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'I have had to stop singing because I can't take the pain': experiences of voice, ability, and loss in singers with hypermobility spectrum disorders

Abstract

Objective.

This study explored the voice experience, singing ability, and wellbeing of singers diagnosed with Hypermobility Spectrum Disorder (HSD) or hypermobile Ehlers-Danlos Syndrome (h-EDS). (h-EDS)¹.

Study Design.

This was a mixed-method study. A purposive sampling strategy was used. Data were collected via an online survey, using written closed and open-ended questions.

Methods.

273 adults (18 - 60 years) completed the survey. This study focuses on a subset of professionally-trained singers (n=71). Responses elicited information about participants' voice health and function, symptoms of hypermobility, singing experiences and training. Data were analysed using template analysis.

Results.

Many participants reported wide vocal ranges and enjoyment of singing but 74.6% of participants across all age groups experienced voice difficulties. Three common themes were identified: (1) '*My unreliable voice*': The ups and downs; (2) Wider effects of HSD/h-EDS on singers, and (3) Need for acknowledgment and support.

Conclusions.

Voice difficulties and hypermobility-related health conditions affected the participants' abilities to sing and perform; this impacted their professional and personal opportunities, communication, relationships, and wellbeing. Our results indicate that symptoms of voice disorder worsen over time. We suggest practical strategies that singers and training providers could implement to support hypermobile singers. More research is needed to fully understand voice difficulties in singers with HSD/h-EDS and to inform tuition and support.

Key words: Voice, Singing, Ehlers-Danlos Syndrome, Hypermobility Spectrum Disorder, Qualitative study

¹ Abbreviations: AAI (Atlanto-Axial Instability); HCTD (Heritable Connective Tissue Disorder); h-EDS (Hypermobile Ehlers-Danlos Syndrome); HSD (Hypermobility Spectrum Disorder); MCAS/MCAD (Mast cell activation Syndrome/Disorder); POTS (Postural Orthostatic Tachycardia Syndrome); TMJ/TMD (Temporo-Mandibular Joint Disorder)

1.0 Introduction

Joint hypermobility describes a condition in which joints move beyond a typical range of motion.^{1,2} Although hypermobility can be benign, its presence can indicate a heritable connective tissue disorder (HCTD) which affects the cellular structures of ligaments, tendons and tissues.¹⁻³ The HCTD group includes Down Syndrome, Marfan's Syndrome, Hypermobility Spectrum Disorder (HSD), and the Ehlers-Danlos Syndromes (EDS), which has 13 heterogeneous sub-types.⁴ Most of the EDS sub-types are very rare⁵; hypermobile EDS (h-EDS) is more common and forms a continuum with HSD.^{2,4} Although HSD and h-EDS are subtly distinct,⁶ both conditions are associated with a range of musculo-skeletal and system-wide health problems that arise from an underlying collagen disorder.^{2,7} Shared symptoms include joint instability, joint dislocations, partial joint dislocations (subluxations), early osteoarthritis, weak muscles, stretchy and fragile skin, and widespread pain.⁶⁻⁹ Common comorbid conditions include chronic fatigue,^{3,10,11} autonomic disorders, postural orthostatic intolerance (POTS),^{6,12} increased sensitivity to allergens and respiratory problems.^{3,4,6,7,10,12} Both conditions are associated with increased anxiety and with reduced quality of life.^{6,13,14} A recent study in Wales (UK) estimated that 1 in 500 have HSD or h-EDS, with females being disproportionately affected.⁵

Currently, a diagnosis of HSD or h-EDS relies on a patient meeting clinical criteria,^{15,16} including assessment against the Beighton score.¹⁷ It measures movement in nine joints (knees, elbows, little fingers, thumbs to wrist and lower back), with each hypermobile joint adding a point to the score.¹⁷ However, a HCTD can potentially affect any joint and collagen-based tissue in the body,^{3,15} including those of the vocal tract. Previous research of voice function in people with hypermobility disorders is limited to clinical case reports¹⁸⁻²³ and two cohort studies^{24,25} all of which involve people with EDS. Case reports have identified joint problems in the vocal tracts of adults and children with EDS, including subluxation of the hyoid bone,^{18,23} subluxation of the larynx,¹⁹ reduced mobility of the arytenoids²¹ and hypermobility of arytenoids.²² Problems with the structure or functioning of the vocal folds,^{18,20,21} hypotonicity in the larynx and pharynx¹⁸ and oesophagus²⁶ were also reported. Although clinical symptoms can be subtle,¹⁸ research suggests that functional voice and throat problems occur more commonly in EDS than in the general population.^{24,25} These include problems with swallowing,^{23,24} hoarse voice in the absence of infections,²⁵ limited pitch range, easy vocal tiring and difficulties projecting or shouting.²⁴

