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The Psychosocial Consequences of BOTOX Injections for Spasmodic Dysphonia: A Qualitative Study of Patients' Experiences

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Summary

Objectives/Hypothesis—The purpose of this study is to examine the psychosocial consequences of BOTOX® (Allergan, Inc. Irvine, CA) treatment for spasmodic dysphonia (SD). This article also explores how patients judge the success of treatment and make decisions about future treatment based on psychosocial issues relevant to them.

Study Design—This study follows the phenomenological tradition of qualitative inquiry in which the objective is to explore the lived experiences of a group of persons who share a common phenomenon, in this case receiving BOTOX injections for SD.

Methods—Six adults with SD who had been receiving BOTOX injections on a long-term basis participated in face-to-face interviews. The interviews were recorded, transcribed, and analyzed according to phenomenological guidelines to identify consistent themes as well as differences among participants' experiences.

Results—The results are summarized in three primary themes that suggest (1) participants' experiences vary over time based on changes in factors such as lifestyle and personal priorities; (2) BOTOX has multidimensional psychosocial implications in physical, personal, and social domains; and (3) participants individualize their treatment regimens, taking into consideration the burden of treatment, scheduling priorities, and other strategies to maximize the benefits of BOTOX.

Conclusions—Based on this study, suggestions are provided for future research into a psychosocial outcome measurement, including longitudinal evaluations that accommodate changing patient priorities over time; multidimensional evaluations that incorporate physical, personal, and social issues; evaluations that include a measure of the burden of treatment; and evaluations that support a shared decision-making model with the voice clinicians.

Keywords

Spasmodic dysphonia; Qualitative research; Quality of life

INTRODUCTION

Spasmodic dysphonia (SD) is a focal laryngeal dystonia that affects an estimated 50,000 people in North America.¹ It is characterized by dysphonia that can take several different forms depending on the predominant type of spasms. Adductor SD (ADSD), the most common form, is marked by intermittent tight voice breaks, whereas abductor SD (ABSD) presents with breathy voice breaks. Patients with mixed SD can have any combination of the above symptoms, and tremor is sometimes present. In addition to these characteristic voice qualities, other dysphonia symptoms might include hoarseness, roughness, strain, or breathiness. The voice disorder is often accompanied by considerable effort and fatigue with talking.

Currently, the most common form of treatment for SD is localized injections of botulinum toxin (BOTOX®; Allergan, Inc. Irvine, CA).² BOTOX temporarily weakens the affected muscles, resulting in a reduction of the laryngeal spasms. Traditional evaluations of BOTOX treatment outcomes have included physiologic measures (videostroboscopy),³ acoustic and aerodynamic measures,^{3–9} and perceptual ratings of voice quality or speech intelligibility.^{5, 9–12}

Another perspective to consider in outcome measurement is that of the person living with SD. Patient-reported outcomes are based in part on theoretical models of multidimensional health outcomes. For example, *the International Classification of Functioning, Disability and Health* (ICF) proposed by the World Health Organization (WHO)¹³ provides a multidimensional biopsychosocial approach to understanding the impact of health conditions and interventions, including those related to communication disorders.^{14,15} The WHO model encourages evaluation from the perspective of the person with the disability to understand issues related to life participation and quality of life.

The importance of psychosocial outcomes in voice disorders is also highlighted by observations in prior research on SD^{16,17} and other voice disorders^{18–20} of often weak-to-moderate relationships between traditional outcome data such as physiologic function or acoustic signal analysis, and the reported impact of intervention on the lives of patients. For example, in a meta-analysis of SD outcome studies, Boutsen et al¹⁶ reported that different effect sizes from BOTOX are observed across different forms of outcome measurement. Specifically, patient reports of symptom improvement had larger effect sizes than measures from other domains such as perceptual voice quality ratings. Many authors are now suggesting that psychosocial constructs should be investigated directly as they cannot be inferred from other types of data. In assessing symptoms of SD, Edgar et al¹⁷ concluded that “neither the acoustic nor the perceptual measures...was able to capture either the conversational impairment or the patient’s perspective of a disorder clearly affecting his lifestyle.” This finding “supports the need to include...patient’s perspective in assessment of the disorder.”

In general, prior research documents a favorable impact of BOTOX injections from the patient’s perspective using a variety of formats, including anecdotal reports, patient diaries, informal rating scales, and various published questionnaires.^{5,10,11,21–37} However, many questions remain regarding the psychosocial outcomes of BOTOX injections. For example, what is the range of different psychosocial issues that concern people who receive BOTOX injections? What issues are most important to these persons? To what extent do psychosocial issues influence patient decisions about continuing BOTOX treatment? How well do patients feel that their psychosocial concerns are being addressed in current clinical environments? Further work is needed to understand what these consequences are and how to best collect that data for use in research and in clinical decision making.

Another way to explore the psychosocial consequences of BOTOX intervention is through qualitative research. Qualitative methods provide a systematic approach to collecting and

describing data from contextualized social phenomena. Qualitative research offers the advantage of providing an authentic view into the individualized and often complex experiences of living with BOTOX treatment for SD in the context of patients' daily lives. Through qualitative interviews, participants can direct researchers to those issues that are of greatest relevance to them regarding BOTOX intervention. The investigators and participants can explore sources of variability among patient experiences as well as identifying common trends. Through this process, factors that might not be addressed in more traditional patient questionnaires can be identified, and irrelevant information can be discarded. An overview of qualitative research in the field of speech-language pathology is provided by Damico and Simmons-Mackie.³⁸

A prior study from this institution³⁹ explored patients' experiences living with SD using qualitative research methods. They found that the psychosocial consequences of SD could be grouped into three main categories: (1) the experiences of physical symptoms such as voice quality, effort, and unpredictability of the voice; (2) internal personal experiences such as affective responses, changes in the patient's self-view, and personal coping; and (3) consequences associated with the external or social environment such as obstacles in the physical environment, the reactions of other people, and altered participation in social roles. Baylor et al³⁹ concluded that each of these three categories provides relevant information for appreciating the psychosocial consequences of SD. Understanding the impact of SD on each person required not only identifying the individual issues but also examining the complex interactions among these factors. Many of these factors, and the relationships among them, have not been explored extensively in the literature and warrant further investigation.

