Speaking Into the Wind: The Impacts of Ehlers Danlos Syndrome

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Author Note

Before reading this paper, please note the content warning for mention of suicide, chronic pain, and medical neglect.

Literature review

Ehlers Danlos Syndrome, also called EDS, is a connective tissue disorder that causes sever, constant pain throughout people's bodies. Connective tissue disorders affect the production of collagen and elastin, which affect tissue composition and subsequently their ability to stabilize joints. Tissues such as tendons, ligaments, and bones have decreased collagen production which weakens their abilities. Because of the decreased connective tissue structure, muscles and other body parts overcompensate, which causes significant musculoskeletal pain, tears, and joint dislocations.

Studies have found EDS affects around 1 out of 5,000 people worldwide, but the exact prevalence is difficult to study because many people are undiagnosed due to the lack of research and medical training on chronic pain disorders. Hypermobile EDS is the most common subtype of EDS, making up about 90% of cases (*Hypermobile EDS (hEDS),* n.d.). It is difficult to receive a diagnosis because the genetic testing available can only identify specific subtypes that fall within the 10% of remaining EDS subtypes. Additionally, the genetic test only results positive for 50%, meaning 1 out of every 2 people, that have those subtypes of EDS (*Genetic testing for Ehlers-Danlos syndrome,* 2016). Researchers don't know which gene is affected by hypermobile EDS, so they rely on physical exams and family history for the diagnosis. But since there are a variety of symptoms and severities of EDS, it is difficult and usually takes years for providers to diagnose patients with EDS (Gensemer et al., 2021). Many people are also misdiagnosed for many years. For example, many people are diagnosed with fibromyalgia, (Tinkle et al., 2017) so they spend significant time and energy attending appointments and trying treatments for their misdiagnoses, which is expensive and tiring, little to no benefit because they are treating a different disorder. Due to the difficulties in receiving a diagnosis, researchers suspect many

people are undiagnosed, or have a misdiagnosis, so the prevalence of EDS is actually much larger than the data shows.

There is a higher prevalence in women, but researchers are unsure if that is due to the more severe musculoskeletal pain women experience causing more women to receive a diagnosis than men, or if women are genetically at a higher risk for developing EDS. Gensemer et al. believe more women have EDS due to the autosomal dominant patterns of inheritance (2021). Another explanation for why more women seem to have EDS includes the stigma that men are less likely to seek medical attention until it is absolutely necessary, which could affect their diagnoses and our understanding of gendered differences. Additionally, Scicluna et al. found that women have more advanced and severe phenotypes of EDS, which could be another reason why more women are diagnosed than men (2022). Though scientists are unsure of the genetic causes of EDS, they do know significantly more women are diagnosed with EDS and their pain increases as they age.

There are many symptoms of EDS, which adds to the difficulty receiving a diagnosis. Almost everyone reports significant musculoskeletal pain that is caused by their joint instability. This pain is different for every person with EDS. From speaking with individuals with EDS, it seems they have a couple joints that have the most significant pain, in addition to other chronic pains throughout their body that are less severe. In the study by Broom et al., individuals wrote journal entries about their experiences with chronic pain, and many individuals wrote about their lack of energy in everyday activities and their limited social interactions (2015). The neurological manifestations of EDS present as headaches and changes in sensory, motor, and reflex reactions (Tinkle et al., 2017). Lastly, EDS can manifest in the cardiovascular system causing tachycardia, hypotension, or symptoms similar to POTS (Postural Orthostatic

tachycardia Syndrome). Cardiovascular manifestations of EDS cause chronic fatigue and sleep difficulties (Gensemer et al., 2021), which is really frustrating for individuals because their bodies are exhausted, but they cannot fall asleep, or stay asleep. These are just a few examples of common symptoms of EDS. Since the pain is different in everyone, the few therapies available also affect everyone differently, making is difficult to manage EDS symptoms.

