financial security and lack of access to affordable medical care is a significant barrier to the musician who might otherwise seek medical intervention.

## Impact of Diagnosis on Professional Life and Identity

The early symptoms of musician's dystonia are described as subtle, but for professional musicians, even a slight loss of motor control can have a catastrophic impact on their ability to perform (Sadnicka et al., 2016). Motor loss, associated with this condition can threaten a musician's career (Frucht, 2009), a trajectory that for most professionals has been charted since childhood or early adolescence.

The impact of musician's dystonia is far reaching for the professional musician. For this population, identity and sense of self-worth are closely tied to level of artistic achievement (Frucht, 2009; Guptill, 2012). Once disconnected from this identity, the diagnosis of musician's dystonia can create a division in the life of a professional musician, leaving a sense of life before symptoms and life since symptoms (Frucht, 2009). Beyond this sense of identity, for many professional musicians, social connections and friendships revolve around musical occupations, so loss of musical ability can lead to isolation from their personal and professional communities of support (Frucht, 2009; Zaza et al., 1998).

Potentially furthering the experience of isolation, musicians fear negative stigma associated with being injured and unable to play at their highest level (Zaza et al., 1998). The fear of losing respect and a damaged reputation reflect not only egocentric or identity concerns, but also the fear of losing work and the subsequent impact on financial well-being (Zaza et al, 1998). Colleagues and musician friends have the potential to offer validation and important support to musicians with focal dystonia, but often these supports are not available, as struggles with performance ability are hidden in an effort to minimize vulnerability (Zazo, 1998).

## Management, Adaptation, Intervention, Discontinuation

Professional musicians are trained to continually manage their playing by problem solving, and making real-time modifications as they play, practice, and perform. When musicians experience difficulties in their playing, they tend to use these skills of modification and adjust their technique, physical posture, practice techniques, and even their instruments in an effort to overcome their problem (Zaza et al., 1998). In fact, it is recommended that musicians attempt to modify their technique to accommodate their dystonic motor patterns as an initial approach to managing dystonia, but often musicians with focal dystonia respond by increasing practice time, ultimately exacerbating the problem (Frucht, 2009).

Prompt treatment for musician’s dystonia may offer the best outcome for musicians (Betti et al., 2018). Frucht (2009) advised that evaluating musicians for musician’s dystonia is time-intensive and that in managed care settings with limitations on time, this type of evaluation may not be possible. Many musicians may be initially reluctant to seek medical attention, stating that the healthcare professionals they have encountered appear to lack understanding and knowledge of the specialized demands of being a professional musician (Guptill, 2008; Guptill 2011; Ting & Rocker, 2019). Practice guidelines and standards of care for musician’s dystonia are largely absent from the literature on this condition, and healthcare professionals echo the musicians' sentiment, indicating that they do not feel confident or equipped to treat musicians (Betti et al., 2018; Ting & Rocker, 2019).

Currently, the preferred treatment for musician's dystonia is the injection of botulinum toxin (Betti et al., 2018). This protocol offers relief for a fraction of individuals with musician's dystonia but can cause weakness in adjacent muscles, interrupting the musician's ability to maintain their performing responsibilities (Betti et al., 2018; Frucht, 2009). Response to treatment varies greatly amongst individuals, and even with the best treatment currently available, most musicians don't return to their former level of skill, and many are unable to continue playing professionally (Betti et al., 2018; Conti et al., 2008; Stah & Frucht, 2016). This outcome is estimated to impact 1% of all professional musicians (Betti et al., 2018).

## Gaps in Research Related to Focal Task-Specific Dystonia in Musicians

While research continues to explore the etiology and pathophysiology of musician's dystonia, there has been little research on the unique lived experience of professional musicians who have this disorder. A limited body of research has explored the experiences of professional musicians with musculoskeletal injuries (Guptill, 2012). This research offers a foundation of knowledge about musicians and injury, and offers a qualitative perspective on the experiences of this population. Compared to musculoskeletal injuries, outcomes for musicians with musician's dystonia are less favorable, and therefore may have a greater impact on the musician's lived experience. For those with musician's dystonia, improvement is rarely sufficient to allow the musician to return to their previous level of playing or professional engagement (Frucht, 2009). This suggests that direct parallels may not be drawn between the day-to-day experiences of these two populations. Aranguiz et al. (2013) suggested that musician's dystonia greatly impacts quality of life, and that this impact has been insufficiently addressed in musician’s dystonia research. Recent research on this topic is limited.

## Research Purpose

The primary purpose of this study was to understand the day-to-day experiences of professional musicians with focal task-specific dystonia.

*Primary research question:*

How do professional musicians with musician’s dystonia describe their professional and personal lived experience before and after having the condition?

*Secondary research questions:*

How do professional musicians with musician’s dystonia describe professional and personal changes and adaptations to their roles and activities because of the condition?

How do professional musicians with musician’s dystonia describe their experiences of supports and barriers to performance of professional and personal roles and activities?

How do professional musicians with musician’s dystonia describe their experiences with healthcare or other services for the management of the condition?

# Chapter 3: Methods

## Research Design

This qualitative study explored the lived experiences of professional musicians with musician's dystonia. Semi structured interviews were conducted following the phenomenological research tradition, with the objective of gaining insight and understanding of the experiences of professional musicians with this disorder. Descriptive surveys were used to obtain demographic characteristics as well as functional limitations. This research was approved by the Institutional Review Board of St. Catherine University (No. 1474).

## Participants and Recruitment

Professional musicians with musician's dystonia were recruited through two approaches. First, as a member of a professional musicians' organization, I was given permission to use the membership directory to reach local professional musicians. An informational flyer describing the study was sent to 917 musicians. Secondly, snowball sampling was used as union members were encouraged to forward information about the study to other professional colleagues.

Email contact was made with eleven musicians fitting the targeted criteria who were recruited and interviewed. Four interviews were selected for analysis in this thesis. The inclusion criteria included: current or retired professional musician status, age between 22 to 75 years, and diagnosis of musician's dystonia.  Informed consent was distributed to identified participants via email and returned in advance of interviews. Each participant was also given an opportunity to ask questions when the informed consent was verbally reviewed prior to being interviewed on Zoom.

## Interview Guide and Descriptive Measures

A semi-structured interview guide was developed and piloted prior to the interviews. All interviews were conducted with an emic perspective, by the primary investigator who is a professional musician with a history of musician's dystonia. Questions were grouped to explore day to day experiences prior to the onset of musician's dystonia, since the onset of symptoms, and current day experiences as a musician with musician's dystonia. In each time period, questions explored roles and routines, identity, and well-being. Participants were prompted to include supports and barriers, and modifications that they made to facilitate daily routines related to instrument performance, and in roles outside of being a musician.

Participants completed two online surveys in advance of the semi-structured interview. The first survey gathered information about primary musical instrument played, professional music involvement and the onset of musician's dystonia, as well as basic demographic information. Participants also completed the Quick DASH (Disability of Arm, Shoulder, Hand) a self-report survey which addresses functional limitations related to upper extremity injury. In addition to the 11 questions on the standard Quick DASH questionnaire, participants completed the 4 question sports/performing arts module.

## Procedures

Interested participants who met the inclusion criteria were sent an introductory email outlining the purpose and expectations of the study. Chosen participants were emailed a written informed consent form, and were given the opportunity to participate or decline participation in the study. Once the informed consent form was returned, interview times were scheduled and participants were asked to complete a background survey and Quick DASH, which were shared as Google Forms and returned online.

A pilot interview was conducted with a former musician who experienced a playing related injury that ended her career. While not meeting the criteria of this study, her injury, lived experiences as a musician, and inside knowledge of the culture of the classical music community were valuable to this study. The interview was followed by a debrief, during which the participant was asked for feedback, strengths and needed modifications of the interview questions and process. These suggestions were incorporated into the guide for interviews.

Each musician participated in a semi-structured interview, which was conducted via Zoom, due to Covid-19 restrictions. Interviews were recorded on Zoom and Google voice typing was used to provide a rough initial transcript. These initial transcripts were then compared to the recordings to create a verbatim transcript for further analysis. During the transcription process, all identifying information was removed and replaced with an identifying number, chosen by the participant. Participants were also invited to participate in a brief 15-20 minute follow up interview to verify the accuracy of the description of their biographical information.

## Data Analysis

Four participants were selected for data analysis in this thesis. Maximum variation sampling was used to select participants that varied by primary instrument family and characteristics of musician’s dystonia. Data analysis led to the identification of emergent themes. Interview transcripts were analyzed using a modified version of Moustaka’s data analysis approach, as delineated by Creswell and Poth (2017). Each interview was analyzed individually and significant statements, with relevance to the research questions were identified, labeled and interpreted. The interpreted statements were coded and grouped to facilitate the identification of themes that were relevant to the experience of each individual. Once themes were identified in each interview, common themes, across participants were identified. In order to give context to these experiences, and in accordance with Moustaka's approach, verbatim examples were chosen to illustrate the experience of the proposed phenomenon, as well as to provide context for describing how the experience occurred among the participants (Creswell & Poth, 2017).

It was ethically important that the musicians' anonymity and data confidentiality be upheld throughout the research process. Recordings and transcripts were kept on a password protected cloud server, and identifying information was removed from the transcripts. General categories were used to describe participant characteristics rather than specific attributes. Recordings were destroyed after use.

# Chapter 4: Results

## Descriptive Characteristics and Functional Limitations

Participants were predominantly males who were under the age of 40 at the onset of musician’s dystonia. One participant received a formal diagnosis of musician’s dystonia within five years of the onset of symptoms, while for two others it took over five years to receive a diagnosis. For one participant, the duration from onset of symptoms to diagnosis was unknown. A majority of the participants experienced hand dystonia, with one having predominantly symptoms of hand dystonia and eventual symptoms of embouchure dystonia as well. One participant experienced only embouchure dystonia. (See Table 1) Member checks were conducted to determine whether an adequate level of confidentiality was maintained in the participant descriptions. (See Appendix C for a brief biography of each participant).

The Quick DASH (Disability of Arm, Shoulder, Hand) questionnaire yielded results across participants that were inconsistent with the information shared in interviews. The four questions from the additional Performing Arts Module explored the difficulty of performing a musical instrument, as experienced over the previous two weeks. Responses on each of the four questions from this module represented the full range from “no difficulty” to “unable” (See Table 1). The accuracy of responses amongst this population were questionable, especially for the participants who were no longer actively performing.

Table 1

*Demographic Characteristics and Quick DASH Items*

| Demographic and DASH Item | Participant 1 | Participant 2 | Participant 3 | Participant 4 |
|---|---|---|---|---|
| Pseudonym | Carl | Anna | James | David |
| Gender | Male | Female | Male | Male |
| Age of Onset | <40 | ≥ 40 | <40 | <40 |
| Time between onset and diagnosis | ≥ 5 years | < 5 years | ≥ 5 years | Unknown |
| Primary Instrument Family | Brass | Woodwind | Bowed string | Plucked string |
| Phenotype | Embouchure | Hand | Hand | Hand |
| Quick DASH: Performing Arts | | | | |
| Usual technique | 5 | 3 | 1 | 5 |
| Arm/shoulder/hand pain | 1 | 2 | 4 | 5 |
| Playing as well as liked | 1 | 4 | 3 | 5 |
| Usual amount of time playing | 5 | 4 | 3 | 1 |

*Note*. Quick DASH: Level of difficulty, 1 = no, 2 = mild, 3 = moderate, 4 = severe, 5 = unable
Usual technique = Did you have any difficulty using your usual technique for playing your instrument?; Arm/shoulder/hand pain = Did you have any difficulty playing your musical instrument because of arm, shoulder, or hand pain?; Playing as well as liked = Did you have any difficulty playing your musical instrument as well as you would like?; Usual amount of time playing = Did you have any difficulty spending your usual amount of time practicing or playing your instrument?

## Cross-Case Analysis Themes

Individual and cross-case analyses were used to identify themes that emerged from the interviews. In the cross-case analysis, six primary themes emerged: singularity of identity, practice as primary reaction, secrecy and shame, independent problem solving with trusted support, trauma response, and negative experiences with medical services. The following descriptions explore these shared experiences across participants.

### *Singularity of Identity*

Two subthemes related to identity were evident across all participants. First, all musicians identified a personal and professional identity that revolved around “musician.” This singularity was evident in role identification, and absence of roles and routines outside of this role. Secondly, all participants identified as having always been a musician.

David expressed the singularity of his work, personal interests, and social network. “I was a one-trick pony in this way. It was music or nothing … it never veered from that. No hobbies. I had lots of friends outside of music, but the best ones inside of music.” Carl saw his professional role as being particularly narrow. “I was a pretty single issue do-er. You just do one thing, and that’s what you do. I just taught [brass], that’s it, and played [brass]. How’s that for narrow? It’s a good life.” Anna expressed an unsuccessful effort to identify as more than a musician. “I've always liked to think that I didn't define myself as a musician first, but having gone through this process, I realize that I did, and I do. It is just central to who I am, and always has been.” Anna also explained that even though she tried to stay connected to people outside of the music world, her priorities as a musician often interfered. “Once or twice a week I might slip in a Bible study with some friends in the afternoon, but I was one of those people that canceled a lot because if I felt like I had to practice, that took priority.” James expressed, “I’m a professional [string player], that is all I’ve ever done. A professional musician … I’ve always identified as a [string] player.”

### ***Practice as Primary Routine and Reaction***

Musicians are accustomed to committing many hours to practicing their instrument every day. Practice as a central routine emerged as a theme in all interviews, with a subtheme of reinforced commitment to practicing when symptoms of musician’s dystonia arose. In the context of the interviews, practice was described as a daily routine around which other life activities were planned. Carl used the terms warming up and practicing interchangeably, depending on what he was working on. “I would get up at 7:30 and warm up for about an hour and I'll go teach … and I come home and warm-up or practice some more and usually go to a concert or recital in the evenings, and that would be the regular weekday occurrence.” David gave context to the musician’s perspective of how much time should be devoted to practicing. “I was one of those typical guys, put in *at least* 7 days a week, 5 to 6 hours a day.” For Anna, a substantial period of practicing before going to rehearsals and performances for the day was a daily routine. “So there's at least two to three hours of practicing in the morning before you go to work.”