PURPOSE

The purpose of this study is to expand on prior research³⁹ by investigating the psychosocial consequences of BOTOX treatment for SD. This article will also explore how participants make decisions about their BOTOX treatment based on relevant psychosocial issues. The potential implications for this research include better understanding of the impact of BOTOX intervention on patient's lives; insight into patient perspectives on making decisions about treatment; and suggestions to improve measurement and utilization of psychosocial information in clinical and research practices.

METHODS

Six adults (five women and one man) who had been receiving BOTOX injections on a long-term basis (more than five injections) participated in face-to-face interviews. Demographic information for the participants is presented in Table 1. The interviews were guided in that participants were asked general questions about their experiences with BOTOX injections. These questions were as follows: (1) How has BOTOX affected your ability to do the things you want to do? (2) How do you make decisions about getting your BOTOX injections (eg, scheduling the next injection or asking about changing the dose of BOTOX)? (3) How do you communicate with the voice clinic team about how BOTOX is affecting your life? Beyond these broad questions, participants were encouraged to talk about any experiences or issues related to SD and BOTOX that were relevant to them that they wanted to share. The interviewers asked questions to seek additional information or to clarify points, but otherwise the nature and extent of the interviews were determined largely by the participants. Four participants returned for brief follow-up interviews. The interviews were recorded, transcribed, verified, and analyzed according to guidelines for the phenomenological tradition of qualitative inquiry.^{40,41}

Participants were also asked to rate their voices on the day of their primary interview because of concern that the extent or nature of their participation in the interview might be affected by how their voices were functioning on that day. Participants rated their voices on a scale of 1–10, where 1 = the worst your voice has been since getting SD and 10 = the best your voice has been since getting SD (including with BOTOX injections). The participants' ratings are available in Table 1 and indicate that most participants felt their voices were good on the day of the interview.

More detailed information about the methods of this study is available in a prior publication.³⁹ All methods were approved by the Institutional Review Board at the University of Washington.

RESULTS

The main themes that emerged from the interviews reflect three general concepts that participants talked about with regard to their experiences with BOTOX. The three themes, along with their sub-themes and illustrative quotes, are presented in the following sections. Table 2 also provides a summary of the themes, sub-themes, and corresponding definitions.

Theme 1: My experiences with BOTOX change over time

Although all participants except one reported that they were in fairly established and routine treatment regimens at the time of these interviews, they emphasized that their experiences had not been consistent throughout their treatment histories. Participants' early experiences with BOTOX seemed to play a significant role in shaping their perspectives on BOTOX and were a critical part of each participant's "story." The first sub-theme, *learning the ropes with BOTOX*, contains participants' descriptions of these initial experiences. The second sub-theme, *looking ahead*, includes participants' thoughts about the long-term future and issues they think might influence their decisions about pursuing BOTOX treatment in coming years. Current experiences with BOTOX are presented in the second and third themes in greater detail.

Sub-theme 1: Learning the ropes with BOTOX—Participants talked about several challenges as they acclimated to BOTOX injections. These challenges included acknowledging that there was a problem with their voices; finding qualified medical assistance; and learning how BOTOX would affect them during the first few injections.

Acknowledging that something is wrong: SD is gradual in onset, and the participants in this study all talked about the transition from a subtle awareness that their voices were changing to an overt recognition of a problem that needed to be addressed. They had not really paid attention to the voice changes until another person or a particular situation drew their attention to their voices. That moment usually provided the impetus for the participants to seek professional help. For example, A.T. (all initials are fictitious), an elementary teacher stated:

I think it started gradually but nobody ever mentioned it. And then one day, a parent said, what's wrong with your voice? And I thought oh my gosh there is something wrong. It's really interesting how you tell yourself that nothing's wrong because nobody else has ever said there was. So right when the parent asked me what was wrong with my voice, the next day I made an appointment. It was that quick because I knew.

Finding my way to the answers: Four of the six participants experienced repeated misdiagnoses and subsequent unsuccessful treatments before they were found to have SD. They were frustrated by what they interpreted as lack of education for health-care providers as to how to recognize SD. M.A. said, "The big issue with me is that doctors other than speech

doctors don't know what this is. The internist didn't have a clue what I had. The throat doctor thought I had the reflux stuff. The doctors don't know about it," Participants attributed much of their eventual success in finding out about SD to their own persistence to get different opinions. M.A. said, "Had I not kept pursuing it with other doctors I could have gone with this reflux thing for a year or two and it wouldn't have been doing any good." IP added, "The main thing [is] I didn't give up." Although the diagnosis of SD brought some grieving because there is no cure, there was also a certain amount of relief to finally know what was the condition. As MA said, "With anything that's wrong with you, knowing is a big deal, and I know what's wrong. Once you knew about it, to me personally it was easier to deal with."

Making the Decision to get BOTOX: Once participants established the diagnosis of SD, they then had to decide about BOTOX therapy. This decision was difficult, largely due to fears of injecting "poison" into the body, and getting an injection in the throat. M.A. expressed a common opinion:

I heard about this treatment where they stick a needle in your throat and my first thought of course was I'm not doing that. Forget it. But it [voice problem] went on long enough that I got so frustrated talking and exhausted at the end of the day that I thought the heck with it. Whatever it takes I'm doing it because this is not a way to live.

