

Research Article

The Consequences of Oromandibular Dystonia on Communicative Participation: A Qualitative Study of the Insider's Experiences

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Purpose: The purpose of this study was to obtain a self-reported account of the experience of living with oromandibular dystonia (OMD) to gain a better understanding of both the daily facilitators and barriers to communicative participation and the strategies used for adapting to life with OMD.

Method: Eight individuals with OMD and dysarthria participated in 1 face-to-face, semistructured interview. Interviews were audio-recorded and transcribed verbatim. Qualitative, phenomenological methods of coding, immersion, and emergence were used in the analysis of interview data.

Results: Three major themes and 7 subthemes emerged from the analysis of interview data. First, "speaking is different now" provided examples of how speech changes are manifested in various life situations. Second, "my roles have changed" addressed how OMD has impacted work, home, and social roles. Third, "I accept it and move on" involved finding strategies that help and adopting a different perspective.

Conclusion: 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 or her personal concerns and goals.

Oromandibular dystonia (OMD) is a focal dystonia affecting the muscles of the lips, tongue, and/or jaw. It is characterized by involuntary, repetitive, sustained, and sometimes painful dystonic contractions of the affected musculature (Clark, 2003). OMD is variable in its presentation and therefore is described based on the location of the dystonic activity. These variants can include jaw closing, jaw opening, jaw deviation, labial, lingual, or a combination of any of these dystonias. When OMD occurs with blepharospasm, it is called *Meige's syndrome* (Cardoso & Jankovic, 1995).

Historically, OMD has been considered a disorder of motor control, characterized by neurochemical imbalance in dopaminergic and cholinergic activity (Duffy, 2013; Dworkin, 1996). Møller et al. suggest that the pathophysiological underpinning of OMD is derived from the dysfunction of the basal ganglia-thalamo-cortical circuits (Møller et al., 2013). There is growing evidence, however, to suggest a sensory component with impairments in the inhibitory integration of somatosensory inputs at the spinal, subcortical, and cortical levels (Frasson et al., 2001; Møller et al., 2013). As in many neurological conditions, the exact cause of OMD is largely unknown. Most cases of OMD seem to be sporadic and idiopathic in nature (Steinberger, Topka, Fischer, & Muller, 1999; Tan, 2004); however, Steinberger et al. (1999) suggested a genetic underpinning with evidence of a mutation of the *GCHI* gene located on Chromosome 14. Other possible etiologies include those with neurodegenerative origins (e.g., Parkinson's disease), exposure to neuroleptics, central nervous system/head trauma, hypoxic events, metabolic disorders, and demyelinating lesions in the upper brainstem (Dworkin, 1996; Sankhla, Lai, & Jankovic, 1998; Tan & Jankovic, 1999).

With an estimated incidence of 3.3 cases per million persons and an estimated prevalence of 68.9 cases per million persons (Nutt, Muentner, Aronson, Kurland, & Melton, 1988), OMD is considered a rare disorder. OMD affects more

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women than men by a ratio of 4:1, with an average onset occurring within the sixth decade of life (Nutt et al., 1988).

Unfortunately, many physicians are unfamiliar with OMD, resulting in cases that are undiagnosed or misdiagnosed as temporomandibular joint syndrome, myasthenia gravis, dental malocclusion, or edentulous movements (Tarsy & Simon, 2006). Patients often have to consult several physicians before their dystonia is correctly diagnosed (Tarsy & Simon, 2006). The treatment of OMD is not curative but is aimed at reducing dystonic symptoms. The most contemporary method of treatment for OMD is localized injection of botulinum toxin (BoNT) into the affected muscles (Goldman & Comella, 2003; Munchau & Bhatia, 2000; Ramachandran & Molloy, 2015). BoNT injections improve the symptoms of dystonia in a temporary manner, with reinjection required approximately every 3 months (Simpson, 1989).

The dystonic contractions associated with OMD can have devastating consequences on the daily functioning of those affected. OMD has been linked to depression and a reduction in quality of life (Bakke, Larsen, Dalager, & Moller, 2013). The altered orofacial aesthetics associated with OMD, such as jaw deviation or involuntary tongue protrusions, can lead to feelings of embarrassment and reduced self-confidence (Lee, 2007). Severe cases may cause jaw pain, difficulty chewing, dysphagia, and dental trauma (Tarsy & Simon, 2006). In addition, OMD can produce reduced speech intelligibility resulting from a hyperkinetic dysarthria characterized by imprecise consonant articulation, vowel distortion, and irregular articulatory breakdown (Darley, Aronson, & Brown, 1969a, 1969b). Darley et al. (1969b) suggested the neuromuscular deficits associated with the dysarthria of dystonia to cause slow, involuntary movements, with irregular rhythm, reduced range, and excessive tone. Duffy (2013) notes that, unlike other dysarthria types, hyperkinetic dysarthria can manifest as an impairment of only one speech subsystem, such as articulation, impacting only muscles of the tongue, as evidenced in lingual dystonia.