Ehlers Danlos Syndrome is the most common hereditary connective tissue disorder known today (Scicluna et al., 2022). However, the United States has limited research on the heritability, diagnosis, and treatment of EDS, so individuals seek care from multiple medical professionals to understand the causes of their symptoms and the best approaches to managing them. Individuals with EDS spend significant time, energy, and money searching for providers and attending appointments. But the progression of pain for people with EDS is inevitable, so the therapies people are trying are only helping to slow the progression of their pain; the therapies do not eliminate their pain, but rather only help to slow the progression of their pain. It is important for individuals to seek care as early as possible, but many patients experience a lack of understanding and empathy from doctors. Patients spend significant time trying to convey the severity of their experiences to providers, but they are frequently brushed off for the severe, constant pains they're experiencing. If providers were more empathetic throughout the diagnostic process, and understood the severity of people's pains, then patients could save significant energy and focus more on the treatments that are beneficial to their symptoms.

Within the past few years, I developed a strong passion for learning about and sharing people's experiences with EDS because this disease runs in my family. One of my siblings took their own life because of the severity of their pain. They experienced inescapable pain, and no treatments decreased their pain to a livable level. Katie, my sibling, put substantial energy

towards trying to be understood by family members, friends, and medical professionals just for almost everyone to dismiss the extent of their experiences. Everyone believed that they were faking it, overreacting, or using it as an excuse to get out of tasks.

My study

The study I conducted is based on a 10-question questionnaire I shared with individuals diagnosed with EDS. I asked questions about how EDS affects their bodies physically, their diagnostic process, their difficulties with the medical system, feeling misunderstood by their peers and family members, additional stressors it's caused in their lives, and what therapies they have found beneficial for their symptoms.

To find participants, I posted images on Instagram explaining my research and the requirements to participate in the study. I received about 20 responses, which was significantly more than I expected. I didn't realize how many people I know have EDS, since I only know a small percent of people. Of the 20 people who initially reached out to me, I received 6 responses to the questionnaire.

Since EDS effects people's energy levels and attention (Hakim et al., 2017), I chose to use an open-ended questionnaire. Meaning, I sent the participants the 10 open ended questions on a document, and they could respond to the questions when they had the energy. Some people submitted their responses via audio recordings, and some submitted typed responses. It was interesting reading everyone's responses to the questions because there are a lot of similarities, but also significant differences between everyone's experiences. Reading about people's experiences was also very emotional, I cried reading many of their responses, because of how exhausted and frustrated these individuals are, and their peers, family members, and doctors are

brushing off the severity and complexity of their symptoms, instead of trying to understand their experiences empathetically.

Since this is an anonymous study, I used pseudonyms for everyone's names, to ensure confidentiality for the participants. Initially, I used numbers to represent the individuals, but it felt too impersonal, and it was hard to follow what individual experienced what symptoms. Using pseudonyms allows readers to easier understand who experienced what symptoms, and the reader can have a more humane connection to these individuals and their experiences.

As I stated above, there isn't enough research on EDS because people do not understand the severity of their experiences. And my purpose in doing this research is to better understand people's life altering experiences with EDS and amply their voices. Instead of me, as the researcher, interpreting their experiences through filters that I have, and paraphrasing their experiences in my words, I think it's important for people to read the experiences of individuals with EDS. Throughout this paper there are many quotes because I want to share people's lived experiences with EDS so more people can understand how severe and life altering Ehlers Danlos Syndrome is.

People's Experiences with EDS

As I stated above, Ehlers Danlos Syndrome causes significant, chronic pain throughout people's bodies. But when people hear 'chronic pain' it's difficult to understand what that really means. Thus, people brush off the extent of their pain and life altering symptoms because they cannot comprehend the severity of their experiences. I think it's important to share people's direct experiences with EDS because there is little research on EDS. All the participants spent a lot of time writing descriptive, well thought out explanations of their experiences, and they

included many well illustrated stories and examples of their life experiences. Additionally, using a lot of the participant's direct quotes minimizes the biases and filters I have while reading and analyzing their experiences.