The triggers that compelled participants to try BOTOX were different across persons. Some, including M.A., sought relief from physical symptoms of effort and fatigue. "I'd come home and just didn't want to talk anymore at all because I was exhausted. That's the point where you say let's do whatever we need to do here." R.N. reported how generalized fatigue affected her decision:

A lot of my energy was going into speaking. I just didn't have as much energy for the rest of life. Before I decided to get BOTOX I had my hands full just cooking meals, cleaning the house. I did minimal work actually. I just got by.

Another issue that motivated participants to try BOTOX was frustration over how SD was impacting their lives. R.N. reported, "Life was just getting too hard and I just couldn't imagine living like this." M.A. added, "It was really frustrating before I started the treatments and that's the point at which I said let's just figure out what's wrong and be done with it."

For participants who were employed, occupational voice demands factored heavily in their decisions to try BOTOX. B.W. said, "I feel like it's a no choice situation. I cannot progress career-wise. I can't even communicate adequately [without BOTOX]." M.A. also reported that work-related communication demands were instrumental in his decision. "With casual things communication is not so important as it is during work because during work, whatever you do, you've got to be heard."

Learning how BOTOX affects me: The primary issue during the first injections was adjusting to the cycle of symptoms and "side effects" that commonly occurs after injections. This cycle includes several days of weak, breathy voice, then several weeks of relatively good voice, followed by a gradual return of SD symptoms. Adjusting the injections to minimize the weak, breathy period immediately after the injection was the most common concern. M.A. shared his experience: "It took about two or three treatments to bracket the correct dosage. He'd [the doctor] start high and then go low and fiddle around so in the first treatment or two there was absolutely no voice for a week. That was frustrating."

Another difficult period was later in the cycle as the optimal voice period ended and the symptoms of SD re-emerged. Some participants talked about how they had experienced such significant relief during their first injections that they almost believed that the voice problem

was permanently treated, although they had been told otherwise. R.N. described how she had to develop realistic expectations for BOTOX:

It's very easy to think I don't have a voice disorder I can talk perfectly fine. And this will happen for weeks when the BOTOX is just working good. And it can promote that idea of denial until you've done it enough and realize that no, you're going to go through the cycle. But I remember going through really good times going hey I think I can do just fine without this. But it [SD] always comes back.

The mild dysphagia that can occur after injections was unsettling at first but did not remain a notable concern. I.P. reported, "The first one or two injections I did have trouble [swallowing], but I don't get that anymore. I don't even think about taking small sips or anything."

Sub-theme 2: Looking ahead—Five of the six participants stated that they planned to continue BOTOX in the long-term future. However, they did express concerns about prolonged use of BOTOX and suggested that their decisions about BOTOX might change depending on future circumstances. As I.P. said, "You do think about the future because it's [SD] something you have to live with. It never goes away."

Some of the future concerns were about the overall effectiveness of BOTOX. I.P. said, "Maybe they're [the injections] not going to work forever. You worry about that." I.P. also voiced worries shared by other participants about the long-term safety of BOTOX. "Is there anything hidden that's going to come out later on? I asked [the doctor] is there any long term side effects when you're thinking of putting BOTOX in your body?"

Lifestyle and logistical issues also influenced thoughts about future BOTOX treatment. For example, I.P. was one of two participants who said they plan to move after retirement, and they were concerned about finding someone who provides BOTOX injections because injections are not available everywhere. "When we relocate...am I going to need to fly back twice a year to see [the doctor]? You think about all that because you think about the future."

B.W. was the one participant who said she did not plan to continue the injections. Her fear and discomfort with injections was so great that she would not be motivated to get BOTOX once she no longer needed to rely on her voice for her occupation:

I'll just keep going along like I am until the day I don't have to work anymore and then I'll never get another one [injection]. That hanging upside down with a needle in your throat just doesn't sound appealing with retirement.

Theme 2: BOTOX has changed my life in different ways

This theme conveys the multidimensional nature in which BOTOX affects participants' lives. The sub-themes in this section are organized according to the topics of physical, personal, and social consequences of BOTOX, much as the consequences of SD were presented in the model of communication-related QOL in the prior study.³⁹

Sub-theme 1: BOTOX has relieved my physical symptoms—This sub-theme contains participants' descriptions of how BOTOX has affected the sound of the voice, the symptoms of effort and fatigue, and the dependability of the voice. All participants experienced improved voice quality with BOTOX. Some participants reported that their voices essentially returned to normal during the period of time that BOTOX was maximally effective. M.A. said, "It's nice to just speak normally. It's a real treat," Other participants said that they did not get a return to normal voice, but that they still felt their voices sounded much better.

Participants also experienced relief from physical effort and fatigue. R.N. contrasted this physical discomfort before and after BOTOX, “My whole neck felt tight and thankfully I don’t feel that at all anymore.” M.A. added, “It’s nice to be able to just talk without forcing words out.” Improved dependability of voice was also a benefit of BOTOX. Although the participants reported that their voices still had a tendency to fluctuate, overall their voices were more reliable than before BOTOX. AT. said, “I can go in a group and I know I can talk and it [SD] doesn’t bother me.”

Sub-theme 2: BOTOX has changed how I feel about myself—This sub-theme includes benefits participants reported in coping, affect, and self-view. For example, the prior study revealed a mismatch between how participants saw themselves and what their voices portrayed about them.³⁹ Participants reported that they often felt they could not be themselves or convey their authentic personalities because of the SD. The relief of the SD symptoms brought about by BOTOX allowed participants such as I.P. to feel and act like themselves again.

You just feel good that you can be yourself and your own personality and not have to be this quiet type person because that’s not me....I’m an outgoing person and my voice is a part of me and my personality. I couldn’t even imagine not being able to speak.

Several participants discussed the freedom from having to worry about their voices. When the SD symptoms were present, participants felt that they had to constantly monitor their voices.³⁹ With the improved voice after BOTOX injections, that vigilance was no longer needed at least for a few weeks. I.P. reported, “I have a good three and a half–four months where my voice is strong. I don’t even think about it.” M.A. concurred: “When I’m in the midstream of my shot, [it] doesn’t even occur to me what I have. It is just absolutely normal which is great. Out of my mind.”