The characteristics of OMD can be further organized according to the World Health Organization's (WHO's) International Classification of Functioning, Disability and Health (ICF; WHO, 2001). The ICF provides a conceptual framework of disability from a biopsychosocial perspective. The ICF asserts that "health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity" (WHO, 2001). The ICF defines *impairment* as a "problem in body function or body structure," *activity* as the "execution of a task or action by an individual," and *participation* as the "involvement in life situations" (WHO, 2001). Eadie et al. (2006) extended the ICF definition of participation to communication by defining *communicative participation* as "taking part in life situations where knowledge, information, ideas, or feelings are exchanged." Communicative participation encompasses many life situations including personal care, household management, leisure, learning, employment, relationships, and community life (Eadie et al., 2006; Yorkston et al., 2008). The ICF model also includes environmental (external)

and personal (internal) contextual factors that contribute to the consequences of a health condition.

Prior research has typically focused on an impairment-based perspective to examining communication disorders (Eadie, 2001; Threats, 2000). Much of the prior research on OMD would be considered "impairment based" according to the ICF. This includes studies investigating pathophysiological underpinnings (e.g., Yoshida, Kaji, Shibasaki, & Iizuka, 2002), physiological and anatomical impairments (e.g., Tarsy & Simon, 2006), genetic underpinnings (Steinberger et al., 1999), and identifying aspects of impaired speech production (Darley et al., 1969b). The literature that falls within ICF activity-based research has focused on outcomes such as speech intelligibility deficits (e.g., Dykstra, Adams, & Jog, 2007; Golper, Nutt, Rau, & Coleman, 1983) and eating dysfunction (e.g., Papapetropoulos & Singer, 2006) in this clinical population. Although these studies have provided a valuable empirical database that has contributed to our understanding of OMD, the literature investigating ICF participation-based outcomes and psychosocial impact is relatively sparse. In addition, prior research investigating ICF environmental and personal factors has received very little attention in the research literature. This is unfortunate because contextual factors help to shape the consequences of a health condition (Baylor, Yorkston, & Eadie, 2005). There has been a shift in attention to the psychosocial aspects of health across the field of health care in general and in the field of communication disorders (Dijkers, Whiteneck, & El-Jaroudi, 2000). Attention has just begun to turn toward addressing the gap in the literature in terms of our understanding of the psychosocial consequences of OMD (e.g., Dykstra et al., 2007; Dykstra, Domingo, Adams, & Jog, 2015; Page, Siegel, & Jog, 2017; Merz, Deakin, & Hawthorne, 2010; Natasi et al., 2016). For example, Dykstra (Page) and her colleagues have used patient-reported outcome measures such as the Voice Activity and Participation Profile (Ma & Yiu, 2001), the Communicative Effectiveness Survey (Donovan, Velozo, & Rosenbek, 2007), and the American Speech-Language-Hearing Association Quality of Communication Life Scale (Paul et al., 2004) to explore activity and participation restrictions, communicative participation, and communication-related quality of life, respectively, in people with OMD (Dykstra et al., 2007, 2015; Page et al., 2017). Across all studies, individuals with OMD reported significant participation restrictions and reduced quality of life as compared to healthy control participants. These studies provide support that there is a need to explore the psychosocial impact of OMD in more detail and depth in order to gain a more detailed understanding of how psychosocial variables, such as communicative participation, are impacted in this clinical population.

Studying the psychosocial impacts of OMD is crucial for acquiring an authentic understanding of the insider's perspective of living with OMD and for comprehending the meaning of disability from the perspective of the individual experiencing it. Although patient-reported outcome measures are important tools to study the psychosocial consequences of OMD, these measures do not capture the

highly individualized, nuanced, and complex nature of a speech disorder. Qualitative research methods are ideally suited for studying the complexity of speech disorders because they identify the individual with the disability as the “expert,” rather than the researcher or clinician (Dowling, 2007). A qualitative approach provides space for “participant voice,” which allows for a genuine account of the insider’s experience. Participants share with the researcher the information and experiences that are of importance to them. In qualitative research, participants are not restricted by rigid questionnaires and rating scales, nor are they influenced by any presuppositions held by health care professionals (Dowling, 2007). Prior researchers have taken a qualitative approach to study the experience of communication disorders within specific medical conditions (e.g., Parkinson’s disease, motor neuron disease, multiple sclerosis, stroke) revealing changes in relationships, social and emotional effects, and perception of stigmatization (Blaney & Lowe-Strong, 2009; Miller, Noble, Jones, Allcock, & Burn, 2008; Miller, Noble, Jones, & Burn, 2006; Yorkston, Klasner, & Swanson, 2001). However, there is currently limited research investigating the impact of OMD on communicative participation.

Purpose

The purpose of this study was to explore the lived experiences of individuals with OMD using a qualitative phenomenological inquiry. By exploring the “lived experiences” of individuals with OMD, we sought to gain a better understanding of both the daily facilitators and barriers to communicative participation specific to this cohort. Information gained from this study may help inform the clinical management of individuals with OMD and dysarthria.

Method

Research Approach

This study was conducted using a phenomenological approach. Phenomenology is a method of inquiry that allows for the exploration of the experiences of a group of people who share a common phenomenon (Dowling, 2007). In this case, the common phenomenon is the experience of living with OMD. Phenomenological research is based on the principle of lived experiences, which are the events that naturally occur in the lives of a specific cohort (Dowling, 2007). Phenomenology has become an increasingly popular research method in the health care field, as it takes the patient’s voice into primary account allowing for findings to emerge that may have not been previously explored. Qualitative research creates a unique relationship between participant and researcher. Rather than attempting to remove the role of the researcher altogether, as is the case in quantitative research, qualitative researchers attempt to interpret, understand, and describe information in a reflexive process (Wilding & Whiteford, 2005). Furthermore, qualitative research adopts a subjectivist paradigm, meaning that reality is a subjective construct based on context and personal

experience, rather than an absolute, as suggested in the positivist tradition (Wilding & Whiteford, 2005). These methods and this study were approved by the Health Sciences Research Ethics Board at Western University, London, Ontario, Canada.

