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# A grounded theory of illness representation among musicians with embouchure dystonia/syndrome

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Musician's Task-Specific Focal Dystonia (MD) is a neurological disorder that disrupts highly trained performance-specific motor programs. Among brass and wind players, the embouchure subtype (Embouchure Dystonia, ED) affects the orofacial musculature, often with career-ending consequences. Little is known about how illness representations influence therapeutic decision-making in this group. To address this gap, we conducted a constructivist grounded theory study using in-depth, semi-structured interviews with 14 brass and woodwind musicians experiencing embouchure-related dysfunction (here referred to as Embouchure Syndrome, ES) to explore cognitive, emotional, and cultural components of illness representation through the lens of Leventhal's Common-Sense Model. Participants described conflicting explanations of symptoms, embodied struggles with tension and control, destabilized identities, and systemic and social barriers to care. Taken together, these accounts formed a theoretical construction wherein musicians oscillate between competing causal models, frame their symptoms along a mind-body continuum, and seek to manage cycles of tension and relaxation within an environment of redefinition of self and with variable opportunities for disclosure and treatment. We suggest that musicians' conception of symptoms influences receptivity to both biomedical and rehabilitative strategies. These findings highlight the need for communication strategies that align with patient illness representation and understanding, for interdisciplinary care models, and for diagnostic framing that accounts for the lived experience of ES and other forms of Musician's Dystonia.

## KEYWORDS

dystonia, embouchure, embouchure syndrome, grounded theory, illness representation

## Introduction

Musicians' Task-Specific Focal Dystonia (MD) is a neurological disorder that causes excessive and inappropriate muscle activation during the execution of musical movements [1]. As a subtype of Dystonia, MD typically affects only the specific movements and muscles that have undergone extensive technical training during the practice and performance of high-level musicianship [2]. Among brass and wind musicians, MD can involve the highly-trained muscles of the oropharyngeal and facial musculature (the "embouchure"), causing symptoms of tremor, lip pulling, and forced jaw closure or opening [3, 4], classified as Embouchure Dystonia (ED) in these cases. Sustained benefit from medical treatment of ED is rare [5], and neuro-rehabilitative strategies are limited. However, neuroimaging studies of ED have revealed differences in somatosensory, motor, and premotor cortical structure and function [6–8], and contemporary models of pathogenesis emphasize maladaptive motor cortex plasticity [9]. This suggests that ED should be amenable to treatment and recovery.

In line with this possibility, many musicians diagnosed with ED report earlier experiences of transient "embouchure problems" that disrupted performance [3]. Survey data of orchestral brass players indicate that such symptoms are relatively common, though only a subset progress to frank dystonia [10]. These findings have been interpreted as evidence for a *continuum of motor dysfunction*, evolving from stress-related performance breakdown (e.g., "choking under pressure") to maladaptive compensations ("dynamic stereotypes") and eventually to the patterned, involuntary movements of dystonia [11]. For the purposes of the present study, we use the term "Embouchure Syndrome" (ES) as a descriptive umbrella referring to musicians' experiences across this continuum of embouchure-related motor dysfunction. This terminology supports examination of illness representation across different points in the clinical trajectory, rather than redefining established diagnostic criteria for ED."

The absence of objective biomarkers, together with the difficulty of interpreting symptoms during their early or evolving stages, often leaves musicians attempting to understand their condition before a stable diagnostic formulation is established. In this context, personal interpretations of illness play a central role in directing treatment choices.

Explanatory models of illness can be useful in understanding the behaviors and coping strategies of illness sufferers. Leventhal's Common Sense Model (CSM) [12, 13] explores how both cognitive representations of illness (i.e., causes, consequences, timeline/acuity, degree of control), and emotional responses determine coping strategies. The CSM has also been successfully deployed to design behavioral interventions that improve health outcomes in chronic [14] and acute [15] disease.

Qualitative research is essential for reconstructing components of the CSM, yet its application to MD has been limited. A prior interview-based study of musicians with MD used thematic analysis, identifying common experiences such as secrecy and shame, trauma, and negative interactions with healthcare providers [16]. Two additional studies have examined causative and predisposing factors [17, 18] for MD. Only one study, focusing on two pianists with MD, has specifically explored illness understanding, highlighting social, physical, and psychological factors influencing treatment strategies [19]. Notably, no qualitative research has focused on subjects with ES.

This study investigates how musicians with Embouchure Syndrome (ES) make sense of their condition and how their explanatory models shape treatment decisions, coping strategies, and clinical engagement. By situating these findings within a landscape in which early diagnostic formulation may be evolving, and where autonomy, therapeutic alignment, and uncertainty about prognosis and management shape decision-making, we aim to illuminate the lived experience of ES and its implications for clinical care. Using the CSM as a guiding framework, we explore the cognitive, emotional, and cultural components of illness representation through in-depth, semi-structured interviews and constructivist grounded theory methodology. What emerges is a narrative arc – from early confusion, through a prolonged negotiation of physical disruption and emotional dissonance that is shaped by internal and external dynamics and fragmented care pathways – that forms a theory of adaptive coping responses among musicians with ES.

## Methods

### General design, sampling/recruitment, and saturation

This was a constructivist, grounded theory, semi-structured interview-based qualitative study. The SRQR checklist was used to ensure the study conformed to accepted reporting standards<sup>1</sup>, [Supplementary Material 1](#). Ethical approval for the study was obtained from the University of California Institutional Review Board.