Participants also reported that BOTOX treatment brought more stability to their coping with SD. After experiencing several injections, they understood what to expect from treatment. Their affective feelings no longer rose and fell with what they knew were temporary fluctuations in their physical symptoms throughout the injection cycles. M.A. said, “Once you go through the stages you know a little bit better how to deal with the pressure of getting the words out so you just manage it.” R.N. summed up this greater stability in coping, “It [the voice] doesn’t have that negative value. I know it’s there but it doesn’t have that hurting quality that it used to have. It’s more even keel.”

Sub-theme 3: BOTOX has changed how I interact in the world around me—This sub-theme contains participants’ reports of renewed ability to participate in activities in their social environments. For participants such as R.N., BOTOX allowed them to return to valued activities and to regain some “sense of a normal life” without the voice “controlling” what they could do. For other participants, the changes brought about by BOTOX facilitated new opportunities. B.W. provided one of the most dramatic examples of how she had been able to make significant advances in her career after BOTOX injections improved her voice:

Once I started getting those [injections] then I started venturing more into demanding that I get paid for what I do. I could easily prove from my work that I was [qualified] but I wanted to be able to vocally represent myself. I went from making fifteen thousand dollars a year to fifty-five thousand dollars a year in a five year span. That was immediately after BOTOX.

Participants also reported improved participation in social and community activities. For example, B.W., who reported that she generally leads a very restricted social life due to the effects of SD, found that she reaches out to people much more when her voice is good with

BOTOX: “Oh I’m in heaven during the good voice period. I do everything. I call everybody on the phone and set up every meeting I can possibly do. Just talk with people. Use every opportunity to use a decent voice.”

Theme 3: Figuring out what works for me

This theme presents participants’ discussions of how they evaluate the success of their BOTOX injections, how they manage the effects of BOTOX, and how they make decisions about proceeding with future injections. The individuality of participants’ approaches to BOTOX emerged strongly in this theme.

Sub-theme 1: Weighing the burden of treatment—Despite the many advantages of BOTOX that participants talked about, they also raised several disadvantages that weighed heavily in how successful they considered their treatment to be, and in how they wanted to manage their BOTOX programs. These burdens of treatment included the experience of getting the injection, the cyclic and sometimes inconsistent voice response after BOTOX, and the need for repeated injections. Participants weighed these burdens differently.

The injection experience: Adjusting to the mental and physical experience of having the injection was a notable hurdle for all participants to overcome. M.A. conveyed the feelings of most participants when he described part of the difficulty with injections as “the fear of just having somebody stick a needle half way through your throat.” Another challenge was the physical discomfort. H.T. reported, “It does hurt.”

Most participants had adjusted to the injection experience over time although they had techniques to manage the stress of the injection. These strategies included creating distractions for themselves or using other mental techniques to, as I.P. noted, “psych myself up.” M.A. also found that coaching from the physician helped him get through the injections: “The best thing [the doctor] does is he talks you through it. It really does help to have the doctor talk you through it and coach you. Just a few words make a huge difference mentally.” Two participants reported that their anxiety about the injections was still significant enough that it was something they had to work through every cycle in order to be able to return to the clinic. B.W. said, “Every time I go through it [the injection], I think I’ll never do this again. I’ll never do this again.”

Another disadvantage associated with the injection experience was the logistics of a very busy clinical practice. Participants talked about the frustration of trying to get appointments when they wanted them and the long waits on injection days. M.A. said, “I don’t fear the day I get the shot. The only thing I fear is [the doctor] is all booked up and he didn’t have an emergency that day so everybody doesn’t get pushed out until the middle of the night.”

The voice response after BOTOX: Although participants listed improvement in the voice as one of the advantages of BOTOX, there were also disadvantages associated with the voice. The primary disadvantage was the cyclic nature of the response. I.P. described the voice as “up and down.” The days immediately after the injection when the voice was at its weakest were the most difficult period of the BOTOX cycle. I.P. reported, “My dad has poor hearing. After I have an injection, I’m [in] that breathy stage. I’ll back off on calling him... because it’s hard for him to understand me and then it’s frustrating for me.” M.A. also noted that, “I probably talk less...when I am going through the break in period after the shot.” B.W. adjusts her work activities because of how people respond to her when she is in the breathy voice phase:

When you have the Marilyn Monroe voice, you don’t go into important situations. They just discredit what you say. Even my friends who are completely on my side [say] how can we take you seriously? It’s just too funny to listen to Marilyn Monroe.

For A.T., the participant with ABSD, the time immediately after the injection was also the most challenging period but for a different reason. Her complaint was shortness of breath (caused by weakening of the posterior cricoarytenoid muscle) that limits her physical activity. She saw the injections as a tradeoff between being able to speak with a stronger voice versus being able to continue highly valued physical activities.

I think my big dilemma is that I like to be physically fit. I like to walk every day. I like exercise, belong to a hiking club. I get my injection and that's it because I can't breathe. I can't do the switchbacks. So I always say you can walk or talk but you can't do both.

Although voice quality was more problematic at the beginning of the injection cycle, the return of physical effort was a dominant symptom at the end of the cycle as the effects of the BOTOX wore off. H.T. described this contrast: "The beginning [of the cycle] I almost whisper. I can't raise my voice at all. But at the end I must push much more." B.W. agreed that "It's very tiring to talk when the BOTOX has worn off." A.T. indicated that part of the effort comes from the need to monitor speech to ensure that you are being understood, "When you're at five–six months it takes a lot of effort to speak. Mental effort really. Not physical. Mentally it's draining. I have to think of when I'm doing each syllable."

