

The consequences of oromandibular dystonia on communicative participation: A qualitative study of the insider's experiences

Allyson Page^{1,2}, Lauren Siegel¹, Carolyn Baylor³, Scott Adams^{1,2}, Kathryn Yorkston³

¹Department of Health and Rehabilitation Sciences

²School of Communication Sciences and Disorders
Western University, London, Ontario, Canada

³Department of Rehabilitation Medicine, University of Washington, Seattle, Washington, USA

Oromandibular dystonia (OMD) is a focal dystonia affecting the mouth and face regions. Individuals with OMD can present with hyperkinetic dysarthria affecting aspects of speech production. As a result, these individuals may experience alterations to communicative participation. Unfortunately, there is a sparse empirical literature that has examined how communicative participation is experienced in this population. The purpose of this study was to obtain a self-reported account of the experience of living with OMD, and to gain a better understanding of both the daily facilitators and interferences to communicative participation. Eight individuals with OMD and dysarthria participated in one face-to-face, semi-structured interview. Interviews were audio recorded and transcribed verbatim. Qualitative, phenomenological methods of coding, immersion and emergence were used in the analysis of interview data resulting in three major themes and seven sub-themes. Overall, this study revealed multiple social, emotional, and functional factors that affect communicative participation in this population. Loss/change of meaningful roles and unique coping strategies used by participants were also highlighted. We suggest that the management of OMD must take a more holistic approach by addressing consequences beyond the physical symptoms, and be tailored to each individual based on his/her personal concerns and goals.