Participants

Eight community-dwelling participants with OMD were recruited via purposeful sampling to participate in this study (five male, three female; $M_{\text{age}} = 68$ years; mean OMD onset of 10.4 years). Purposeful sampling was utilized due to the rarity of OMD and the consequent small number of potential participants. Participants were diagnosed with OMD based on medical history and a physical and neurological examination by a neurologist specializing in movement disorders. Participants were judged to demonstrate hyperkinetic dysarthria by a registered speech-language pathologist. The presence of hyperkinetic dysarthria associated with OMD was the primary inclusion criterion of this study. The criteria as described by Darley et al. (1969a, 1969b) were used to determine the presence of hyperkinetic dysarthria. The following additional inclusion criteria are included:

1. All participants with OMD had no prior history of speech, language, or hearing problems (except those related to OMD). This information was determined via chart review and confirmed through patient report.
2. All participants were required to read, speak, and understand English as judged by the registered speech-language pathologist.
3. Recruitment was limited to an age range of 25–80 years. This age range was chosen not only to capture the average age of onset of OMD (age: 66 years; range: 40–80 years) but also to capture those individuals who may fall outside the mean age and range.
4. All participants were receiving BoNT injections to manage symptoms of OMD.
5. Individuals with any type of OMD (i.e., lingual, jaw opening, jaw closing, mixed) were eligible to participate in the study. All participants were recruited from the Movement Disorders Centre, London Health Sciences. An overview of participant characteristics is given in Table 1.

Data Collection

Interviews

Each participant attended one face-to-face, semistructured interview. Interviews were conducted in a private room by the primary researcher who was not involved in the clinical care of the participants. Interviews lasted between 60 and 90 min and were audio-recorded for later transcription. Because participants had reduced speech intelligibility due to dysarthria, interviews were scheduled at 5 weeks post-BoNT injections to correspond to the peak effectiveness of BoNT treatment and to ensure the greatest comfort

Table 1. Demographic information of participants with oromandibular dystonia (OMD).

Participant ID	Sex	Age (years)	Years since diagnosis	Years receiving Botox	Type of OMD	Sentence intelligibility pre-BoNT	Sentence intelligibility post-BoNT	Occupation
GM	M	69	4	3	Meige's (labial)	94.36	94.36	Chief executive officer
ST	F	78	2	3 months	Jaw opening	97.82	94.00	Homemaker, retired
NF	F	60	10	8	Lingual	90.91	98.36	Receptionist
JR	M	44	2	3 months	Meige's (labial, jaw closure)	96.54	95.27	Self-employed
FI	F	69	21	21	Jaw closure, lingual, labial	91.82	93.82	Teacher, retired
SP	M	78	13	11	Labial, jaw closure	95.27	88.55	Principal, retired
EP	M	80	23	22	Meige's (jaw opening, jaw closure)	94.00	90.55	Ad exec, retired
BR	M	68	8	3	Jaw closure	96.73	96.73	Engineer, retired

Note. Sentence intelligibility scores are expressed as a percentage and are derived from the Sentence Intelligibility Test (Yorkston, Beukelman, & Tice, 2011). The reader is referred to Dykstra et al. (2015) for additional information relating to speech intelligibility scores presented in Table 1. BoNT = botulinum toxin; M = male; F = female.

when speaking for a prolonged time. All participants presented with speech intelligibility that was reduced but understandable to the interviewer. If the interviewer did not understand a word or sentence spoken by a participant during the interview, she asked for clarification and repetition to ensure correct understanding and meaning.

Interviews were guided by four general questions:

1. Tell me about your history with OMD; for example, when did your symptoms start and how did that affect you?
2. What impact has dystonia had on your life?
3. What is communication like for you?
4. Are there times when people don't understand you?

Participants were encouraged to share their thoughts, experiences, and feelings about the questions they were asked. From there, the participants guided the content and direction of the interviews based on what was relevant and important to them.

Analysis

Interview Analysis

Interviews were transcribed verbatim from audio recordings by the primary researcher. Interviews were analyzed following qualitative, phenomenological guidelines including the process of summarizing and coding the interview transcripts, the interpretation of themes, and the identification of cases to serve as exemplars (Benner, 1994; Creswell & Poth, 2018; Dowling, 2007). First, the research team immersed themselves in the data by reading transcripts multiple times for familiarity. Then, the research team created a set of codes based on the content of the interviews. Codes provide a way of organizing the content of the transcripts into topic areas. Codes were developed in an iterative manner via multiple readings of the interviews and discussions among the research team. Dedoose qualitative software (Dedoose Version 6.1.18, 2015) was used to code and index interview transcripts based on subject matter and then to index and sort the codes by highlighting relevant excerpts of text. For example, one of the codes that emerged from the data was “emotional reactions,” and an excerpt highlighting the emotional consequences of OMD was identified: “I probably felt sorry for myself, and a little bit depressed, and frustrated learning to deal with [OMD]. Working around different scenarios and different life situations each day, it's not fun” (N.F.). The Appendix lists and describes the 17 codes that were initially generated. Following the processes of coding the transcripts and then sorting the excerpts by coded topics, the coded topic areas were read in detail and summarized for patterns that emerged. Themes were developed to reflect the most salient patterns within and across coded topic areas. The goals for the final qualitative analysis were to (a) identify commonalities and differences among participants' experiences, (b) reflect the complexities and multiple realities among participants through descriptive accounts,

and (c) illustrate the themes through the language of the participants (Benner, 1994).