We identified and recruited participants through both purposive sampling and snowball sampling. We initially used purposive sampling to recruit interview participants with a known history of ES from professional and community contacts of one of the authors (G.R.). To maintain anonymity, the nature of these contacts is not detailed but may include first or second-degree colleagues, students/teachers, friends,

<sup>1</sup> <https://www.equator-network.org/reporting-guidelines/srqr/>

professional society/organizational contacts, or community members (also see *Reflexivity*) below. Snowball sampling was then used to recruit additional participants based on recommendations from prior interviewees. Theoretical sampling was also used to explore perspectives from musicians with outcomes that differed from those of the early subjects, from non-professional musicians, and from musicians with different social contexts within the orchestra. We also theoretically sampled to ensure sufficient representation of men and women, and several “classes” of instruments, because early interviews suggested to us that these factors might influence illness experience and coping strategies. The final sample is reflective of the intended diversity of professional status, gender, and instrument, as was suggested by the initial analysis. After analysis of 14 sequential interview transcripts, the emergence of new concepts began to taper and no new conceptual categories were identified [20, 21]. At this point, two authors (M.Z., X.M.) determined theoretical saturation had occurred and no further recruitment was performed.

## Interview guide

An initial interview guide was constructed to ensure coverage of topical areas of interest ([Supplementary Material 2](#)). This interview guide went through substantial revision following the third interview to more closely align the structure of the interview guide with the CSM framework in order to focus our investigation on questions of illness representation, adaptation, and coping. Minor iterative refinement continued as interviews progressed (question phrasing and ordering), and to explore themes revealed by the initial interviews (theoretical sampling, e.g., orchestral and sectional social relationships and trust; significant life events; questions of early identity formation).

The interviews lasted between 60–90 min. Before initiating an interview, participants were informed of the purpose of the study and assured the protection of their anonymity and confidentiality. Verbal informed consent was obtained from all interviewees. The interviews were conducted via Zoom (Zoom Video Communications, Inc). Meeting audio/video was recorded locally. Each interview was conducted by two to three members of the research team, with one member leading the interview and the other(s) co-leading and taking analytical notes. The interviewer began with prepared topical questions, then used flexible probes to follow up on subtopics or concepts introduced by participants (e.g., How did this [event, interaction] shape your later approach to seeking out a treatment?) and encouraged elaboration beyond the scope of the structured interview guide using open-ended follow-up questions (e.g., ‘tell me more’, ‘can you offer an example?’). This approach was designed to elicit rich, participant-driven narratives and to surface unanticipated perspectives. Following the interview,

videos were transcribed (Alpha-Dogs Transcriptions, Inc.) word-for-word (omitting hesitations or filler words). Post-interview memos were obtained by one author (X.M.) detailing setting, participant affect, thematically-illustrative quotes, and concepts for further exploration.

## Coding and theoretical construction

All coding was performed in Atlas.ti (Lumivero, LLC) Open coding was first performed on each resultant interview transcript by assigning preliminary gerundial codes to segments of data within the interview. Open codes from each researcher’s analysis were compared in order to identify recurrent concepts, categories, and themes within the interview data.

Open codes capturing similar content were grouped, and a distinct, overarching axial code was created to encompass groupings of open codes. The assembled list of axial codes was used to generate a codebook ([Supplementary Material 3](#)). Each interview transcript was then line-by-line coded using the axial codes. Each transcript was separately coded by two authors. ATLAS.ti was used to summarize the overlapping patterns and code co-occurrences that arose during axial coding. Memos were then drafted to document interpretive insights emerging from axial codes and the ways in which these codes appeared in relation to one another across narratives. Observed recurrences were treated as heuristic guides for theory development rather than as quantitative indicators. Memos consisted of short statements grounded in quotations from the interview data. Memos were then related to one another and grouped according to content. The organization of these higher order memo groupings was then used to draft a theoretical construction. Because not all musicians with ES ultimately receive a formal neurological diagnosis, we anticipated variation in diagnostic status within the sample. During coding and memo development, we therefore remained attentive to whether participants with and without formal diagnoses of ED articulated different causal beliefs, emotional responses, or treatment pathways.

## Reflexivity

The research team comprised members with varying degrees of insider knowledge and personal proximity to the topic. X.M. is a neurologist and lifelong horn player with clinical and research expertise in musician’s neurological disorders. G.R. is a professional horn player with lived experience of ES, including recovery through therapeutic approaches referenced by several participants. X.M., B.A., and G.R. contributed to the conceptual framing of the study and co-developed the interview guide. G.R. also recruited from his professional contacts (see above). His participation in the interviews was appreciated to potentially affect the responses of interviewees, however also allowed a fluid approach to interviewing that appreciated

TABLE 1 Participant demographics.

