

Research Article

Exploring the Psychosocial Impact of Botulinum Toxin Type A Injections for Individuals With Oromandibular Dystonia: A Qualitative Study of Patients' Experiences

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Purpose: The purpose of this study was to explore the psychosocial impact of botulinum toxin (BoNT) injections for oromandibular dystonia (OMD) and to gain a better understanding of how participants judge the success of this treatment.

Method: Eight individuals with OMD and dysarthria participated in one 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: Two major themes and six subthemes emerged from the analysis of interview data. The first theme, *Botox*

has changed me and my experiences, explored the participants' perspective of receiving BoNT injections and its psychosocial impact. The second theme, *What communication is like for me*, explored the psychosocial impact of BoNT on speech production and participation.

Conclusions: Our results suggest that BoNT has a variable impact on domains related to quality of life, satisfaction with treatment, speech production, and communicative participation. This study adds novel information related to the psychosocial consequences of BoNT treatment in the management of OMD and builds on a literature that studies the consequences and experiences of living with OMD.

Dystonia is a neurological movement disorder characterized by random, unpredictable movements and abnormal postures that can vary in speed, duration, and amplitude (Duffy, 2013). When dystonia is focal to the oral and facial regions, it is called oromandibular

dystonia (OMD; Duffy, 2013). OMD can result in forceful involuntary muscular contractions or abnormal postures of the jaw; lower facial, labial, and lingual muscles and may cause difficulties with mastication and deglutition, alter orofacial aesthetics, and impair speech production (Bakke et al., 2013). When speech production is impaired, it is the result of a slow hyperkinetic dysarthria (Darley et al., 1969). Although Darley et al. (1969) characterized the distinctive features of hyperkinetic dysarthria to encompass imprecise consonant articulation, vowel distortion, and irregular articulation breakdowns, OMD can be associated with an impairment in only one speech subsystem, such as the articulatory system, as evidenced in lingual dystonia (LD; Duffy, 2013). Regardless of the speech subsystem(s) impacted by OMD, a reduction in speech intelligibility is often a consequence (Dykstra et al., 2007).

Considered a rare neurological disorder, OMD has an estimated annual incidence of 3.3 cases/million and a prevalence of 68.9 cases/million persons (Nutt et al., 1988). The average age of onset is approximately 66 years (range:

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40–86 years of age), with more women affected than men by a ratio of 4:1 (Nutt et al., 1988). OMD can affect different orofacial structures, and as such, there are six distinct types of OMD that include jaw-closing dystonia, jaw-opening dystonia, jaw-deviation dystonia, lip dystonia, or a combination of any of these. When any of these types are combined with blepharospasm, it is called *Meige's syndrome* (Cardoso & Jankovic, 1995).

OMD is associated with dysfunction of basal ganglia-thalamo-cortical circuits (Møller et al., 2013) and neurochemical imbalance in dopaminergic and cholinergic activity (Duffy, 2013; Dworkin, 1996). Although once considered primarily a disorder of motor control, more recent evidence suggests abnormalities in inhibitory integration of somatosensory inputs at the spinal, subcortical, and cortical levels (Frasson et al., 2001; Møller et al., 2013). The cause and mechanism of OMD are relatively poorly understood. Although OMD is most often idiopathic or sporadic in nature, it also can be associated with genetic and environmental etiologies (Lee, 2007; Steinberger et al., 1999). Mutation of the GCH1 gene located on Chromosome 14 was described by Steinberger et al. (1999) suggesting a genetic underpinning of OMD. OMD can also occur secondary to central nervous system trauma, metabolic disorders, neuroleptic exposure, hypoxic brain damage, and ischemic or demyelinating lesions in the upper brainstem (Jinnah et al., 2015; Sankhla et al., 1998; Tan & Jankovic, 1999).

There currently exists no cure for OMD. Clinical management seeks to reduce dystonic contractions of the orofacial musculature, to aid in the reduction of pain that can be associated with dystonic contractions (Jankovic, 2018; Jinnah, 2015; Khan et al., 2015), and to improve speech production (Dworkin, 1996; Dykstra et al., 2007), mastication and deglutition (Jankovic et al., 1990), orofacial aesthetics (Merz et al., 2010), and quality of life (QoL; Page et al., 2017). Education and counseling are also important components of a comprehensive approach to management (Jinnah, 2015) due to the complex nature of OMD and the challenges often encountered in finding the accurate diagnosis and pursuing intervention that is, at best, symptom management.

Although a variety of treatment approaches exist (i.e., pharmacological, sensory, prosthetic, behavioral), chemodenervation achieved via injection of botulinum toxin type A (BoNT) is considered to be the most effective and the primary therapeutic treatment option for patients with OMD (Kazerooni & Broadhead, 2015; Teemul et al., 2016). Despite an empirical literature demonstrating improvement following BoNT injections, there can be side effects to this treatment. Blitzer et al. (1991) suggested that injections in the tongue for treatment of LD increased the potential for dysphagia and aspiration. Other side effects of BoNT can include weakness, dysarthria, and dry mouth (Goldman & Comella, 2003).

Most research studying OMD has focused primarily on impairment-based outcomes such as genetic and pathophysiological underpinnings (e.g., Berardelli et al., 1985; Fabbrini et al., 2009; Steinberger et al., 1999). Although

these studies have contributed significantly to our understanding of OMD, there remains a relatively sparse empirical literature that has explored psychosocial outcomes in this clinical population. The term *psychosocial health* derives its origin from the World Health Organization's definition of health as "a state of complete physical, mental, and social well-being, and not merely the absence of disease and infirmity" (World Health Organization, 1948). Psychosocial factors include those that reflect individual responses to disease and which can also be altered based on the social contexts in which they exist (Martikainen et al., 2002). This can include examining an individual's experience as the result of a health condition and his/her appraisal of QoL (Martikainen et al., 2002). A diagnosis of OMD can result in alterations to psychosocial health. For example, Bakke et al. (2013) reported that oral dysfunction arising from OMD resulted in social embarrassment, reduced QoL, and depression. Charles et al. reported that their patients with dystonia felt lonely and helpless, leading to social isolation (Charles et al., 1997). Across a number of studies, Page (previously Dykstra) et al. have studied how individuals with OMD and associated dysarthria experience living with this neurological disorder. Based on this body of research, participants self-reported reductions in functioning across domains related to communicative effectiveness (Dykstra et al., 2015), communication-related QoL (Page et al., 2017), and communicative participation (Page et al., 2019).