Trustworthiness

Several steps were taken to ensure the trustworthiness of the data. Audio recordings were first transcribed by the primary author. A research assistant who was otherwise uninvolved in data collection and analysis reviewed the transcripts and made any notations of where there were discrepancies between what she heard on the recording and what the written transcript contained. Discrepancies were resolved via consensus of the research team. No discrepancies that affected the content or meaning of the transcripts were identified.

“Triangulation” was achieved by involving a research team consisting of individuals with varying backgrounds including doctoral training in qualitative methods, years of experience conducting research using the phenomenological approach, and experience treating OMD. Triangulation ensures authenticity of the results because consensus can be reached despite the inherently different biases and strengths of those involved (Miles & Huberman, 1994). “Constant comparison” was used by comparing emerging analyses with previous interpretations in an iterative and reciprocal manner ensuring the data were viewed as a whole rather than in fragments (Anderson, 2010). For example, after each interview was coded, the researchers compared it with all previously coded interviews, and any necessary changes to coding were made. Similarly, after each topic area was analyzed, the researcher compared resulting interpretations to previous interpretations and made necessary changes. Analysis in this manner ensures rigor in design and that findings are representative of the experiences of all participants involved.

“Reflexivity” refers to the process of being explicitly aware of one's background, position, values, and beliefs throughout the research process and using this information to contextualize one's interpretations (Finlay, 2002). Reflexivity acknowledges the existence of researcher bias and encourages researchers to provide reflective insights and engage in explicit, self-aware meta-analysis throughout the research process (Finlay, 2002). Reflexivity is seen as an essential component because it improves the quality and validity of research (Guillemin & Gillam, 2004). Reflexive notes were recorded alongside an audit trail (a form of reflexivity) to aid in the trustworthiness of the data. Audit trails are an account of all of the research decisions and activities throughout the study process.

Results

Three major themes and seven subthemes emerged from the analysis of interview data (see Table 2). The first theme, *Speaking is different now*, contained information about the physical effort required to speak with OMD. The three subthemes under this category included *What my speech is like*, *My environment matters*, and *I use strategies*. The second major theme was *My roles have changed*. This theme

Table 2. Themes and subthemes describing the consequences of living with oromandibular dystonia (OMD).

Themes	Subthemes	Definitions
Speaking is different now	What my speech is like My environment matters	Speech is effortful, quiet, slow, and less intelligible Situational factors, that is, eating, fast-moving/group conversations, unfamiliar listeners, unplanned speech, background noise, and phone conversations
	I use strategies	Strategies to improve ease of communication and intelligibility, that is, using easier words; using shorter, less complex sentences; slowing rate of speech; increasing loudness; and have others speak for me
My roles have changed	Things that are different	Job status, from caregiver to care receiver, household management, and change in social activities
	Why I've made changes	Fatigue, intelligibility deficits, appearance, and reactions of others
I accept it and move on	Things that help	Educating others, new activities, and using humor
	OMD has given me a different perspective	Being thankful for other abilities and positive attitude

addressed changes in participants' everyday lives since their diagnosis and incorporated two subthemes: *Things that are different* and *Why I've made changes*. The third major theme was *I accept it and move on*. This theme focused on how participants were able to deal with living with OMD. The subthemes under this category were *Things that help* and *OMD has given me a different perspective*. Each of these themes and subthemes is provided in Table 2 and will be described in greater detail below with quotes from participants to demonstrate how these themes were derived from the interviews to describe the consequences of OMD.

Theme 1: Speaking Is Different Now

Participants described both internal and external factors that affected their speech production, including physical aspects of dystonia and environmental factors. Participants then described how they adapted their speech to improve their intelligibility.

What my speech is like. Participants described changes in their speech production such as increased physical effort, slowed rate of speech, and difficulty articulating certain speech sounds. N.F. (all initials are fictitious) explained that, when she first started having symptoms of OMD, her speech slowly became "slurred," and it was more difficult to speak. As her symptoms worsened, she explained, "There was a point of, you could still understand what I was saying but it was an effort. A big effort to be able to make it clear." E.P. described his speech as "...thicker and changed and slower; took more time to formulate the jaw, tongue, throat muscles to make the pronunciations that would normally roll off your lips prior to that." S.P. similarly described trouble speaking because "the lips didn't seem to want to make the sounds." These examples highlight authentic patient experiences of effortful and impaired communication resulting from the dysarthria associated with dystonia such as slowed rate of speech, impaired articulation, and reduced speech intelligibility.