One of the participants, Beatrice, is affected by an overall weak feeling throughout her body. She also has rib pain that causes shooting spasms and a fracture in her back, that she's been told will never heal, that causes debilitating pain and inflammation. She described her low back feeling like a "burning, screaming, deep, untouchable bone pain that no pain meds can kill." Describing feelings, especially pain, is difficult. But her explanations of her pain illustrate the intense bone pain she feels. She also said, "occasionally my whole body will start to be affected where even my toes, ankles, knees, hips, elbows, and neck etc will all ache and pop and sublux." Subluxations are partial dislocations of a joint, but they are just as painful as full dislocations. Because of the changes in collagen composition in tissues, people's joints are less stable, so subluxations and dislocations are common. (*Managing dislocations and subluxations in hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders*, 2016). Beatrice's list of joints aching and subluxing are extensive. On top of all the pain she's experiencing in most of her joints, her subluxations, and her intense back pain, she feels weak.

Lane, another participant, explained how her pain was so intense her freshman year of college when she was living on campus, that she would frequently be on the phone with her mom or the ER. She was trying anything to minimize her pain, but nothing would reduce her pain. She explained how her whole-body cramps, "but it really wasn't a cramp like, I really have no idea how to explain it." It begins in her arms and legs and it's a "horrible, horrible" pain. She said it "starts in a band around my arm, leg, or hand, and from the band down to the end, it's just like excruciating pain." It's unbearable to think about excruciating pain radiating down your entire

extremity. Muscle cramping is not as common as joint paint, but in a study Lies Rombaut et al. performed investigating the experiences of people with EDS, they did find muscle cramping to be a significant symptom of EDS (2010). Lane's been having significant leg pain since she was young. She remembers laying "on the ground in tears because I would be having so much pain in my legs." Currently, she said that her EDS symptoms are "manageable until it flares up. And then it's really really, really painful." Flare ups refer to time periods that people's symptoms significantly increase (*Managing hEDS & HSD flares*, 2022). Flare ups can affect any part of the body including pain, GI tract issues, insomnia, or brain fog.

Another participant, Ray, noted that "EDS has affected everything in my body from my bones and muscles to my GI tracts, Vascular system and nervous system." Throughout her life she said she's had many injuries that caused significant pain and were difficult to treat. Recently, her most impactful symptom of EDS is the "damage that it did to my GI tract causing muscle paralysis and vascular compressions damaging my stomach and intestines. This combined with nervous system dysfunction has been untreatable and disabling." Connective tissue is necessary for the digestive tract to function, so EDS also impacts people's digestion. There is a variety of GI issues people experience including acid reflux, constipation, indigestion, and diarrhea. (*Gastrointestinal problems in hypermobile Ehlers-Danlos syndrome and hypermobility spectrum disorders*, 2017). Ray emphasized that her symptoms have progressed with time and her "dislocations have become more frequent but less catastrophic and many things such as dizziness, pain, nausea, and migraines have become debilitating." This demonstrates how all her symptoms are progressing independently from one another, but they all significantly affect her overall life experience.

Ray also said “I know from the moment I wake up if the day will be okay or not. Most mornings I have pain radiating down the right side of my body from dislocating my shoulder just trying to get comfortable in the middle of the night. I have to carefully get up in the morning so my hip won’t give out just from standing. The pain is excruciating, it feels the world is literally trying to break you piece by piece, it would put most people in tears or land them in the emergency room, but it's almost something you adapt to. I will never accept it but what once was the worst pain I thought I would ever experience is now pushed to the back of my mind as I fight through the battles of everyday life.” Ray illustrates her pain and frustration so well in this quotation, and she conveys how EDS affects her constantly throughout the day. From the moment she wakes up, her body is already in so much of pain because her shoulder often dislocates in her sleep. I included this quote because she emphasizes how differently her body feels every day, and how her first movements in the morning determines how her body will feel the rest of the day. You can hear how intense her experiences are, and how she’s forced to deal with them every day while also trying to navigate being a young person in today’s fast paced, competitive world.