In addition to investigating how individuals with OMD experience living with this disorder, researchers have also sought to explore how BoNT injections impact psychosocial health in this population. Unfortunately, this research is relatively sparse, possibly due to the rarity of OMD and the resultant difficulties in recruiting research participants (Charous & Comella, 2011). In 2001, Bhattacharyya and Tarsy acknowledged this as a fundamental gap in the literature and, since then, there have been several research groups that have examined how treatment with BoNT injections impact psychosocial outcomes (e.g., Bhattacharyya & Tarsy, 2001; Charous & Comella, 2011; Merz et al., 2010). Across these studies, significant benefit has been reported following treatment with BoNT injections on the social support and physical health domains of the Glasgow Benefit Inventory (The Glasgow Health Status Questionnaires Manual, 1998; Bhattacharyya & Tarsy, 2001; Charous & Comella, 2011) and the cosmetic, psychosocial functioning, speech, and eating domains of the Oromandibular Dystonia Questionnaire (OMDQ-25; Merz et al., 2010).

Psychosocial health has also been explored using patient-reported outcome measures related specifically to communicative participation for individuals with OMD and dysarthria receiving therapeutic BoNT injections (see Dykstra et al., 2007, 2015; Page et al., 2017), with varying results. For example, all domains of the Voice Activity and Participation Profile (Ma & Yiu, 2001) showed significant positive change over the course of a BoNT injection cycle in Dykstra's et al. (2007) case study on LD. However, communicative effectiveness (Dykstra et al., 2015) and

communication-related QoL (Page et al., 2017) did not change significantly over the course of a BoNT treatment cycle in 10 participants with OMD, suggesting relative stability in these constructs.

Although this emerging body of research is important in aiding our understanding of OMD through patient-reported psychosocial outcome measures, a potential problem with questionnaires is that they do not allow for an in-depth or individualized exploration of what factors and issues might be underlying the participants' responses. Since each individual can perceive the same phenomenon in different ways, their lived experiences, specific understandings, and historical backgrounds will be unique (Finlay, 2002). Qualitative research methods acknowledge a subjectivist view of reality based on context and personal experience (Wilding & Whiteford, 2005). Through a subjective lens, qualitative research methods can provide an understanding of each individual's perspective (Creswell, 2014). Gaining an authentic perspective of the in-depth experience of receiving BoNT treatment can inform a nuanced understanding of the depth and detail of individual experiences, determine if patient-reported outcome measures are capturing all relevant information or if other patient-reported outcomes should be explored, facilitate the interpretation of questionnaire responses gathered clinically, aid in the refinement or development of new patient-reported outcome measures, and finally provide a unique perspective that can serve to inform meaningful indicators of treatment success. One such qualitative research methodology, phenomenology, has been upheld as the approach of choice in areas in which there is little published material, or where areas need to be described in more depth (Wilding & Whiteford, 2005). Although several studies have utilized qualitative research methods to study the experience of living with various neurologic communication disorders (see Baylor et al., 2007; Blaney & Lowe-Strong, 2009; Miller et al., 2008, 2006; Page et al., 2019; Yorkston et al., 2001), there appear to be no published studies that have used qualitative research methods to explore the psychosocial impact of treatment with BoNT injections for individuals with OMD.

The purpose of this study was to obtain a self-reported account of the psychosocial consequences of BoNT injections for individuals living with OMD. Using qualitative, phenomenological methodology, this study explored how participants judged the success of BoNT treatment based on the psychosocial issues relevant to them.

Method

Research Approach

This study was conducted using an interpretive 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 and receiving Botox injections. 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, because 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). This study was 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 men, three women; $M_{\text{age}} = 68$ 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. However, based on the research of Creswell and Poth (2018) and Morse (1994), our sample size of eight participants falls within their guidelines for determining adequate sample sizes in phenomenological research studies. Creswell and Poth (2018) recommend sample sizes ranging between five and 25 participants, while Morse (1994) recommends at least six participants in order to ensure sufficient data are obtained to describe the phenomenon of interest and allow research questions to be addressed adequately. The current study was part of a larger study that examined speech intelligibility, communicative-related QoL, and communicative participation in the same group of participants (see Domingo et al., 2019; Dykstra et al., 2015; Page et al., 2017, 2019). Participants were diagnosed with OMD based on medical history and a physical and neurological examination by a neurologist specializing in movement disorders (M. J.). Participants were judged to demonstrate hyperkinetic dysarthria by a registered speech-language pathologist (A. P.). The presence of hyperkinetic dysarthria associated with OMD was the primary inclusion criterion of this study. The criteria described by Darley et al. (1969) were used to determine the presence of hyperkinetic dysarthria. Additional inclusion criteria included the following: (a) 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 via patient report. (b) All participants were required to read, speak, and understand English as judged by the registered speech-language pathologist. (c) Recruitment was limited to an age range of 25–80 years. This age range was chosen to not only capture the average age of onset of OMD (66 years; range: 40–80 years) but

also to capture those individuals who may fall outside of the average age and range of onset. (d) All participants were receiving BoNT injections to manage symptoms of OMD. (e) 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, semi-structured 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. Since 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 when speaking for a prolonged period of 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 six general questions:

1. How do you feel your Botox treatment has helped you?
2. Has using Botox affected your ability to do the things you want to do?
3. Have you noticed changes in your speech since using Botox?
4. What is the biggest impact Botox has had on your life?
5. What has Botox had the least impact on in your life?
6. What has been the impact of Botox with regard to participating in daily activities?

Participants were encouraged to share their thoughts, experiences, and feelings about the questions they were asked. From there, the participants guided the content and the 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

Table 1. Demographic information and characteristics of participants with OMD.