My environment matters. Participants highlighted environmental factors that made speaking more difficult and/

or less intelligible. One obstacle common to all participants was eating. Multiple participants expressed difficulty participating in conversations while focusing on eating safely, and some participants reported avoiding situations that involved eating while engaged in conversation. For example, F.I. explained, "Just thinking, oh gosh, you know? You invited people over, you have to talk or eat or both, for a whole evening, it's a big stress for me." Because many social situations involve food, this can be a significant barrier for individuals with OMD. In addition to the difficulties of participating in conversations while eating, participants also described difficulty speaking in group conversations. G.M. stated:

If there were three of us [in conversation], how can you just keep on participating in a conversation? I had a hard time to get in there in that conversation. A very hard time getting in. By the time I would try and get ready to say something, the other person's talking. And so I was always kind of behind in getting into that conversation.

Participants also reported unfamiliar listeners, noisy environments, and speaking over the phone as external factors that made speaking more difficult. Four of eight participants reported difficulty speaking over the phone. For example, S.T. explained:

Well I think there are times [others don't understand me], but they don't want to let on, and then I have to repeat it.... But I can tell, and especially on the phone, I notice I have to repeat; that they don't understand.

S.T. explained that speaking in noise exacerbated her dystonic spasms:

I don't talk if we're out and it's a big noise. I just don't talk. It's too hard. You have to talk too loud and my jaw just goes crazy.

I use strategies. Participants described the strategies they used to improve their speech intelligibility. B.R. explained:

I have a little strategy. If I was talking to someone and I had a real problem, I find myself choosing my

words. Instead of saying, “well it’s a very overcast day” I might say something like “it’s quite cloudy.” Things that would be easy for me to say.

E.P. also found that choosing his words more carefully helped. “The words I would normally use that are more than three or four syllables, I just can’t get it out. So I have to stay with shorter words that I can pronounce, and that sound clearer.” Other strategies participants used were increasing loudness, slowing rate of speech, and overenunciating. E.P. explained, “If it’s a bad period, then I just try that much more. The alternate ways. Usually I can bring my voice up and speak slower and use fewer words, and it will get more through.” G.M. also described slowing his speech as a strategy to improve his speech intelligibility.

I probably need to talk slower I think when, because of dystonia. Once in a while, [xxx] would say, “What’d you say?” and I’d have to be well, ok, I’m just talking too fast with her, maybe I just got to slow down a bit.

J.R. noted that he increased his loudness as a strategy to be understood by others:

I feel like I gotta talk louder so people can hear me. Maybe, I think that they can’t hear me or can’t understand me so I spit it out more louder so they can understand me.

S.P. noted, “I make a special effort to enunciate everything as well as I possibly can.”

Theme 2: My Roles Have Changed

The consequences of OMD extend beyond changes in speech production. Participants explained how OMD impacted their roles in the workplace and at home, as well as in social activities. Results varied among loss of roles, role restrictions, and role changes. Interferences extended to many common life situations and resulted in emotional difficulties.

Things that are different. One area of the participants’ lives that was significantly impacted by OMD was work. Two participants revealed having to leave their jobs as a result of OMD that they otherwise would have continued.

I had been [an educator].... I tried to continue [working] until the end of June that year. I had a lot of difficulty, during the speaking part.... I found I was losing a lot of confidence trying to do it, you know? I’d find I was doing a lousy job, so I just decided to leave it. (F.I.)

When talking about her job, N.F. said:

My speech had deteriorated and I just finally had to leave [my job]. I’m a pretty tough person and I pushed it to the very end because I loved my job. Considering I like to work, that’s a big impact because I’m not doing what I like the most in my daily life.

N.F. stated that she was off work for 2 years due to symptoms of OMD. She also explained the negative effects of job loss, such as financial worries: “My whole lifestyle was diminished. I mean I’m only getting 60 percent of my

income, you know?” The participants with jobs who continued to work stated that OMD significantly interfered with their productivity. Participants reported decreased confidence at work, taking more time than usual to complete tasks, and needing more help. For example, B.R. stated, “[OMD] was really affecting my job, because I probably spent 80% of my time on the phone, and I even got from my colleagues ‘pardon?’, ‘what?’ It was kind of embarrassing at times, especially at work.”

In addition to occupational changes, participants explained how OMD affected their roles in the family and in the household. One participant (N.F.) with young children explained having to shift responsibility to other members of her family as a result of her diagnosis.

A lot of those meetings, the bank etc., had to finally be done by my husband or children...because I’m not communicating what the needs are. I could write a cheque, but if there was any discrepancy over anything in the family household that needed to be dealt with it’s usually through communication.

N.F. further described feelings of hopelessness and guilt for not being able to carry on with her responsibilities and also disclosed that her children expressed anger at having to take on more work around the household. Many participants described a change in their social activities. S.T. stated that, because of her dystonia, she would “prefer to stay at home a lot of times.” She continued, “I avoid going out. As long as I’m at home, where I’m comfortable, there’s nobody around.... I’d prefer to just, be alone.” F.I. explained that, because of dystonia, she preferred solo activities that were less “socially interactive” such as knitting or painting. J.R. explained that he used to go out and socialize with new people at least once a week. Because of dystonia, J.R. said:

I like to watch movies at home. So I just stay home and watch movies in my own space. [Sometimes, but not often, I’ll] invite my friend or my cousin. You know, watch TV or play video games, stuff like that. They know me and know what happened. So I’m comfortable around them.

OMD can therefore have a significant impact on the individual and his or her family. Reasons for these changes will be discussed in the next section.