Another disadvantage associated with BOTOX was unpredictability of the voice response from one injection to the next. This was a particularly relevant concern for H.T.: "I've had mixed results. Sometimes it's good. Sometimes it isn't. There are times when it's perfect. I mean it's like I could talk again. And the other times like this when it's not so good." Even the other participants who felt they were on fairly stable treatment regimens reported that there is some inconsistency that catches them off guard. M.A. said, "My voice is doing really pretty good this time after ten days or fifteen or whatever. Last time for whatever reason it took a longer time to get back to normal and I don't know why. It's just different last time, but this time is real good."

One particular challenge associated with the fluctuation in voice was dealing with expectations of people in their environments. Most participants reported that family and friends who were familiar with their voice problems were tolerant of the variations in voice and the accompanying variations in participating in activities. However, A.T. was one of two participants who reported receiving negative reactions from other people:

I don't think people understand it. There are really understanding people and then others, it's like well you talk most of the time so why can't you do that [now]? ... If you can do it one meeting, you can't do it the next meeting—definitely people don't understand that. And I've tried to explain that the toxin wears off and so that's a real dilemma.

BOTOX is not a cure: The final treatment burden that the participants reported is that BOTOX is not a permanent cure. R.N. tried to keep some perspective on the need for repeated injections:

It's not a cure. It just treats the symptoms so it's not going to go away. It's going to need repeat treatments. But then I tell myself you know three–four times a year is not bad compared to three times a week hooked to a dialysis machine.

Sub-theme 2: Getting the most from BOTOX—This sub-theme contains information about how participants try to maximize the benefits and minimize the disadvantages of BOTOX. The participants had different concepts of the ideal BOTOX injection. For B.W., the ideal injection would be, "Pain free and very quick. Then the second thing would be no breathy period. And the third thing would be it would last longer" A.T. defined her ideal injection: "To be able to say every sentence correctly, long words, long sentences. Ideally I'd like to be able

to talk to people so they don't wonder why I'm struggling to speak. That's how it used to be." I.R. provided a third example of the ideal injection:

A true success is when a patient... can speak without ever thinking about having spasmodic dysphonia. Where I don't even think about it. It's like my voice is like it used to be and I can talk to anybody and not feel self-conscious.

None of the participants experienced these ideal injections, and they expressed awareness that they likely never would due to the nature of SD, the nature of the treatment, restrictions posed by the environment, or other factors. However, they continued to aim for these optimal outcomes through various strategies. The most common strategy was to schedule their injections according to their individual needs. Examples of other strategies that will be discussed include adjusted participation in life situations and efforts to physically control the voice.

Scheduling injections seemed to be a delicate balance between getting as close as possible to the ideal injection without experiencing the catastrophes that they knew could occur if injections were given too soon or too late, or if doses were too large or too small. For example, a larger BOTOX dose given in an effort to maximize the length of "good voice" might also produce a prolonged period of extreme breathiness immediately after the injection. Potential catastrophes, described as their worst BOTOX injections, included very uncomfortable injections, prolonged periods of breathy voice or shortness of breath after the injection, and lack of voice improvement.

The participants had different "triggers" that cued them to get their next injection. As I.P. said, "I've kind of set my own schedule—what works for me and [I] feel comfortable with it." For H.T., change in voice quality was the primary reason for scheduling the next injection: "I find my voice is very bad at the end of three months and so I find that the perfect time [to get another injection]." However, most participants found that triggers other than, or in addition to the voice, were very instrumental in their scheduling decisions. For two participants, the return of physical effort and pain signaled the need for another injection. M.A. said, "I start feeling the pressure coming back... That's just a little mental trigger that I better get on the telephone and get an appointment." The pending post-injection shortness of breath featured prominently in A.T.'s scheduling decisions.

I'm more concerned that I'm not going to be able to go hiking with my friends. It's what I won't be able to [do].... That's probably why I don't come in is I'm finally getting in shape. Finally where I want to be again and now I have to have my shot. It's a real struggle. That's one of the reasons I wait. If it's summer I'm not going to give up hiking.

Some participants planned their injections around life situations that required voice use. For example, B.W. postponed the injections as long as possible until she felt she was no longer able to perform her occupational duties adequately with her voice: "I... wait until it's [the voice] starting to affect me at work." She also discussed plans for her BOTOX doses with her doctor in order to minimize her post-injection breathy voice because of how it limited her at work. "I can't have a month of breathiness just for my work. I can get away with some stuff for a couple weeks but I can't go a month without talking with the chiefs and talking about serious things." Other participants, such as M.A., planned around social events:

Sometimes you have to think ahead. Like this Christmas. We decided I'd try and get my appointment after the holidays instead of before because you're seeing friends and family and you just don't want to deal with the quiet voice. You'd rather deal with maybe a little more difficulty speaking than dealing with the after-shot effects during the holidays.

Other triggers included comments that people made to the participants that made them aware that their voice symptoms are noticeable once again. B.W. said:

I know because people start making comments to me. Comments like oh, you must have a terrible cold. And after I get two or three of those then I know it's not just my voice sounding funny for that one day. And I'm like oh I've overrun. I need to call and get in.

Another scheduling trigger was maintaining a positive self-view. Some participants felt that although they could tolerate fluctuations in their physical symptoms, the changes in how they feel about themselves with the SD symptoms cause them to schedule their next injection. I.P. said, "In the back of my mind I'm wondering should I wait longer to get the shots? But my voice is such a part of me and my personality that I choose not to."

One final scheduling consideration was clinic logistics. One participant, I.P., scheduled her injections ahead of time at 6-month intervals, regardless of her symptoms or life activities, so that she could guarantee being the first patient each day to avoid the wait in the clinic. M.A. left a buffer of good voice at the end of each cycle to give him extra time in case an appointment is not readily available: "At the time I get my shot my voice is still manageable.... If I had to —[the doctor] was on vacation or something and I had to go another month I could probably deal with that without a big problem."