Participant ID ^a	Sex	Age (years)	Years since diagnosis	Years receiving BoNT	Type of OMD	Injection site, dosage, and type of BoNT	Sentence intelligibility pre-BoNT	Sentence intelligibility post-BoNT
GM	M	69	4	3	Meige's (labial)	Orbicularis oris: 10u total h/s (Xeomin)	94.36	94.36
ST	F	78	2	3 months	Jaw opening	R&L lateral pterygoid: 30u total, R&L digastric: 40u, f/s (Botox)	97.82	94.00
NF	F	60	10	8	Lingual	Genioglossus: 15u total, R&L digastric: 40u total, f/s (Botox)	90.91	98.36
FI	F	69	21	21	Lingual, labial, jaw closure	R&L pterygoid: 30u total, R&L digastric: 10u total, f/s (Xeomin)	91.82	93.82
SP	M	78	13	11	Labial, Jaw closure	Orbicularis oris: 60u total, R&L masseter 40 units total, f/s (Botox)	95.27	88.55
EP	M	80	23	22	Meige's (jaw opening, jaw closure)	R&L lateral pterygoid: 120u total, R&L digastric: 30u total, f/s (Xeomin)	94.00	90.55
BR	M	68	8	3	Jaw closure	R&L masseter: 30u total, medial pterygoid: 30u total, f/s (Botox)	96.73	96.73
JR	M	44	2	1	Meige's (jaw closure, labial)	R&L masseter: 40u total, medial pterygoid, 40u total, f/s (Botox)	96.54	95.27

Note. The reader is referred to Domingo et al. (2019) for additional information relating to injection site and dosage information presented in Table 1. Sentence intelligibility scores are expressed as a percentage and are derived from the Sentence Intelligibility Test (Yorkston et al., 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; OMD = oromandibular dystonia; M = male, F = female; R = right; L = left; u = units; f/s = full strength; h/s = half strength.

^aInitials are fictitious to protect the identity of participants.

including the process of summarizing and coding the interview transcripts, 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 (Socio-Cultural Research Consultants, LLC, 2017) was used to code and index interview transcripts based on the topics reflected in the codes and then to sort the transcript excerpts into the coded topics for summarization. For example, one of the codes that emerged from the data was “facial aesthetics” and an excerpt highlighting this code was identified: “I don’t feel like I’m worried about my face being moved so much. It’s calmed my face down a bit.” (J. R.). Appendix contains the codebook used for this analysis. 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). 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 engage in explicit, self-aware meta-analysis throughout the research process (Finlay, 2002). Reflexivity is seen as an essential component as it improves the quality and validity of research (Guillemin & Gillam, 2004). Reflexive notes were recorded to aid in the trustworthiness of the data.

Results

Two major themes and six subthemes emerged through the qualitative analysis (see Table 2). The first theme, *Botox has changed me and my experiences*, explored the participants’ perspectives on receiving BoNT injections and the psychosocial impact of receiving these injections. The four subthemes under this category include the following: *I feel normal again*, *I feel appreciative of what Botox does for me*, *Botox doesn’t fix everything*, and *My face looks different*. The second theme, *What communication is like for me*, concentrated on the psychosocial impact and changes to speech production and communicative participation that participants experienced as a result of receiving BoNT injections. The two subthemes under this category include the following: *My speech has changed* and *I can now participate*. All themes and subthemes will be further expanded on below, alongside direct quotes from the participants’ interviews to explain the development of each theme.

Theme 1: Botox Has Changed Me and My Experiences

Participants expressed how BoNT treatment changed their self-perception, and they described the psychosocial impact of receiving BoNT injections. Participants also shared their experiences of receiving BoNT injections. They discussed how receiving their injections resulted in positive emotional reactions, such as happiness, hopefulness, increased self-confidence, and self-esteem. However, many participants also expressed that receiving BoNT injections resulted in less positive experiences, such as disappointment, uncertainty, frustration, fear, and worry. Participants also discussed the psychosocial impact of BoNT injections on their facial appearance.

Subtheme 1: I Feel Normal Again

Participants discussed how they perceived themselves postinjection and their view of “disability.” While dystonic symptoms did not fully resolve for participants postinjection, a sentiment expressed was the experience of feeling more “normal” in their daily activities. E. P. (all initials are fictitious) discussed how the injections helped him from “slipping into the grey area of disability.” He expressed concern about how he would feel about his self-concept without receiving BoNT injections:

Yes, yes, I need the shots or else I’m in the area of being disabled. I think I would probably be very

Table 2. Themes and subthemes describing the consequences of living with OMD.

Themes	Subthemes	Definitions
Botox has changed me and my experiences	I feel normal again I feel appreciative of what Botox does for me Botox doesn't fix everything My face looks different	Participant perspectives of a "normalizing" effect of receiving injections with respect to participating in everyday activities Beneficial/positive psychosocial changes experienced as the result of receiving BoNT injections such as happiness, thankfulness, increased self-confidence and self-esteem, hopefulness, improvement to QOL Unmet expectations such as disappointment, uncertainty of the duration, and effect of the injection over the course of the injection cycle and side effects such as pain, muscle atrophy, dry mouth, and bruising Both positive and negative alterations to facial appearance/orofacial aesthetics, self-consciousness as a result of BoNT injections
What communication is like for me	My speech has changed I can now participate	Variable changes (positive, negative/neutral) to speech production (i.e., response rate, rate of speech, speech intelligibility, articulation, and physical effort) Participants reported improvements in their ability to have meaningful conversations and express emotions and opinions accurately through their speech

Note. OMD = oromandibular dystonia; BoNT = botulinum toxin; QoL = quality of life.

limited, definitely. I think the continual eye movement and jaw movement really make you look as a handicapped person, whereas [Botox] has prevented me from slipping into that area or suffering any of those thoughts or lower self-esteem.

Participants also mentioned the idea of feeling "normal" again as a result of the injections. N. F. explained that she was going to be "hitting the line of permanent disability," due to her OMD. However, once she received the injections, she described a transformation in her perspective, "It is amazing, it makes me feel normal...I feel like I've gone from disabled to abled." She also stated that postinjection, "You can develop a normal life and just be aware of a few things, you know common sense things." J. R. also touched on this perception of feeling normal again and how "feeling normal" postinjection improved his participation in everyday activities. "You don't feel as embarrassed of uncontrolled movements. I'm able to go outside and be as normal as possible."

Subtheme 2: I Feel Appreciative of What Botox Does for Me

Participants discussed the beneficial psychosocial changes they experienced as the result of receiving BoNT injections. J. R. stated: "It improves the quality of your life, most definitely." B. R. similarly mentioned how he found BoNT injections helpful, "Yeah it works. It seems to do its job for me." N. F. discussed that the injections provided her with "inspiration and confidence" and it "gives me my life back." F. I. discussed how the injections had provided her with confidence, "I feel more confident, I think, a bit more confident because you know, I feel like I try to control [my tongue] when it's moving a lot. If the Botox is

controlling that movement, that's an important thing that it's doing really." G. M. mentioned similar changes with the impact BoNT treatment had on his life and how it improved his outlook:

It has changed my life I think maybe not as far as other people can see, but for me I think it's changed my life. It tends to give you some confidence as well, I think. Dystonia can take some confidence away, but Botox gives some of it back and I think that's the big thing.