Cierra said their pain is mainly in their back and neck, specifically in their trapezius, and their hip clicks and hurts. Both of their trapezius muscles are “solid as rocks” causing intense pain that continues to get worse with time. Their chronic pain started developing when they were 15, and they now struggle imaging a time when they didn’t have pain. Cierra emphasized how difficult it is to get comfortable at night, so their sleep is significantly impacted by EDS. Since they have pain throughout their body, it’s impossible to find a position that is comfortable for all their limbs, joints, and muscles. This makes falling asleep difficult because individuals cannot escape pain. Once they do fall asleep, they often wake up in the middle of the night because they

have moved into a hyper-extended position that causes them pain. Tang found there is a high correlation between people's onset of pain and their initial symptoms of insomnia, which demonstrates the impacts chronic pain and insomnia have on each other (2008). Sleep is necessary to heal the body, which is especially important for people with EDS.

When talking about her symptoms of EDS, Gina said she's always struggled describing her pain even though it's been 9 years of experiencing it. She said "I don't really think I can explain it—all I can say is that the pain is super severe and can cause spasms and can render me unable to move at all without literally yelling from the pain. Sometimes the pain in my hips causes me to collapse to the ground because my hips can no longer support the weight of my body." Her pain is sometimes so intense that she's unable to move at all without screaming in pain. It's difficult to even imagine how significant her pain is, and it's something she's experiencing daily. Gina used a lot of description in her responses, which helps portray how significantly EDS affects her life. She explained how when she was a young teenager, she had to quit all sports because of her hip pain. This intense pain lasted her about three years, even while she was lying in bed. With time, the flare ups occur less intensely and less frequently, lasting between 1-5 days.

The symptoms of the respondents listed above demonstrate the variety of symptoms people experience from EDS. These experiences listed above aren't the participants complete list of body pains, subluxations, or muscle tears. Additionally, on top of these intense physical body pains, there are so many life alterations and additional life stressors that occur because of EDS.

Symptom Progression

EDS is a progressive disease, meaning people's symptoms are continuously changing and evolving over time. Since the structure and function of tendons decreases, it causes the stability of joints to decrease as well. Therefore, muscles must overcompensate for the tendons to hold loose joints in place. Once joints are unstable, it's difficult to regain stability. For example, once a joint subluxates one time, it's more likely to subluxate again. With time, as muscles are overworked to hold joints in place, they get tight, or even tear, causing immense pain. The progression of people's symptoms isn't linear; some people experience improvements in certain areas, while other areas experience significantly worse symptom progression.

Gina remembered her first symptom of EDS, exercise intolerance, appearing when she was 10. Since then, her exercise intolerance has continuously progressed. At age 12 she started developing chronic pain and joint subluxations, but they became severe when she was 13. Within only one year, she experienced a significant increase in pain. She noted that her most intense pains and joint subluxations occurred between ages 13-15, with only minor improvements until age 19, when she started experiencing significant improvements in both pain and subluxations. Even though her pain is slowly improving, she noted that her "symptom progression has not been linear" because other symptoms have gotten worse. She said that currently, "my most severe EDS symptoms are my eating issues (ie. Rumination Syndrome), chronic fatigue, exercise intolerance, insomnia, and brain fog." She still experiences joint pain that causes significant pain if she does anything more strenuous than walking, but the "other issues I just listed [are] much more disabling." Her joint pain is significantly worse if she does any activity more strenuous than walking, but that's not even her most severe symptom.