Subject pseudonym	Gender	Primary instrument	Professional status	Formal dystonia diagnosis
Logan	M	Trumpet	Professional	No
Harley	F	French horn	Professional	Yes
Max	M	French horn	Professional	Yes
Eden	M	Trumpet	Professional	No
Charlie	F	Oboe	Professional	No
Ollie	M	French horn	Amateur	No
Blair	M	Trumpet	Professional	No
Francis	M	French horn	Professional	Yes
Kelly	M	Tuba	Professional	Yes
Alex	M	French horn	Professional	Yes
Pat	F	Bassoon	Professional	Yes
Jordan	F	Trombone	Professional	No
Darcy	F	French horn	Professional	Yes
Gerry	F	Flute	Professional	No

subtleties in response not seen by the other authors. For participants with the closest ties to G.R., X.M. therefore led the interviews with follow-up or probing questions by G.R. M.Z., a medical student and former bassoonist, conducted several interviews and co-led data coding but was not involved in study design. This allowed him to contribute analytic perspective while maintaining distance from the underlying research framework. The interview guide was reviewed by a qualitative methods consultant prior to data collection (R.C.C.). Coding was conducted collaboratively by M.Z. and X.M., with iterative discussion to refine categories and resolve discrepancies (G.R., M.Z., X.M.). Participants were recruited by G.R. and M.Z., both of whom had prior professional or educational relationships with some interviewees which may have facilitated trust and disclosure during interviews but could also introduce the possibility of response bias (i.e., avoidance of interpersonally difficult topics). These dynamics were considered during analysis and interpretation; authors coded with reflexivity in mind to ensure that findings were grounded in the full range of participant experiences and interpretations not limited by personal relationships with the authors. Given the stigma associated with ES, social media posting and cold calling were not felt to be efficient or representative methods of recruitment.

## Results

Participant demographics are shown in Table 1. Of our 14 participants, 8 had ongoing symptoms and 6 had recovered

from ES. Of those with ongoing symptoms, 2 were actively playing and 6 were inactive. Of those who had recovered, all had returned to playing. All 14 participants experienced decline in musical capacity necessitating time away from performance. 7 had seen a specialist neurologist and received a formal diagnosis of dystonia. Across interviews, the presence or absence of a formal ED diagnosis did not produce clearly separable explanatory models. We present our findings as a narrative arc reflecting the disruption, embodiment, transformation, and adaptation that characterized participants' journeys. This structure organizes six core categories into a temporal sequence that mirrors how musicians experience ES over time.

## The initial disruption of embouchure syndrome

### Dissonant beliefs

Participants experienced conflicting beliefs regarding their relationship with their instrument, etiology of symptoms, and treatment strategy. Most interviewees endorsed self-disparaging beliefs when playing their instrument after the onset of symptoms, often accompanied by depersonalization, even as they sought to regain a sense of control through practice and self-motivation.

“But it just felt like it was not me playing the horn. It was like somebody else.” - “Alex,” Horn Player

Our participants expressed multifactorial/polycausal theories of their symptoms and often expressed confusion about a root cause or origin:

“The moving pieces [multiple causes] were isolated practice without playing with other musicians, having the technical problems with the instrument, [and] compensating without knowing . . . On top of that, [this time period] was probably one of the most stressful periods of my life . . . I don’t know how much that contributed to it, but I believe it must have been something.” - “Blair,” Trumpet Player

Here the interviewee places blame on their physical environment, their instrument, their own behaviors, and their external stressors without specifying if one factor or the sum of all factors brought about their symptoms.

Interviewees often perceived a fundamental misalignment between their personal experiences of illness and the frameworks used by clinicians to interpret those symptoms:

“In retrospect, I think I should have trusted my gut. I feel like it was a misdiagnosis in my case, honestly, I really do. I’m not a medical doctor, I don’t have that kind of perspective, but I know myself, and I know how things have been since that time.” - “Charlie,” Oboe Player

Charlie expresses that his beliefs differed from those of the treating specialist but that he still heeded the provider’s recommendations, thereby simultaneously trusting and distrusting. Over time his illness understanding changes, and his recounting of this initial diagnostic interaction reflects this evolution.

## Embodied crisis: the physical and psychological burden

### Mind body continuum

Participants shared a common understanding that the physical and mental could not be separated in regard to their conception of their ES symptoms, reflecting that musicians understood their symptoms along a continuum of mind-body explanations:

“I understand that there is mental and physical, but my brain is in my body. And it is physical. The brain, it’s an actual physical thing. So I don’t really give into the physical or mental thing.” - “Eden,” Trumpet Player

Participants reported experiencing a disconnection between the mental and physical aspects of playing. Some subjects also identified psychological and physical maneuvers that could restore proper communication between mind and body (some

of which were suggestive of the *sensory trick* characteristic of dystonia) although the duration of benefit varied widely from case to case.

“. . . anytime [the mouthpiece] feels different physically on the face, that normally helps me for maybe a week or two . . . But then as soon as that starts to feel familiar or if things naturally shift back, then [the benefit] goes away again. Also setting my brain to a different place, so literally thinking very strongly something different while I’m playing, also helps for a period of a week or two. But then that [benefit] also invariably just starts to collapse.” - “Francis,” Horn Player

A musician’s decision-making about therapeutic options was often guided by the conception of symptoms along the mental/physical continuum:

“. . . I think it was actually just a buildup of tightness and tension . . . I think it was injured in that it wasn’t working properly . . . and you’re like, all right, something’s clearly not working here, I’ll go to the dentist, see if something’s there. And then from there . . . well, try chiropractic, try physio . . .” - “Gerry,” Flute Player

One participant felt synergistic relief from mind/body tactics – physical exercises helped to ground the mind and reduce mental symptoms:

“Again, the physical/mental - it helped me physically to understand what my issues were, what I can work on . . . actual physical things: do this, do this - you know, ‘exercises’ - that was very helpful. Also, the having answers and actually having things to be able to do to see benefits from was extremely mentally helpful for me. Knowing that I’m gonna wake up, I’m gonna work on this . . .” - “Eden,” Trumpet Player

The direction of this synergistic relief varied: isolating physical symptoms sometimes helped soothe some players’ mental state, while beginning with psychological concerns eased physical symptoms for others:

“I have friends who went and nothing worked. So I was like I will not go to that path, I will try something else. And I went to see him [psychologist] and he asked me a lot of question about my life and my youth and the way I am, the way I think, all my psychological setting, and all my traumas also. And I was sure everything was related to that, in my case.” - “Darcy,” Horn Player

Here, the subject emphasizes the prominent influence of psychological background on the development of ES, and

consequently the subject pursued psychological therapies to improve their physical symptoms.