In spite of this daily commitment to practicing, the participants described a “double down” mentality when they experienced a loss of control when dystonia symptoms surfaced. When Anna experienced early symptoms of musician’s dystonia, she assumed that she was out of shape and needed to practice even more. “I thought for a while, I thought it was just I was letting things slip, so I just practice more. Practice, practice, practice.” James reimagined the way he practiced in an effort to overcome his loss of control. “You know what I did originally… I went back to playing very notey etudes. I went back to playing etudes.” Carl, who knows a number of other musicians with musician’s dystonia shared his own reaction to his emerging dystonia symptoms, and reflects on that of his colleagues as well. “I knew that I had not practiced enough … so I practiced literally seven hours a day, and it was gone. In two weeks, I couldn’t play a note. And stupid me, and other musicians do the same thing. They think they forgot muscle memory, so they practice more, and they destroy themselves, which is exactly what I did.”

### ***Secrecy and Shame***

Emerging from all four participants were stories of the importance of privacy and keeping their experience of musician’s dystonia confidential. Initially, Anna didn’t like the idea of participating in research about musician’s dystonia. “You know, I got your email and to be honest, I got it and I was like yeah, no. No one needs to know about this, still, and I deleted it.” Anna didn’t know if she would ever publicly share her experience. “You know, it's not something that you want out there, even when you're done playing because it's such a stigma, you know?”

Carl shared his strategies for ensuring that he didn’t get hired to play anything he couldn’t handle with his musician’s dystonia symptoms. When called to play a concert with an orchestra he shared, “I said, let me check and see if I can do that. I looked, I didn’t care about the dog gone date, I cared about the score! Made sure there was nothing I couldn’t play.” When he was pressed to select a piece to play on a recital, ‘“I looked around for a piece and couldn’t find a piece. So finally, he called me back and said, ‘Listen, I have to have a piece if you’re going to play, I have to put it in the program.’ So I said, okay, I’ll write a piece.”

James identified the transition from being a musician who relied on public attention to do his job, to trying to conceal his playing. “Before, I always sought exposure. I didn’t want to be exposed at all you know. I didn’t want people to hear me play, playing the way I was playing … I sat in the back of the section and collected my money, never playing very well.” Similarly, David noted the same duality, “That’s what I remember, this kind of duality. This need for privacy while being a person who … is on stage … it has been a career of fairly consistent, I don't want to say lying, but sort of trickery. Not deliberate obfuscation in order to gain advantage over someone, but over some*thing*. To overcome the *thing*, the focal dystonia … And to this day, I think no one I work with … knows about it.”

### *Independent Problem Solving with Trusted Support*

All four participants identified a trusted support to whom they turned while using their own problem-solving skills to adapt around their musician’s dystonia symptoms. Anna noted the importance of her long-trusted instrument repair person. “I remember taking my [woodwind] to him all the time because I was sure there was something wrong with it. He would tune it up … he did that for a long time, and then finally he said ‘You know, we could make some modifications. I've made sandpaper keys.’ And so we started to modify my [woodwind] so that my fingers wouldn't slip off, which helps a *little* bit. So, he was instrumental … in helping me not just come to terms with things emotionally, but extend my career just a little bit by modifying my [woodwind] in ways that I could still have as much control over it as possible.”

David and James spoke repeatedly about “workarounds” or “working around” the problems associated with musician’s dystonia. Pivotal in David’s experience was a trusted peer who encouraged him to work around his symptoms by redefining his choice of repertoire in order to accommodate his limited technique. “I was rescued by a dear guy in town … who came up with this incredible idea. He said, ‘Look, here’s what WE’RE gonna do’…” For David, this idea of working around the problem idea allowed him to continue his career. “Try to get creative, and see if there aren't workarounds and more workarounds and more workarounds … The human mind is seemingly, endlessly capable of being creative in this way.”

For James, a longtime mentor committed to working with him to retrain, working around his symptoms. He recounted his mentor’s reaction. ‘“Look, I’m not going to let you go until we have a handle on this.’ So, I went to see him for a year and a half, never playing more than one note in a lesson and never played any music. It was always about how you're touching the [bowed stringed instrument]. What muscles are you using. Really focused on how to work around this. So, what ended up happening was that over the years I found ways to work around the dystonia."

### *Trauma Response*

Most participants reflected a traumatic response to the experience of being a professional musician with musician's dystonia. Two associated subthemes included detailed memories of specific events around the onset of musician's dystonia and the use of strong emotional language to express dystonia related events.

Participants shared stories about playing with musician's dystonia in granular detail. Carl recounted several rehearsals and performances. He remembered thoughts that were going through his head, and shared a measure by measure explanation of the musical score as his playing faltered. James shared the story of the weeks leading up to the onset of his symptoms, including a trip he took, the weather at the time, the repertoire he was playing, and the thoughts he was thinking during the rehearsals before the onset. "I can almost remember the very days. It's all etched. It's all perfect in my memory."

All four participants used strong, emotional words to explain the impact their symptoms had on their playing, using phrases like, "utterly embarrassing," "demoralizing," "hair raising," "horrible." Carl dreaded performing with dystonia and he recounted his emotions while driving to a performance, as well as his reflection after it was over. "I was, as you can imagine, scared to death … it was very embarrassing and it was demoralizing, unbelievably scary and just a shock." James struggled as he had to continue playing exposed solos even as he lost his fine motor control. "I can't go on like this. I can't keep performing like this where you know, I'm really ready to shoot myself in the head."

### ***Experiences with Healthcare, Support is What Matters***

While the healthcare services used by the participants varied, two kinds of experiences emerged as themes. First, participants spoke positively about practitioners who focused on building therapeutic relationships. Even if their musician’s dystonia symptoms did not change, they recounted these individuals as being helpful practitioners. Inversely, musicians spoke negatively of healthcare encounters in which a strong therapeutic relationship was not established, whether or not the practitioner was helpful.

Anna was conflicted about the musician’s dystonia specialists who diagnosed her condition. “I had mixed feelings about it at the time because it was a lot of information and it was kind of like, it was amazing to know, actually have a name for it, and to know exactly what was happening with what finger that I didn't understand before. I had a means of going forward. From that perspective, that was invaluable. But at the same time, it was also kind of like this, ‘Well now you’ve been diagnosed and your careers over, goodbye.’ And so I was also kind of stunned at the same time … you feel so betrayed.”

Carl, concerned by his loss of motor control went to a clinic for a full neurological workup. When Carl was asked if the neurologist was able to provide him with any help he replied, “Well, I wasn’t going to die immediately from a neurological disease. That’s about it.” He spoke also of a physician who worked with a lot of musicians. She lived in another state, but she talked with him regularly over the phone giving him support. “She was real supportive and at one point she said … ‘I’ll support you for disability if you would like to do that. I would recommend you apply for disability because all the musicians I know who have musician’s dystonia have very grave difficulty working in the industry and not being able to perform. It is very difficult for them emotionally.”’

David spoke highly of several psychologists he visited to ensure that his symptoms weren't psychologically based. The psychologists assured him it wasn't in his head. '"No kid, look, everything is fine, get out of here. You've got a disability. I'm sorry, this is what it is.' I didn't get upset from that, in fact, it bolstered my confidence." David characterized his experiences with a hand specialist as being less helpful. "I found her completely cold and uncaring. One of the first things she said was something to the effect of, 'Why don't you just use a pick?' So of course, I got the hell away from her because she was dangerous."

# Chapter Five: Discussion and Conclusions

This study has brought to light the unique nature of the musician’s experience with focal task-specific dystonia or musician’s dystonia, illustrating the importance of contextual and personal factors when treating this population. Musicians with focal task-specific dystonia represent a population with unique strengths and unique needs in the therapeutic setting. Healthcare providers are charged to employ a different perspective in working with musicians with musician’s dystonia.

## Broad Life Implications

Evident throughout this study were broad life implications for musicians with musician’s dystonia. Musician’s dystonia does not only represent a disruption of the work role for musicians, but impacts daily routine, social engagement, financial stability, self-expression, as well as self-perceived value and mental health. The disruptions that are experienced at the onset of musician’s dystonia are not easily resolved and are evident for years to come. For musicians who have been living with musician’s dystonia for decades, this disruption may have subsided in some areas of life while remaining significant in others.

In working with professional musicians with musician’s dystonia, it is critical that healthcare providers understand the significance of this diagnosis across the musician’s lifetime, and across areas of occupational participation. The burden experienced by the musician with this diagnosis remains, even if the musician no longer plays their instrument. When working with a client with musician’s dystonia, it is imperative that the healthcare provider acknowledge the broad impact of the musician’s experience.

## Collaborative Relationships

Musicians are trained to continually self-assess and self-correct as they play. This constant awareness of motor skills and muscle memory makes this population self-sufficient in handling many of the physical playing related problems they encounter. This may also cause musicians to delay seeking medical help, as they perceive themselves as the experts on their bodies and the demands of playing their instrument. The role of the therapist in working with this population must therefore be as a collaborator, not as the expert. This study shows that musicians prioritize a trusting relationship with care providers, indicating the importance of relationship building. By the time a musician seeks medical help in solving a playing related problem, the issue is likely to need more than a quick fix. Care providers should understand that musicians are highly motivated to improve and will dedicate months to years to this improvement. A care provider should not assume that if they can't offer a quick solution that they are not useful to a musician, who will return time after time to someone who offers them support and a collaborative approach.

## Trauma

Musicians express their experience of musician's dystonia using language that indicates they have experienced a traumatic life event. As research continues to show the long term physical and mental health implications of trauma, and the experience of re-traumatization through health care intervention, it is appropriate to incorporate evidence-based, trauma informed care when working with this population. Trauma informed care has been introduced as an approach for a variety of conditions, when trauma may be a part of a individual's history. A trauma informed approach follows six principles: safety, trustworthiness, peer support, collaboration, empowerment and choice, and cultural issues (Centers for Disease Control and

Prevention [CDC], 2020). These principles can guide relationships based on caring, awareness and sensitivity, reducing the possibility of exacerbating trauma (CDC, 2020; Hamberger et al., 2019). Trauma-informed approaches include active collaboration between the healthcare provider and the client, encouraging the client to dictate priorities, and being prepared to provide support, whether they choose to accept or decline suggested treatments (Hamberger et al., 2019). Given the musician's experience in self-analysis and self-care, this trauma informed care approach is well suited to building a productive and supportive relationship with this population.

## Quick DASH

The use of the Quick DASH, including the Performing Arts module, yielded inconsistent results and may indicate a need for revisions for this population. Participant responses to the survey questions were inconsistent with the descriptions they provided in their interview explaining their experience with musician's dystonia. For example, the question "In the past week, did you have any difficulty playing your musical instrument as well as you would like?" While none of the participants have been able to return to their professional performing careers, one participant reported having only moderate difficulty performing as well as he would like. One participant, who could no longer play his instrument at all replied that he had no difficulty playing as well as he would like in the past week. These discrepancies indicate a lack of specificity that would be needed to accurately capture perceived functional levels at different periods of time, from onset and throughout the progression of musician's dystonia. Revising the questions and clarifying the criteria for using it with this population would be appropriate to get an accurate understanding of their perceived level of function.

## Implications for Occupational Therapy Practice and Research

Professional musicians with musician's dystonia struggle to understand and define a sense of identity that is separate from "self as musician." Musician's dystonia is a chronic condition, resulting in lifelong changes in all aspects of life. For musicians who can no longer perform, long held beliefs about the value of commitment and hard work to something meaningful can come into question. Finding outlets for expression outside of the role of performer and finding a new currency on which to measure self-worth are critical for the mental health of this population.

Occupational therapy practitioners are uniquely equipped to assess the broad needs of professional musicians with musician's dystonia. The *Occupational Therapy Practice Framework: Domain and Process* (4th ed.) (AOTA, 2020) provides a guide for understanding "Client Factors." These factors include *values,* such as a commitment to an art form; *beliefs*, such as "hard work pays off;" and spirituality, a sense of value, meaning and purpose in life. These are all themes that can be central to understanding the experiences of this population (AOTA, 2020).

The Occupational Profile is the first step in the occupational therapy evaluation process and is central to the way that therapists understand their client's perspective and priorities (AOTA, 2021). This tool is invaluable to occupational therapists, who strive to understand client context and to restore meaning in the lives of their clients (AOTA, 2021). For a professional musician with musician's dystonia, this tool can offer therapists a formal process for identifying the broad implications of living with this condition, and how it changes over time. Performance Patterns, as stated in the Occupational Profile include, "the client's patterns of engagement in occupations, and how have they changed over time" (AOTA, 2020. p. 21). In order to formalize evidence-based best practices in working with this population, it may be appropriate to expand upon the Performance Patterns section of the Occupational Profile, providing an addendum that can be used with the Performing Arts Medicine community.

Also significant among the skills of the occupational therapist is the principle of therapeutic use of self. The *Occupational Therapy Practice Framework: Domain and Process* (4th ed.) (AOTA, 2020) highlights the integral role of therapeutic use of self as a cornerstone of occupational therapy practice. This principle guides occupational therapists in developing therapeutic relationships with clients that are centered around empathy and a collaborative approach (AOTA, 2020). This principle relies on a strengths based approach to building hope and supporting clients in discovering meaning (AOTA, 2020).

The findings from this study suggest opportunities to explicate the domains in the *Occupational Therapy Practice Framework: Domain and Process* (4th ed.) (AOTA, 2020) for this unique client population. Development of specific guidelines, assessments, and occupation-based interventions may improve outcomes for musicians with musician's dystonia.

Given the limited scope of qualitative research on musicians with musician's dystonia, there are many opportunities for furthering the understanding of this experience through future research. Of greatest importance is the promotion of research from the perspective of the musician, giving voice to the phenomenon of musician's dystonia. It is only through understanding this experience from the musician's perspective that we can adequately address their unique healthcare needs.