Many participants noted the benefits and praise they received for their hypermobility in sports at a young age. Throughout Sydney's childhood and adolescence, she was a dancer. Her flexibility, a direct impact of hypermobile EDS, allowed her to have a wide variety of movements. She also mentioned the "party tricks" and cool moves she performed because of her flexibility. But now, in her upper 30's, she said that "my body feels old beyond its years as my joints feel loose and my muscles fatigue due to having to work harder to keep me put together." Her shoulder, hands, feet, ankles, SI joint and hip all "slip out of place easily" and with age it requires more muscle and energy to hold her joints in place. She noted that when she was young, she had a lot of strength and control over how her body moved, but now she experiences a lot of instability, especially on the left side of her body. She feels like she's going to fall when she's walking because if feels like she's "walking on a tilted boat-deck. Not sturdy at all." Sydney included how impactful this is mentally as well. She said, "it isn't just the pain that is impactful, but the vulnerability, the actual increased likelihood of falling or injuring myself, and the mental distress of not knowing what my body is doing, why it is doing what it is doing, why it isn't doing what I want or need it to do, and whether it will ever improve in pain level or function." As she explained, it's not just the progression of the pain, but also the stress of having less control over your body and not knowing why it's feeling the way it is. She also mentioned the significant mental challenge of knowing she can no longer go on walks further than around her block, which she can only do when she's at her best. While she's walking, she must constantly pay attention to which muscles are being used so her joints stay in place while she walks. Her experiences demonstrate how she was praised for her hypermobility when she was young, so she did not understand the negative consequences and significant pain she would have a couple years later.

From these responses, it is apparent how disabling the effects of EDS are. These examples also demonstrate how differently the symptoms of EDS manifest in everyone. This contributes to the difficulty in diagnosing and managing chronic pain because everyone has different chronic muscle and joint pains. Chronic pain is inevitable for people with EDS, so finding ways to manage their current pain levels is something many people must figure out on their own. This requires a lot of energy and time because people are constantly adjusting their bodies to reduce their pain.

Anxiety of Symptom Progression

Since the symptoms of EDS are destined to progress, many people worry about the uncertainty of how their symptoms will progress. Many people reported the continuous fear or anxiety of symptom progression because they cannot predict how their bodies will be in the future. Beatrice said that “moving heavy objects, cleaning in certain motions, sleeping in an unfit space, etc all end up causing me pain. It makes me so fearful of what it’ll be like as I continue to age and as your body naturally degenerates.” EDS symptom progression isn’t linear, and individuals have no idea how their body will feel until they wake up in the morning and make their first movements. Ray also noted the anxiety she experiences because “there is always the fear of symptom progression, what my future looks like, and concern of the opportunities it will take.” This is something that’s difficult to talk about with people who don’t have EDS because they often don’t understand the vast effects EDS has on people’s lives. How can people think about their future when they have no idea how their symptoms will progress that week, let alone 3 years?

Gina said that she frequently worries about the progression of her symptoms. Interestingly, many of her symptoms have improved over the past couple years, especially since starting treatments for sleep apnea and Rumination syndrome. With these improvements, she said she's hopeful for how she'll feel in the future. But she also worries "about if the pain will eventually get super severe again (it probably will). I do find myself being very pessimistic about my future, though—if I'm this disabled at the age of 21, how disabled am I going to be in the future?" This quote demonstrates her internal monologue of the uncertainty of the future. It may sound pessimistic, but it's inevitable for individuals to question their future due to the progressive nature of EDS. Many people I've talked with who have EDS have expressed similar thought processes as well.

Medical Professionals Lack Empathy and Understanding

Many people struggle portraying the severity of their symptoms to providers, so they don't receive sufficient care or empathy from professionals (Halverson et al., 2023b). The Western Medical system lacks funding for EDS research. Therefore, researchers don't understand the causes of EDS nor the best ways to manage symptoms (Langhinrichsen-Rohling et al., 2021). As a result, medical professionals have little information about EDS, so they have little empathy for their patients because they don't understand how significantly EDS affects their lives. But this isn't necessarily the individual providers faults because the Western Medical system needs to allocate their funding towards EDS research more effectively. I know this because when my sibling passed away in 2022 because they could no longer handle the pains caused by EDS, there were no ongoing EDS studies in the United States that their tissues could

be studied in. Because of this lack of funding and research, medical professionals have little information about EDS, and often respond with little empathy towards their patients.