Compared to the general population, hypermobility may be more prevalent in musicians and performers,²⁷ for whom the condition is both an asset²⁸ and a liability.^{29,30} People with hypermobility disorders may have increased vocal dexterity or vocal range²⁴, which may be advantageous for singers. Although singers are already at risk of dysphonia,³¹ HSD/h-EDS increase the risk of both dysphonia^{21,24} and injury to connective tissues, which are more vulnerable to damage than in the wider population, and can be slow to heal.³² It is important to understand how hypermobility affects singers with these conditions so that appropriate support, management and treatment can be developed. Aside from Meizel's³³ personal account of the loss of her singing voice from the detrimental effects of a hypermobility disorder, we found no studies which examined voice in singers with HSD or h-EDS. As such, there is very little understanding of voice function in singers with hypermobility disorders or how singers with hypermobility are affected by their condition. Therefore, our study aims to (1) explore the experiences of trained singers diagnosed with HSD or h-EDS and (2) identify the ways in which their condition impacts their voice and wellbeing.

1.0 Material and Methods

Data presented in this paper derived from a larger survey of adults with hypermobility spectrum disorder (HSD or h-EDS) that aimed to elicit descriptions of respondents' experiences of using their

voice, both good and bad. This included structured questions and scales, along with open-ended questions. Closed questions enabled the gathering of demographic data and aspects of participant voice function. A purposive sampling strategy was used.³⁴ This article presents the analysis of the responses to the open-ended questions. Principles of the consolidated criteria for reporting qualitative research were followed.³⁵

2.1. Design and setting

Following ethical approval by Bishop Grosseteste University the survey was advertised on the websites and social media sites of the Hypermobility Syndromes Association and Ehlers-Danlos Society. The study was written in English and was designed for an English-speaking demographic. The survey was open to anyone over 18 years who had been diagnosed with a hypermobility spectrum disorder. Data collection took place over a period of 10 weeks (18th September 2020 - 30th November 2020). Interested participants were invited to contact the first author directly. Informed consent was obtained prior to data collection. Participants had an opportunity to ask questions.

2.2. Data analysis and rigour

Written qualitative data was extracted in an excel spreadsheet and analysed using template analysis.³⁶ Original IDs have been recoded to ensure anonymity. Data analysis stages are provided in Appendix A. To ensure trustworthiness, the project followed criteria of credibility, transferability, dependability and confirmability.³⁷ Data were collected from participants with different backgrounds and age (credibility). A genuine understanding and clarification of what was being said by participants was ensured (dependability). Data analysis aligned with principles of rigour and cross-checking; independent input from each researcher was employed. The coding template was developed at meetings of the research team where emergent codes and themes were discussed. A list of themes was generated from these discussions and cross-checked over a 12-week period. Regular reviews were held to assess any new themes which emerged. Anonymised quotations were included in the analysis (confirmability). Participant characteristics are included in Table 1 and findings summarized in Figure 1 (transferability).

3.0 Results

3.1. Participants

The survey was completed by 276 participants **from countries across Europe, America, Africa, and Australasia. Most respondents were from USA (48%) and the UK (22%).** Following initial screening, three inputs were removed: two responses had been completed by under 18-year-olds and one respondent did not have a diagnosis of h-EDS or HSD. 156 (57%) identified as singers, **102 of whom (65.4%) had experienced voice difficulties.** For the present study, participants without formal singing training were excluded. This criterion was intended to minimise the possibility that voice difficulties were the result of inexperience or improper training.

This study presents the experiences of 71 of the 156 participants who identified as singers, and who had trained in one or more singing discipline including classical (67%), theatre or pop (45%), and rock (34%). All but six participants had been singing for at least ten years; three had at least two years' experience and three no longer sang regularly. Almost three quarters (74.6%; n=53) reported difficulties in using their voice for singing. Only 14 of these (26%) had received support from a speech therapist; seven (13%) had seen a laryngologist. Of these 14, seven were in the USA, two in the UK, one in New Zealand and four from countries across Europe. More than half of the 71

participants (59%) relied on their voices for daily activities. The majority of these worked as teachers, educators, or instructors (n=28) or as singers and performers (n=11). Three participants (<5%) no longer enjoyed singing but the majority (88%) were actively singing several times a week.

A breakdown of participant demographics by age group is given in Table 1. Most participants were female (96%); three chose not to disclose their sex or gender. Participants across all age groups experienced voice difficulties, but these were least common in participants aged 18-25 (45%). A range of Beighton scores were present (2-9) in singers with voice difficulties. Three participants did not have scores, but reported hypermobility in joints other than those assessed by the Beighton test.¹⁷

Table 1. Participant characteristics

Age group	Gender	Beighton score (mean and range) – all singers (n=71)	Percentage of participants with voice problems	Beighton score (mean and range) of participants with voice difficulties (n=53)
16-18 (n=1)	Female	6	100 % (n=1)	6
18-25 (n=11)	Female	8.4 (7-9); n/s (n=1)	45 % (n=5)	8.2 (7-9) (n=5)
25-30 (n=16)	Female (n=14); Non-disclosed (n=2)	6.4 (5-9)	75 % (n=12)	7.2 (5-9)
30- 40 (n=22)	Female (n=21); Non-disclosed (n=1)	6.4 (2-9); n/s (n=1)	82 % (n=18)	6.3 (2-9); n/s =1
40-50 (n=15)	Female	7.7 (5-9); n/s (n=1)	87 % (n=13)	7.8 (5-9); n/s =1
50-60 (n=6)	Female	7.8 (7-9); n/s (n=1)	67 % (n=4)	7.0 (7); n/s =1