In addition to scheduling their injections, there were other strategies participants tried to optimize their outcomes. Although all participants agreed that there was very little they could do to physically control the sound of the voice, some participants did find that they could do some things to enhance or prolong the benefits of BOTOX. For example, R.N. applied some techniques she learned in voice therapy to manage her voice at the beginning and end of the injection cycles:

I benefited from speech therapy and I know it didn't take care of my problem but I'm convinced it's one of the things that has helped me compensate on both ends of BOTOX. It's [SD] present but it's workable....I know how to put a little more umph in my voice without straining it. I can talk a little bit louder or easier onsets to not aggravate the spasms.

When they could not control their voices, they looked for other things in the environment that they could control. For example, B.W. found that educating her coworkers about her voice took the pressure off of her to have a good voice, "because they [coworkers] are used to it and they will be more forgiving about however I talk." Other strategies included reducing the amount of talking and relying on alternative means of communication such as e-mail.

Sub-theme 3: Making decisions with the voice team in the clinic—In this final sub-theme, participants talked about their interactions with the voice clinic team. They expressed appreciation for the flexibility of scheduling their injections around their personal priorities, the receptiveness of the clinicians to their concerns, and the opportunity to discuss treatment plans and make decisions jointly with the clinic team. Participants did, however, express dissatisfaction with some aspects of the evaluation protocol. There was concern that the voice rating scale that focuses on severity of spasms was not individualized enough to address their specific symptoms. R.N. said, "One of the things that I do have [is] the tremor quality to my voice, and that's one thing that's not asked. Sometimes it's hard to judge spasms when they're really tremors." B.W. added, "I think it could be more individualized. I feel like they cannot tell anything about what's difficult for me from their records."

Another concern raised by participants was that the consequences of SD beyond the voice symptoms were not adequately recognized. A.T., the teacher, would have appreciated more support in dealing with the impact of SD on her professional life:

I'm sitting in a job thinking should I really be doing this? It was hard for me on my own to figure out should I be teaching or shouldn't I be teaching.... I would have liked some sort of guidance... and I don't know if just going in and reading five sentences—I'm thinking you don't know what Tin going through. You're not close to what I'm going through. I can read, 'a puppy bit the tape' or whatever but that's not it.

Of all participants, H.T. was the most dissatisfied with her communication with the voice care team. She felt that she did not understand why different adjustments had been made in her treatment. Interestingly, she was also the one participant who seemed most satisfied to leave most treatment decisions to the speech-language pathologist (SLP) and physician.

I am not a professional and I feel he [the doctor] knows much more so I can't assume to tell him. Just the last couple of times I've said to him, 'Stay with the same because it helped me.' That's the only time I have told him.

Participants recognized the challenges in making evaluations more sensitive to the concerns of individual patients. HT. said, "It's a personal thing rather than technical. You cannot be objective. It's relative. It is so subjective which makes it very difficult to measure," When asked about their willingness to keep data at home between injections to enhance the information available to clinicians, the participants were willing to do so, although they felt that occasional or retrospective reports could capture most of their concerns. R.N. explained that keeping frequent data defeated one of the main benefits of BOTOX, which was the freedom from thinking about SD:

I used to take detailed notes and I thought later on this is excessive. This is being way too absorbed in your voice. When I was thinking about my voice all the time...it turned out to be more of a pressure thing. Our goal is to have it be less in your thoughts or be less pervasive.

In summary, the results of this study showed that participants' experiences with BOTOX changed over time, BOTOX treatment impacted many aspects of participants' lives in addition to the basic physical symptoms of SD. Strategies for managing the effects of BOTOX were highly individualized and took into account the burden of treatment as well as other variables. Participants felt that the voice clinic personnel were approachable and open to their concerns, but that many formal evaluation protocols were not adequately sensitive to the personal and multifaceted experiences of BOTOX treatment.

DISCUSSION

The purpose of this article was to explore participants' experiences with BOTOX injections for SD and how those experiences shape their judgments about the success of treatment and their decisions about ongoing treatment. In this section, the results will be discussed in the format of four suggestions that might warrant greater attention when evaluating the psychosocial consequences of BOTOX. These suggestions are to (1) evaluate psychosocial consequences on a longitudinal basis with the recognition that patient priorities might change over time; (2) incorporate the multidimensional physical, personal, and social experiences into outcomes measurement; (3) include a measure of the burden of treatment; and (4) use information about psychosocial outcomes in the context of a shared decision-making model that brings together the experiences of patients and the technical knowledge of clinicians to guide future treatment.

Longitudinal measures

The participants reported that their experiences with BOTOX changed over time. Their first injections were characterized by learning how BOTOX would affect them and how they wanted to manage their injections. Although most participants were now in more stable treatment routines, they anticipated future changes in their treatment goals. They attributed these changes to several variables, including how their voices physically responded to BOTOX, occupational and social priorities, lifestyle changes, their injection experiences, their personal coping styles, and accessibility of BOTOX treatment. These results suggest that assessment of the psychosocial consequences of BOTOX should be ongoing to understand and respond to changing patient needs and goals. For example, evaluations of early injections might focus more heavily on physical symptoms and experiences with side effects, while adjustments are made to find the optimal injection parameters. Once patients have established a fairly predictable physical response to BOTOX, other psychosocial issues such as compensatory strategies or life participation goals might warrant more attention.

Several prior studies have followed participants over multiple BOTOX injections.^{5,10,21–28} However, most of these studies focused on patient reports of physical symptoms and do not address other psychosocial consequences in detail. One series of studies has examined the broader psychosocial consequences of BOTOX on a longitudinal basis using the Voice-Related Quality of Life (V-RQOL) scale.^{29,35} Rubin et al²⁹ demonstrated that there continued to be significant differences between preinjection and postinjection scores over a series of six injections (starting with a patient's first injection). Although the magnitude of change in V-RQOL scores dropped significantly from the first to the second injection, the magnitude of change for all subsequent injections did not differ significantly from the first two injections.²⁹ The authors interpreted this finding to suggest that patient expectations for BOTOX might change during the initial injections, and that the most accurate measures of psychosocial outcome might therefore be observed after several BOTOX injections.