Participants also expressed their happiness and thankfulness as a result of receiving BoNT injections. N. F. discussed how "The difference between it is survival. I have a job because of Botox. I can talk, I can be happy." E. P. also shared: "I feel very happy and fortunate they have something for us. I mean without it I wouldn't want to face the consequences. I'm very happy about the relief I do get from it."

Subtheme 3: Botox Doesn't Fix Everything

Despite being appreciative of the benefits of BoNT treatment, all eight participants also acknowledged that BoNT injections did not fix everything. Participants described that their expectations were not fully met and they discussed such as side effects including pain, muscle atrophy, and bruising. Although G. M. experienced improvement with the injections, he recognized that Botox "doesn't make things perfect, but it does make it as near perfect as it can get." He further stated:

I wish I wouldn't still have to have the of moving my mouth around. I wish I didn't have that. Botox fixes that a bit, but it still hasn't gotten my tongue under control. I would still have to move it around; I'd still

have to manage that when I didn't have to manage that before. That might be one thing that it does still leave you with something.

My expectations were not fully met. S. P. discussed how his expectations of the injections were not met. He had been told once receiving the BoNT injections his face would get back to "normal." He stated: "But that didn't happen. I guess that was a disappointment, but I guess you could live with those things, you know?" F. I. who had been receiving BoNT injections for 21 years described her uncertainty of the effect of BoNT injections:

I'm not sure now; heaven knows I'm not sure ha-ha.... Yeah, I think it's almost a psychological effect now. You know I've come to expect to receive months of Botox and something will change anyway, whatever it is...doesn't sound very positive does that?

E. P. similarly discussed what he wished could be changed: "I wish my muscles didn't deteriorate and I would get better and get cured." Similarly, S. T. stated, "I thought it might help the jaw a little more. But then, it's only the first time, so I wasn't expecting miracles." F. I., N. F., and B. R. discussed the longevity and variability of symptom relief over the course of the 3-month injection cycle. F. I. stated: "Um, yeah I mean I think it's good for my confidence for those first few weeks before it starts to drop off." N. F. and B. R. discussed the impact of the BoNT injection as it wears off. N. F. stated: "I don't have as much control when the Botox is wearing off." She discussed what she noticed once the injection began wearing off.

I notice that the pain and the tension does start coming back. I can tell within six weeks of the injection. The tiredness, the fatigue, the muscle is there, the aches, the pain, the movement, the twitches or you can feel them coming back.

B. R. also mentioned:

When I am on the back side or sort of mid-point of the [Botox], when I start to work up to having another injection, that's when it's worse. I'll start to notice little things and then it gradually, it gets very, very pronounced.

I have side effects. Participants also discussed how they experienced side effects, such as muscle atrophy, bruising, and pain due to the injections. E. P. discussed how receiving BoNT injections for 22 years affected his masseter. He stated: "The muscles have deteriorated such that they aren't normal, even the doctor found difficulty when giving me the injections too, especially on the jaw muscles; the eye area is very thin and easy to bruise." E. P. also mentioned how he experienced side effects over the course of the injection cycle:

Well, all of sudden you're going from unable to control the movement of eyes from closing, your mouth from opening and all of a sudden you're experiencing the extreme opposite, I have to first get used to it the 6 or 7 days and then you feel the Botox just restricting your muscles from the movement that it's hard to

shut your eyes, it's the reverse of what's happening and the same way with your mouth is. It's hard to open your jaw muscles it's so restricted. You're loosening up the muscles or at the best of times for at least a month minimum after that the last month is a slow decline. But at the time during last two weeks, you really need it.

"Pain" was described by many of our participants as a disadvantage of BoNT injections, although the sources of "pain" were varied. For example, pain as a result of the injections was a common experience for four of the eight participants. S. P. discussed the pain of the actual injection, the muscular trauma, and the healing time.

It really was quite sore. I had 25 needles. That's sore for a while. Any muscle if it's damaged is going to be. It's not going to act normal for a while. It takes two weeks sometimes it would be a little bit longer, till the healing. Till the muscles healed from the injury, from the trauma.

N. F. also mentioned the pain associated as a result of receiving the injections and also the challenge of correct dosing. She explained:

Oh the injection hurts for about 30 seconds, it swells, you have to be careful each day. It does create more swelling so you have to be more aware, you have to physically be aware of what you're doing and how much swelling you do have.... And being in the tongue you know what are going to be the side effects of that injection, am I going to be back in emergency in 24 hours from now or three days from now with a swollen tongue and not being able to breathe.

N. F. described other experiences of pain postinjection: "There are other symptoms too. I do have problems with the biting of the tongue once in a while. I have to be careful of that. So I have a few nodules from biting the tongue too hard." Similarly, B. R. discussed that "sometimes I'll bite the inside of my mouth or heaven forbid I bite my tongue and then it sends you right off to the ceiling." He further described more uncomfortable side effects such as dry mouth:

I get up in the morning and sometimes this lower lip is stuck to my teeth. And if you wake up and you don't recognize that effect, you pull your lip away, you know, just getting up and you open your mouth, that creates a lot of little sorts of micro tears in the back of the lip; and then the first thing you know, the thing is swelling and it's very sore.

Subtheme 4: My Face Looks Different

Participants described changes related to orofacial aesthetics as a result of receiving injections. They discussed their perceptions of how BoNT injections affected their facial appearance, as well as how the injections have impacted the function of their muscles, their level of self-

consciousness, and how other people have reacted to their facial appearance.

I don't have to worry about how my face looks. Participants discussed their perception of positive changes to their facial appearance postinjection. F. I. said she was less worried about dystonic facial twitches, especially when she was in social situations, during the first couple of months after her injections.

For the first half anyway [referring to the first half of the cycle], I don't seem to have to worry as much about, you know, if I'm going into a social situation especially if I'm going to be sitting there twitching all the time or am I going to be reasonably personable?