Why I’ve made changes. Participants provided insight into why their roles changed as a result of OMD. One of the reasons was the inability to be understood by others. E.P. and F.I. provided examples of common life situations where they had trouble being understood by others:

I was in [coffee shop] getting a coffee and I told [the employee], I said two black coffees medium size. And she looks at me and says, “What?” I knew she didn’t understand me. So I said, “Two black coffees medium size!” [yells] She jumps up in the air! Same thing happened over the meat counter at [grocery store]. And I said, “A half pound of roast beef!” [yells]. I felt so bad for her.... (E.P.)

In F.I.'s situation, she was unable to successfully complete her task as a result of her speech.

I took in the [roll of film] to be developed in [drug store]... So I am carrying the [roll of film] and I wanted to say, "I need to get this developed." I am trying to say this to him, and he says, "Well, I can't help ya if you can't speak, can I?" I thought, well "Okay, you're right!" Actually, I just walked out.

These examples highlight the difficulty some participants faced while trying to continue on with their regular activities and responsibilities. Another reason for role changes was the emotional consequences associated with OMD, such as those experienced during unsuccessful interactions. Participants identified affective reactions to OMD, including feeling self-conscious, worried, embarrassed, and overly aware. For example, J.R. explained:

I might not approach a woman that I probably would before. Because, I didn't even know what, what to say. Because my voice is going to come out weird, and you'd be like "what is she going to think?" So I might not say anything.

S.T. disclosed that she avoided going out because of feelings of self-consciousness. "I do avoid being out with people. I feel people are looking at me, now they probably aren't, but I feel that way—self-conscious."

N.F. highlighted how the facial spasms associated with OMD resulted in feelings of worry and fixation. She explained, "I can feel the movements underneath coming through the jaw and through my lips and whatever. I don't know. Are they looking at me? Can they see that it's moving?" Participants explained that they sometimes chose to avoid difficult situations because of how they made them feel. Lastly, the fatigue felt from prolonged periods of speech restricted the ability of some participants to participate in roles. For example, S.P. explained:

And another thing I did notice was if I'm speaking for a while, like when I go to Bible study and the pastor asked me to read from the Scripture. And the longer I keep reading, the more difficult it is for me to enunciate the words.

N.F. explained that the fatigue from having to speak all day contributed to her decision to leave her job: "...it would be noticeable by the end of the day that it was more difficult for me to speak things clearly, and I was fatigued."

Theme 3: I Accept It and Move On

The third major theme reflected how participants were able to carry on with their lives after being diagnosed with OMD. Participants explained strategies that they found useful including support from family and friends, educating others, alternative activities, and using humor. Participants also revealed changes in perspective.

Things that help. Participants explained some strategies that were helpful for adapting to life with OMD. For example, N.F. explained that educating others about OMD

and alternative modes of communication helped ease communication.

When I was losing a lot of communication, and a lot of friends and people didn't know how to speak [to me], or even figure out that there's an alternative as well as I did. I was actually the one training everyone, "Well you're going to have to do this..." They don't have alternatives in communication really.

Participants also discussed how finding fulfillment in new roles and skills helped them deal with some of their losses. For example, F.I. was able to find new work that made use of her nonspeech skills. She explained:

I decided I did enough [educating], and I got into the [computer work]. And I thought, "Oh this is wonderful! Because I don't really have to speak, and I can still [work] and get paid for it."

Three participants explained that maintaining a sense of humor helped them deal with difficult situations. N.F. stated, "I tried not to lose my sense of humour to some degree. I had a few scenarios there, and you have to be able to laugh at yourself, so I think that helped me get through it as well."

OMD has given me a different perspective. All participants unanimously reported that they came to accept OMD and "move on." E.P. explained, "It's annoying occasionally, but I don't let it hang me up. You can't! Just move on." Four participants (S.T., G.M., J.R., and B.R.) used the phrase "I just have to deal with it." For example, B.R. explained:

I have this little quirky thing, you know? So, I just have to deal with it. Sort of like a limp, you know? You limp, you don't necessarily avoid that person. That's the way it is.

N.F. expressed, "I have seen lots of people that have been worse off than I," and G.M. felt that his diagnosis of OMD "is not life or death." E.P. disclosed, "I don't feel that I'm a victim.... I don't want to sit and think about it, 'Oh poor me I can't do this!' and maybe some people maintain that way, but I just don't." J.R. said, "I like to get the most out of everything. I'm not gonna sit there and worry about it. Deal with it however it comes. Day by day." Another example of perspective was the participants' newfound appreciation for what they were still able to do. N.F. explained, "I could physically do things, I could walk, I could breath, I could touch. I can do lots of things just not speak." N.F. also disclosed that OMD made her a more perceptive person. "Discovering what a good listener is was remarkable to me. I found a way to gain from that and become a good listener instead of a good speaker." The ability to focus on the positive aspects of their lives was a meaningful and useful strategy used by participants to aid in their acceptance of their diagnosis of OMD.

In summary of the results, participants reported changes in their speech production and identified some common environmental factors that interfered with communication.

Strategies that improved communication were discussed. In addition to alterations in speech production, participants experienced changes to their work, social, and family lives. Participants also explained some strategies they used to deal with OMD and expressed the ability to lead meaningful and fulfilling lives despite their diagnosis of OMD.

Discussion

The purpose of this study was to better understand the consequences of living with OMD and dysarthria and the functional, social, and emotional interferences with communicative participation it may cause. This was accomplished with a focus on participant self-report of their lived experiences related to their OMD. This discussion will further explore the results from this study and how they relate to communicative participation as well as previous research. Finally, clinical implications and directions for future research are presented.