### Tension/relaxation

Musicians suffering with ES often experience both physical and psychological tension with the concurrent desire to relax that tension. Players often expressed this non-dualistically, consistent with their conception of the mind-body continuum:

“... I really think that physical tension is really anathema, really the enemy of healing any kind of embouchure dysfunction. And desperation begets tension. So I’m trying to find a way of being less desperate.” - “Harley,” Horn Player

“I think the genesis of all of this happening for me was that I have a lot of anxiety and stress, which would kind of manifest in my body as tension. And I think that’s what contributed to the dystonia.” - Bassoon Player

Multiple subjects identified external sources of stress that coincided with symptom onset or worsening, such as marriage, having children, the COVID-19 pandemic, and changes in the home.

“Yeah, it was during the pandemic. I was building a house, or rebuilding a house, should say. It was a massive project. Of course [I] had no real outlet for playing other than just keeping sort of the daily playing as much as possible, but really bare minimum... So there wasn’t any interaction with other musicians, which was a thing to itself.” - “Blair,” Trumpet Player

Participants offered various approaches to mitigate tension. Often these involved modifying expectations in their playing and their relationship with their instrument.

“I’ve learned to accept a different standard in my playing, in a way, to go a little bit easier on myself.” - “Harley,” Horn Player

Some interviewees conveyed that “letting go” of tension and fear functioned as an effective coping/therapeutic strategy.

“I was still shaking [referring to lip tremor]. It was less shaking, I could control – I don’t like that word control – maybe appease myself... I really think when we control things in life, it’s because there’s fear. And fear, it’s my enemy. So because I learned to appease my state, I started to practice that in the orchestra.” - “Darcy,” Horn Player

Here the word “appease” was explained as *to sooth*, or *to resolve* through abandoning the fear of failure. Thus, through acceptance of symptoms, this participant reported being able to regain some psychological strength and confidence. Likewise, several additional participants begin to mitigate their emotional turmoil and entertain a path to recovery by accepting their symptoms and current musical output.

Multiple respondents found benefit from adopting a relaxed pace of work and practice or even time away from work which was distinguished from simply taking time away from the instrument:

“If we have a week off or over the summer months, if I have some momentum in my practicing, I feel like I’ve gotten my playing to borderline resilient, like it could handle some pressure.” - “Eden,” Trumpet Player

### Shifting ground: identity in transition

#### Changes in identity

ES threatened participants’ sense of self, as musical identity had become deeply intertwined with personal identity over a lifetime of training and performance. Changes to this core identity were of paramount importance to the sense-making process of ES symptoms, and our participants expressed deep suffering in accommodating this change:

“Like when you’re in this life, it kinda feels like that’s what your everything is” - “Francis,” Horn Player

“And I think what we do as musicians maybe goes to our self-worth a lot, you know, what we are is what we do.” - “Eden,” Trumpet Player

Several interviewees described perceiving their earliest musical development as intuitive, spontaneous, or even effortless – a self-concept that became deeply embedded in musical identity. The disruption of this perceived “natural” ability intensified the experience of ES as a fracture of identity:

“By the time I was in high school, I had a pretty picture-perfect embouchure. But I never thought that hard about it. I was a very, very expression forward player. I didn’t think that hard about production. I found that sound quality and sound production in general came very easy to me as a young player, like it was pretty second nature... I just kind of had a pretty natural approach.” - “Alex,” Horn Player

Loss of identity was often associated with feelings of hopelessness that prompted the desperate pursuit of multiple therapies and changes in practice habits as symptoms began to manifest:

“INTERVIEWER: *What led you to see these various people?*  
SUBJECT: *Well, there’s nothing else that I want to do in my life. I want to be a trombone player. So what led me to see them was just doing whatever it takes to be able to keep doing that.* - “Jordan,” Trombone Player

“Well, when I’m at home practicing, I kind of sigh to myself internally, oh, here it comes again, maybe I should just stop practicing now instead of trying to work my way around it. But then I don’t know, maybe my work ethic kicks in and I try to work my way through it. And then I just keep getting more and more frustrated.” - “Kelly,” Tuba Player

## Navigating an unsupportive landscape

### Systems

Participants reported a lack of support from several overarching systems, including the musical education system, workplace human resource systems, and healthcare systems.

Musicians experienced a lack of education regarding embouchure problems, especially related to manifestation of ES and its management:

“*No teacher I ever studied with or spoke to ever talked about these things.*” - “Eden,” Trumpet Player

Participants often proposed more research and pedagogy on ES as a way to eliminate the social stigma surrounding the condition:

“If there was more of a codified understanding of this condition that could be taught at an early age in school, and then it wasn’t so taboo. I think it’s getting better, but yeah I wish that people didn’t feel bad talking about it publicly.” - “Alex,” Horn Player

Once graduated and in the workforce, our subjects reported ongoing workplace stigma around ES that infected workplace systems. Our participants were rarely or never informed of resources available to them, and often reported the need to acquire a formal diagnosis to obtain workplace support:

And so it’s just like, next, like you don’t think about it, no one talks about it. And I think it should be normalized to a level where at least if someone’s having an issue, they know an entry point where they can start and where they can go would be, so they’re not just flying blind. - “Gerry,” Flute Player

“Focal dystonia, like if you hear that label, it sends shivers down your spine, but it also makes it sound really serious . . . it does give you a good diagnosis to be able to say I have this medical problem, I can’t play on the instrument anymore . . . if you are gonna end up going on disability, then having an actual medical label I think is really helpful.” - “Francis,” Horn Player

The short supply of providers, limited recognition and financial coverage by insurance agencies, and variability in the clinical management of ES indicate an inadequate system for musicians’ care. First, our subjects rarely knew how to find a provider to diagnose ES. Upon identifying one, they then had to consider financial feasibility, insurance eligibility, and most commonly very limited provider qualifications before proceeding with a treatment or management plan.