In Hilbert's study people reported physicians telling them their pain was imaginary, even though they spent years experiencing symptoms and spending time, effort, and money attending doctor's appointments (1984). The lack of professional understanding of their symptoms causes patients to second guess their pain, which negatively affects their mental health because they are questioning their own feelings and experiences (Broom et al., 2015). Before Sydney was diagnosed with hypermobility, many providers commented on her "great range of motion." They emphasized how everything seemed fine, and that her "arm wasn't going to just fall out of the socket despite it feeling at the time like it was hanging from my body, unsupported, detached, 'unhooked.'" She felt she was being gaslit in these situations because they were praising her for her extreme hypermobility, despite the significant pain she was experiencing. As a result of this, she now experiences joint subluxations and dislocations because she began "doubting my own sensations and signals from my body, both limb, trunk, and nervous system." Medical professionals overlooking the severity of people's experiences causes individuals to ignore their symptoms because they are not receiving medical validation. One participant in Hilbert's study explained how frustrating and confusing it is knowing something is changing in your body, but physicians and labs results indicating that nothing is wrong (1984).

Ray provided an example of a time she almost lost her life because a medical professional believed she was faking her symptoms. She said "I was seen as a frequent flier in the ER at that time because I was undiagnosed, facing severe symptoms, and searching for help. I presented with a fever of 104, incoherent, severe pain, tachycardia, and hypotension. I was left lying on the floor of the ER waiting room for hours before I was taken back to then be told I was

being dramatic and faking my symptoms. Within 20 minutes of being in my room I coded and had to be transferred to the ICU for septic shock and multiorgan failure. It was due to ignorance that I almost lost my life that day." Organ rupture and failure are risks of EDS that have life threatening consequences. Ray's example vividly demonstrates how she was in a life-threatening situation because providers brushed off her experiences. Because medical professionals lack empathy for people with EDS, they overlook the severity of their experiences, causing many people to question their lived experiences with EDS.

Additionally, Cierra said "I don't think any doctor has understood the pain I'm in. Being a female with poor insurance adds a lot of barriers to how doctors view you. It's also hard to explain to people what's wrong, and a lot of the time people just think I hurt occasionally and its nothing a bath or massage can't solve. But its pain 24/7 and its so much harder to do things normal people do with no problem." Cierra mentions insurance and how that adds barriers to their access to doctors and treatments. Insurance barriers are especially impactful for people with EDS because they attend many medical appointments. It's incredibly frustrating that there are doctors and treatments that may be helpful to certain individuals, but they cannot access them due to insurance barriers.

Gina mentioned that she can only recall one time a professional has understood the extent of her pain. She said a massage therapist "felt how tight my muscles were and told me she was sorry I was in so much pain." Because Gina's experiences have so rarely been validated, she remembers this instance of someone just telling her that her muscles feel tight. The therapist didn't give her a method to manage her pain or anything, she just simply acknowledged how tight she is and how much pain it must be causing. And this is an experience Gina vividly remembers as a time she felt understood. This demonstrates how often professionals dismissed

Gina's experiences because she can only recall one time where her experiences have even been validated. Everyone that I've talked to and read about who has EDS has felt misunderstood by at least one professional in their life, often many.

Many people with chronic pain report professionals not fully listening to their experiences and the extent of their symptoms, therefore they don't provide the patients with beneficial treatment options. Gina explained how she'd been in severe pain for years and didn't receive proper treatment recommendations including various injections that aid with pain, or to use KT tape to help stabilize her joints. The lack of recommendations to treatments that could possibly reduce her pain are evidence enough that her experiences were "misunderstood by most medical professionals." Physicians need to center the patient's treatments according to their symptoms because often providers focus on helping one symptom or region in the body, instead of healing the body tissues as a whole.