The (n=) with numbers in brackets indicates the number of participants in each group by age, gender, and voice problems. The mean Beighton score and the range of scores is given for each age group; in all participants and in participants who experienced voice difficulties. Where participants had hypermobility in joints other than those measured in the Beighton Score, this is shown by n/s.

3.2 Qualitative themes

Three main themes and related subthemes (Figure 1) were identified: (1) ‘My unreliable voice’: the ups and downs (1.1 Voice ability and dysfunction; 1.2 Searching for explanations and meaning), (2) Wider effects of HSD/h-EDS on singers (2.1 ‘I’ve lost a lot of control’; 2.2 ‘A profound loss’) and (3) Need for acknowledgement and support. In presenting the findings, italics indicate verbatim quotations, followed by the participant’s study ID number, their gender, and their Beighton Score (BS). The coding template and defining features of the themes are provided in Appendix B.

INSERT Figure 1. Experiences of voice, ability, and loss in singers with hypermobility spectrum disorders.

3.2.1 Theme 1: ‘My unreliable voice’: the ups and downs

Voice ability and dysfunction

Most participants described their voice as having qualities that benefitted them as singers, whilst also experiencing difficulties when using it. Described benefits included having an unusual or interesting tone, enhanced flexibility, and a wide range for singing or speaking. These enabled the participants to take on unusual or varied vocal parts when singing, including roles traditionally ascribed to men:

I've always had a large range and found my placement in choirs to jump as needed. It's always fun when you can sing with the Tenors for one song and then go up to a high Soprano for another! (P28, female, aged 25-30, BS8).

I have a large vocal range which has always surprised my choir leaders and singing teachers (P44, non-disclosed, aged 30-40, BS7)

However, singing across the full vocal range or in specific parts of the range could trigger symptoms of voice dysfunction:

I was also an alto in choir because it's rare, even though I hated singing low. It's like my vocal cords pop when reaching low tones (P3, aged 30-40, BS8)

Commonly, participants experienced unexpected changes in phonation when singing or speaking. Some found that no sound might emerge when they tried to sing or speak, or that extra work was needed to initiate phonation:

It necessitates great energy and conscious effort to control and produce sound (P48, female aged 18-25, BS9)

Many commented on the unreliable nature of their voice. They experienced 'unusual fluctuations', 'cracks' or 'breaks' which interrupted them mid-flow, often without warning:

While singing, occasionally run into bars of music where I simply... stop being able to phonate (P57, female aged 25-30, BS9)

Sometimes I get random cramps that stop me mid-sentence (P17, female aged 25-30, BS6)

Whilst sudden loss of phonation was usually transitory, continued voice use could cause ongoing discomfort, voice loss, changes in voice quality or pain. Speaking and singing with volume was problematic and many described their voice as tiring easily, even from short periods of use:

For the past 5 years I get vocal fatigue easily when talking and singing which will lead to sounding hoarse or loss of my voice completely for the remainder of the day (P27, female 40-50, BS9)

Speaking for a solid duration of more than 10 minutes or so is also painful. I struggle to project, my voice cracks, and I start to lose my voice quickly. (P59, female aged 30-40, BS8)

Searching for explanations and meaning

Participants sought explanations of their voice dysfunctions from healthcare professionals and by looking for possible links between their HSD/h-EDS symptoms and voice symptoms. A few had undergone medical assessment that led to explanations for their voice difficulties. These included confirmation of organic voice issues, such as vocal polyps, oedema, vocal ulcers, and vocal folds that failed to close fully:

A video stroboscopy in 2019 showed my right vocal cord doesn't close all the way and vibrates at a different frequency (P51, female aged 40-50, BS9)

I had vocal nodules and polyps at age 17 (P61, female, aged 30-40, BS5)

Some participants were diagnosed with functional disorders through medical consultations. For some, vocal fold dysfunction occurred when they attempted to use certain parts of their vocal range

or if they attempted a particular vocal style. For others, problems arose or were exacerbated when their muscles were overly-tense or if they applied excessive muscle tension to initiate phonation:

CMD [craniomandibular] issues and chronic hyoid displacement issues cause voice and articulation problems... endoscopic exam proved muscular disbalance between vocal cords with hypertension of muscles - closing of vocal cords is mostly complete, but if high mandibular and hyoid tension, higher vocal dysfunction (P22, female aged 30-40, BS7)

I ended up seeing a specialist and we discovered that my vocal cords don't vibrate at all, and my pharynx squeezes my voice box in order to create sound instead. (P35, female aged 30-40, BS7)