More evidence on adaptive, remedial, and compensatory approaches are needed across instrument types. Given the differences in physical demands and techniques between instruments, guiding principles and approaches could help prepare therapists to feel more confident in working with this population. This resource could include information ranging from ergonomic principles that facilitate technical demands, to minor instrument modifications that can promote and prolong a musician’s ability to play their instrument.

The Quick DASH, Performing Arts module provides a starting point for healthcare providers who are working with musicians with musculoskeletal injuries, but given the unique characteristics of musician’s dystonia, an assessment that better captures the hallmark characteristics of this disorder is warranted. Some relevant questions could include: Are your symptoms influencing the way that you feel about playing your instrument?; Have you made modifications to your technique or your instrument?; Do your symptoms influence the way that you practice?; Are you comfortable playing in the same settings as prior to the onset of your symptoms?

Finally, the field of professional music is highly specialized, presenting unique physical, emotional, and mental demands upon musicians. This field also has a set of cultural assumptions that are often not understood by those outside of the field. Given these characteristics, interdisciplinary relationships amongst healthcare providers and musicians would provide the best environment for discovering and promoting best practices for working with professional musicians with musician’s dystonia. Few examples of this kind of partnership are evident, but may support an emerging area of research and practice.

### Limitations

A number of limitations of this study provide directions for future qualitative research on musician’s dystonia. First, having a diagnosis of musician’s dystonia was an inclusion criterion for participation in this study. While it is common in health sciences research to require a formal diagnosis for the condition which is being studied, the relative limited understanding of this disorder may make this criterion unnecessarily limiting. Future research on musicians with musician’s dystonia might consider a broader approach to determining eligibility of participants.

Another limiting factor is the unknown accuracy of self-report on the QuickDASH assessment. Given the chronic and typically pain-free characteristics of musician’s dystonia, this tool is of questionable usefulness for understanding the functional limitations of musicians with hand musician’s dystonia. It should be considered whether there are other screening tools that better convey the experience of this group.

While consistent with the tradition of small sample size in qualitative research and phenomenology, the generalizability of these findings is limited. To better represent the lived experiences of professional musicians with musician’s dystonia, future research on this topic will continue to broaden our understanding of this population.

Finally, the primary investigator, who is a professional violinist and has a history of musician’s dystonia, used an emic approach in both interviews and data analysis. While this inside perspective can add depth to the understanding of the findings, this perspective also has the potential to increase bias.

## Conclusions

This study explored how professional musicians with musician’s dystonia described their professional and personal lived experience, before and after having the onset of the condition. In the spirit of the phenomenological approach used, the aim of the research was to provide an account, from the perspective of the musician living with this condition. The findings illustrated the broad impact that musician’s dystonia has throughout all areas of the musicians’ lives and the persistence of these experiences over many years. The themes from qualitative interviews emphasize the importance of collaborative approaches and rapport building when working with this population.

# Appendix A Expanded Literature Review

## Appendix A.1 Abbreviated Critical Appraisals of Evidence

| | |
|---|---|
| Type of Article | Overall Type: Primary research study<br>Specific Type: Descriptive cross-sectional using self-administered questionnaires |
| APA Reference | Ajidahun, A.T., Mudzi, W., Myezwa, H., Wood, W-A. (2016). Upper extremity disability among string instrumentalists-use of the quick DASH and the NDI. *Cogent Medicine, 3*(1), 1234535. https://doi.org/10.1080/2331205X.2016.1234535 |
| Abstract | "Purpose: Playing the string instrument predisposes musicians to musculoskeletal problems in the upper extremity and trunk which usually affects more than one anatomical region. These musculoskeletal problems could result in difficulty in performing activities of daily living and playing a musical instrument. The aim of this study was to evaluate disability associated with musculoskeletal problems of string instrumentalists in South Africa by using the quick Disability of the Arms, Shoulder and Hands (DASH) and the Neck Disability Index (NDI) as measuring tools. Materials and methods: String instrumentalists from both amateur and professional orchestras were recruited via an electronic and a paper based survey to participate in the study by completing a self-administered questionnaire. The prevalence of musculoskeletal problems affecting performance was 56.6% and the trunk and shoulders were mainly affected. The overall disability scores of the QuickDASH and the NDI were 12.9 ± 13.2 and 11.5 ± 9.8 respectively. Symptomatic individuals had higher disability scores, 13.9 ± 13.8 (QuickDASH) and 15.0 ± 10.5 (NDI). Conclusion: The presence of musculoskeletal problems in one or more anatomic regions results in activity limitation and participation restriction of activities of daily living and it also impedes performance, therefore, it is important to evaluate the biomechanical structures involved in playing in order to proffer injury prevention strategies directly focussed on the basic components of performance." (p. 1) |
| Author | Credentials: PhD candidate at the time of publication<br>Position and Institution: faculty of Health Sciences, Department of Physiotherapy, University of Witwatersrand<br>Publication History on Google Scholar: 12 citations |
| Publication | Type of Publication: Peer-reviewed journal<br>Publisher: Taylor and Francis Online<br>Other: Usage: 262K annual downloads/views |
| Date and Citation History | Date of Publication: 2016<br>Google Scholar Cited By: 8 articles |
| Stated Purpose or Research Question | "Therefore, this study objectively measured disability among string instrumentalists in South Africa using the quick Disabilities of the Arm Shoulder and Hands (DASH) and the Neck disability Index (NDI). The study also explored disability associated with PRMDs among instrumental musicians as a baseline for future studies, such as evaluating the effectiveness of injury management programs." (p. 3) |
| Author's Conclusion | "The presence of musculoskeletal problems among string instrumentalists is associated with disability which impedes activities of daily living (ADL). This study has shown that the QuickDASH and NDI are useful instruments in measuring upper extremities and neck disability among string instrumentalists. A biomechanical analysis of the causative factors of upper extremity problems especially in the shoulder with an approach to exploring |

| | |
|---|---|
| | injury prevention strategies could reduce musculoskeletal problems and eventual disability among string instrumentalists.” (p. 8-9) |
| Relevant Findings for This Study | • The QuickDASH has 11 Likert items and is associated with three ICF domains.<br>• The QuickDASH has two optional subscores that may be used to document the impact on performance and broader work routines.<br>• The QuickDASH is an effective self-report measure for documenting musculoskeletal problems and disability of string instrumentalists.<br>• The QuickDASH scores for 99 musicians may be used as a comparison group for the participants in this study. |

| | |
|---|---|
| Type of Article | Overall Type: Literature Review<br>Specific Type: Scoping Review |
| APA Reference | Sofaer, S. (1999). Qualitative methods: what are they and why use them? *Health Services Research*, *34*(5 Pt 2), 1101–1101. |
| Abstract | "Objective. To provide an overview of reasons why qualitative methods have been used and can be used in health services and health policy research, to describe a range of specific methods, and to give examples of their application.<br>Data Sources. Classic and contemporary descriptions of the underpinnings and applications of qualitative research methods and studies that have used such methods to examine important health services and health policy issues.<br>Principal Findings. Qualitative research methods are valuable in providing rich descriptions of complex phenomena; tracking unique or unexpected events; illuminating the experience and interpretation of events by actors with widely differing stakes and roles; giving voice to those whose views are rarely heard; conducting initial explorations to develop theories and to generate and even test hypotheses; and moving toward explanations. Qualitative and quantitative methods can be complementary, used in sequence or in tandem. The best qualitative research is systematic and rigorous, and it seeks to reduce bias and error and to identify evidence that disconfirms initial or emergent hypotheses.<br>Conclusions. Qualitative methods have much to contribute to health services and health policy research, especially as such research deals with rapid change and develops a more fully integrated theory base and research agenda. However, the field must build on the best traditions and techniques of qualitative methods and must recognize that special training and experience are essential to the application of these methods." (p. 1101) |
| Author | Credentials: Dr.P.H.<br>Position and Institution: Senior Research Consultant, former Director of Public Health at UC Berkeley School of Public Health<br>Publication History: 22 Articles |
| Publication | Type of Publication: Peer-Reviewed Journal<br>Publisher: Health Research and Educational Trust<br>Other: Health Services Research(Vol. 34, Issue 5 part 2) |
| Date and Citation History | Date of Publication:1999<br>Google Scholar Cited By: 1247 |
| Stated Purpose or Research Question | "To provide an overview of reasons why qualitative methods have been used and can be used in health services and health policy research, to describe a range of specific methods, and to give examples of their application." (p. 1101) |
| Author's Conclusion | "As noted at the outset, health services and policy research is young as a field of inquiry. At this stage of its development, researchers and funders cannot afford to ignore the potential contributions of qualitative methods in identifying important questions, in building the capacity to conduct and replicate research, and in constructing useful theories. However, the contributions of qualitative research will not be maximized unless the methods are applied with rigor as well as creativity. The purchasers and consumers of research have every right to demand vigilance in ensuring that those who design and conduct this research have the right training and experience and that they acknowledge and, to the extent possible, protect against the investigator-dependent nature of this research" (p.1103) |
| Relevant Findings for This Study | Qualitative research methods provide rich descriptions of complex lived experiences and give voice to those who are underrepresented and who's views are rarely heard. |

| | |
|---|---|
| Type of Article | Overall Type: Conceptual article<br>Specific Type: Literature review |
| APA Reference | Whittemore, R., Chase, S., & Mandle, C. (2001). Validity in Qualitative Research. *Qualitative Health Research*, *11*(4), 522–537. https://doi.org/10.1177/104973201129119299 |
| Abstract | "Much contemporary dialogue has centered on the difficulty of establishing validity criteria in qualitative research. Developing validity standards in qualitative research is challenging because of the necessity to incorporate rigor and subjectivity as well as creativity into the scientific process. This article explores the extant issues related to the science and art of qualitative research and proposes a synthesis of contemporary viewpoints. A distinction between primary and secondary validity criteria in qualitative research is made with credibility, authenticity, criticality, and integrity identified as primary validity criteria and explicitness, vividness, creativity, thoroughness, congruence, and sensitivity identified as secondary validity criteria." (p. 522) |
| Author | Credentials: PhD, APRN, FAAN<br>Position and Institution: Yale University School of Nursing<br>Publication History: 32 Articles |
| Publication | Type of Publication: Peer-Reviewed Journal<br>Publisher: Journal of Advanced Nursing |
| Date and Citation History | Date of Publication: 2001<br>Google Scholar Cited By: 2935 |
| Stated Purpose or Research Question | "This article explores the historical development of validity criteria in qualitative research through a review of antipodal tensions. The tension between qualitative and quantitative research, the tension between epistemological purism and pluralism, and the tension between rigor and creativity in the scientific process will be addressed. A framework of critical multiplism guides the subsequent synthesis of contemporary viewpoints into a reconceptualization of meaningful validity criteria in qualitative research. It is proposed that flexibility amid common criteria provides the best assurance that the art of qualitative research will illuminate the science of qualitative research and the science will give credence to the art." (p. 523) |
| Author's Conclusion | "Specification of validity criteria in qualitative research has implications for both the research process and the research product. Past experience demonstrates the incompleteness of an overemphasis on process (science without art) as well as the potential for pseudoscience by an overemphasis on the research product (art without science). Researchers and consumers of research cannot become seduced by a catchy phrase or meticulous application of a systematic methodology. Attention to both process and product, art and science, contribute to validity and subsequently quality in qualitative research. Quality in research is dependent on honest and forthright investigations (Marshall, 1990). Searching for alternative explanations and a self-critical attitude is imperative. Every study has biases and particular threats to validity, all methods have limitations, and research involves multiple interpretations as well as a moral and ethical component inherent in judgments (Marshall, 1990; Smith, 1990). What becomes most important is to determine the validity ideals of a particular study (criteria), employ the optimal methodological techniques, and to critically present the 534 QUALITATIVE HEALTH RESEARCH / July 2001 TABLE 3: Assessment of Primary and Secondary Criteria of Validity Criteria Assessment Primary criteria Credibility Do the results of the research reflect the experience of participants or the context in a believable way? Authenticity Does a representation of the emic perspective exhibit awareness to the subtle differences in the voices of all participants? Criticality Does the research process demonstrate evidence of critical appraisal? Integrity Does the research reflect recursive and repetitive checks of validity as well as a humble presentation of findings? Secondary criteria Explicitness Have methodological decisions, interpretations, and investigator biases been addressed? Vividness Have thick and faithful descriptions been portrayed |

| | |
|---|---|
| | with artfulness and clarity? Creativity Have imaginative ways of organizing, presenting, and analyzing data been incorporated? Thoroughness Do the findings convincingly address the questions posed through completeness and saturation? Congruence Are the process and the findings congruent? Do all the themes fit together? Do findings fit into a context outside the study situation? Sensitivity Has the investigation been implemented in ways that are sensitive to the nature of human, cultural, and social contexts? research process in detail. Validity cannot be assumed, and presentation of research findings must invite the opportunity for critical reflection by consumers. The importance of explicating "how we claim to know what we know" (Altheide & Johnson, 1994, p. 496) is as essential as the claim to what we know. This contemporary synthesis of validity criteria in qualitative research facilitates the decision-making process for investigators and the evaluative process for consumers of research. Further development of validity criteria requires ongoing dialogue." (p. 535) |
| Relevant Findings for This Study | Research findings need to be presented with a clear explanation of the validity criteria and the specific techniques used so that the readers can judge the validity of the study. |