“And so again, this was sort of the point where it was like okay what practitioners do I even see? So I went first to urgent care ‘cause I wasn’t really having luck getting into places like regularly, just to see if they could see anything. And they basically told me to get Botox in my jaw. And I said, well, if I do that, then I might not be able to play the flute. And they were basically like, well yeah, you might not be able to play the flute again and that’s just life. [LAUGHS] So I freaked out.” - “Gerry,” Flute Player

Some musicians were able to identify a provider with expertise in MD or ES, but often this was complicated by long wait times for an initial consultation, requiring players to search elsewhere:

“So some people said, okay, well, Dr. [redacted], you’ve got to go see him, not only is he covered under . . . our [redacted] health insurance . . . he has worked with training musicians for injuries . . . His whole purpose of the clinic was to treat injured musicians. So I thought, okay, perfect, he has seen all this stuff before, he knows what to do. At the very least, he’s a good starting point.” - “Charlie,” Oboe Player

“It’s so difficult to see a neurologist. I would have wait maybe two years. So I was like, ah, okay, I have friends who went and nothing worked. So I was like I will not go to that path, I will try something else.” - “Darcy,” Horn Player

### Social dynamics

Participants often reported challenges in managing social dynamics and perceptions within the orchestra, including elements of adherence to professional orchestral etiquette: technical mastery, emotional regulation, and unspoken orchestral hierarchy. Musicians with ES also reported facing

social pressures in obtaining treatment and in the patient-provider relationship.

Players described an isolating workplace atmosphere where colleagues do not discuss ES symptoms, how to cope, or where to seek help:

So it's kind of this thing of it's a fend for yourself culture, I would say, except then when you might talk to individual musicians, I discovered that a lot of them had dealt with things in the past, and they have people to go to. - "Gerry," Flute Player.

However, in many cases our participants reported more support from members of their section (fellow players of the same instrument). Interviewees also revealed a deeper connection to their section and, consequently, greater trust:

"En Francais - 'entraide': we have each other, that kind of thing. So we helped so much someone else, so I didn't feel bad to ask for help. It was my turn, you know. Maybe it's going to be someone else and we understand it's not about the performance that much. So if we have each other, it's still the notes and it's still the music. So I felt very free to tell them when I was feeling bad, insecure, and I need help. So they were there for me. So that was very, very helpful." - "Darcy," Horn Player

Here, section members have mutual expectation to help and seek help from the fellow members within the section. Because of this intra-sectional intimacy and commonality, ES sufferers often began their search for help with these colleagues first. This often took the form of counselling, technical suggestions, or offers to cover difficult passages or take on other musical responsibilities.

Participants often described a negative social dynamic with their conductor, often provoked by changes in performance, and which exacerbated anxiety and stigmatization:

"And we had this conductor who was pretty rude. And I don't normally react to conductors who are difficult, but this one in particular was very difficult. And I felt like I was sort of the target of him . . ." - "Gerry," Flute Player

"The conductor is also like right where my bell is. So this would be kind of a sketchy situation under the best of times. And I remember right off the bat you're on the high A, and it's a piano entry, I think. And I couldn't do it. I couldn't do it. It was not consistent. I was missing 50 percent of it. So conductor turns to me and said, 'leave it out', which I don't think I've ever experienced that in my life, right. So that was terrible. And I couldn't explain why. I just was like . . . yes, yes, sir." - "Blair," Trumpet Player

Outside of the orchestra, subjects reported difficult social dynamics with clinical practitioners, often upon establishing new care relationships. Some subjects even adopted treatment recommendations to prioritize a solid patient-provider relationship given the sparse availability of clinicians:

"I said, 'I'm not saying that this isn't a factor, but I don't think that's what's happening in my particular case, personally.' But I thought, okay, you know, he's the doctor . . . I'm gonna keep doing what he's saying." - "Charlie," Oboe Player

Conflicted social dynamics also arose when different providers offered conflicting advice. Subjects reported the need to act diplomatically, manage their providers emotions, or convey respect and deference in order to maintain the relationship. This was necessitated by the perceived paucity of expertise:

If I had kept going with [Expert A], the other problem was that her method and [Expert B]'s method they didn't work well together, so you had to kinda choose one or the other. And eventually, because I had had success with [Expert B] in the past, I decided okay, maybe I should go with what I know and just come back to [Expert A] later. So I let [Expert A] know, I said, listen, the two methods are fighting with each other a little bit, and I feel like I'm actually stuck because I'm not going forward in either direction. So if you don't mind, I think I'm gonna keep going the other way and I'll let you know how it goes." - "Alex," Horn Player.