Similarly, J. R. discussed how he felt the injections changed his facial appearance and how he is less concerned about dystonic movements in his face. He stated, "I don't feel like I'm worried about my face being moved so much. It's calmed my face down a bit." N. F. and S. P. also reported positive changes to their facial appearance post injection. N. F. stated, "There's your whole appearance issue." When asked what Botox had the most impact on, S. P. stated "facial appearance." S. T. mentioned that, prior to her injections, "the kids noticed" changes in her appearance and had said "Mom, you got to do something!" She described what her face looked like prior to receiving BoNT and the resultant changes postinjection. She stated:

My mouth was drawn down. It almost like - have you seen Bell's palsy? Yeah. Almost like that. Only it wasn't Bell's palsy. But that all cleared up [post-injection] because the muscles were relaxed and they could find a way to bring all the facial features back to where they were supposed to be.

I feel self-conscious of my appearance. BoNT injections did not improve facial aesthetics for all participants. Some participants described perceived negative effects to their facial appearance, or they perceived no noticeable change following injections. G. M. discussed that, postinjection, he needed to use his tongue to clear food from sticking to his teeth, and he described how he thought this affected his appearance. He stated that, "It's an appearance thing, so you don't want to be sticking your tongue out of your mouth." He also discussed how the injections made him self-conscious of his appearance. He explained that, as a result of the injections, he has a "grimacing" expression, yet the benefit of Botox "outweighs anything it does to appearance." He stated:

It does something to my appearance. Well I think that the marks here, and you know, it only happened about 6 months ago and the Doctor said we have to adjust [the injections] on the other side. Right now when you - it's kind of hard - it pulls one way so we have to pull it back the other way. Yeah, so I think the Botox, has an effect on appearance. Almost every 3 months we've probably adjusted a little bit. The corners of my mouth were falling down I was almost like well, a grimacing type thing. So we have to counteract that by putting

more Botox on the other side so it kind of pulls it up. You can kind of see the red marks in the corner of the mouth up there. I noticed right away, and I think everybody else notices right away. So we kind of do that but I don't want to look like the Joker after.

F. I. stated that, although she is uncertain of how Botox is specifically helping her dystonia, she continues to take the injections for cosmetic reasons.

My mouth was continually moving. So they would to try and inject around my mouth, so that would be lessened. But I'm not really sure that that did help. I mean it has made me feel that the movement is diminished. I know I've noticed that lately I am getting about half of what I used to get fifteen, twenty years ago. We're almost working towards trying to lessen the motion so that they're not moving, you know - in almost distorted ways. So, I mean it's becoming almost a cosmetic thing, I have to admit that.

Theme 2: What Communication is Like for Me

Participants described changes to their speech production and communicative participation as a result of receiving BoNT injections and the psychosocial impact associated with receiving the injections. Results were varied, with some participants experiencing noticeable improvements to their speech production, while other participants experienced little to no change in their speech production postinjection.

Subtheme 1: My Speech Has Changed

All participants described changes to their speech production as a result of receiving BoNT injections. Participants discussed changes to their speech intelligibility, articulation, response rate, and amount of physical effort required to speak.

When my speech is at its best. Participants compared and contrasted their speech production before and after receiving BoNT injections. B. R., F. I., and E. P. discussed how their speech intelligibility had improved postinjection, but they also described when their speech production was most improved over the course of the injection cycle. B. R. stated:

Oh my speech was terribly slurred. I think the clarity and the understandability sort of show up when I'm in this position right now. Like this far from having another shot (6 weeks post-injection). I think [Botox] loosens up these muscles in my face and allows me to pronounce words easier, so I don't have this sort of slurring, if you will.

Similarly, F. I. mentioned: "I have to think about the speech thing whether it does help. Uh, I think it does help initially when I have it, for the first you know, few weeks anyways and then there's the, you know, wearing off process." E. P. also stated: "You're much more restricted with formulation of words, and the length of time it takes you to get it out, when you receive the Botox. After Botox is in for a month or so, your speech progressively gets better." S. P.

also described that, although the injections worked to improve his speech production, it took time for his speech production to be optimized.

I had problems enunciating words. I couldn't enunciate them clearly and maybe people thought I got marbles in my mouth and wouldn't speak very clearly. And that started to improve after I'll say, for a year. And after that, I felt really good about it because after the first week, or maybe like two weeks I felt like I could speak clearly.

How my speech has improved. Participants explained how their articulation improved postinjection, and they also described their reactions to changes in their speech production. For example, N. F. discussed how Botox provided her with the ability to regain her speech and how it improved her articulation.

I can't say enough about the use of Botox. I mean I can remember, I can speak...hello, you know. I don't think you can imagine going from "wah wah wah" and then 10 seconds after that injection to be able to say something, a word. I'm just flabbergasted. So it's super extreme as far as nothing to 100%. I couldn't say a word, it's just phenomenal to me.

N. F. continued: "I think my speech is pretty good. Most people don't notice that I ever had a speech problem." N. F. also felt as though she was given a second chance when she regained her speech postinjection. She discussed how the BoNT injections gave her the confidence to speak publicly. She said, "It was almost like a debt I had to pay right because I'm so thrilled to have [my speech] back."

G. M. stated:

I know I've been asked whether I'll be taking Botox my whole life. I don't know if I'll have to or not, but with age, things change or not. When people ask, I don't mind taking that the rest of my life. It's a godsend. It's fixed the thing that I wanted fixed most [speech].

S. P. also described how his speech production improved postinjection. He stated, "The Botox relaxes some muscles, and it's easier for me to form the letters. I have less trouble speaking."

Although S. P. described improvements in his speech, he also described some difficulties that arose postinjections. He stated:

I found that it's either the trauma of the needles in the face, or the Botox itself that would cause me to speak. I have a problem with speaking and particularly enunciating because the lips didn't seem to want to make the sounds, you know? You want them to make like o's and a's and you know, r's...or particularly anything that would have an "o" in it... and lips, and even as I'm speaking to you right now. Anything with an "o" in it, the lips don't seem to one to come together enough to clearly enunciate that "o."

Participants explained how the injections increased their ability to respond when speaking. G. M. discussed how his response rate was "a lot quicker," he stated:

Well, it has definitely helped me. Umm, see, my tongue and my brain. It seems to be a lot more in sync. Before I took Botox we probably could have measured the time it took after you had asked the question for me to start replying. There is a wire between my brain and my tongue that before was broken. Now it's fixed that wire.