Most participants had no medically-confirmed explanation for their difficulties, leaving them struggling to understand and explain their experiences. One participant described the sounds and sensations that arose as she sang, breathed and swallowed. Her words capture how unpredictable the vocal system can be when its different structures are vulnerable to unexpected change. The way she questions her own descriptions suggest feelings of anxiety and uncertainty around what is happening in her body:

[I] have several times had two notes come out instead of one, followed by significant pain (this only happened when I was singing at the top of my range) ...Some days I can't take a full breath without coughing, and it feels like each time I cough the tissue inside my windpipe and lungs is getting inflamed and somehow flappy? Like loose tissues stretched out like balloons and flopping around when I breathe? Also sometimes when I swallow I can feel the bones in my throat clacking (P60, female, 25-30, BS8)

Many participants linked their voice issues to changes in musculo-skeletal functions, such as joint pain, instability, subluxations, and laxity. Temporomandibular joint disorder (TMJ/TMD) was frequently described as affecting their speaking or singing. However, participants highlighted that overlapping musculo-skeletal issues made it hard for them to pinpoint one cause:

I also have AAI [atlanto-axial instability] and TMJ, so I have a lot of issues with the ligaments in my neck and head, so it can be hard to tell where some of my pain and vocal dysfunction is coming from. (P14 female aged 40-50, BS n/s)

TMJ is an issue for me like for many singers, but perhaps more complicated in my situation and I had a lot of muscle tension to work through. My neck is feeling unsupported these days when I sing. (P11 female aged 25-30, BS7)

Some participants described how their voice function was affected by non-articular health conditions that are comorbid with HSD, including acid reflux or Gastro-Oesophageal Reflux Disease (GERD), dysautonomia, Postural Orthostatic Tachycardia Syndrome (POTS), chronic fatigue, sensitivity to allergens and post-nasal drip. One participant explained how multiple physical and cognitive symptoms affected her ability to sing:

feeling faint and unable to catch my breath, difficulties in environments with triggers (smoke machines, hairsprays etc), cognitive distortion, and I frequently vomited in my university days and had uncontrolled GERD causing irritation, and I had hard to control severe postnasal drip which was very difficult ... Dysautonomia symptoms and mast cell activation symptoms made it impossible for me to sing properly for about two years and I am just starting again as things are more controlled. (P11; female, aged 25-30, BS7)

Voice symptoms and function also changed in response to hormonal changes, such as menstruation and pregnancy, stress, and ageing. Many participants experienced deterioration over time. One participant described how she began to lose volume and voice function, despite training, and another mourned the premature loss of her operatic voice:

I now struggle just to speak and be heard ... I studied voice for many years and have never had this issue until the past 10 years or so. It's getting worse as I age. (P34, female aged 50-60, BS7)

[I] used to sing and have operatic voice. Now can hardly sing a line. My voice trembles. (P58, female, aged 25-30, BS9)

3.2.2 Theme 2: Wider effects of h-EDS/HSD on singers

'I've lost a lot of control'

Voice difficulties and the wider effects of hypermobility caused problems for singers when performing repertoire and songs, with many highlighting the unpredictability of these effects. Some were unable to perform full sets because of fatigue, lack of strength and associated health conditions:

Sometimes I struggle to stand and hold music throughout a long concert (I think potential due to POTS) and the overall tiredness it would cause in my body would affect my vocal technique (P62, female, 25-30, BS9)

Many struggled to master the technical aspects of singing, despite ongoing training. Participants described difficulties accessing their full vocal range, transitioning between registers, producing and sustaining the desired pitch, and achieving power or volume. Some experienced problems with breath management or lung capacity. However, it was the unpredictable nature of symptoms that were most problematic. When they could not rely on their own voice or their physical capacity, participants either stopped singing, pushed themselves beyond their limit or waited for another day, even if this left them feeling inadequate:

The inconsistency in my voice is probably what is most noticeable. Some days my voice pours out like silk and I can sing for hours on end, and my range is absurdly wide - I can hit tenor notes and an octave above the other sopranos. Then all of a sudden it will be painful to sing at all, my range shrinks in half, and it feels like I have to work five times harder for each note. On those days, if I try to push through it I will end up with laryngitis." (P60, female aged 25-30, BS8)

I often wake up on a recording day and just don't have the voice or sometimes the lung capacity to give a performance worthy of recording and I'll have to sit it out. Other times I may start a recording session feeling good, but my voice quits on me or just isn't a reflection of what I can really do, so we have to re-record another day. (P5, female aged 30-40, BS9)

Participants also noticed how their own performing ability compared unfavourably to that of their peers and expressed increasing frustration with themselves and their teachers as they failed to make progress:

I've been well trained and all, and yet it's a running joke among my opera friends that I just can't keep up in terms of holding really long phrases (P57, female aged 25-30, BS9)