| | |
|---|---|
| Type of Article | Overall Type: Primary research<br>Specific Type: Survey research followed by focus groups |
| APA Reference | Willison, D. J., Steeves, V., Charles, C., Schwartz, L., Ranford, J., Agarwal, G., ... & Thabane, L. (2009). Consent for use of personal information for health research: do people with potentially stigmatizing health conditions and the general public differ in their opinions?. *BMC Medical Ethics, 10*(1), 1-12. https://doi.org/10.1186/1472-6939-10-10 |
| Abstract | "**Background**<br>Stigma refers to a distinguishing personal trait that is perceived as or actually is physically, socially, or psychologically disadvantageous. Little is known about the opinion of those who have more or less stigmatizing health conditions regarding the need for consent for use of their personal information for health research.<br>**Methods**<br>We surveyed the opinions of people 18 years and older with seven health conditions. Participants were drawn from: physicians' offices and clinics in southern Ontario; and from a cross-Canada marketing panel of individuals with the target health conditions. For each of five research scenarios presented, respondents chose one of five consent choices: (1) no need for me to know; (2) notice with opt-out; (3) broad opt-in; (4) project-specific permission; and (5) this information should not be used. Consent choices were regressed onto: demographics; health condition; and attitude measures of privacy, disclosure concern, and the benefits of health research. We conducted focus groups to discuss possible reasons for observed consent choices.<br>**Results**<br>We observed substantial variation in the control that people wish to have over use of their personal information for research. However, consent choice profiles were similar across health conditions, possibly due to sampling bias. Research involving profit or requiring linkage of health information with income, education, or occupation were associated with more restrictive consent choices. People were more willing to link their health information with biological samples than with information about their income, occupation, or education.<br>**Conclusions**<br>The heterogeneity in consent choices suggests individuals should be offered some choice in use of their information for different types of health research, even if limited to selectively opting-out. Some of the implementation challenges could be designed into the interoperable electronic health record. However, many questions remain, including how best to capture the opinions of those who are more privacy sensitive." (p. 1) |
| Author | Credentials: ScD<br>Position and Institution: Department of Clinical Epidemiology & Biostatistics, McMaster University<br>Publication History: 113 Articles |
| Publication | Type of Publication: Peer-Reviewed Journal<br>Publisher: BMC Medical Ethics |
| Date and Citation History | Date of Publication: 2009<br>Google Scholar Cited By: 77 |
| Stated Purpose or Research Question | "The purpose of this study was to examine the attitudes of people with a range of potentially stigmatizing health conditions concerning the need for consent for the use of their personal information for different types of observational health research, and to compare their attitudes with those of the general public." (p. 2) |
| Author's Conclusion | "The public is generally supportive of research use of personal health information, but do not wish to entirely relinquish control. Despite having a relatively researchfriendly sample, we still observed substantial individual variation in opinion as to the degree of control that people wish to have over use of their personal information for research. |

| | |
|---|---|
| | Opportunities for individual choice over use of one's personal health information could be designed into the planned pan-Canadian inter-operable electronic health record system. People's desire for control over use of their personal health information increases when there is a commercial element to the research. Additional public engagement is required to better understand this. Finally, this study attempted to address the question of how much control patients would like over use of their personal health information for research. While we fully appreciate the rationale for restricting researchers from directly recruiting patients on the basis of prior knowledge about their health condition, it is ironic that, to meet ethical requirements respecting individuals' privacy, this study has likely under-represented the interests of those very people whose voices need to be heard. When addressing questions like the one we have posed here, there need to be ways to better reach those who have the most at stake." (p. 11) |
| Relevant Findings for This Study | Populations who have conditions that are stigmatized are likely underrepresented in the literature on health, even though they are the individuals who need to be recognized in the research. |

## Appendix A.2 Qualitative Methods and Analyses

### *Phenomenology*

Phenomenology, as understood in the qualitative research literature, describes a search for a common meaning, shared by individuals, of their lived experiences of a phenomenon (Creswell & Poth, 2018; Neubauer et al.). In this context, the individual is seen as the vehicle through which a lived experience of a phenomenon can be described (Priest, 2002) and ultimately, understood. Through this approach, new meanings can inform our understanding of a phenomenon, and inspire a greater appreciation for perspectives outside of our own experience (Neubauer et al., 2019).

Phenomenology is particularly well suited for informing healthcare providers about the experiences of their patients. Phenomenology explores the subjective meaning of an individual's experience, with attention to both *what* was experienced, and *how* it was experienced (Neubauer et al., 2019). These insights are key to shaping the empathy, and therapeutic skills that are the hallmarks of good practitioners, and central to shaping the clinical reasoning of healthcare providers (Neubauer et al., 2019).

### *Qualitative Interview Tradition*

Phenomenological research uses in-depth interviews to gather data from participants who have an experience of a phenomenon. Recommendations on the appropriate sample size for phenomenological research vary in the literature, with a common range extending from five to ten participants (Creswell & Poth, 2018; Groenewald, 2004). Qualitative research uses semi-structured and unstructured interviews, with structured interviews being reserved for quantitative research (Groenewald, 2004).

Semi-structured interviews rely on predetermined, open-ended questions as a starting point for an interview, with additional questions emerging in response to the dialogue that develops between researcher and participant (DiCicco-Bloom & Crabtree, 1998). This in-depth interview style typically ranges from 30 minutes to several hours, allowing the researcher to gather deep understanding of the participant's experience (DiCicco-Bloom & Crabtree, 1998).

Given the in-depth and personal nature of qualitative interviewing, the qualitative researcher must quickly build a trusting relationship with the participant, as the success of this type of interview is dependent on strong rapport (DiCicco-Bloom & Crabtree, 1998).

### *Data Analysis*

Many approaches to data analysis in phenomenological research have emerged over the past 50 years (Priest, 2002), Moustaka's 1994 version was the basis for this research. This approach, as delineated by Creswell and Poth (2017), is outlined below:

- Describe the researcher's personal interaction with this study for the purpose of acknowledging underlying assumptions in order to more clearly represent the participant's viewpoints.
- Code the transcribed interviews and list significant statements.
- Group significant statements and identify themes from the data.
- Use verbatim examples to illustrate "what" the participants experienced with the phenomenon.
- Include a contextual description to illustrate "how" this experience occurred among participants.
- Extract the "essence" of the phenomenon from the data and write as a composite description including "what" the participants experienced and "how" they experienced it

## Appendix A.3. References

Ajidahun, M. (2016). Upper extremity disability among string instrumentalists-use of the quick DASH and the NDI. *Cogent Medicine*, *3*(1). https://doi.org/10.1080/2331205X.2016.1234535

Altenmüller, E., & Jabusch, H. (2009). Focal hand dystonia in musicians: Phenomenology, etiology, and psychological trigger factors. *Journal of Hand Therapy*, *22*(2), 144-155. https://doi.org/10.1016/j.jht.2008.11.007

Altenmüller, E., & Müller, D. (2013). A model of task-specific focal dystonia. *Neural Networks*, *48*, 25–31. https://doi.org/10.1016/j.neunet.2013.06.012

American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy*, *74*(Suppl. 2), 7412410010. https://doi.org/10.5014/ajot.2020.74S2001

AOTA. (2021). *Improve your documentation with AOTA's updated occupational profile template*. aota.org. https://www.aota.org/Practice/Manage/Reimb/occupational-profile-document-value-ot.aspx

Aránguiz, C. (2015). Focal dystonia in musicians: Phenomenology and musical triggering factors. *Neurología (Barcelona, English Ed. )*, *30*(5), 270–275. https://doi.org/10.1016/j.nrleng.2013.12.014

Betti, S., Spoto, A., Castiello, U., & Sartori, L. (2018). Testing rTMS-induced neuroplasticity: A single case study of focal hand dystonia. *Neural Plasticity*, *2018*, 12. https://doi.org/10.1155/2018/6464896

Centers for Disease Control and Prevention. (2020, September 17). *Infographic: 6 Guiding Principles To A Trauma-Informed Approach*. Centers for Disease Control and Prevention. https://www.cdc.gov/cpr/infographics/6_principles_trauma_info.htm

Chan, C., Driscoll, T., & Ackermann, B. (2013). The usefulness of on-site physical therapy-led triage services for professional orchestral musicians: A national cohort study. *BMC Musculoskeletal Disorders*, *14*(1), 98–98. https://doi.org/10.1186/1471-2474-14-98

Conti, A., Pullman, S., & Frucht, S. (2008). The hand that has forgotten its cunning—Lessons from musicians' hand dystonia. *Movement Disorders, 23*(10), 1398-1406. https://doi.org/10.1002/mds.21976

Creswell, J., & Poth, C. (2019). *Qualitative inquiry & research design : choosing among five approaches* (Fourth edition.). SAGE.

DiCicco-Bloom, B., & Crabtree, B. (2006). The qualitative research interview. *Medical Education*, *40*(4), 314–321. https://doi.org/10.1111/j.1365-2929.2006.02418.x

Fitzpatrick, N., Finlay, L. (2008). “Frustrating disability”: The lived experience of coping with the rehabilitation phase following flexor tendon surgery. *International Journal of Qualitative Studies on Health and Well-being,* 3(3), 143-154. https://doi.org/10.1080/17482620802130407

Frucht, S. (2009). Focal task-specific dystonia of the musicians’ hand—a practical approach for the clinician. *Journal of Hand Therapy, 22*(2), 136-143. https://doi.org/10.1016/j.jht.2008.11.006

Furuya, S., Tominaga, K., Miyazaki, F., & Altenmüller, E. (2015). Losing dexterity: Patterns of impaired coordination of finger movements in musician’s dystonia. *Scientific Reports, 5*(1), 13360. https://doi.org/10.1038/srep13360

Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods, 3*(1), 42–55. https://doi.org/10.1177/160940690400300104

Guptill, C. (2008). Musicians' health: Applying the ICF framework in research. *Disability and Rehabilitation*, *30*(12-13), 970–977. https://doi.org/10.1080/09638280701800517

Guptill, C. (2011). The lived experience of working as a musician with an injury. *Work (Reading, Mass.), 40*(3), 269–280. https://doi.org/10.3233/WOR-2011-1230

Guptill, C. (2012). Injured professional musicians and the complex relationship between occupation and health. *Journal of Occupational Science, 19*(3), 258-270. https://doi.org/10.1080/14427591.2012.670901

Hamberger, L., Barry, C., & Franco, Z. (2019). Implementing trauma-informed care in primary medical settings: Evidence-based rationale and approaches. *Journal of Aggression, Maltreatment & Trauma*, *28*(4), 425–444. https://doi.org/10.1080/10926771.2019.1572399

Ioannou, C., Furuya, S., & Altenmüller, E. (2016). Objective evaluation of performance stress in musicians with focal hand dystonia: A case series. *Journal of Motor Behavior*, *48*(6), 562–572. https://doi.org/10.1080/00222895.2016.1161590

Ioannou, C., Furuya, S., & Altenmüller, E. (2016). The impact of stress on motor performance in skilled musicians suffering from focal dystonia: Physiological and psychological characteristics. *Neuropsychologia*, *85*, 226–236. https://doi.org/10.1016/j.neuropsychologia.2016.03.029

Jabusch, H., Zschucke, D., Schmidt, A., Schuele, S., & Altenmüller, E. (2005). Focal dystonia in musicians: Treatment strategies and long-term outcome in 144 patients. *Movement Disorders*, *20*(12), 1623–1626. https://doi.org/10.1002/mds.20631

Kenny, D., & Ackermann, B. (2015). Performance-related musculoskeletal pain, depression and music performance anxiety in professional orchestral musicians: A population study. *Psychology of Music, 43*(1), 43-60. https://doi.org/10.1177/0305735613493953

Mainka, T., Erro, R., Rothwell, J., Kühn, A., Bhatia, K., & Ganos, C. (2019). Remission in dystonia – Systematic review of the literature and meta-analysis. *Parkinsonism & Related Disorders*, *66*, 9–15. https://doi.org/10.1016/j.parkreldis.2019.02.020

Münte, A. (2002). The musician's brain as a model of neuroplasticity. *Nature Reviews. Neuroscience*, *3*(6), 473–478. https://doi.org/10.1038/nrn843

Neubauer, B., Witkop, C., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education*, *8*(2), 90–97. https://doi.org/10.1007/s40037-019-0509-2

Perkins, R., Reid, H., Araújo, L., Clark, T., & Williamon, A. (2017). Perceived enablers and barriers to optimal health among music students: A qualitative study in the music conservatoire setting. *Frontiers in Psychology*, *8*, 968–968. https://doi.org/10.3389/fpsyg.2017.00968

Paulig, J., Jabusch, H., Großbach, M., Boullet, L., & Altenmüller, E. (2014). Sensory trick phenomenon improves motor control in pianists with dystonia: prognostic value of glove-effect. *Frontiers in Psychology*, *5*, 1012–1012. https://doi.org/10.3389/fpsyg.2014.01012

Sadnicka, A., Kassavetis, P., Pareés I., et al. (2016) Task-specific dystonia: pathophysiology and management *Journal of Neurology Neurosurgery and Psychiatry*, 87, 968-0974 https://doi.org/10.1136/jnnp-2015-311298

Schneider, J., Scholz, D.S., & Altenmüller, E.(2021). Impact of psychic traumatization on the development of musicians' dystonia: Six exploratory case studies. *Medical Problems of Performing Artists, 36(1), 1-9.* https://doi.org/10.21091/mppa.2021.1001

Schuele, S. U., & Lederman, R. J. (2004). Occupational disorders in instrumental musicians. *Medical Problems of Performing Artists*, *19*(3), 123+. https://doi.org/10.21091/mppa.2004.3021

Sokolowski, R. (2000). *Introduction to phenomenology*. Cambridge University Press.