## Discussion

Our analysis identified six core domains that reflect how musicians with ES construct and respond to their illness experience. Interpreted through the CSM, these domains span all levels of illness representation. At the level of socio-cultural context, participants described systemic gaps in education, healthcare access, and workplace accommodations (*Systems*), as well as entrenched norms of silence, stigma, and emotional regulation within orchestral culture (*Social Dynamics*). These contextual forces interacted with the self-system, including traits such as perfectionism, early musical identity formation, and internalized performance values. Cognitive illness representations were characterized by *Dissonant Beliefs* about causality, chronicity, and control, often in relation to experiences of *Tension/Relaxation* and the *Mind-Body Continuum*. Emotional representations encompassed *Tension/Relaxation* as both a symptom and a psychological response, frequently provoked by *Dissonant Beliefs* and compounded by a destabilized sense of self rooted in *Changes in Identity*. In response, participants engaged in diverse coping procedures and coping appraisals which were rooted in all six of our core

TABLE 2 Translational implications of illness representation in subjects with ES.

Core domain	Influence and effect	Recommendations for clinical care
Dissonant beliefs	Uncertainty, cycling between therapies, fragile trust	Clarify patient’s understanding of symptom causation, compare it with the neurologic assessment, and <i>establish a shared symptom explanatory framework</i> prior to initiating treatment to optimize adherence
Mind–Body continuum	Determined which providers were sought and which treatments felt credible	<i>Explain how neural dysfunction interacts</i> with stress, attention, and learned motor behavior; avoid strict organic–psychological dichotomies; <i>incorporate behavioral or psychological expertise</i> when indicated
Tension/Relaxation	Relief strategies evaluated based on perceived mitigation of tensions	<i>Reduce maladaptive strategies</i> and performance arousal; <i>define success through incremental functional gains</i> and improved self-regulation rather than cure
Changes in identity	Motivated urgency/desperation and drove emotional coping	<i>Explicitly recognize threats to professional identity</i> ; normalize adaptation; open early dialogue about role modification, career sustainability, and long-term planning
Systems	Delayed care, reliance on informal networks	<i>Establish care pathways and referral networks</i> ; proactively address access barriers; and <i>document to support occupational disability accommodations</i>
Social dynamics	Influenced willingness to seek help and persist with therapy	Recognize stigma; guide patients in decisions about disclosure; <i>welcome trusted peer or sectional support</i> to clinic to reduce isolation and facilitate coping

categories. Below we outline this CSM-informed structure, framing ES as a multi-causal illness shaped by a dynamic process of sense-making. Within each section we offer suggestions for improving clinical communication and intervention strategies tailored to ES diagnosis, treatment, and professional support, which to this point have often been woefully inadequate (Table 2) [16]. Figure 1 offers a theoretical synthesis of how participants related these domains within their narratives; the connections are interpretive and are not meant to imply uniform or directly causal effects.

### The self and socio-cultural context

Our finding of the centrality of *Changes in Identity* to ES aligns with a substantial literature on chronic illness, particularly Charmaz’s foundational work on identity disruption [22]. Participants described a fusion of self with their musical role that began in early childhood and was reinforced by traits such as perfectionism and sensitivity - features previously reported in musicians with dystonia [17, 19]. The “natural player” theme, common across interviews, conveyed an early, intuitive connection to musical tone and expression. This stands in contrast to pedagogical traditions which emphasize technique [17]. For brass and wind players, the pedagogy of embouchure development may play a role here: instruction typically relies on aural feedback rather than visual or tactile cues about musculature and form.

Clinicians and scientists have reinforced and propagated ideas around the centrality of musical identity, especially traits such as perfectionism [18, 19], and premonitory anxiety, neuroticism, and sensitivity [23, 24] as risk factors for MD. An important question for future research is therefore how providers should approach conversations around changes in

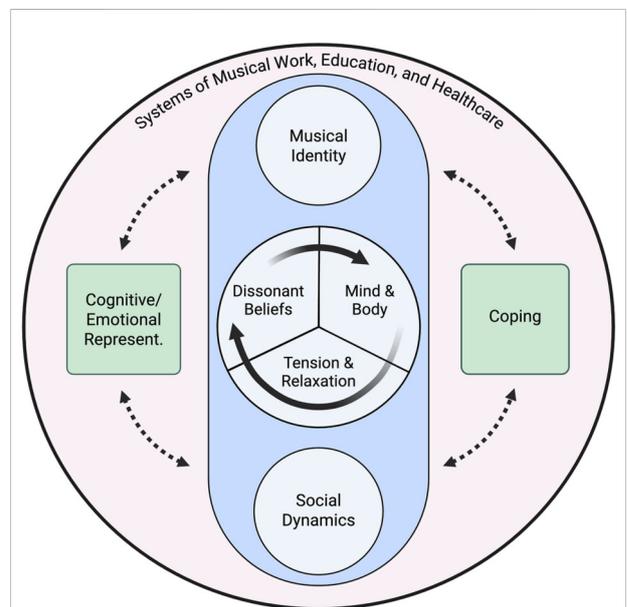


FIGURE 1 Theoretical model of how components of illness representation relate to coping (including therapeutic decision-making) among musicians with Embouchure Syndrome (ES). The three more internalized, psychologically grounded categories (Mind–Body Continuum, Tension/Relaxation, and Dissonant Beliefs) are depicted as interlocking segments of a whole, while the remaining two - Changes in Identity and Social Dynamics—are positioned separately to reflect their emphasis on selfhood in a social context. Arrows represent interpretive relationships derived from participants’ narratives rather than direct causal pathways and are intended as a theoretical heuristic to illustrate how core domains interact in shaping illness understanding. All are embedded within the broader context of Systems.

identity: de-emphasizing the importance of perfectionism versus normalizing change and encouraging adaptation and coping. Qualitative analyses of ES treatments could focus on

identity-reformation, and thereby improve understanding of how to guide musicians through these transitions.