I've had voice teachers confused at why I struggle so much with agility and control on some days, when other days it seems so effortless. They also could not believe that I was working on my breathing because I did not make any improvement on how long I could sustain notes. (P60), female aged 25-30, BS8)

Some adapted to their difficulties by changing genre. For others, the negative effects of hypermobility halted their progress permanently or caused them to stop singing:

When my voice started to mature in my early twenties I progressed quite far in private singing lessons to semi-professional level, but often felt the 'blips' in my voice (such as some unevenness around the passagios, cracks in certain notes), having to work hard to keep the voice forward/project, and vocal fatigue stopped me from progressing further (P62, female, aged 25-30, BS9)

I have had to stop singing because I can't take the pain. (P42, female, aged 40-50, BS7)

Despite ongoing difficulties in singing, many participants felt that singing supported their physical and emotional capacity and helped relieve some of their HSD/h-EDS symptoms. For some, the physical rigour needed for singing helped offset some of the postural and muscular issues that arise from hypermobility. Singing helped relieve some secondary symptoms, such as pain, or gave them pleasure and a means to explore and understand their voice:

Singing has helped me with the things that don't come naturally with hEDS, such as posture, core strength and how to use your voice. It also gives me some relief from my chronic pain (P46, female aged 18-25, BS9)

Singing, and learning to improve my singing technique (despite some glitches!) has really helped me to understand my voice better when it comes to speaking too. Besides it's a wonderful thing to do, and regardless of any hypermobility issues, I thoroughly enjoy it. (P62 female, aged 25-30, BS9)

'A profound loss'

There was a significant impact on emotional wellbeing and quality of life for participants who lost their singing voice or singing potential. Some described an acute feeling of loss and grief, or existential crisis. Participants described their voice as a defining element of their own identity that now seemed irretrievable:

I've always loved singing and it's been a profound loss for me not being able to sing anymore. (...) This affects my life quality (P8, female aged 40-50, BS7)

Losing my good singing voice is my #1 regret. If given a choice, I would choose to have my voice miraculously cured before any other symptom, which is saying a lot, since I suffer from hEDS, MCAS [Mast Cell Activation Syndrome], POTS and two autoimmune diseases, just to mention a few of my top diagnoses (P51, female aged 40-50, BS9)

For some, the treatment of voice difficulties was also hard to bear. Enforced voice rest exacerbated the anxiety that their condition was unpredictable, and hastened the painful process of their lives being suspended:

I spend a large portion of my life on vocal rest (...) As a former singer/stage actress, I long for the day that I can use my voice predictably again. Heck, I'd settle for a day without pain. (P14, female aged 40-50, BS n/s)

Participants who were struggling to speak or sing experienced both physical and emotional pain. Often, their language indicated contradictory emotions: they expressed love for the profession and a desire to succeed, but instances of failure or a perceived inability to cope could lead to self-downing and feelings of embarrassment. Their experiences and symptoms helped them realise the severity of the condition, in the absence of a diagnosis:

I went home after every college choir practice with my throat throbbing and burning with pain, barely able to speak, and with horrible headaches and TMJ flare-ups from trying to force my voice to be strong and steady ...I wasn't even diagnosed with EDS yet, and just had to grit my teeth and accept that I was an unexplained freak of nature; I felt not just embarrassed, but positively unworthy of the beloved profession I was pursuing (P59, female aged 30-40, BS8)

feeling like "an idiot" to suffer from intensive throat pain after just a short piece of singing...(P22, female aged 30-40, BS7)

There was indication of little to no awareness or acknowledgement of their physical concerns in professional contexts. Participants felt neither understood nor supported which exacerbated their anxiety. This had an irrevocable impact on their career path, a journey with which they had developed a profoundly intimate relationship and sense of identity:

Sometimes I feel like they can't see it is my voice that is unreliable, not me. (P5, female aged 30-40, BS9)

After two degrees at conservatories, I did a doctorate at a university, but by that time I had exasperated my teachers and felt like I wanted to die after every performance, because I could not be consistent at all...I changed careers, but it hurt more than any relationship breakup in my life. (P4, female aged 40-50, BS8)

Some participants quietly shouldered the burden of losing their voice and their ability to fully participate in social opportunities. It was important for them to be with their friends and loved ones: to enable this, they developed self-protective strategies and masked their true emotions:

I'd love to cheer and sing during games or with good friends, but knowing the consequences I've ended up pretending to be cheering/singing just to show my joy in the moment (P10, female aged 40-50, BS6)

Not singing was a self-defeating strategy which allowed one participant to escape uncomfortable situations. Their decision to remove themselves gradually from singing to an audience conveyed a sense of helplessness:

I sing in front of others less and less. Performing is frightening when I can't count on my voice being reliable anymore. (P34, female aged 50-60, BS7)

Participants described an intrinsic pressure to be true to themselves and appear fine to others. This presented as a paradox: to preserve their voice they needed to restrain themselves from using it:

I mumble the words at religious services because otherwise I will be hoarse or voiceless by the end. (P59, female aged 30-40, BS8)