Stahl, C., & Frucht, M. (2017). Focal task specific dystonia: A review and update. *Journal of Neurology, 264*(7), 1536-1541. https://doi.org/10.1007/s00415-016-8373-z

Steinmetz, A., Stang, A., Kornhuber, M., Röllinghoff, M., Delank, K., & Altenmüller, E. (2013, December 12). From embouchure problems to embouchure dystonia? A survey of self-reported embouchure disorders in 585 professional orchestra brass players. *International Archives of Occupational and Environal Health*, *87*, 783–792. https://doi.org/10.1007/s00420-013-0923-4

Ting, A., & Rocker, J. (2019). Evaluation and treatment of musicians from a holistic perspective. *The Open Journal of Occupational Therapy*, *7*(4), 1-10. https://doi.org/10.15453/2168-6408.1581

van der Steen, M., van Vugt, F., Keller, P., & Altenmuller, E. (2014). Basic timing abilities stay intact in patients with musician's dystonia. *PloS One*, *9*(3), e92906–e92906. https://doi.org/10.1371/journal.pone.0092906

van Vugt, F., Boullet, L., Jabusch, H., & Altenmüller, E. (2013). Musician's dystonia in pianists: Long-term evaluation of retraining and other therapies. *Parkinsonism & Related Disorders*, *20*(1), 8–12. https://doi.org/10.1016/j.parkreldis.2013.08.009

Zaza, C., Charles, C., & Muszynski, A. (1998). The meaning of playing-related musculoskeletal disorders to classical musicians. *Social Science & Medicine (1982)*, *47*(12), 2013–2023. https://doi.org/10.1016/S0277-9536(98)00307-4

Zosso, A., & Schoeb, V. (2012). Musicians' social representations of health and illness: A qualitative case study about focal dystonia. *Work*, *41*(1), 53-59. https://doi.org/10.3233/WOR-2012-1243

# Appendix B. Research Methods

## Appendix B.1 IRB Proposal

ST. CATHERINE UNIVERSITY

### ST. CATHERINE UNIVERSITY REQUEST FOR APPROVAL FOR THE USE OF HUMAN SUBJECTS IN RESEARCH APPLICATION

### IRB APPLICATION DOCUMENT CHECKLIST

The items listed below are the application, forms and supporting documents to be uploaded to Mentor IRB for your protocol/application submission. Consent forms and additional supporting documents may be uploaded separately; directions for Mentor IRB can be found on www.stkate.edu/irb or https://stkate.box.com/s/7rt8t0x2sieqfsj9gkzrossf5fr5uwcf.

☐ IRB Application

☐ PI Documentation/CITI Training for Investigator(s)*

☐ PI Documentation/CITI Training for Faculty Adviser (if applicable)*

☐ Informed consent form

☐ Child assent form (if applicable)

☐ Recruiting materials (phone script, fliers, ads, etc)

☐ Survey/questionnaire(s), focus group or interview questions (if applicable)

☐ Conflict of interest/financial interest disclosure (if applicable)

☐ Letter(s) of support (if you are conducting research at another agency, school, etc).

☐ Data management plans meets Data Management Policy (policy below)

***PI Documentation/CITI Training is the completion report received for fulfilling the required Human Subjects Research education requirements in CITI Program. Each person will need to**

**upload their PI Documentation to their individual Mentor IRB account. Directions are located in Mentor IRB.**

**IRB RELATED POLICIES:**
Listed below as well as throughout the application are St. Catherine policies related to human Subjects research

- IRB Policy: https://stkate.box.com/s/4vxto2w6azt1k9jclim5gc1bqktoe3uv
- Intellectual Property Policy: https://stkate.box.com/s/51my44r6a5no8nurqydhcxpjlj1rwzkm
- Research Misconduct Policy: https://stkate.box.com/s/qzx5oev241s3uw1btpd5fwgickgfzjvx
- Research Data Management Policy: https://stkate.box.com/s/0m4yf9cumy12f2yq5kwo4wlhm9qf86c8

Complete the following application in its entirety. You may excerpt material from your thesis or grant proposal, but your application should be relatively concise. Consent forms and additional supporting documents may be uploaded to Mentor IRB separately. For questions, contact the IRB Coordinator at 651-690-6204 or irb@stkate.edu.

**Date of application:** September 20, 2020

**Investigator name(s) and credentials (e.g., PhD, RN, etc.): (*List all co-investigators*)**
Jill Olson Moser, OTS
Dr. Julie D. Bass, PhD, OTR/L, FAOTA

**Project Title:** Living with Focal Dystonia: The Musician's Perspective

**Department:** MAOT

**Level of Review:**
*In the Mentor IRB system, you must select the Review Type; selecting Exempt and Expedited will prompt additional questions for you to fill out. For more information on the levels of review, go to the Mentor IRB Info page: Determine the Level of Review.*

☐ **Exempt** ☒ **Expedited** ☐ **Full** ☐ **Quality Improvement** ☐ **Not Research**

**Will another IRB review this research application?**

☒ **No** ☐ **Yes – First reviewed by an External IRB** ☐ **Yes – First reviewed by St. Kate's IRB**

***If YES – First reviewed by an External IRB, you may not need to complete a St Kates IRB application and can instead use your external IRB application. Please include a copy of the approved external IRB application and the letter of approval from the external IRB with your Mentor IRB submission.***

***If YES – First reviewed by St. Kate's IRB, please indicate your plans for review and identify the external IRB:***

**Note:** *Cooperative Research occurs when a research protocol requires approval from outside institutions (e.g., a hospital IRB or other college/university) as well as St. Catherine University. Sometimes it is possible for an IRB to accept an external IRB's review to reduce duplication of review effort. If you have questions about cooperative research and how to determine when only one IRB will need to review your IRB application, contact the IRB coordinator at IRB@stkate.edu or reference the Cooperative Research Policy Addendum.*

1. **RESEARCH SUMMARY:** *Complete each section in clear, easy to read language that can be understood by a person unfamiliar with your research and your field.*

**a.** **Purpose of the research:** *Provide a clear, concise statement of your purpose.*

The purpose of this phenomenological study is to understand the lived experience of professional musicians who have focal dystonia, a task specific neurological movement disorder. This research will examine the perceptions of participation in meaningful occupations experienced by professional musicians with focal dystonia.

**b.** **Background:** *Provide a concise summary in 1 - 2 brief paragraphs to explain the importance of the research and how it fits with previous research.*

The relationship between a musician and their musical instrument is integral to their sense of self (Zosso & Schoeb, 2009), and their lives are shaped in many ways by their ability to play their instrument (Frucht, 2009). Because of this, the impact of an injury is not only a physical barrier to carrying out their job, but additionally, a potential barrier to performance of other roles and everyday activities.

Due to the physically demanding and repetitive nature of their work, professional musicians are prone to injury. Research suggests that as many as 90% of musicians self-report experiencing musculoskeletal pain (Kenny & Ackermann, 2015). In addition to pain, musicians may experience debilitating injury that is marked by loss of motor control. Focal dystonia is a task specific neurological movement disorder. While focal dystonia is typically not painful, it causes the loss of dexterity and impairs voluntary motor control of highly trained movements (Altenmuller, 2009). Standard treatments for focal dystonia provide improvement in the majority of patients, but the degree of recovery is rarely sufficient to allow the musician to return to professional performing (Frucht, 2009).

While there has been extensive research into the etiology, pathophysiology and treatment of focal dystonia, there is limited research exploring the musician's lived experience of how this disorder is affecting their lives. Research is needed to understand the ways in which this diagnosis changes participation in roles and activities and the phenomena of a diagnosis of focal dystonia amongst professional musicians.

**c.** **Research Methods and Questions:** *Give a general description of the study design and specific methods you will use in your investigation. Specify all of your research questions and/or hypotheses. Reviewers will consider whether the information you are gathering is necessary to answer your research question(s), so this should be clear in your application.*

This research will be conducted using qualitative interviews from the phenomenological research tradition. The study is designed with a limited scope to explore the lived experiences of professional musicians who have been diagnosed with focal dystonia.

The primary research question is:
How do professional musicians with focal dystonia describe their professional and personal lived experience before and after having the condition?

Secondary research questions include:
How do professional musicians with focal dystonia describe professional and personal changes and adaptations to their roles and activities because of the condition?
How do professional musicians with focal dystonia describe their experiences of supports and barriers to performance of professional and personal roles and activities?
How do professional musicians with focal dystonia describe their experiences with healthcare or other services for the management of the condition?

Research subjects will complete a brief demographic survey, the Quick DASH (a self-report measure of arm, shoulder, and hand function), and one semi-structured interview session of 60-90 minutes, conducted over Zoom. Interview questions will be broad and open ended. Interviews will be recorded and transcribed and themes will be coded and identified. After themes have been identified, all participants will have the option of participating in a brief member check interview (15-20 minutes) to verify the accuracy and trustworthiness of findings.

Following transcription of individual interviews, data analysis will follow a simplified version of Moustaka’s data analysis as delineated by Creswell and Poth (2017):

- Describe researcher’s personal interaction with this study for the purpose of acknowledging underlying assumptions in order to more clearly represent the participant’s viewpoints.
- Code the transcribed interviews and list significant statements.
- Group significant statements and identify themes from the data.
- Use verbatim examples to illustrate “what” the participants experienced with the phenomenon.
- Include a contextual description to illustrate “how” this experience occurred among participants.
- Extract the “essence” of the phenomenon from the data and write as a composite description including “what” the participants experienced and “how” they experienced it.

**d.** **Expectations of Participants:** *Give a step by step description of all procedures that you will have participants do. Attach any surveys, tests, instruments, interview questions, data collection forms, etc. that you will use with participants.*

- Participants will be recruited with the use of union personnel listings, available to the researcher due to her union membership. Recruitment will continue with the use of snowball approach.
- Interested participants will be sent an introductory email outlining the purpose and expectations, as well as providing the opportunity to indicate interest. (see attached)
- Chosen participants will be given a written informed consent form and will be given opportunities to participate or to decline participation in the study. (see attached)
- Participants will complete a brief survey and Quick DASH questionnaire for descriptive purposes. (see attached)
- Participants will participate in a semi-structured interview of 60-90 minutes. (see attached)
- After themes have been identified, all participants will have the opportunity to review an excerpt of the transcript and make any additions, revisions, or deletions to the description of self as professional musician.

**e. Estimated Time Commitment for Participants:**

| | |
|---|---|
| 5 minutes | Zoom contact to review informed consent form |
| 10-20 minutes | Survey and Quick DASH questionnaire |
| 60-90 minutes | Semi-structured interview (1 session) |
| 15-20 minutes | Optional follow up interview/email |
| 75-135 minutes | **Total Time Commitment** |

**f. Access to Existing Data:** *If you are analyzing existing data, records, or specimens, explain the source and type, means of access, and permission(s) to use them. If not accessing existing data, indicate "NA"*

N/A

**2. SUBJECTS:** *Provide your best estimates below.*

**a. Age Range of Subjects Included:** 22-75 - the aim of this research is to explore experiences of people within the age span of what is considered typical for professional engagement amongst members of the music community.

**b. Number:**

(Indicate a range, or maximum, if exceeded, you will need to submit an amendment)

4-6 Total ☒ Not Gender Specific ☐ Female only ☐ Male only

**c. Target Population:** Describe your target population (the group you will be studying; e.g. seniors,
children ages 9-12, healthy adults 18 or over, etc.)

The intended participants for this research study are current or former professional musicians who have been diagnosed with focal dystonia.

**d.** **Specific Exclusions:** *If women and/or minorities are to be excluded from the study, a clear rationale should be provided in section "f" below.*

**e.** **Special Populations Included:** *Select any special population that will be the focus of your research.*
NOTE: *These groups require special consideration by federal regulatory agencies and by the IRB.*

- ☐ **Minors (under age 18)**
- ☐ **St. Catherine Employees**
- ☐ **Students**
- ☐ **Elderly/aged persons**
- ☐ **Individuals with impaired decision-making capacity**
- ☐ **HIV/AIDS patients**
- ☐ **People in prison**
- ☐ **Hospital patients or outpatients**
- ☐ **People who are educationally disadvantaged**
- ☐ **People who are economically disadvantaged**
- ☐ **Minority group(s) and/or non-English speakers *(please specify)*** ______________
- ☐ **Other Special Characteristics and Special Populations *(please specify)*** ______________

**f.** **Provide reasons for targeting or excluding any special populations listed above**.

**g.** **Do you have any conflict of interest (financial, personal, employment, dual-role) that could affect human subject participation or protection?** *Dual-role examples: faculty–student (does not apply to action research projects for education students), medical practitioner-patients, supervisor-direct reports, etc.*

☐ **Yes** ☒ **No**

***If Yes, please indicate the steps you will take to minimize any undue influence in your research, recruitment and consent process. You can also reference the university Financial Conflict of Interest policy: https://stkate.box.com/s/ymgyislnxtvn3887om50bzdtu7ezaulu***

**3. RECRUITMENT: LOCATION OF SUBJECTS** *(Select all that apply)* **:**

☐ **St. Catherine University students**

☐ **School setting (PreK – 12)**

☐ **Hospital or clinic**

☐ **Other Institution *(Specify)*:**

☒ **None of the above *(Describe location of subjects)*:** Recruitment will begin with use of union personnel listings, available to the researcher due to her union membership. Recruitment will continue with the use of snowball approach.

**<u>NOTE:</u>** *If participants are recruited or research is conducted through an agency or institution other than St. Catherine University, submit either written or electronic documentation of approval and/or cooperation. An electronic version should be sent from the email system of that particular institution. The document should include the name of the PI, Title of the approved study, as well as the name and title of the appropriate administrator sending the approval. You should include an abstract/synopsis of your study when asking for approval from an external institution.*

**a. Recruitment Method:** *Describe how you will recruit your subjects? Attach a copy of any advertisement, flyer, letter, or statement that you will use for recruitment purposes.*

Research participants will be recruited using fliers distributed via email to members of the local musician union. The researcher is a standing union member and has access to member contact information. Snowball sampling will be used, as research participants will be invited to recommend potential participants.

The researcher will recruit 4-6 willing participants who match the criteria of being a current or former performing professional musician with focal dystonia.

Once participants are identified and have consented to participate in the study, individual interviews will be scheduled. Due to Covid19, these interviews will take place via Zoom. All interviews will be recorded and transcribed by the student researcher and reviewed by the faculty advisor for accuracy.

**b. Incentives:** *Will the subjects be offered inducements for participation? If yes, explain. Note: Please contact the SPREE office about the use of incentives within your research, as there are important university policies that fall outside of the protection of human subject,* SPREE@stkate.edu *or x8811*
*Incentive policy link*: https://stkate.box.com/s/sg18t87402as14xdtc0pppy2rt5w7swp

Yes, Participants will receive a $20 Amazon gift card.