This self-system exists within a broader socio-cultural context that shapes the interpretation and management of ES symptoms. Because of the ensemble nature of orchestral performance, social dynamics often shape how musicians with ES navigate their condition. The importance of perfection in performance was a recurring theme, and participants described feeling scrutinized by both colleagues and conductors. The combination of high professional expectations and the interdependent structure of ensemble playing creates an environment in which disclosure, adaptation, or inconsistency feel untenable. At the systemic level, our findings highlight a lack of shared understanding, formal education, treatment guidelines, and disability services for embouchure syndrome. Together, culture and systems provide the backdrop against which musicians experience symptoms, seek information, and begin coping.

Social dynamics also interact with identity and self. Subjects projected internal fears onto imagined judgments from colleagues, which often went unspoken and unverified. Some musicians coped by maintaining a sense of agency through preemptive withdrawal. Others, particularly those with stronger intra-sectional support, expressed greater resilience and openness.

These dynamics highlight a key clinical implication: clinicians should recognize that decisions about seeking help are deeply entangled with identity and social positioning. Conversations around ES must therefore validate not only physical symptoms but also the consequences on status, identity, and future within their profession.

## Cognitive and emotional illness representation

The *mind-body continuum* was central to how musicians understood their illness. Many perceived symptoms as a somatic response to psychological stress but struggled to locate their symptoms within any one explanatory model. Notably, individuals often oscillated along this *mind-body continuum* rather than adopting a single explanation, indicating a fluid and context-dependent understanding of causation. This ambiguity mirrors findings in broader chronic illness literature, where causal attributions range from internal and physical to psychological or situational [25]. Clinically, this finding underscores the importance of validating a proposed approach to treatment focusing on both individualized physical and psychological therapy [26].

*Tension/Relaxation* was also key, with many participants attributing their symptoms to excessive physical tension or psychosocial stress while believing that deliberate relaxation could help restore control. These personal causal theories

(e.g., “overuse” or stress-induced strain) intertwine with perceived control strategies (e.g., learning physical or psychological relaxation techniques).

Our participants often held *multiple* conflicting explanations (*Dissonant Beliefs*), generating tension between what they felt, what they believed, and what they were told. This kind of incoherence was especially salient at moments of interaction with the health system. Several subjects described feeling most alienated from their providers during their initial consultations, citing a lack of shared understanding, or insufficient communication and guidance. In contrast, when participants felt that the therapeutic approach aligned with their own explanatory models - particularly when those approaches offered coherent explanations and concrete strategies - they expressed trust and willingness to engage with treatment. These findings echo prior work identifying the diagnostic encounter as a key site of misalignment between patient and provider beliefs [27], and a frequent source of dissatisfaction when poorly communicated [28]. Unsurprisingly then, interventions focused on establishing a shared explanatory model of illness and initiating early education have been shown to improve patient satisfaction [29], therapeutic adherence [30], and even biomarkers relevant to health outcomes [31].

In addition to these cognitive representations of illness, musicians with ES experienced profound emotional responses that were related to *Tension/Relaxation*, *Dissonant Beliefs*, and *Changes in Identity*. Heightened physical tension often carried an affective counterpart, whereas moments of relief or successful relaxation brought emotional calm. Likewise, holding *Dissonant Beliefs* about the illness bred distress: several musicians reported feeling confused, powerless, or even guilty as they oscillated between explanations. Perhaps most striking was the salience of *Changes in Identity*. Subjects experienced emotions akin to mourning the loss of their musical self: depression, demoralization, and social withdrawal; these emotional representations are integral to the illness experience and run parallel to cognitive beliefs [32]. Recognizing this emotional dimension has practical implications: psychological support to address fear, stress, and identity issues should be employed as a core component of comprehensive ES care [26]. This may also enhance patients capacity to re-engage with rehabilitation, ultimately facilitating physical recovery.

## Coping procedures

Vacillating appraisals of ES along the *Mind-Body Continuum* align with the CSM's notion that clear causal and control beliefs guide coping, and therefore a lack of coherence can impede effective self-regulation. In our study, these *dissonant* cognitive representations led participants to experiment with a wide array of coping remedies (therapies). This trial-and-error approach may reflect adaptability, but it also indicates an unmet need for clearer education about ES. Helping patients reconcile or

integrate their beliefs could foster a more consistent coping strategy. For instance, framing ES as a condition with both neurological and psychological dimensions might reduce confusion and empower musicians to pursue integrated management (e.g., physical therapy *and* psychotherapy) with greater confidence. Clinicians should provide explanations that bridge mind-body dualism (e.g., noting that anxiety can exacerbate neurological symptoms) while aligning medical advice with the patient's internal models where possible to improve adherence. Additionally, care models should recognize that musicians often experience fluctuations in symptoms, interpretation, and response to therapy, and should allow movement between approaches without shame.

Participants who engaged in a range of coping behaviors repeatedly reported a sense of instability in their outcomes. This dynamic appeared less related to the particular position a subject adopted on the mind-body continuum, and more to whether a chosen therapy [1] restored a sense of control and [2] mitigated emotional turmoil. Illness representations that emphasize severe consequences and emotional salience - especially if unresolved - can lead to maladaptive coping strategies such as behavioral withdrawal and denial, which are strongly associated with negative emotional outcomes [33]. This pattern reflects a common vicious cycle that our subjects described: trying something, becoming demoralized when it did not cure them, and withdrawing.