When speaking or singing for very long, the sound of my voice changes and I lose strength (gets gravely, hoarse, breaks, lose my vibrato, can't maintain the note as long) and so I only sing at home now versus daily classical singing in the past... (P25, female aged 30-40, BS8)

For some participants, their voice difficulties affected family communication. The use of sign language, lip-reading and augmentative communication helped relieve vocal pain and create opportunities for interactions. For some, this required adjustment by family members, including their children:

I switch to sign language to avoid pain as I'm fluent in that as some family are deaf (P24, female aged 40-50, BS9)

I home-school my 3 young children. I use a speech device, my children lipread and use basic sign language to supplement on the days when my voice isn't "working." (P14, female aged 40-50, n/s)

3.3.3 Theme 3: Need for acknowledgement and support

Commonly, participants faced difficulties in getting support from medical professionals and vocal coaches. In the absence of available information or a firm diagnosis, participants attributed their difficulties in performing or singing to various causes. These included anxiety, poor vocal technique, the effort of social interaction, or a virus. A lack of information led to frustration as they tried to make meaning of their situation. This led to some giving up their career aspirations even though they remained 'unsure of the full cause' of their voice difficulties (P52, female, aged 30-40, BS2). Others pursued answers, but their journeys could take years and involve multiple forms of assessment and unsuccessful treatment:

For 16 years I have pursued every possible avenue, exploring everything from Gastro issues to muscular dysfunction. I have been to numerous otolaryngologists in the US, had laryngeal massage, taken supplements (including The Cusack Protocol), been scoped a zillion times, had 3 full courses of speech therapy, acupuncture and so many other things. To no avail. But, once I started to view it through the EDS lens, so much made sense, especially in concert with my ligament laxity. (P14, female aged 40-50, n/s)

Furthermore, participants expressed a need for greater awareness and knowledge among health professionals. They felt alone and unsupported as they struggled to find answers or solutions, given that some doctors appeared unsympathetic or lacking in knowledge. For some, the learning process came through pain, injury, and self-assessment:

Doctors didn't seem to care or understand how much of a loss this is to me (P14, female aged 40-50, BS n/s)

[they] were barely versed in the basics of EDS, much less the lesser-known challenges (P59, female aged 30-40, BS8)

Hypermobility needs to be discussed more in music education as many of my peers (mostly instrumental majors and myself with instrumentals too) had to figure this out on their own from pain and injury (P11, female, aged 25-30, BS7)

4.0 Discussion

For singers, as for musicians and dancers²⁹, hypermobility seems to offer mixed blessings. Although most of our participants (95%) still enjoyed singing, 74.6% experienced voice difficulties (Table 1). This applied across all age groups and Beighton scores. Previous voice research has not included

people with a BS of less than 5,^{24,25} nor those with HSD.^{18,20–22} Assessment criteria changed in 2017¹⁵ and the current cut-off point for diagnosis is a BS >3 or >4, depending on age, sex and race. Participants in our study who were below the cut-off experienced comparable benefits and difficulties to participants with higher Beighton scores. This suggests that voice may be an additional area of concern in HSD/h-EDS, irrespective of Beighton score or diagnosis.

Our findings indicate a high prevalence of dysphonia, in line with previous research.^{18,20–25} Our participants experienced difficulties achieving volume and maintaining modal phonation, vocal fatigue with little use, and unpredictable breaks in phonation. Some described occasional painful spasms in their throat, coughing, choking, or other unpleasant laryngeal sensations. These echo descriptions of patients with EDS who present with subluxations of the hyoid bone^{18,23} or larynx¹⁹, swallowing difficulties^{18,23} and breathing difficulties³⁸. However, few participants had undergone laryngeal assessment or received speech and language therapy, despite ongoing difficulties.

As singing places higher demands on the vocal tract than speaking,³⁹ it is unsurprising that difficulties with phonation had significant consequences for our participants when singing. They experienced sudden voice breaks when singing, and they struggled to control their breath, pitch, intonation, and volume. Some participants directly linked their voice difficulties with their musculo-skeletal issues, especially with symptoms that occurred in their jaw, neck or back. Singing involves the whole body⁴⁰ and places especially high demands on the muscles of the neck, shoulders and thorax⁴¹. **These joints can all be affected by ligamentous laxity in hypermobile conditions, creating instability and uneven stresses on the joints, muscular imbalance and excessive tension.**^{4,42} **Poor proprioception is also common in hypermobility, which can make it difficult for people to recognise that they are over-tensing muscles.**⁴³ A few participants had received confirmation of excessive laryngeal muscle tension and use of the ventricular folds. In people with Down Syndrome these same functional vocal symptoms are linked to their laryngeal hypermobility and poor muscle tone.^{44,45} However, ventricular phonation and use of excessive laryngeal tension can also arise from poor posture, anxiety and stress,⁴⁶ all of which commonly occur in HSD/h-EDS and Down Syndrome. These findings point to a combination of physiological and behavioural triggers that are associated with hypermobility, and that can interact and exacerbate voice problems.