The findings of the current study are consistent with those of Rubin et al²⁹ in terms of highlighting the importance of evaluating psychosocial outcomes over time. However, some questions arise when comparing the results obtained in the V-RQOL studies with the current study. For example, the V-RQOL studies show significant changes in questionnaire scores before and after each injection, which suggests that participants experienced notable declines in V-RQOL before each injection followed by significant improvement after each injection. In contrast, participants in the current study did not report as much variability across individual injections. As R.N. stated, they were on more of an "even keel." This difference could occur for many reasons, including participants scheduling their injections before their voices declined notably, or feeling that they simply coped better with the overall situation. Differences in the methodology between the V-RQOL studies and the current study might account for the varying interpretations.

Wingate et al³⁷ examined the effects of BOTOX in older SD subjects. Although that study covered only one injection cycle, the authors recognized that people might have different responses to BOTOX at different ages or stages in life. Wingate et al³⁷ found that there was no significant change in Voice Handicap Index (VHI) scores from preinjection to postinjection in their subjects who were over the age of 65 and had been receiving consistent injections for at least one year. They attributed the lack of significant group response to several possible variables, including changing patient expectations for voice outcomes with BOTOX over time (similar to Rubin et al²⁹) or changes in laryngeal characteristics with aging. Wingate et al³⁷ examined life stressors as possible contributors to VHI outcome and found no significant relationships between the life stressor scale used in their study and VHI results. However, questions arise regarding the interpretation that "life stressors" do not seem to contribute to voice "handicap" outcomes based on results from the current study. Participants in the current

study anticipated changes in life events, voice use demands, social participation roles, and personal priorities that might affect their satisfaction with BOTOX in future years. There are many possible reasons for these different findings, and further research is needed to explore how life situations might affect patient-reported outcomes, and how these life “stressors” can best be documented.

Additional research is needed to explore the longitudinal consequences of BOTOX injections and the best methods for measuring these consequences. Some relevant research topics might include exploring how different psychosocial constructs or participant characteristics respond to treatment and might therefore serve as good outcomes indicators (eg, age, amount of experience with BOTOX, voice use demands). In addition, investigation of logistics such as the optimal timing for longitudinal measurement of psychosocial outcomes might help identify evaluation schedules that provide meaningful data for treatment planning with greatest efficiency.

Multidimensional evaluations

Recently, Baylor et al³⁹ proposed a model of communication-related QOL to demonstrate the multidimensional nature of the psychosocial consequences of SD. Many psychosocial benefits of BOTOX reported in this phase of the research can also be explained according to that model. Participants described improvements in their experiences of physical symptoms, particularly better voice quality and alleviation of physical effort and fatigue. Participants reported that the voice was not entirely dependable after BOTOX, but that this symptom was greatly improved. BOTOX also affected experiences in the personal domain of the model. Participants reported more stable and positive coping. Finally, participants reported many social benefits in terms of being able to continue their careers, resume participation in valued social activities, overcome environmental obstacles to communication, and interact more positively with other people around them.

Otolaryngologists and SLPs might be most concerned with evaluating patients’ physical symptoms because that is what the BOTOX injections directly treat. However, it is critical to understand the personal and social components of the communication-related QOL model as well because these consequences often contribute heavily to patients’ judgments about the success of treatment. For example, participants in this study suggested that the importance of changes in voice quality and fatigue depended on how these symptoms affected other aspects of their lives such as returning to employment or having more positive interactions with other people. Evaluating a broader range of psychosocial constructs could improve patient satisfaction by leading to changes in intervention, additional patient education in coping or compensatory strategies, referrals to other professionals for additional assistance, or simply supportive acknowledgment of patient concerns.

Most previous studies that include patient reports of experiences with BOTOX have focused on physical symptoms and side effects such as changes in voice quality and effort.^{5,10,11,22–28} Other studies have gone beyond the physical symptoms to assess other psychosocial consequences of BOTOX using general health-related questionnaires^{11,30–32} or questionnaires written specifically for populations with speech or voice disorders such as the V-RQOL discussed above,^{29,35} the VHI,^{30,36} and the Erickson Scale of Communication Attitudes. These studies have demonstrated significant changes in patient-reported experiences as a result of BOTOX treatment. The current study supports this body of prior research in finding that BOTOX treatment contributes to meaningful improvements in many aspects of participants’ lives.

The need for evaluations that capture the multidimensional nature of psychosocial responses to BOTOX is highlighted in two statements by Wingate et al³⁷ who found no significant

differences in VHI outcomes for older BOTOX recipients. First, Wingate et al³⁷ suggested that greater knowledge of participants' coping strategies would be helpful in understanding their responses on the VHI and other life stressor scales. The current study supports this statement and provides examples of how coping strategies influenced participants' satisfaction with BOTOX. Wingate et al³⁷ also noted that participants in their study reported a "positive BOTOX effect...regardless of how they responded on the VHI." This statement suggests that the VHI might not have captured all essential issues contributing to patient satisfaction with BOTOX. Qualitative methods used in the current study, therefore, were valuable in revealing other aspects of patient satisfaction above and beyond voice effects.

Closely associated with the need for multidimensional psychosocial measures is the desirability of individualized outcome measures. For example, Wingate et al³⁷ reported that although their group results showed no significant difference on the VHI before and after treatment, this overall finding might obscure sizable, yet variable, changes in many individual scores. The current study also demonstrated the individuality of psychosocial consequences in that different issues carried different levels of importance for each participant. For example, some participants were more concerned about physical discomfort whereas others were more worried about their ability to perform occupational duties. Individual patients were motivated to seek treatment because of different concerns, and their broader goals for treatment were varied. It is critical to understand the broader goals for each patient to evaluate whether treatment helped the patient meet those goals and was judged by the patient to be successful.⁴² Future research is needed to investigate how psychosocial measures can best address the multifaceted and individualized concerns of people with SD.