S. P. also mentioned how the injections helped him. He stated:

You're not thinking of, how should I answer that question, what words should I use, it's sort of like an automatic situation. So when I get [Botox], it's like putting your speech on autopilot. It just seems to work. It makes me think quicker.

Talking is less effortful. Participants discussed the amount of physical effort they exerted when speaking. G. M. discussed how the injections had helped him decrease the amount of physical effort he required to speak. He stated:

I don't have to work so hard on the speech things. It's helped because I always felt I had to work on certain things to make it always the best or the better, but without Botox, I would have a hard time I think doing that.

B. R. mentioned that, postinjection, he was able to put in less effort. He explained:

It helps your speech for sort of a month and a half or two months. Then after that, it's a little more difficult. So you're not conscious of making an effort. You're not conscious of your speech being slurred. So I think that's the biggest thing it has done for me.

Speaking can be effortful. S. P. also discussed physical effort, but his experience was in contrast to G. M. and B. R. S. P. stated that after receiving the injections, he needed to exert extra effort when speaking, "I have to put just a little more effort to making, enunciating certain sounds. I found that it's either the trauma of the needles in the face, or the Botox itself that would cause me to speak."

I'm uncertain if my speech has improved. Not all participants described a positive change to their speech production postinjection. Some participants discussed their uncertainty about any noticeable changes to their speech production, with some participants stating that they experienced no change to their speech production postinjection, as well as one who previously noted some positive changes. J. R. explained, "Oh. No, no. My speech. I feel, no, it hasn't increased; it hasn't done my speech at all. It's about the same. It hasn't gotten worse. It hasn't gotten better." S. T. also discussed her uncertainty when asked if there were changes she had noticed. She said, "Uh, not a whole lot, speech, maybe." Similarly, when

G. M. was asked about speech intelligibility and any changes that were experienced in his speech, he responded, "Um, I don't know...I don't think so."

Although E. P. mentioned improvements in his speech, he also discussed some speech problems he wished BoNT injections had helped with. He stated: "Umm, I wish I had less speech problems. I know I'm limited in speech slowness and pronunciation but you just have to accept it and move on." E. P. who had been receiving BoNT injections for 22 years explained that his speech production had changed over the years. He attributed this change to be the result of the deterioration of his facial muscles due to his long history of receiving BoNT injections to manage his OMD. As a result of muscle atrophy, E. P. mentioned that he received the injections less frequently. He stated:

For the last year or so I find that even at the end of [the cycle] now because of the deterioration of the muscles, that period before I get the shots I'm still having trouble, slight limitations than what it used to be. I used to probably speak better before, but it's getting progressively worse so I can't get [the injection] every three months, for the jaw anyway.

E. P. also described changes to his speech intelligibility and speech rate as a result of receiving the injections for 22 years and stated, "Umm, speech became thicker and changed, slower, took more time to formulate the jaw, tongue, throat muscles to make pronunciations that would normally just roll of your lips prior to that."

Subtheme 2: I Can Now Participate

Participants described their ability to participate in meaningful activities with their families and friends, and how the ability to participate affected their psychosocial functioning. Participants also explained how changes to their speech production postinjection affected their communicative participation, including their ability to have meaningful conversations, communicate in various settings, and their ability to express their emotions and opinions accurately through their speech.

The meaning and importance of communication to me. Participants discussed the meaning of communication and communicative participation and the importance of these in their lives. G. M. discussed that his "communication ability is a lot better," as a result of receiving injections. He explained that the injections had made it easier to talk and increased his confidence to communicate with others. He stated:

I think the big thing is that I'm not totally afraid to talk. So if I didn't have the Botox, I would feel very hampered about talking. But either one-on-one or in a group or anything. I feel maybe more confident about that. I think I would always kind of keep trying harder to do something, but this makes it a lot easier. If they're going to ban Botox, I would be very, very afraid.

N. F. explained how the ability to communicate changed her life. She stated:

My speech, gave me my job back. Gave me my husband's conversations back, relationships, children and family and work. Isn't that life? That's everything. And you know now I'm able to give back, and I wouldn't be able to before. I feel like I'm contributing to the community.

N. F. further discussed the importance of communication and how the injections improved the important relationships in her life, her employment, and her well-being. She stated:

I have a job because of Botox. I can talk, I can be happy. I can laugh and communicate all of that emotionally, socially everything. It makes a difference between living and really not. You're just surviving. When you're not speaking and you don't have that communication, you're surviving. You can find other ways to study or read and educate yourself but you're not sharing. It's not a sharing thing. It's a very personal, inward type of existence whereas with speech; the difference is night and day. You can communicate, you can share.

How I and others view my communication now. N. F. and S. P. both discussed how other people viewed their ability to participate and communicate postinjection. N. F. mentioned her experience participating in her job postinjection and how people viewed her ability to communicate. She stated:

I think it's affected in so many ways when I went back to work, I became more confident. I became like a mentor kind of. Some of the people and my acquaintances that I knew were so surprised even I think the occupational health and safety person were shocked literally that I was ever able to come back to work from seeing me before I went and then coming back.

S. P. also mentioned how others viewed his communication skills postinjections. He stated:

Very few people ever asked me to repeat anything; either on the phone or in conversation with an acquaintance or even strangers. The fact is, I had people tell me maybe in the second year, "You're speaking well, we never knew you were any different than what you are right now."

Similar to N. F., S. P. discussed how his communication had changed postinjection and the meaning he attributed to these changes by stating: "I find it easier to speak and to communicate in a way I want to communicate it. That's a big difference to me and important to me." S. P. elaborated:

People can hear what I want to say, not only the words, but the meaning to the words, I think are important. And that's important to me. And I said,

“Well I didn’t mean it that way, I wasn’t upset.” “How come you’re such an old grouch?!”

Regaining effective communication. S. P. further discussed the importance of regaining effective communication postinjection, and he also described the challenges he faced when he could not communicate effectively. He stated:

Two-way communication is easier, more relaxed, and less stressful, and I’m saying the same thing maybe, but you know, if you get that good communication with somebody else, and the most natural situation, you know, it’s just, the other person’s more fun to be around, and you’re more fun to be around the other person, right? But if you have serious impediment, it’s difficult for two reasons: they don’t understand you and they get frustrated, and they’ll feel sorry for you, like you can’t communicate any better than what you’re doing. I know I always feel that way if someone has a problem that you feel that you can’t communicate with that person so well, but you feel sorry for him that he or she is in that situation.