Many singers linked their voice difficulties to the systemic health conditions **that are commonly associated with h-EDS/HSD, including dysautonomia/POTS, MAST cell disorders, acid reflux or GERD, and asthmatic symptoms.**^{3,7} These comorbidities can make it difficult for HSD/h-EDS patients to identify specific causes of vocal dysfunction. Beyond any negative effects of joint hypermobility itself, Dysautonomia/POTS may lead to muscle weakness and a feeling of dehydration.^{12,47} Vocal fold inflammation from GERD may disrupt phonation,⁴⁸ and allergic- and MAST cell- disorders may be further sources of inflammation or altered mucus production/composition.⁴⁹ Over time, conditions such as GERD and repeated infections can damage the vocal folds.^{48,49} This places singers with HSD/h-EDS at risk because it often takes years of care to discover their medical issues.¹⁴ Additionally, symptoms may vary from day to day according to other internal and external factors. For many of our participants, their struggles to understand and find solutions to unpredictable voice disorders were as debilitating as their voice difficulties and other health needs. Despite this, most still found pleasure in singing and felt that it offered benefits to physical function and voice.

Some younger participants experienced significant voice difficulties (Table 1) but many participants identified loss of voice function, ability, and stamina over time. The risk of voice difficulties in singers increases with age³¹ and varies with genre^{31,50}. **However, the prevalence of voice difficulties in our participants (74.6 %) is higher than previously reported in singers (46.01 %). Hypermobility may be an additional risk factor for voice disorders,**^{21,51} and frequent over-stretching and over-use of

vulnerable joints can exacerbate problems in hypermobile groups.^{32,42} It is possible that the very wide and flexible voices that our participants describe increases the risk of developing injury or joint problems in the voice. **Hormonal changes may be an additional factor to consider: some participants identified changes in their voice that coincided with hormonal changes, including pregnancy and their menstrual cycle. Changes in levels of oestrogen can affect voice function during the menstrual cycle, pregnancy, and menopause.**^{52,53}

4.1 Implications for Practice

Our findings stress the need for meticulous assessment of vocal function and health in singers with HSD/h-EDS who experience voice difficulties. Clinicians who are experienced in assessing and supporting voice symptoms in patients with HSD/h-EDS exist in the UK (e.g. at University College London). However, a referral from a doctor and confirmed diagnosis may be needed to access this type of support. Despite efforts by global and national organisations to raise awareness of HSD/h-EDS in the medical community,^{54,55} a diagnosis can take years and multiple agencies, during which time symptoms worsen and quality of life deteriorates.^{5,56} Early assessment and care is needed as voice problems can be present from a very young age²¹ but this process should be ongoing. **For women, voice function may need assessment at different stages of the menstrual cycle, and during perimenopause and menopause. However, in hypermobile groups, voice difficulties that are usually associated with ageing can occur 2-3 decades earlier⁵¹. Clinicians should not rule out the possible influence of musculoskeletal and systemic health issues, alongside possible hormonal effects. For example, case studies of women in their 40s with EDS/h-EDS identified multiple HSD-related issues that affected voice. In order to restore voice function, therapy included medication to control GERD, massage, food management, and exercises to stabilise the neck and laryngeal function.**⁵⁷ Careful assessment is essential to finding the best therapy, and is especially important given the struggles some participants faced in managing their voice without support or information.

There is a need for greater awareness about HSD and h-EDS in singers and their vocal coaches. Some of our participants struggled because neither they nor their teachers understood how their diagnosis affected their voice or because they had not yet received a diagnosis. The inclusion of technology in vocal coaching can help singers and their teachers understand voice problems.⁵⁸ For example, voice analysis software such as Praat⁵⁹ can offer insight into hypermobile voices using spectrographic display and measures of voice quality.⁴⁵ Acoustic analysis is non-invasive and can be used during live performance for immediate feedback, or from suitable studio recordings. Such methods cannot replace laryngeal assessment but may provide insight into the nature of voice difficulties, triggers of voice dysfunction, and changes over time. This may be especially effective if combined with auditory and postural assessment by the teacher, and somatosensory insight from the singer.

Although singing is sometimes compared to elite athletic activity,^{39,60,61} this idea is complicated by chronic illnesses and disabilities like those of patients with HSD/h-EDS. **Singers and their coaches may need to manage the comorbid conditions that are common in HSD/h-EDS, such as chronic fatigue, POTS, and sensitivities to allergens.** Medications and lifestyle adjustments may make a difference to singers experiencing health and voice difficulties. However, singers and their vocal instructors may also need to develop adaptations to training, rehearsal, and performance as they would and should with any other disability. Some potential adaptations include:

- If Dysautonomia/POTS is identified or suspected, a singer may find sitting to sing helpful, either in a wheelchair or in a stationary chair. **Corsets or compression clothing may also reduce symptoms associated with POTS and support breath for singing.**⁶²