Burden of treatment evaluations

One major focus of discussion for the participants in this study was the burden of BOTOX treatment. The burdens that participants reported included apprehension and physical discomfort with injections, the temporary nature of the treatment, the "side effects" such as the postinjection breathiness, the sometimes inconsistent response of the voice to BOTOX, and the difficulties negotiating clinic logistics. It was important to understand how participants weighed these disadvantages against the advantages in order to understand their interpretations of successful treatment.

Although many prior studies have included patient reports of "side effect" symptoms such as breathy voice or dysphagia, further investigation into the burden of BOTOX treatment and its impact on psychosocial outcomes has rarely been reported. However, models that include the burden of treatment in outcome measurement exist elsewhere in the health-care literature. For example, Devins et al⁴³ explored "illness intrusiveness" and its role in determining the psychosocial impact of chronic conditions, including laryngectomy. Devins et al⁴³ defines "illness intrusiveness" as the extent to which the illness or its treatment interfere with important facets of a patient's life, such as involvement in valued activities.^{44,45} According to this definition, illness intrusiveness reflects not only the burden of the health condition, but also the burden of treatment. Future research into psychosocial outcome measurement for SD and BOTOX should include consideration of the burden of treatment. It may lead to better understanding of patient satisfaction with treatment as well as to better strategies for minimizing the burden of treatment to further improve patient satisfaction.

Decision-making evaluations

Participants in this study gave many examples of how they took an active role in planning their treatment and in maximizing their success. The most common example was scheduling their injections around their individual priorities such as occupational demands, social activities, or fear of the injection. Other strategies participants used, particularly at the beginning and end

of cycles when their voices were not at their best, included using voice therapy techniques, adopting positive coping attitudes, and modifying communicative participation. These strategies seemed to improve the psychosocial outcomes of participants by giving them some control over their treatment and its outcomes.

These examples suggest that the participants valued having an active role in their treatment. Five participants spoke positively of having their opinions regarding treatment recognized and respected by the voice team. Even the one participant (H.T.) who reported that she was generally content to leave the decisions to the physician said that she did want to have a better understanding of the changes the voice team made in her treatment. The desire of participants to be engaged in treatment planning supports a shared decision-making model in which health-care providers and patients jointly share the responsibility for determining the course of health-care interventions.⁴⁶ In shared decision-making models, clinicians provide education about treatment options and recommend the options they feel would be most appropriate. Patients are encouraged to express their preferences regarding treatment, and the final decision is a consensus between clinicians and patients.

Joint decision-making is important because prior studies in other health-care arenas have suggested that patients use different information than healthcare professionals in considering treatment options. For example, although professionals might be more interested in data from research studies and other technical sources of information, patients are likely to be more interested in how treatment is going to affect them personally.^{46–48} The current study supports these findings because the participants reported that it was their physical, personal, and social experiences with SD that shaped their satisfaction with past treatment and decisions for future treatment. One objective for future research is to explore how information that patients bring to the clinic about their psychosocial experiences can be documented in outcome measurement and treatment planning in a meaningful yet practical way.

CONCLUSIONS

This study has identified several psychosocial consequences of BOTOX injections that seem to be important for understanding how patients judge the success of their BOTOX treatment, and how they make decisions about future injections. Future research is needed to explore these issues in larger numbers of participants, and in different participant sub-groups such as different types of SD, voice use demands, and other demographic or functional variables. The long-term goal is for this research to lead to psychosocial outcome measurements that are useful in treatment decision making because the information in them is specific, relevant, and meaningful to both patients and clinicians.

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TABLE 1

Participant Demographic Information

Case	Age (yrs)	Gender	Occupation	Primary Voice Demands	Type of SD	No Years Post First Injection*	No. of Injections [†]	Voice at Interview [‡]
I.P.	49	F	Not working (unrelated to voice)	Social/volunteer work	ADSD	8	19	7–8
B.W.	53	F	Technical writer	Work	ADSD	7	22	8
A.T.	59	F	Substitute elementary teacher	Work/community groups	ABSD	6	12	8
M.A.	57	M	Small business owner/professional	Work/social	ADSD	7	19	6–7
H.T.	80	F	Retired	Social/volunteer work	ADSD and tremor [§]	6	31	5
J.R.N.	52	F	Nurse	Work/social	ADSD and tremor	6	23	7–8

Abbreviations: ADSD, adductor SD; ABSD, abductor SD.

*Number of years that each participant has been receiving BOTOX injections.

†Total number of BOTOX injections that each participant has received.

‡Participants were asked to rate their voices on the day of interview on a scale with 1 = the worst the voice has been and 10 = the best the voice has been since onset of SD.

§Participant had familial head tremor in addition to voice tremor.

TABLE 2

Themes, Sub-themes, and Definitions

Theme	Sub-themes	Definitions
My experiences with BOTOX change over time	Learning the ropes with BOTOX	Learning about SD and BOTOX and adjusting to the first few injections
	Looking ahead	Thoughts about long-term use of BOTOX and anticipation of future decisions
BOTOX has changed my life in different ways (the effects of BOTOX are multidimensional)	BOTOX has relieved my physical symptoms	How BOTOX has affected physical symptoms of voice quality, effort, and voice dependability
	BOTOX has changed how I feel about myself	How BOTOX has affected personal issues of affect, self-view, and coping
	BOTOX has changed how I interact in the world around me	How BOTOX has affected social issues such as participation in physical and social environments
Figuring out what works for me	Weighing the burden of treatment	Disadvantages of BOTOX such as the injection experience, the logistics, and the temporary effects (cyclic nature)
	Getting the most from BOTOX	Strategies to optimize the response to BOTOX
	Making decisions with the voice team in the clinic	Clinic evaluations could be more individualized and personalized