Similar dynamics have been documented in patients with chronic fatigue syndrome (CFS). In this population, avoidant coping is common and often leads to reduced physical activity, which in turn exacerbates symptoms. Patients with strongly negative illness beliefs tend to withdraw entirely, while even those with more moderate views frequently remain committed to a rigid physical model of illness which discourages activity and sustains dysfunction. However, studies have shown that this pattern can be disrupted through structured, supported interventions [25]. These are most effective when they enhance patients' sense of control, which is central to adaptive coping. Specifically, individuals who perceive greater control are more likely to engage in active coping strategies - such as seeking support or reinterpreting symptoms - whereas those with low perceived control more often adopt avoidant behaviors.

For musicians with ES, this suggests that clinical strategies should prioritize restoring a sense of control to ensure active engagement, even if recovery is incomplete. Supporting identity reformation, reframing therapy as goal-aligned, and offering space for gradual reappraisal may enhance adherence.

A lingering question in our study is whether musicians' beliefs about the cause of their condition guide their therapeutic decisions, or whether those therapeutic decisions, once undertaken, reshape their beliefs over time. That is, do individuals select treatments that align with their existing explanatory models, or do they adopt the frameworks offered by clinicians and practitioners they come to trust?

This bidirectional chicken-or-egg dynamic may not have a clear answer. However, parallels in chronic HIV care offer insight: in that context, improved adherence to treatment often followed a psychological shift in which patients accepted their illness identity, moved beyond denial, and transitioned from externally imposed compliance to internally motivated engagement, (characterized by autonomy and alignment with personal values) [34]. Thus it may be that the alignment between illness representation and internal motivation—rather than the specific explanatory models of patient and clinician—is most critical for sustained engagement and recovery.

Interventions for ES may therefore benefit from approaches that emphasize internal motivational alignment over prescriptive instruction. Rather than simply instructing patients to follow a particular therapy, clinicians should aim to build an illness narrative that reflects the musician's own evolving understanding of their condition. Concrete strategies may include asking patients to describe their current theory of causation, eliciting their goals and priorities, and collaboratively mapping a treatment pathway that integrates both clinical rationale and personal meaning. By fostering internal ownership of the recovery process—rather than passive compliance—clinicians may encourage engagement and support durable rehabilitation outcomes.

## Study limitations

While the CSM offers an empirically supported framework for analyzing how individuals understand illness, it may not fully capture the cultural and interpersonal dimensions of meaning. Future studies of ES could benefit from incorporating alternative frameworks that center these dynamics. For example, Kleinman's explanatory model foregrounds the cultural dimensions of illness and may offer insight into how socially embedded beliefs influence health behavior [35]. Similarly, models such as Social Representation Theory and frameworks proposed by Kirmayer and Sartorius (2007) [36] address the ways in which collective understandings and institutional norms shape illness representation. However, these socially oriented frameworks may be less powerful in modeling individual decision-making within the clinical encounter, where the CSM remains especially useful for guiding tailored, patient-centered interventions.

By nature of its design, our study is not generalizable. In-depth interviews allowed us to capture perceptions and experiences without sacrificing detail. The coding process identified commonalities and trends within interview data to compare how commonly an idea was represented among our data. Still, the small sample size of our study may underestimate the prevalence of less common codes, themes, and concepts. Our sample also included musicians both with and without a formal neurological diagnosis of dystonia. Although we did not observe distinct illness representations between these groups, the study

was not powered to determine whether important differences may emerge in larger or differently sampled populations. Future work should explicitly compare trajectories before and after diagnostic confirmation to better understand how diagnostic labeling may influence coping and treatment engagement.

Snowball sampling likely provided the most substantial bias to this study. Although nearly every voice of brass and woodwind sections was represented, the sampling process yielded a disproportionate number of brass players. Because section-mates could act as preferred confidants after presentation of ES symptoms, the nucleation point for snowball sampling (in this case, a horn player), lead to accumulation of a one type of instrumentalist or concept.

## Data availability statement

The datasets presented in this article are not readily available because of the presence of identifiable information in source data (interview transcripts). Coding-related data (i.e., co-occurrence frequency matrices and similar) is available upon request. Requests to access the datasets should be directed to [xenos.mason@med.usc.edu](mailto:xenos.mason@med.usc.edu).

## Ethics statement

The studies involving humans were approved by University of Southern California Social/Behavioral IRB. The studies were conducted in accordance with the local legislation and institutional requirements. The ethics committee/institutional review board waived the requirement of written informed consent for participation from the participants or the participants' legal guardians/next of kin because of determination of exempt status.

## Author contributions

MZ: Investigation, Analysis, Visualization, Writing (Original Draft). GR: Conceptualization, Investigation, Writing (Review and Editing). RC: Methodology, Analysis, Writing (Review and

Editing). BA: Conceptualization, Methodology, Writing (Review and Editing). XM: Conceptualization, Data Curation, Administration, Investigation, Methodology, Funding, Supervision, Visualization, Writing (Original Draft). All authors contributed to the article and approved the submitted version.

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## Supplementary material

The Supplementary Material for this article can be found online at: <https://www.frontierspartnerships.org/articles/10.3389/dyst.2026.15771/full#supplementary-material>

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