- Physical exercises could be built into the singer's training regime to help strengthen the whole body and muscles around vulnerable joints. Short-term use of mobility aids such as splints and kinesiotape should be considered to support unstable joints in singers who experience intermittent musculo-skeletal symptoms.
- A microphone could be used to help the voice to carry in rehearsal. Other than convention (or lack of access to equipment), there is no reason for a singer not to be allowed to use such amplification in any performance.
- Repertoire and/or singing styles that demand less physical effort could be chosen, so that fatigued singers can focus consistently on the basics of their technique and expressive communication without losing too much precious energy.
- Singers can choose to use sheet music or prompting if memory is negatively affected by cognitive difficulties.
- Singers may need to accepting the hypermobile voice as valid, no matter how imperfect it sounds. Accepting an imperfect voice may be the most difficult to achieve, given how closely voice is intertwined with identity in singers (see Meizel 2020³³).

Singers and their vocal coaches need access to information about hypermobility and its potential impact on voice and health. Health education should be tailored to a singer's context and should be offered to music educators. However, this may remain challenging if neither party is aware of an underlying health condition. The British Association for Performing Arts Medicine (BAPAM) organises occasional events on hypermobility for musicians:⁶³ these events emphasise the importance of a healthy lifestyle, exercise programmes aimed at muscle strengthening, as well as healthy practice and technique. **Discussions about hypermobility and its management could be facilitated by organisations that provide health training to musicians, singers and performers, such as: The International Federation of Musicians (Latin America, Africa, and Europe);⁶⁴ The National Association of Schools and Music (USA)⁶⁵; the Australian Society for Performing Arts Healthcare (ASPAH);⁶⁶ and the Healthy Conservatoires Network (UK).⁶⁷ Strength training and physiotherapy is an important element of care in HSD and h-EDS⁶⁸ and its value needs to be emphasised when training musicians and educators.^{69,70} Such training should include raising awareness of singers' health problems, but also of relevant health services that they can access. This could include discussing the bidirectional relationship between health and performance quality and technique, and support to implement healthy practice strategies and health-related behaviour changes in musicians' daily routines.⁷⁰⁻⁷² Programmes to raise awareness about voice disorders in HSD/h-EDS should also include the potential emotional challenges of the diagnosis and the need to design appropriate services to address these. For many of our participants, the loss of their voice had a significant effect on their emotional wellbeing, their quality of life, and their identity, as well as their professional potential.**

4.2 Contribution, limitations and future research

To our knowledge, this is the first study to explore voice function in singers with HSD/h-EDS. It adds to our understanding of voice difficulty in hypermobile conditions, and identifies practical approaches to supporting and informing singers with HSD/h-EDS. However, we recognise limitations in our study. We cannot be confident that our sample represents all singers with HSD/h-EDS: the sample size is relatively small; most participants were female; and it is possible that those with a voice difficulty were more likely to respond to the survey than those without a voice difficulty. Additional demographic details could have increased our understanding and analysis, such as the specific diagnosis of HSD or h-EDS, and details about the onset and duration of voice difficulties and HSD/h-EDS- related health symptoms.

Further research should explore the extent of voice difficulties in singers with HSD/h-EDS, including male singers. A more focussed and longitudinal study is needed to explore the stability of voice

function over time, especially in relation to joint stability, health conditions associated with HSD/h-EDS, and changes in age and hormones. Future research needs to address the support needs of those diagnosed with HSD/h-EDS, and that of their family when sign language or speech devices are introduced in daily communication.

5.0 Conclusions

Our findings identify how multiple factors associated with HSD/h-EDS can affect vocal performance in singers, and how the loss of vocal ability or capacity affects their professional opportunities and quality of life. Four key messages arise from this study. Firstly, singers with HSD/h-EDS may be at increased risk of voice difficulties irrespective of their age or Beighton score. Early assessment and tailored support is paramount to reducing the impact of voice difficulties. Secondly, it is essential to establish training programmes to raise awareness of possible voice issues amongst health care providers, music teachers and training schools, and singers. Thirdly, intervention should be tailored, and family centred. Family members may be as affected as the patient when sign language, speech devices or new communication codes are introduced in their routine; having access to support is important for all affected. Fourthly, singers and their vocal coaches may need to make necessary pragmatic adaptations during training, rehearsal, and performance (e.g. use of mobility aids, microphones).

Given the complexity of hypermobility disorders, a multi-level, systemic approach is needed to support and inform singers with the condition. Fuller understanding of voice difficulties in HSD/h-EDS may be needed before this happens.

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Data management and sharing

The authors have full control over the primary data for this study. Analysed data are stored in a shared OneDrive folder hosted by Bishop Grosseteste University. As per the ethical committee approval, this dataset is subject to ethical restrictions, and informed consent of study participants does not include the publication of raw data in terms of full survey responses. Access to the study data for secondary analysis can be made through reasonable request to the corresponding author. Requests for access to data will be reviewed by the project management group.

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