Speech Production

From the phenomenological analysis of the data, three overarching themes emerged. The first theme, *Speaking is different now*, dealt with the effects of dysarthria resulting from OMD. Participants in this study reported alterations and reductions to speech intelligibility. This is consistent with the prior literature on dystonia. Darley et al. (1969a) studied the effects of hyperkinetic dysarthria associated with dystonia on speech intelligibility and found speech dimensions such as imprecise consonant articulation, vowel distortion, and abnormal direction and rhythm of movement to contribute to a decrease in speech intelligibility. Dykstra et al. (2007) also described reduced speech intelligibility in an individual with lingual dystonia. In the current study, the main concerns reported by the participants included problems being understood, the increase in effort required to produce intelligible speech, and fatigue after speaking for prolonged periods of time. Participants described their speech production as being slurred, slow, and difficult to understand. Furthermore, participants reported that challenging communicative contexts created barriers to communication such as speaking over the phone, participating in fast-paced conversations, and noisy environments.

Participants explained how changes in speech production affected their communicative participation in everyday life. They reported unpredictability of when they may or may not be understood by others, which resulted in less frequent communicative participation, especially in high-stress/unfamiliar situations. Baylor et al. (2005) also found “unreliability of the voice” to be a concern for participants with spasmodic dysphonia (SD), contributing to the avoidance of social situations. One of the most difficult real-life situations for participants in the current study was communicating while eating a meal. Most participants spoke to how it was difficult for them to maintain a conversation while focusing on what they were eating and watching for choking and/

or food spillage. This was a difficult adjustment to make for participants who previously enjoyed participating in social situations such as group conversations around the dinner table.

Participants further explained strategies they used to improve their intelligibility. The most commonly reported strategy was being vigilant with speech production and preplanning the types of words and sounds that were easier than others to produce. Many participants stated that they simplified their speech by using shorter, less complex words and sentences and speaking slower and louder. Baylor, Burns, Eadie, Britton, and Yorkston (2011) found a similar phenomenon in their qualitative study of communicative participation across different communication disorders. Participants described planning speech carefully, simplifying sentences, and specifically avoiding words that were difficult to say as being a helpful communicative strategy. One participant referred to this strategy as “dumbing down” her speech. This information helps to illustrate the restrictions to communicative participation experienced by individuals with OMD.

Roles

The second major theme, *My roles have changed*, identified participants’ occupational, familial, and social roles that were affected by OMD. The most significant role loss identified by participants was occupational. Of the five participants who were working, two had to leave their jobs as a result of the speech production deficits resulting from OMD. Job loss is often associated with economic instability and emotional difficulties (Smith et al., 1998). The participants who continued to work with OMD revealed being less productive and needing to make changes to their job. These findings support previous research that found a significant impact of disordered communication on work life such as job modifications, avoidance of pursuing new job opportunities, or job loss (Baylor et al., 2005; Smith et al., 1998).

Other areas of participants’ lives that were affected by OMD were social and leisure activities. As a result of reduced intelligibility and perceived reactions of others, participants became more hesitant of socialization and sometimes needed convincing from family and friends to attend social activities. In some cases, participants chose to avoid social situations altogether. Participants explained a preference for spending more time alone, or with close family and friends, rather than socializing with new people. Baylor et al. (2005) also found changes in the social lives of individuals with SD, with participants stating that they found themselves “sitting in the background” at social activities instead of participating like they normally would.

Coping Strategies

The third major theme, *I accept it and move on*, reflected how participants managed with a diagnosis of OMD. There is currently limited research that has examined the coping strategies of individuals with communication disorders. Epstein, Hirani, Stygall, and Newman (2009) explored coping mechanisms of individuals with muscle

tension dysphonia and adductor SD by administering the Voice Disability Coping Questionnaire. In Epstein et al.'s study, *coping* was defined as "the individual's cognitive and behavioural efforts to manage the stress of illness." Individuals were found to be either "proactive" by using strategies such as information seeking and social support to eliminate the stressor or "avoidant" by the use of denial and withdrawal. In the current study, all of the participants described being proactive in many ways of living with OMD as they emphasized the acceptance of their diagnosis and the need to "move on," although there was also evidence of avoidant coping in the examples of withdrawing from or avoiding social situations. Some positive coping strategies used by our participants included maintaining a positive attitude, using humor, educating others, and being thankful for their other skills (e.g., being a good listener). Similarly, Baylor et al. (2005) found that, for individuals with SD, strategies such as educating family and friends about their disorder helped them to gain support and reduce unpleasant interactions with others. Participants also reported dealing with their SD by adopting a positive attitude and keeping their SD in perspective relative to other medical conditions. A future study may wish to explore if coping strategies (i.e., proactive vs. avoidant) differ as a result of the severity of dystonia.

Clinical Implications

Understanding the restrictions to communicative participation that affect individuals with OMD is extremely useful in order to improve rehabilitation efforts in the field of speech-language pathology. A benefit of employing qualitative methodologies to collect this information is the ability for participants to speak openly about their disorder without any preconceptions from the health care community. The results of this study highlighted specific sources of difficulty, strategies used, and areas of importance to individuals living with OMD, in their own words. By listening to participants' authentic stories and experiences, this study leads to two main conclusions that have clinical importance.