## 4. RISKS AND BENEFITS OF PARTICIPATION

**a. Select all that apply. Does the research involve:**

☐ **Use of private records (medical or educational records)**

☐ **Possible invasion of privacy of the subjects and/or their family**

☐ **Manipulation of psychological or social variables**

☐ **Probing for personal or sensitive information in surveys or interviews**

☐ **Use of deception**

☐ **Presentation of materials which subjects might consider offensive, threatening or degrading**

☐ **Risk of physical injury to subjects**

☐ **Other risks:**

**b. <u>Risks</u>:** ***Briefly describe the risks of participation in your study, if any. Describe the precautions taken to minimize these risks. Please use "no foreseeable risk" rather than no risks.***

Minimal risk is foreseen for participants in this study. Interviews will be prefaced with instruction that information shared by the participant should be of the nature that would be shared with friends or family. Participants will be assured that if at any time the interview process feels overwhelming, they may withdraw from the study or decline from answering any question with which they are uncomfortable.

**c. <u>Benefits</u>:** *List any anticipated <u>direct</u> benefits to your subjects. If none, state that here <u>and</u> in the consent form.*

1. **Direct Benefits:** *List any anticipated direct benefits to your subjects. If none, state that here <u>and</u> in the consent form.*

None

2. **Other Benefits:** *List any potential benefits of this research to society, including your field of Study.*

This study aims to help inform and improve relationships between injured musicians and occupational therapists by increasing understanding and awareness of the lived experience of musicians with focal dystonia.

**d. <u>Risk/Benefit Ratio</u>:** *Justify the statement that the potential benefits (including direct and other benefits) of this research study outweigh any probable risks.*

The benefits of this study outweigh the risks, as there is currently very little research exploring the lived experience of musicians with focal dystonia.

Minimal psychological risks are foreseen to occur throughout this study and will be managed appropriately by informing participants of their rights to withdraw from the study at any time, or decline any question they are not comfortable answering.

e. **<u>Deception</u>:** *The use of deception in research poses particular risks and should only be used if necessary to accomplish the research, and when risks are minimized as much as possible. The researcher should not use deception when it would affect the subject's willingness to participate in the study (e.g, physical risks, unpleasant emotional or physical experiences, etc).*

**Will you be using deception in your research?**

☐ **Yes** ☒ **No**

***If yes, justify why the deceptive techniques are necessary in terms of study's scientific, educational or applied value. Explain what other alternatives were considered that do not use deception and why they would not meet the researcher's objective. Attach a copy of a debriefing statement explaining the deception to participants.***

**5. CONFIDENTIALITY OF DATA**

a. **Will your data be anonymous?**

☐ **Yes** ☒ **No**

(*Anonymous data means that the researcher cannot identify subjects from their data, while confidential data means that the researcher can identify a subject's response, but promises not to do so publicly*.)

b. ***How will you maintain anonymity/confidentiality of the information obtained from your subjects*?**

*Interview Example: I will assign pseudonyms to each interview participant. I will de-identify the data, and store the key separate from the recordings and transcripts. I will have the transcriptionist sign a confidentiality statement*

All data, including consent forms, interview transcripts, audio files, and field notes, will be kept on an encrypted cloud system, such as St. Kate's Google cloud system.

All transcription will be completed by the researcher and reviewed by the faculty advisor for accuracy.

Copies of all transcripts will be stored on the cloud and qualitative data analysis will also occur in the cloud. All participants will select a unique identifier number and all data will refer to them only by their number, which will also be kept on the cloud.

*c.* **Data Storage**: ***The IRB expects you to review the Research Data Management Policy (linked at the top of the application) and to make sure your data storage plans meet the St. Kate's policy requirements. For additional guidance see the Research Data Management Guidance document: https://stkate.box.com/s/p73h5om7knkhbcmk84cuanidx4ukhi0b***

**Select your Data Level and describe your data storage plans:**

☐ **Public** ☒ **Confidential** ☐ **Protected-disclosure could cause harm** ☐ **Restricted-full review only**

*Where will the data be kept, and who will have access to it during that time? Examples: I will store audio files and electronic files on a password protected computer or cloud (indicate which; please avoid using flash drives as they are one of the hardest 'tools' to protect and one of the easiest to exploit or lose, it is suggested to encrypt data on the cloud such as using a file password). I will store all paper files in a secure location (a locked filing cabinet) that is accessible only to myself and my advisor.*

All audio and electronic files will be kept on a password protected computer and an encrypted cloud system with passwords known only to myself and my advisor. All paper files will be transferred to an electronic format via scanning and will be shredded after they are secured in the encrypted cloud.

**d.** **Data Destruction***: How long will it be kept? What is the date when original data will be destroyed? (All studies must specify a date when original data that could be linked back to a subject's identity will be destroyed. Data that is stripped of all identifiers may be kept indefinitely). Example: I will destroy all records from the study within six months of the conclusion of the study but no later than June 2017.*

All records from the study within 5 years of its conclusion, and no later than December 31, 2024.

**e.** **Data Transmission/Sharing/Access:** *Will data identifying subjects be made available to anyone other than you or your advisor? If yes, please explain who will receive the data, how it will be transferred/shared and justify the need. Example: The data will only be available to me and my advisor.*

The data will only be available to the student researcher and the research advisor

**f.** **Official Records:** *Will the data become a part of the medical or school record? If yes, explain.*

No

6. **INFORMED CONSENT**

   a. **How will you gain consent?** *State what you will say to the subjects to explain your research.*

      You are invited to participate in a research study called, “Living with Focal Dystonia; The Musician’s Perspective.” The study is being conducted by Jilll Olson Moser, a Master’s candidate student in Occupational Therapy at St. Catherine University in St. Paul, MN. The faculty advisor for this study is Dr. Julie D. Bass, PhD, OTR/L, FAOTA, at St. Catherine University.

      The purpose of this study is to explore the day-to-day experiences of professional musicians who have focal dystonia. This research will explore the experience of focal dystonia on professional musicians’ participation in meaningful activities. The aim of this study is to inform and guide the approaches used in working therapeutically with professional musicians.

   b. **<u>Consent Document</u>:** *Attach the consent or assent form or text of oral statement. A template is available in Mentor IRB. Example: “See attached”*

      See attached

   c. **<u>Timing of Consent Process</u>:** *Note: In studies with significant risk or volunteer burden, the IRB may require that subjects be given an interim period of 24 hours or more before agreeing to participate in a study*

      A PDF version of the informed consent form will be emailed to participants prior to sending surveys and before the interview date. The consent form will also be read aloud with the participant prior to the in-person interview.

   d. **<u>Assurance of Participant Understanding</u>:** *How you will assess that the subject understands what they have been asked to do* (Note: *It is not sufficient to simply ask a yes/no question, such as “do you understand what you are being asked to do?”)*

      Researcher and participants will meet in advance of the interview for a brief Zoom video call to review the informed consent form. At the end of each section, I will ask "What questions do you have about this section?" and "What is your understanding of this section?"

7. **CITI TRAINING –** Work with your faculty advisor or contact IRB@stkates.edu if you have any questions about whether you should complete additional training modules within CITI. *You can also reference the HSR Mandatory Education Policy: https://stkate.box.com/s/b9zal9zd1813f1pxo4s35r5u5204ujaa*

   c. **Select all the CITI training courses/modules you completed:**

   **<u>REQUIRED COURSE:</u>**

**Human Subject Research Training Course – only one course is required**

☒ **Human Subject Research - Social & Behavioral Research Investigators**

☐ **Human Subject Research - Education Action Research Program**

☐ **Human Subject Research - Biomedical Research Investigators**

**<u>OPTIONAL MODULES:</u>**

☐ **Financial Conflict of Interest Course (suggested if you answered YES to Section 2 part g)**

☐ **Avoiding Group Harms - U.S. Research Perspectives (suggested if you checked any special populations in Section 2 part e)**

☐ **International Research (suggested for PIs doing research outside of the US that is NOT federally funded)**

☐ **International Studies (suggested for PIs doing research outside of the US that IS federally funded)**

☐ **Cultural Competence in Research (suggested when study related to a marginalized or minoritized population)**

☐ **Internet Based Research (suggested for PIs using internet resources during their research (outside of recruitment) – Skype, survey tools, internet activity monitoring, etc)**

☐ **Other (prisoners, pregnant women, children):**

## 8. ASSURANCES

**By submitting this application, the researcher certifies that:**

- **The information furnished concerning the procedures to be taken for the protection of human subjects is correct.**
- **The investigator has read the IRB policies and to the best of his/her knowledge, is complying with Federal regulations and St. Catherine University IRB Policy governing human subjects in research.**
- **The investigator will seek and obtain prior written approval from the IRB for any substantive modification in the proposal, including, but not limited to changes in cooperating investigators, procedures and subject population.**
- **The investigator will promptly report in writing to the IRB any unexpected or otherwise significant adverse events that occur in the course of the study.**
- **The investigator will promptly report in writing to the IRB and to the subjects any significant findings which develop during the course of the study which may affect the risks and benefits to the subjects who participate in the study.**
- **The research will not be initiated until the IRB provides written approval.**

- **The term of approval will be for one year. To extend the study beyond that term, a new application must be submitted.**
- **The research, once approved, is subject to continuing review and approval by the IRB.**
- **The researcher will comply with all requests from the IRB to report on the status of the study and will maintain records of the research according to IRB guidelines.**
- **If these conditions are not met, approval of this research may be suspended.**

## Appendix B.2 Summary of DASH

Table 2

*Individual Responses on Quick DASH items*

| Quick DASH Item | Carl | Anna | James | David |
|---|---|---|---|---|
| Open tight or new jar | 1 | 3 | 1 | 1 |
| Heavy chores | 1 | 2 | 1 | 1 |
| Carry shopping bag | 1 | 2 | 1 | 1 |
| Wash your back | 1 | 2 | 1 | 1 |
| Use knife to cut | 1 | 1 | 1 | 1 |
| Recreational activities | 1 | 4 | 1 | 1 |
| Interruption to social activities | 1 | 2 | 1 | 1 |
| Limits in work or activities | 1 | 3 | 1 | 3 |
| Arm, shoulder, hand pain | 1 | 2 | 2 | 1 |
| Tingling arm, shoulder, hand | 1 | 1 | 2 | 1 |
| Difficulty sleeping | 1 | 2 | 1 | 1 |
| **Performing Arts Module** | | | | |
| Usual technique | 5 | 3 | 1 | 5 |
| Arm, shoulder, hand pain | 1 | 2 | 4 | 5 |
| Playing as well as liked | 1 | 4 | 3 | 5 |
| Usual amount of time playing | 5 | 4 | 3 | 1 |

*Note*. Quick DASH: Level of difficulty, 1 = no, 2 = mild, 3 = moderate, 4 = severe, 5 = unable
Usual technique = Did you have any difficulty using your usual technique for playing your instrument?; Arm/shoulder/hand pain = Did you have any difficulty playing your musical instrument because of arm, shoulder, or hand pain?; Playing as well as liked = Did you have any difficulty playing your musical instrument as well as you would like?; Usual amount of time playing = Did you have any difficulty spending your usual amount of time practicing or playing your instrument?

## Appendix B.3 Interview Guide

### Introduction

As you know, the primary purpose of this research is to understand the experiences of professional musicians who have focal dystonia. But I recognize that you might have experiences in other aspects of your life (besides performing) that have changed since having this condition. I'd like to address these experiences as well.

### Describing Self as a Professional Musician

- To begin with, please describe yourself as a professional musician - similar to a brief bio that you would share with colleagues or audiences.

### Before Symptoms

I'd like to spend about 15 minutes of our interview talking about the time before you started experiencing focal dystonia.

- First, describe your **life as a professional musician** before the onset of focal dystonia symptoms.
    - You can think of it in terms of your **typical activites, daily routines**
        - You could talk about **typical days or weeks, or even typical seasons**
    - You can include typical professional activities you engaged in.
    - What about your **lifestyle and overall well-being** during this time?
    - How would you describe your **identity** during this time?

Final cue:

- How would you describe your ability to perform all of these professional activities?

- So, still thinking of the time before you had Focal Dystonia, What was your life like **outside of being a professional musician**?
    - Again, you might think of it in terms of **everyday activities, routines** that weren't based on your profession.
    - What about your **lifestyle and overall well-being**?

  - And your **identity** apart from being a musician during this time?

Final cue:

  - How would you describe your ability to perform all of these personal activities?

**Is there anything else you would like to add about this period of time?**

---

## Since onset of symptoms

In the next 15 minutes or so, I'd like to move ahead and hear about the time in which you started experiencing symptoms of focal dystonia.

- Can you describe **changes in your daily habits and routines** as a professional musician that took place when you started having symptoms?
  - If you'd like, you could think of any **changes in your activities and roles**.
  - What about your **lifestyle and overall well-being**?
  - And your **identity** as a musician during this time?

---

- Can you tell me about changes in habits and routines **outside of your role as a musician** that you connect with this timeframe?
  - Again, you might think of it in terms of **everyday activities, routines** that weren't based on your profession.
  - What about your **lifestyle and overall well-being**?
  - And your **identity** apart from being a musician during this time?

**Is there anything else you would like to add about this period of time?**

---

## Current

Now, I'd like to hear about the past year, and what it is like to live with a diagnosis of focal dystonia.

- How would you describe your roles and routines related to life as a musician now? How have they changed?
  - You might include changes in your day-to-day life
  - What about everyday activities that are a part of your typical days or weeks, or even seasons?

- Can you describe changes in your typical activities and routines outside of your role as a musician?
    - You could think in terms of day-to-day activities and routines.
- In the past year, how would you describe your ability to perform these professional and personal activities?
- How would you describe your lifestyle and overall well-being?

---

**I'd like to spend the next 15 minutes getting at some more specifics.**

- In addition to what you've already shared, have there been any other **changes or adaptations** that you made in your **professional or personal** life activities after your diagnosis?
- Describe any **supports** that really helped you in this journey from your initial symptoms up to now.
    - They may be supports related to your role as a professional or more personal roles
- Can you describe any **barriers or obstacles, or challenges** you encountered in your role **as a professional** musician with focal dystonia?
- What about **barriers, obstacles or challenges** related to more **personal** roles?
- Can you tell me about any **healthcare or other services** you have received to help you manage your focal dystonia condition, especially as related to your role as a professional musician.
    - Were there services that were helpful to you?
    - Not helpful?
    - Were there supports or barriers that you associate with the services that you received?