Similarly, N. F. explained the importance of communication and how it impacts the ability to express one’s needs. She stated, “Communication is a big. I mean with any diagnosis you have to have communication, you go to any doctor and you have to be able to say what’s wrong with you.”

Although J. R. discussed that his speech stayed “about the same” post-Botox injections, he still felt that the injections had allowed him to become “more social.” He stated: “Because I’m not making it affect my job, work-wise, I can be more social.” Similarly, E. P. stated, “I find the Botox gives me ability to sit through a movie or just have a conversation with some people, whereas I would be severely restricted.” S. T. also described, “Well, I don’t hesitate to be out and be talking as much as I was before. It improved my daily activities by going out with people.”

Discussion

The purpose of this study was to obtain a self-reported account of the psychosocial consequences of BoNT injections for individuals living with OMD. Using phenomenological methodology, this study explored how participants judged the success of BoNT treatment based on the psychosocial issues relevant to them. This was achieved by understanding the insider’s perspective through an interview process, where participants discussed and shared their treatment experiences. The discussion will further explore the results of the study and compare findings to previous literature that has explored similar concepts. Finally, clinical implications and directions for future research are presented.

Perspective and experience. From the phenomenological analysis of these data, two major themes emerged from this research. The first overarching theme, *Botox has changed me and my experiences*, explored the participants’ perspective on receiving BoNT injections and the psychosocial impact of receiving these injections. Participants discussed

that, prior to receiving BoNT injections, they felt disabled by OMD, but following injections, many participants reported feeling less disabled and a return to a predisability sense of “normal.” A study by Baylor et al. (2007) examined the psychosocial consequences of Botox treatment for spasmodic dysphonia (SD) and reported similar findings to our research. Baylor et al. (2007) found that postinjections, participants experienced a relief of SD symptoms, allowing them to feel and act like themselves again.

Participants also discussed the beneficial psychosocial changes they experienced as the result of receiving BoNT injections. Our participants discussed that they experienced increased confidence and self-esteem in their ability to regain control of their orofacial movements and discussed the concept of a “second chance.” Our participants’ appraisal of increased confidence and self-esteem as a result of receiving BoNT injections is similar to the findings reported by Charous and Comella (2011). This study examined QoL following Botox injections for individuals with jaw-opening dystonia. Their participants reported feeling more optimistic, less embarrassed, and generally felt better about themselves as a result of the injections (Charous & Comella, 2011). Our results are also consistent with the findings of Nastasi et al. (2016) who reported that their participants with LD rated positive changes in QoL as measured by the OMDQ-25 following BoNT injections. Finally, Bhattacharyya and Tarsy (2001) found that participants reported less depression and anxiety related to OMD, and improvements in QoL post-BoNT treatment, as measured by the Glasgow Benefit Inventory.

Although the participants in this study expressed some positive psychosocial benefits of BoNT injections, all eight participants also acknowledged that BoNT injections did not fix everything. Participants described unmet expectations and negative side effects as a result of the injections. Unpleasant side effects included muscle atrophy, bruising, and pain due to the injections. Our participants described the burden of BoNT treatment such as dissatisfaction with the cyclic and changing nature of response over the course of their BoNT injection cycle, as well as physical and emotional impacts. Participants in our study reported that their confidence decreased as the BoNT injections wore off, as well as loss of control, pain, tension, and fatigue, which developed toward the end of the injection cycle. Dry mouth is another reported side effect of Botox injections (Goldman & Comella, 2003). Dry mouth was described in our research as an unwanted side effect, although, for some individuals with OMD, decreased oral secretions is a desired goal of treatment.

Unmet expectations regarding the effectiveness of BoNT injections in providing relief from a number of OMD-related symptoms was also reported in our study. Many of our participants described what they had wished BoNT injections could have helped with or changed. Participants mentioned that they wished they could regain control of continuous orofacial movements, that their face would go back to “normal” postinjection, that their muscles would not deteriorate, and that, after treatment, they would get better and be cured. The results of our study demonstrate

that BoNT injections do not fully meet expectations for every participant and this treatment can be associated with dissatisfaction and unwanted side effects.

Finally, changes to orofacial aesthetics were described as a result of receiving BoNT injections. Many participants discussed experiencing positive changes to their facial appearance postinjection. These participants explained that they felt less self-conscious and less worried about unwanted dystonic movements, such as facial twitches, following injections. In addition, some participants stated that the most important aspect of receiving Botox injections were the positive changes to their facial appearance. This finding is consistent with that of Merz et al. (2010) who highlighted the importance of facial aesthetics in the participants they studied with OMD. The results of the Merz study revealed that the *cosmetic* subscore of the OMDQ-25 demonstrated the greatest positive difference between pre- and post-BoNT injections. In our study, not all participants experienced positive changes to their facial appearance following BoNT injections. Some participants reported feeling self-conscious as a result of the injections. Taken together, these findings indicate that individuals with OMD are highly sensitive to their outer appearance (Merz et al., 2010).

Speech production and participation. The second overarching theme, *What communication is like for me*, explored the psychosocial impact related to participants' speech production and communicative participation as a result of receiving BoNT injections. Participants discussed changes to their speech intelligibility, articulation, response rate, and amount of physical effort required to speak. Many of our participants described an improvement to their speech intelligibility and speech production. Dykstra et al. (2007) explored the effect of BoNT on speech intelligibility in an individual with LD and reported positive changes to both single word and sentence intelligibility following BoNT injections. Participants with SD in the Baylor et al. (2007) study reported a sense of "freedom" from not having to worry about their voice postinjection. Despite some of our participants reporting improved speech production as a result of BoNT injection, other participants perceived minimal or even no changes to their speech production postinjection. This finding is similar to that of Dykstra et al. (2015), who reported that 7/10 participants with OMD and dysarthria did not show significant improvements in speech intelligibility over the course of a BoNT injection cycle. Several of our participants also reported dissatisfaction with the cyclic and inconsistent changes to their speech production over the course of their injection cycle. Our results suggest that the benefits of BoNT on speech production are variable not only over the course of the injection cycle but also across our participants.

Many participants in our study also described that they required less effort to speak post-BoNT injection. However, not all of our participants experienced reduced effort when speaking. Baylor et al. (2007) also reported similar results in their participants with SD. More specifically, immediately after the injection, participants felt that their voice was at its weakest and that, toward

the end of the injection cycle, the amount of physical effort to speak would return.

