

# Task-Specific Focal Dystonia in Musicians: Implications for OT

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Focal task-specific dystonia, known as musician's dystonia, is a motor disorder that affects approximately 1% of professional musicians [1]. 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 [1]. Professional musicians begin intense training at an early age, establishing roles, routines, and an identity that is closely tied to their occupation as a musician [3]. The onset of musician's dystonia disrupts participation in meaningful occupations. The body of literature on musician's dystonia is limited, with the existing literature centering largely around epidemiologic studies and research on pathophysiology. Absent from the research is an account from the musician's perspective, which could identify the priorities for providing therapeutic support to this population. Thus, the purpose of this study was to explore musicians' perceptions of the lived experience of focal task-specific dystonia. A qualitative, specifically phenomenological approach was chosen for this research in order to explore the lived experience of musician's dystonia. Two online surveys were used as a method of triangulation: a demographic survey and the QuickDASH (Disability of Arm, Shoulder, Hand) self-report survey addressing functional limitations related to upper extremity injury. Eleven musicians fitting the targeted criteria were recruited and interviewed. Each musician participated in a semi-structured interview of broad, open-ended questions related to life experiences during three time periods (before symptoms, during onset, and current) and perspectives on health care services for the condition. Interviews were transcribed and individually analyzed using a modified version of Moustaka's data analysis approach [2]. 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. Descriptive statistics were used to summarize results of the surveys. Six primary themes emerged across the 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 individuals with musician's dystonia, including significant experiences of loss, isolation, and struggle to find adequate support through healthcare. Results of the QuickDASH were inconsistent with narrative reports of functional limitations for some participants. These findings suggest areas in which healthcare providers may improve their support of professionals with musician's 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 professionals with musician's dystonia, in order to provide the best care for this population. Modification of the QuickDASH may be needed to improve evaluation of functional limitations for this population.

**IMPACT STATEMENT:** The methods and findings of this study support AOTA's Vision 2025 emphasis on client-centered and collaborative approaches to improving occupational therapy. This study aligns with several research priorities (AOTA, 2016) that address chronic conditions, emotional factors, injury prevention, occupational transitions, and healthcare experiences.

## References

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