The first is that the consequences of OMD extend beyond the speech impairment. There has been a shift in focus in health care and disability management from simply minimizing symptoms to improving broader biopsychosocial aspects of living with health conditions. This concept was solidified by the WHO's 2001 definition of *health* as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." It is now more widely accepted that poor physical or mental health is likely to have many consequences including restrictions on social roles and shifts in social relationships (Dijkers et al., 2000). From the analysis of data in this study, concepts relating to social interaction, role shifts, and affective responses emerged as salient to the participants. Speech difficulties were rarely presented from only the physical perspective but more commonly referred to in the context of social communication. For example, some participants expressed worry that, because they had difficulty producing

speech, others might misinterpret the meaning of their words. Participants also highlighted contextual factors that restricted their communication such as background noise, speaking over the phone, and speaking with unfamiliar listeners.

The second conclusion is that living with OMD is a unique experience that is dependent on demographic factors such as employment status or age. For example, an individual diagnosed with OMD with young children might seek out strategies to aid in household management and child rearing, whereas an older individual might be more worried about choking while eating and maintaining community involvement. This is consistent with the phenomenological framework of inquiry that supports conceptualization of not just one reality but of "multiple realities." According to this concept, there exists no one "truth" to be uncovered; instead, each individual constructs his or her own reality based on his or her personal experiences (Denzin & Lincoln, 2000). The results of this study, therefore, support the idea that the treatment of OMD, and all communication disorders, must take social, emotional, and functional consequences of each individual into account as well as physical symptoms. Furthermore, a treatment plan should be tailored to each individual based on his or her personal concerns and goals. Clinical tools such as patient-reported outcome measures that take into consideration the individual's viewpoint on communicative participation, communication confidence, or other aspects of the lived experience can assist clinicians in identifying specific areas of concern for each individual and in documenting the value of services provided to address these areas.

Summary and Conclusions

This study has presented a perspective of the consequences of OMD on communicative participation as experienced by the insider. The results of this study suggest that communicative participation is affected not only by the physical symptoms of OMD but also by many significant social and emotional components. Changes to communicative participation can affect an individual's job, family, and social life. Lastly, the consequences of OMD are unique to each individual based on his or her goals and lifestyle.

This study adds to the very minimal literature on the psychosocial aspects of OMD and builds upon the small empirical literature of the consequences of living with OMD. The results of this study make a significant and novel contribution to the literature due to the phenomenological research methodology used. Participants in this study were able to speak openly about their experience of OMD in the absence of a structured questionnaire or a narrow line of questioning. As a result, novel phenomena emerged that will aid in the understanding of the consequences of OMD for researchers, clinicians, family members, and even newly diagnosed patients.

Although this study included a small number of participants, the overlap in theme content suggests that saturation

was achieved through the identification of the main consequences of OMD on communicative participation. Future studies may benefit from a larger and more varied sample of participants to ensure theme saturation. Additionally, the exploration of potential differences to communicative participation based on the location of OMD (e.g., lingual vs. jaw opening vs. jaw closing) would allow for greater generalizations of our findings. Finally, using qualitative methods, we are currently exploring the effect of BoNT therapy on communicative participation in order to understand how participants with OMD experience this method of treatment.

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Appendix

Coding Dictionary

Code	Definition
Aesthetics Change of roles	Change in orofacial aesthetics due to OMD Change of role from caregiver/parent/spouse role to care receiver, as well as change of role from care receiver to caregiver (from child's perspective), from able bodied to disabled, loss of independence
Communication	Ability to communicate; conversations, presentations, and communication that serve a social function
Diagnosis	Medical appointments, medical procedures, assessments, treatments, symptoms of OMD, and side effects
Eating	As a result of OMD: difficulty eating, chewing, swallowing, choking, aspirating, drooling, and strategies used
Emotional reactions	Emotional reactions that result from living with OMD and its treatment: depression/sadness, frustration, fear, anger, shock, surprise, excitement, loss, confidence, embarrassment, self-consciousness, uncertainty, and denial
Fatigue Job	Fatigue due to symptoms related to OMD Type of employment, loss of employment, job description, regaining employment, employment choices, and personal meaning of employment
Pain	Physical pain: due to dystonic symptoms and botox injections
Perceived reactions of others	Reactions of others that are the result of the person's OMD: anger, frustration, sadness, helplessness, pity, and honesty about the impact of OMD
Perspective	The ability to reflect on experiences as a result of OMD and provide perspective on disability, living with a communication disorder, experiences unique to OMD, being grateful, second chances, and giving back
Resilience	Ability to work through difficult situations, ability to work through emotional or physical pain, strength of character, outlook, and coping mechanisms (e.g., humor, trying to cover up the problem)
Social outings	Trips, vacations, parties, gatherings, volunteer work, and social interactions
Speech production	Aspects of speech production, difficulty producing intelligible speech, difficulty being understood by others due to OMD, and specific aspects of speech production difficulties
Strategies	Strategies used to make speech better, make speech worse, and alternate ways of communicating
Strategies to improve symptoms of OMD	Sensory tricks and strategies used to help with nonspeech aspects of OMD
Support	Relationships and individuals who play a supportive role to the individual with OMD. This can take the form of emotional support, physical support, and supportive environments.

Note. OMD = oromandibular dystonia.