EDS is not a visible disability, unless the individual is using braces or devices to assist them. Since people's pain doesn't manifest externally, providers cannot see physical indicators of pain, such as bruising or swelling, so many are told they're exaggerating the severity of their situation. Beatrice said she was brushed off because doctors thought she was "too young to have back pain," which prolonged how long it took for her to receive proper care for her pain. Because she was brushed off so frequently, she would amplify her pain by "jumping, dancing, and doing very active activities without taking my body into consideration." Aggravating tissues early on has significant impacts on the rate that people's symptoms progress. Unfortunately, since many individuals were gaslit or misunderstood by medical professionals, it was a common theme for participants to continue worsening their tissues and pain for many years because they didn't have medical validation for their symptoms.

Difficulty Receiving Diagnosis

As mentioned above, there is insufficient research on the causes of EDS and the most beneficial treatments. The lack of research on EDS and the lack of empathy from medical professionals causes individuals to attend medical appointments for years to understand what's going on in their bodies and trying to receive diagnoses. This takes away years of time that patients could focus on finding proper treatments to benefit their symptoms, instead of wasting significant time, energy, and money at appointments trying to receive a diagnosis. If professionals had a better understanding of EDS and could recognize it quicker in patients, patients could spend more time and energy finding treatments that are beneficial to slowing the progression of their symptoms.

It took many participants countless years of attending medical appointments to receive diagnoses. Beatrice recalled having significant back pain throughout her life, and first seeking medical advice when she was eight. She had several X-rays, which appeared 'normal,' so the providers would send her home with no beneficial information about her pain. She learned about EDS through her Massage Therapy School. Her teacher saw her "flexibility, pain, as well as reactions to certain modalities" that indicated symptoms of EDS. She brought up EDS to her Primary Care Provider and Orthopedic Surgeon, who both formally diagnosed her. Following her diagnosis, they recommended genetic testing to confirm her diagnosis, but as noted above, genetic testing doesn't have high accuracy and it's difficult to get into testing facilities because they're booked out for years.

It took Gina seven years to receive a diagnosis after seeing "three different physical therapists, my primary care doctor, some radiologists, a neuromuscular dentist, a rheumatologist, a cardiologist, a massage therapist, a psychiatrist, and a gastroenterologist who specializes in

patients with EDS." This is not an uncommon experience for people with EDS because very few professionals have knowledge about EDS, so individuals seek care from varying professionals before getting a diagnosis. Gina mentioned how a physical therapist was the first to mention to her that she may have hypermobile EDS. She then made an appointment with a rheumatologist who moved her body into various positions and used the "hypermobile EDS diagnostic criteria" to diagnose her with hypermobile EDS. Sydney reported seeing an "Otolaryngologist (sleep apnea), Neurologist (Migraine, nerve pain, dysautonomia/POTS), General Practitioner (pain, fatigue, iron deficient anemia, anxiety and ADHD), Psychiatrist (ADHD), Chiropractor (joint pain, instability), Physical Therapist (joint pain, instability, mobility, shoulder, hip, SI joint, and foot specific), Orthopedist (Shoulder pain), [and a] Rheumatologist (clinical exam for diagnosis of hEDS)." She visited countless professionals for EDS and other co-existing conditions. Before seeing each professional, she had to complete substantial paperwork, communication with insurance, scheduling, and taking time off work to prepare for these appointments.

Many people reported that they were diagnosed with one or many things before being correctly diagnosed with EDS. Lane got many tests done, that came back negative, so they thought she had fibromyalgia. She did research on EDS and brought it up to her doctor, who agreed that's probably what she has. This was a common experience she had with receiving diagnoses for her other disorders as well. She has postural orthostatic tachycardia syndrome (POTS) and celiac disease in addition to EDS, which also took a long time to diagnose. She expressed her frustration with not being able to receive diagnoses because she spends a lot of time attending appointments, and leaves without much relevant information to her symptoms. Gina mentioned that she was misdiagnosed with "Hypermobility Spectrum Disorder, as well as exercise-induced asthma and Vocal Cord Dysfunction" before getting diagnosed with EDS. She

had many X-rays and an MRI taken for her chronic pain. One time the X-rays indicated bursitis, but otherwise there were no indicators of the cause of her pain. These are just two examples of patients reporting misdiagnoses before receiving the correct diagnosis of EDS.