---

**Last 15 min**

We've really covered a lot of ground. I feel like I have gotten a lot of insights from what you've shared. What are other things you like me to know about your experience as a professional musician who has focal dystonia?

# Appendix C. Results and Findings: Individual Case Analysis

## Appendix C.1 Participant 1: Carl

Carl was a classically trained brass player and began performing professionally in his early 20’s. He was working as a tenured professor when he began to experience symptoms of embouchure dystonia. Carl spent a decade trying to manage his symptoms in order to continue performing and teaching, but ultimately found he was unable to fulfill the requirements of these positions. Carl transitioned into working as an administrator until the time of his retirement.

### *Theme One: Identity*

Carl’s strong expression of a musician’s identity was a recurring theme in the interview, and included subthemes of a singular personal identity, positive regard for his identity and life, and a high level of achievement associated with the identity.

Carl identified himself first as a [brass] player. He spoke enthusiastically about his years as a busy, in-demand performer, noting that he had a great quality of life and was professionally at the top of his game. On multiple occasions, Carl referred to himself as a “one-trick pony,” and a “single-issue do-er.” He described many facets of his career that centered around his role as [brass] player. Carl took pride in his musical abilities and the reputation he had built. Having secured a job as a professor straight out of graduate school, he was confident in his ability to continue performing at the top of his field, and had honed his problem-solving skills and his ability to self-assess his playing.

The culture of brass playing included pride in musical power and strength. Carl’s identity as a [brass] player included this cultural pride and confidence in his musical abilities and power: “I was a very aggressive player and I felt pretty much invincible ... I could play pedal notes that would, well, they would rip the walls down.”

Throughout his years of training and his professional life, Carl’s schedule was built around practice time. He noted that his vacation time was particularly meaningful, in that it allowed him time to get in additional hours of daily practicing. Through this valued routine, Carl gained a high level of confidence in his muscle memory and his body’s ability to respond consistently to the physical demands of playing [brass]. This confidence gave him a sense of self-sufficiency and invincibility and was central to his self-identity. In speaking of the early onset of musician’s dystonia, Carl described his reaction: “Well I can overcome this if I do it right. So, I'm going to go back to basics, and I’ll do it right and I’ll be fine ... why would I look to somebody else? I never did before.”

### ***Theme Two: Problem Solving Using Traditional Lens***

A theme that emerged throughout the interview was Carl’s confidence in his ability to solve his playing related problems. The influence of his training on his self-assessment and problem solving, his reliance on this training when his symptoms began, and the importance with which he regarded practice, were subthemes evident throughout the interview.

Carl’s confidence and self-sufficiency were prominent characteristics as he began experiencing symptoms of musician’s dystonia. Through many years working as a professional, he had experienced a predictable synergy between his musical decision-making and his ability to technically execute whatever was needed. Carl’s training as a student had taught him to analyze problems and problem-solve. He was confident in his muscle memory and felt that if he maintained his practice routine, he would always be consistent. As a professional he was able to self-assess his playing and to self-correct. These skills reinforced his feeling of confidence and self-sufficiency. Carl recounted the words of one of his early mentors, who taught him, “If you reach a certain level, if you reach a level in playing [brass], you can do anything, because it is always a matter of personal dedication and effort.” Carl took these words to heart, and these attributes were central to the way he did his job.

As a reflection of this mindset, when Carl first noticed symptoms of musician’s dystonia, he was shocked. He determined that he had lost his muscle memory due to some changes in his practice routine in the preceding months. He was confident that he had identified the source of his symptoms and knew he had the dedication to correct the problem. “I never had trouble, ever. And then man, all of a sudden, I fought that like crazy! I thought, what in the world is going on? I liked to play a lot of high stuff on [brass] and I thought that was the problem, I was doing too much of it. So I went back to playing lower stuff ... I went back to practicing ... I knew I lost my muscle memory. That's what I figured had happened. So, I practiced literally 7 hours a day.”

As a professional at the top of his field, the ability to self-correct and to adapt his playing to the style and demands of any ensemble he played with was central to his success. He recounted the first time he was unable to self-correct and was then asked by the conductor to modify the way he was playing: “So we rehearsed it again and this time, [the conductor] looked at me and he wanted more volume. And boy, that had never happened to me in my life.” Carl responded by working even harder. “I went back to my office and I played pedal notes, trying to get back the pedal range that I couldn't, couldn't play loud enough, and at the end of two days, I couldn't play pedal notes anymore. After that, I never had a pedal range.”

### *Theme Three: Smoke and Mirrors*

Carl’s strong desire to uphold his reputation and obscure the difficulties he was experiencing emerged as themes during his interview. Subthemes included his perceived need to hide his symptoms, and the use of strategies to obscure the problems he was having performing.

Central to Carl's experience with musician's dystonia was his effort over many years to hide his symptoms. He recounted being asked to play a recital, and the difficulty of identifying repertoire that would be possible to play without any evidence of musician's dystonia. "I looked around for a piece, and I couldn't find anything. So finally he called me back and said, 'Listen, I have to have a piece if you're going to play, I have to put it in the program.' So I said, okay, I'll write a piece ... luckily, it went okay. Not great, but okay. Nobody knew it. I got a standing ovation ... a relief just fell off my heart."

Carl was also careful before committing to any concerts by first reviewing the music to make sure that it would not reveal his difficulties. He spoke of getting a call to play with a prominent ensemble. "I said, let me check and see if I can do that. I looked. I didn't care about the dog gone date, I cared about the score. I made sure there was nothing I couldn't play, and I could play it all. It was in the range I could still play."

### ***Theme Four: Trauma Response to Specific Events***

Carl's deep emotion in connection to his musician's dystonia experiences was a theme that emerged throughout the interview, with a subtheme of vivid and visceral memories of his experiences.

When Carl shared the story of the onset of musician's dystonia, it was decades after the experience, yet his emotional reaction was still strong. His memories were detailed and specific, and he recounted not only events that happened, but what he was thinking and feeling at the time. The potency of these memories may be considered within the context of traumatic experiences, with his ongoing experience being akin to a grieving process. Carl recounted the first rehearsal where he was unable to disguise symptoms of his dystonia. "It was very embarrassing, and it was demoralizing, unbelievably scary and just a shock." He continued to adapt and continued to perform successfully until a dress rehearsal where a piece of music was added to the program at the last minute. The added music would expose an aspect of his playing that was affected by musician’s dystonia. He remembered his one-and-a-half-hour drive to the hall for the first performance. “As you can imagine, I was scared to death. I knew I couldn't play it ... I think I shook all the way down ... It was pretty hair raising, I won’t forget that one. Pretty, very embarrassing.”

As Carl’s efforts at modification failed, he began to doubt whether he would be able to continue playing. “Could this possibly be the end of me playing? It couldn’t possibly be? That’s not going to happen. That can’t be.” His disbelief gave way to resignation as he began to recognize that he may not be able to work his way out of his symptoms. “I had to just walk out on them one day because it wasn’t working. That was pretty disastrous, but I couldn’t play anymore, because dystonia is permanent.”

As Carl began to accept that his playing career was over, he began to reframe his loss. Carl referred to a colleague with musician’s dystonia who had much more mild symptoms. The colleague was able to continue playing but was unable to maintain his level of performance. “I was actually fortunate in that mine destroyed me. It absolutely destroyed me. I mean, like [mentions colleague] who could continue, but embarrassing every time. That would be more torture than anything.”

## Appendix C.2 Participant 2: Anna

Anna had a flourishing freelance career as a woodwind player for close to 25 years. She experienced musician's dystonia symptoms in her hands, and after two years of seeking an explanation, was formally diagnosed. Anna gradually stepped away from her most demanding performing roles, while maintaining teaching responsibilities. Anna eventually quit performing and while she tried to quit playing entirely, in time she returned to playing with amateur musicians and friends.

### *Theme One: Undeniable Identity*

A strong identification with music as a profession and a lifestyle stood out as an important theme in the narrative that Anna related during her interview. An early experience of success led to the adoption of "musician" as identity at a young age. This fast track to success was a striking subtheme, as was the emotional high that she experienced as a result of her busy and demanding performing schedule.

Anna's professional experience started early when she recorded the music for a movie score just before her 17th birthday. "From there on out, all I did was play [woodwind]. I just played [woodwind] all the time." Her career took off right out of college when she was in the right place at the right time. She was asked to fill in with a major orchestra as a substitute for a full season when the contracted player was injured. From that time on, Anna was in demand and busy as a freelance musician. Anna loved performing. She thrived on the competitive nature and intensity of the music industry. "If you don't know what it feels like to be on top of your game then it's hard to describe to someone … I had a lot of moments during that time where everything, you know the stars aligned, and I felt one with my instrument, and right with the world … it's a beautiful feeling." In spite of this, Anna strove to see her identity as separate from her role as a professional musician, but her experience with musician's dystonia changed her perspective. "I've always liked to think that I didn't define myself as a musician first, but having gone through this process, I realize that I did, and I do. It is just central to who I am, and always has been." Anna worked to redefine herself in the wake of her diagnosis, but regardless of what she tried, her heart wasn't in it. "Once you've latched onto that identity, it sort of owns you. I think it is just a matter of perspective because if you reject that identity and it's still yours, that's just going to mess with your head."

### ***Theme Two: Using Old Solutions for a New Problem***

As a musician, Anna developed effective routines to address occasional problems that arose with both her body and her instrument. When her musician's dystonia symptoms first emerged, she continued to apply the same routines, but found that they were no longer effective. Her reliance on these old, and now ineffective routines, emerged as a central theme. Her intense commitment to intense daily routines arose as a subtheme.

Anna's days revolved around hours of practicing, followed by late nights performing. She recognized that this routine took a toll on her body. She exercised daily and trained for a marathon to relieve the stress of her work on her body. She soaked in a hot tub each night after returning from work around midnight. When she entered a period in which her playing wasn't as perfect as she'd grown to expect, she couldn't understand why. "For a while I thought it was just that I was letting things slip, so I just practiced more. Practice, practice, practice." She analyzed her technique in the mirror and started to notice that her fingers weren't tracking the way they should be. She concluded that she must be carrying too much tension in her body. "I took up yoga and some other things just to try, but it didn't go away." Anna wasn't ready to admit that something was really wrong. She made regular trips with her [woodwind instrument] to her trusted repair person, searching for a problem with her instrument that would explain why her playing was changing.

### *Theme Three: Symptoms Worsen and No One is the Expert*

When Anna's symptoms worsened to the point that she sought professional help, she discovered that the clinicians she encountered were largely in the dark about how to help her. The lack of effective treatment strategies emerged as a theme in her interview. Subthemes were her initial self-treatment of her symptoms, her pursuit of medical help, and her experiences and feelings about her interactions with the medical and therapeutic communities.

During this time, Anna had no inclination to seek medical intervention for her problem. As she watched herself practice in the mirror, she noticed that her fingers weren't landing correctly on the keys. "It was while I was watching and trying to figure out what was going on that I realized my fingers weren't tracking on the keys exactly, a couple fingers in particular weren't covering the holes but I couldn't feel it. I couldn't feel that they weren't covering." Around this time, she started to notice that she wasn't feeling things with her fingertips and arms. "I would accidentally put my finger into boiling water and not realize that it was there for like a split second longer than I should have." She was getting injured regularly, once forgetting to use hot pads when she pulled a pie out of the oven, and at the worst point, cutting her hand and arm with a hedge trimmer. She didn't notice until her daughter saw blood that Anna had unknowingly trailed into the house. "I had no clue! I didn't feel it! It was those types of things that actually drove me to seek medical attention, not the decreased playing itself."

For Anna's husband, the injury from the hedge trimmer was a turning point, and he insisted she see a doctor. Anna saw several doctors, including a neurologist who told her she was fine. She kept looking for an answer and after seeing a few more doctors, she was given a referral to a musician’s dystonia clinic where she was soon formally diagnosed, more than 2 years after she started experiencing symptoms. Anna described the diagnostic process as thorough, detailed, and informative, but she also found the process to be very scary and difficult. “I had mixed feelings about it at the time. It was a lot of information … it was amazing to have a name for it, and to know exactly what was happening with what finger that I didn't understand before. From that perspective, that was invaluable. But at the same time, it was also like, ‘Well now you’ve been diagnosed, and your career is over, goodbye.’ I just remember feeling so betrayed on so many different levels. By my body, by these people.” Anna was given an estimate of how long she could expect to be able to continue playing. “At that time, they told me that if I didn't stop playing Broadway shows that I would have about three years of playing left, and if I did quit, then maybe 5, maybe a little longer. That was a time frame that weighed heavy on me a lot. It was just an estimate, but my brain latched onto it and really used it against me.”

Anna did follow up with an occupational therapist after receiving her diagnosis for about six sessions, but on the third session, the occupational therapist told her that she couldn’t help her. “I think she honestly thought that I wasn't trying, and she got kind of frustrated with me because it was clearly like, the level at which most people should be able to do it, and she was going to get more specific from there. And then in her mind, you can tell that she was expecting that it would be a few levels before she would have to work with me on it, and I couldn't even do her baseline, and she just got kind of frustrated, she didn’t know what to do. And that you know, I felt bad. I could tell she hadn't really experienced anybody like me before.”

### *Theme Four: Occupations After Dystonia*

Anna’s search for new occupations in the days after she gave up on performing, surfaced as a theme during her interview. Two subthemes to arise were her loss of her chosen occupations and her exploration of new occupations and a new lifestyle.

When Anna stepped away from performing, her pace of her life changed drastically. “Since I don’t play at that high, competitive level anymore and I don’t practice a lot anymore, it was really hard to get used to a slower pace of life. It was very, very difficult for me.” Anna spoke of the process of trying to redefine herself and trying to cultivate new interests. “I tried to look at things that I was already sort of interested in. I thought, well I can explore this and see if I can make a career out of it.” Anna’s peers are still performing and she wishes she could have held on for another ten years.  I feel like people who are my age, they're still performing, doing their thing. Maybe thinking about retirement, but not really pursuing it yet. So it would have been nice to hang on to it a little bit longer.”