Changes to communicative participation following BoNT injections were also described by participants. Our results align with the results reported by Dykstra et al. (2007) who found a positive difference in all participation restriction scores on the Voice Activity and Participation Profile following BoNT injections.

Other studies have reported that participants rated themselves as more "social" postinjection (Charous & Comella, 2011), reported improvements in daily communication (Faham et al., 2019), and reported a reduction in social isolation and public avoidance (Epstein et al., 1997). Similarly, the majority of participants in our study reported the importance and meaningfulness of participating in social activities with family and friends and that participation was improved postinjection. Our participants also reported how they were able to return to work following BoNT injections. Participants (N. F. and J. R.) reported that BoNT treatment allowed them to return to work and resume meaningful occupation. Our results support that communicative participation is identified as important and is improved as a result of BoNT injections.

Clinical Implications

The results of this study provide information about the psychosocial consequences of BoNT treatment for OMD that can help inform clinical practice. Although qualitative research makes no claims about generalization to larger groups, its purpose seeks to find an in-depth understanding of the experiences of those interviewed. While this study design is not intended to necessarily generalize to the full population, consistent patterns found in the data suggest that the findings are likely highly representative of the experiences of others with OMD, and these data likely provide a window of insight into important experiences and perspectives.

Understanding the participants' perspectives on treatment can help improve rehabilitation in this clinical population. The results of this study highlighted the positive and negative consequences of BoNT injections relating to QoL, speech production, and participation from the perspective of the participant. From these results, we were able to distill the following conclusions that have clinical applicability and importance when working with this clinical population.

The first is that BoNT injections generally result in positive outcomes and psychosocial consequences; however, chemodenervation should not be viewed as leading to uniform outcomes or addressing all concerns. This is an important clinical issue because BoNT injections is the primary therapeutic treatment for patients with OMD (Teemul et al., 2016) and is considered to be the "gold standard" and the most effective treatment for OMD (Kazerooni & Broadhead, 2015). We advocate that adjunctive therapy, in addition to chemodenervation, should always be considered in order to provide broader and more holistic care for this patient population. These adjunctive approaches to management

might include education and counseling (Jinnah, 2015), relaxation techniques to attenuate muscular pain (Jinnah, 2015), and speech therapy (Dworkin, 1996; Goldman & Comella, 2003). These approaches should be explored with patients and recommended based on the patients' individual needs and preferences for their clinical care.

Although our participants reported that BoNT injections resulted in variable speech production and facial appearance outcomes, these factors were reported as a priority and important for our participants in judging the success of their treatment. Therefore, it is prudent for clinicians to provide additional management such as the provision of a bite block that could improve not only facial appearance but also articulatory precision, and hyperactive movements associated with hyperkinetic dysarthria (Dworkin, 1996; Goldman & Comella, 2003). Additionally, communicative interaction strategies, such as dyadic strategies to improve communication or modifying the communicative environment to improve visual and auditory acuity, may be appropriate to ensure successful communicative participation (Duffy, 2013; Page et al., 2019). Furthermore, since the experience of having OMD is variable and individualized, any treatment plan should be tailored to the individual based on his/her priorities and personal concerns related to OMD. Finally, assessing psychosocial outcomes of BoNT injections should be ongoing in order to understand and to respond to evolving patient needs, goals, and priorities (Baylor et al., 2007).

Summary and Conclusions

This study explored the lived experiences of eight individuals receiving BoNT as a treatment for OMD. The results of this study suggest that BoNT treatment has variable impact and effect across domains related to quality of life, expectation and satisfaction with treatment, speech production, and communicative participation, with all participants reporting some degree of benefit associated with BoNT injections. All participants acknowledged the value in this treatment, although not everyone experienced positive changes in all OMD-related symptoms and experiences. There were examples of either neutral or negative changes in some areas of function after BoNT injections. This information is important in augmenting our understanding of the impact of BoNT treatment, through a psychosocial lens and from the perspective of the individual receiving this treatment. This research adds novel information relating to the psychosocial consequences of BoNT treatment in the management of OMD and builds on a small but growing literature that seeks to study the consequences and experiences of living with OMD. Although all participants had a diagnosis of OMD, each participant displayed their own unique presentation of this neurological disorder (i.e., type and location of OMD) and they also were managed with individualized BoNT treatment plans determined by their neurologist (M. J.), including tailored dosing and sites of injection (see Table 1). Our participants, therefore, were representative of the heterogeneity characteristic of OMD. Furthermore,

despite the relatively small number of participants interviewed and the heterogeneity of OMD types displayed in our participants, the overlap in theme content suggests that saturation was achieved through the identification of the primary psychosocial factors of BoNT injections for this clinical population. However, future studies may wish to include a larger sample size to allow for a separate study that stratifies participants into groups based on location of OMD (i.e., jaw opening vs. jaw closing vs. lingual vs. labial). This stratification could help to delineate if the location of OMD produces potential differential psychosocial experiences as the result of receiving BoNT therapy. The results of this study also have practical clinically based utility because our findings can potentially aid clinicians in targeting relevant and meaningful outcomes of treatment success. With expansion, this line of research inquiry can aid in the eventual development of appropriate patient-reported outcome measures that capture the issues relevant and meaningful to this clinical population.

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Appendix

Coding Dictionary

Code	Definition
Botox injection	Frequency and dosage of injection, site of injection, side effects, impact of BoNT wearing off
Eating/drinking	As a result of BoNT injections: impact on eating, chewing, swallowing, choking, aspirating, and strategies used to improve eating
Facial aesthetics	Changes to orofacial aesthetics due to OMD and BoNT injections
Job	Type of occupation, loss of occupation, regaining occupation, personal meaning of occupation
Pain	Physical pain due to BoNT injections or dystonic symptoms
Personal perspective	The ability to reflect on experiences as result of OMD and BoNT injections, perspectives on disability, living with a communication disorder
Psychosocial effects	Positive/negative emotional reactions as a result of receiving BoNT
Resilience	Perseverance, overcoming physical and emotional barriers, strength of character, coping strategies (avoidance, humor)
Social aspects	Ability to interact in social settings, effect on relationships with family and friends posttreatment
Speech	Aspects of speech production: difficulty being understood as a result of OMD, reduced speech intelligibility, articulation, rate of speech, effort

Note. BoNT = botulinum toxin type A; OMD = oromandibular dystonia.

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