Beyond considering career options, Anna worked to identify hobbies that would feel meaningful. She had never had hobbies before, and now she had to acknowledge her physical limitations, as her musician’s dystonia continued to impact her fine motor control. “I got into things that don't take a lot of dexterity because I don't have that control, that fine motor control in any area now. It eventually went across the board to anything that I would do with my fingers.” Anna has found the most comfort from activities that are contemplative, keep her active, and provide structure to her days. Anna has still not found a passion that feeds her the way her career in music did. “I've never been interested in anything as much as I've been interested in music, but there were some peripheral things I thought I could explore and see if I could make a career out of it. My heart really wasn't in it, I just tried.”

### *Theme Five: Stigma and Support*

An emerging theme in Anna's interview was her initial reluctance to participate in this research, stemming from the stigma that she perceived around the diagnosis of musician's dystonia in the music world. The role of close friends in encouraging her to step outside of her comfort zone to share her story and share her music, even if imperfect, was a notable subtheme.

Anna didn't expect that she would participate in research about musician's dystonia. "You know, I got your email and to be honest, I got it and I was like yeah, no. No one needs to know about this, still. And I deleted it." It was only the urging of a close friend that caused her to reconsider. "You know, it's not something that you want out there, even when you're done playing because it's such a stigma, you know? … but he called and said he thought I should do it."

Those who do know that Anna has musician's dystonia include some amateur musicians with whom she plays music, who she considers to be close friends. Some of her friends push her to occasionally perform in low stakes situations. "They have been supportive in ways that I didn't initially see to be supportive. They pushed me really hard to [perform] and I said, you don't understand, I can't do that! They would tell me that yes, I could, no one would be there." The support Anna needed to make these performances possible was the encouragement of these friends saying, "You haven't performed in a while and you should. It doesn't matter how it turns out." While Anna identifies the pushing of her friends as a support, she still struggles to imagine sharing her diagnosis publicly. "It is still a concern at this point you know. I think down the road maybe it'll be easier, I don't know, we'll see."

## Appendix C.3 Participant 3: James

During the first fifteen years of James' career as a string instrument player, he was an active chamber musician and held principal positions in orchestras around the US and abroad. At the onset of hand dystonia, James was a principal musician of a European orchestra. After a short period trying to satisfy his professional responsibilities while managing dystonia, he quit his job and moved back to the United States. James continued performing in less exposed positions while seeking medical help and the guidance of a former teacher. While he has adapted his approach to playing, and routinely sees glimpses of his former abilities, he has spent the ensuing years teaching privately and rarely performing.

### *Theme One: Aspirational Identity*

A recurrent theme in James' interview was the evolution of his ideas about what his identity of "musician" entailed. His ongoing pursuit of musical excellence emerged as a subtheme.

Learning to play the [bowed string instrument] came naturally to James and by the time he finished college, he was an accomplished musician with a clear vision for his future. "When I was coming out of school, I wanted to have a great career. I wanted to be as good a musician as I possibly could, and so I worked very hard at that." James identified himself as a professional [bowed string instrumentalist] and stated, "That's all I've ever done, a professional musician."

James took pride in his flexibility as a musician, actively analyzing his playing and making adjustments to enhance his musicality. "I was listening to recordings of myself and there was something about my tone that … I thought I'd like to change and it involved the richness of my vibrato … So the first night I played Don Carlo I thought, oh, my vibrato could be a little bit better, I thought I could play it in a different way. So the next day I went back and played it exactly the way I wanted to. And you know, my vibrato had always been the kind where I could do things with it. Anyway, the second night it was great. It worked great!"

Musician's dystonia impact James' vibrato, an aspect of his playing that he felt set him apart. "I always identified as a [bowed string instrument] player … you know, and even though my playing was falling apart, I always felt like a good one. I never felt like, oh boy I can't play the [bowed string instrument], even though I was having a real hard time … performing isn't the only way to be a musician. As a performer you've only got that one chance to get something across you know, but when you're teaching you can hammer it, you can hammer it over and over. So it's not all about your playing well."

### *Theme Two: Working Around Dystonia, Search for Guidance*

Another important theme to arise during Jame's interview was the wide range of specialists that musicians with musician's dystonia turn to as resources. His range of perceptions of each one's support formed a subtheme.

James had a particularly close relationship with one teacher with whom he kept in touch after studying with him in his early 20's. James consulted with this teacher when he was preparing for something important or working to make changes in his playing. When symptoms of musician's dystonia surfaced, returning to his teacher was James' first stop. "I immediately went back to see my teacher. And I saw him for about three lessons and it was gruesome. It was gruesome. It was just utterly draining."

After that experience James pursued a medical solution to his symptoms. He went first to a chiropractor that a friend recommended, and then to work with a famous hand therapist in Manhattan. "I remember going to see my hand specialist and she would get out these huge books and be looking things up trying to figure out what I had … she was the hand therapist for all the musicians in New York. She had a beautiful apartment down by Lincoln Center with a big view of Lincoln Center. She was making a lot of money. She gave me a lot of exercises to do.” When these methods weren’t successful, James went back to school, thinking of pursuing a second career unrelated to music.

Eight years after the three gruesome lessons with his teacher, James returned. “I finally went back to him when I was 46, 47 years old, and he was the one that gave me the tools to deal with it. No medical person did … I went to see him and he said ‘well where'd you go? Why didn’t you come back?’ You know, he was disturbed. And he said, ‘Look, I’m not going to let you go until we have a handle on this.’ So I went to see him for a year and a half, never playing more than one note in a lesson and never played any music.”

### ***Theme Three: Seeking, Then Avoiding Exposure***

Before his musician’s dystonia symptoms began, James was pursuing the dream of becoming a world-class performer. Chasing the dream, prior to the onset of symptoms was a prominent theme of the history he related during the interview. The change in his thinking with respect to his desire for public attention and exposure arose as subthemes.

Like many musicians, James spent his early career seeking professional exposure. He auditioned for principal [bowed string instrument] positions that would showcase his talent and leadership. He accepted engagements to perform concertos with orchestras, and he loved being a featured chamber musician at summer music festivals. “The chamber music I was playing in the summer was satisfying. It was exciting. I was doing what I what I felt like I really wanted to do.” Having established a career in which he was constantly exposed, the onset of musician’s dystonia symptoms was impossible to hide. “Before I always sought exposure, I didn’t want to be exposed at all you know. I didn’t want people to hear me play, playing the way I was playing.”

Job security is a concern for many musicians, but for James who had a secure principal position at the onset of symptoms, it wasn’t worth the exposure that came with it. “They weren’t going to get rid of me because I was having a problem, and they wanted me to stay, but I thought no, I can't go on like this. I can't keep performing like this, where I'm really ready to shoot myself in the head because it's Ahhh! I just was miserable.” James played with other groups with which he’d been the principal string player, but now sat in a position where he would not be exposed. “I didn’t want to play that with dystonia! So I sat in the back of the section and collected my money. Never playing very well.”

### *Theme Four: Mental Health Across Time*

Another theme that emerged from James’ interview was his sense that he possessed certain personality traits that served to buffer him from the trauma of his situation. Important subthemes that emerged were the recognition of the toll that musician’s dystonia can take on mental health, and the particular feelings and experiences that impact mental health.

Before the onset of musician’s dystonia, James hadn’t experienced injuries that impacted his playing. While he observed his peers struggling with injuries, he felt confident that he was on track to remain healthy. “I’d never, ever had a struggle like that before, you know. I had friends that had struggles and I thought, oh that will never happen to me, and if it ever happens to me, oh I’m just going to give up.” At the onset of symptoms, James did want to walk away from playing. “I thought, no, I can't go on like this. I can't keep performing like this where you know, I'm really ready to shoot myself in the head,” but giving up was not as easy as he’d first imagined. “Well you know, it happens to you, and well, it’s a different story than you thought it would be.”

James spoke with strong words about the mental health impact of musician’s dystonia, but always framed his expression by highlighting his ability to avoid a potential mental health crisis. “When it first hit it was really bad, it was very depressing … I guess I’m a somewhat boring personality or really very stable or something, because as miserable as I was, I never considered, you know hurting myself or, I always was able to enjoy other aspects of my life you know.”

For James, who spent his life striving to make the most beautiful tone on his instrument, making a bad sound was distressing. As he discussed his experience of playing with musician’s dystonia, he repeatedly mimicked an ugly sound. “I was just miserable, and I can still remember [mimics ugly sound] oh the struggle!” When James first returned to his former teacher for help, the experience of trying to play was overwhelming. “I immediately went back to see my teacher, and I saw him for about 3 lessons, and it was gruesome. It was gruesome. It was just utterly draining.”

James turned to exercise as an outlet for his frustration and a routine over which he had control, even as he lost control of his playing. “I’ve always been an exerciser, so that’s a real help, because you always feel like you’re doing something for yourself, so as far as self-care, that has been critical I think … but yeah, I was always amazed that I didn't kill myself, you know, that I didn't feel like it. I didn't struggle with that. I’ve realized I’m essentially a happy person.”

## Appendix C.4 Participant 4: David

With a burgeoning international career as a musician, David who played [plucked string instrument] experienced the onset of musician's dystonia symptoms during a period in which all aspects of his career were falling into place. With the use of modifications to technique and repertoire, David has worked to maintain an active and rewarding career with musician's dystonia for over 30 years.

### *Theme One: Workarounds*

David's creative ways of working around his developing physical limitations became a theme in the personal history that he shared in the interview. Important subthemes were the compulsion David felt to find ways to continue in his profession and the motivational power of needing to earn an income.

David was amazed at his luck as he was offered the job security of a teaching position, at the same time receiving contracts for international touring engagements. "*Everything* was happening exactly perfectly except I couldn't *freaking play!*" David felt that somehow, he had to stay on stage. His body was his currency and his only way to make money. With the help of a close friend, he began to make a plan that used his imagination and confidence to compensate for his lack of dexterity. His friend encouraged, "'Look, here's what we're gonna do … you're going to start commissioning your ass off, and in the process of course, you're going to tell these composers to trim their compositions to exactly the technique you're going to have to reinvent.' And I did, and I rearranged every piece that I did so I could play it."

David spoke at length about the "workarounds" that saved his career. While initially he didn't have the confidence to rewrite parts, he quickly identified music that was impossible for him to play, and felt like he was running out of repertoire that he could play. "I do remember for a good ten years until I was forty wondering what I'm going to be. If I’m going to keep my job, be a [plucked string instrument] player, if I’m going to keep doing this, how is this going to happen? It was only later on that I started to realize that there were lots of different ways to perceive the instrument and then conceive playing it.”

### *Theme Two: Identity, Duality*

David’s perception of the contrasting elements in his own personality surfaced as a theme during his interview. Subthemes to emerge were his concept of having both a natural and a professional identity, and the way in which his self-identity evolved in response to his need to survive professionally.

David was quick to introduce himself as a happy person who had a life of lucky breaks. He also identified himself as someone who has an inner duality, and he shared a story of struggle. David pointed to a true identity, how he sees himself, and a well-crafted and cultivated identity, by which he is outwardly known. Both, rooted in being a [plucked string instrument] player. “My interior world, of course, was one of a soloist, so somebody who spends a huge amount of time alone. And so then entering society, it was something I knew I had to change. I had to have a different persona … I remember very consciously as an undergrad looking at all the other [plucked string instrumentalists] , who were on the shy side, and that I could ‘win’ over them, and I guess that was part of my persona, if I just talked. So I started talking and it worked.”

This duality became a recurring idea in the story of David’s adjustment to living with musician’s dystonia. “I knew I had to stay on stage. That was sort of like an athlete, I knew I had to stay off the bench, and on the pitch as much as I possibly could all the time. That was my currency, my body was my currency. And again, there’s the conundrum again. If my body is the currency, and I'm injured, on the disabled list, whatever they call it in sports … What am I? Who am I? I know who I want to be."

### *Theme Three: Smoke and Mirrors*

David's perceived need to keep others in the dark about his condition was a recurring theme throughout the interview. Subthemes were the importance of secrecy to maintaining a musical career after injury, and the strategies used to maintain this secrecy.

In order for David to continue being "[plucked string instrument] Guy," he felt it was critically important to keep his musician's dystonia a secret. "As soon as you out yourself as not being able to do something, you disappear from people's call lists ... what I remember most is that I had to be very, very secretive." David quit interacting with other [plucked string instrument] players who would recognize his modified technique, and he avoided having to field questions about it. "I didn't want to have this conversation and it didn't play into my need for confidentiality and privacy." David chose his repertoire, his social engagement, and his musical circles to maintain his secret. "So if there's anything, it has been a career of fairly consistent, I don't want to say lying, but sort of trickery. Not deliberate obfuscation in order to gain advantage over someone, but over some*thing.* To overcome the *thing,* the focal dystonia."

### *Theme Four: Experiences with Healthcare Intervention*

David's range of experiences with different types of healthcare providers emerged as a theme during the interview, with his specific responses to mental health support and medical treatment forming subthemes. The onset of musician's dystonia symptoms at the same time David's career was taking off made him doubt himself. He went to a series of psychologists fearing that his sudden success was causing him to stumble under the pressure. "I just wanted to make sure there wasn't some way I was cutting myself down. Self-sabotage, afraid of success, all these kinds of things.” The psychologists all agreed that his symptoms were physical and not psychological. “‘No kid, look, everything is fine, get out of here. You’ve got a disability.’ I didn’t get upset from that, in fact, it bolstered my confidence.”

He spent months traveling to work with a specialist, and during the same timeframe seeing chiropractors and acupuncturists. “Everything was going swimmingly, except nothing worked” Years later he tried again, visiting another specialist. “I found her completely cold and uncaring. One of the first things she said was something to the effect of ‘Why don’t you just use a pick?’ So of course, I got the hell away from her because she was dangerous.” In the end, it was the psychologist who David credits as being the biggest support. “It was actually the shrinks who didn’t do anything directly other than telling me to leave that undoubtedly supported me. When you know it is the weather and not your attitude, this is actually a leg up.”