Many people with EDS do not have official diagnoses for EDS. Cierra, who has not been formally diagnosed with EDS, tests a "9/9 on the Beighton scale (hypermobile test)" and has gotten genetic testing done, but since hypermobile EDS doesn't appear on genetic testing, doctors are unable to officially diagnose them with EDS. They sought physical therapy in 2020, where they were told they had "poor posture" and received exercises that were harmful to people with EDS. Lane also reported that she has not received a formal diagnosis because her doctors said that "there's no real way to test for it." She did her own research on EDS and brought it up to her doctor, who will say she has EDS in appointments, but won't type it in her medical chart since she hasn't been formally diagnosed. Having information in your charts is important for insurance reasons and communicating between doctor's before visiting a new provider.

Some people get diagnosed quicker than others, it depends on the information the providers have about connective tissue disorders and EDS. Sydney sought medical care over the past 20-25 years for many specific recurring pains including knee pain, hand pain, and neck pain, but she doesn't recall any medical professional asking about the hypermobility or pain of her body as a whole, they just focused on specific areas of her body. After learning about hypermobility and EDS, it only took her about 4-5 months before she was diagnosed with EDS. Sydney was diagnosed with EDS based on her symptoms, including "chronic, widespread pain for longer than 3 months, recurrent joint dislocations," dental crowding, hyperelastic skin, family history of EDS, and a high score on the Beighton test of hypermobility. Her EDS diagnosis was confirmed by four separate specialists. X-rays confirmed the slight joint separation of her

clavicle, showing the effects of EDS. Interestingly, she had an MRI of her shoulder that demonstrated that the instability of her shoulder, although incredibly painful, was not causing further damage to her tissues because the joints can move around without harming the ligaments or tendons. The difference between the experiences of Sydney and the other participants in relation to seeking diagnosis is significant. But even though she got a diagnosis quickly after seeking medical care, it took her over 20 years to initially seek care because she didn't have knowledge about hypermobility. The symptoms and severity of EDS present differently for everyone, causing people to be undiagnosed or misdiagnosed for years; therefore, they're not referred to effective treatments early on, which is important for managing symptoms of the progressive disorder.

Medical burnout

Many respondents reported fatigue or burnout from attending countless medical appointments and not receiving respect or beneficial treatments from medical professionals. Therefore, they're now scheduling fewer appointments because it's a waste of their time, energy, and money. Individuals put significant energy into researching medical specialists and explaining their symptoms to new providers. After all of this, people reported frequently feeling their appointments were a waste of time and energy because they left with no beneficial information. People also get their hopes up when seeing a new provider, thinking they'll know a beneficial treatment for their pain, but many people reported feeling poorly when leaving appointments. Because there is limited research on EDS, doctors have limited information about what treatments are beneficial for people with EDS.

Katie explained many times how they would try prescribed treatments, such as cortisol shots in their feet, specific muscle exercises, and stretches, but leave those appointments in more pain than they started with. Katie's doctors wouldn't understand EDS, so the treatments weren't beneficial for their body. Additionally, since their tissues have decreased collagen, it takes people with EDS longer times to heal (Tinkle et al., 2017), so if they over stretch and slightly strain a muscle, it takes them significantly longer to heal compared to people without EDS. This was an issue Katie experienced many times because people didn't understand why they were hesitant to try different therapies. Katie constantly had to decide whether a therapy was worth the risk of increasing their pain, or possibly causing another injury. Since they were the individual making this decision, the 'blame' of trying, or not trying, a therapy is put on themself. For example, they were hesitant about the cortisol shots in their feet, which ultimately caused them significant pain and they didn't take all the injections they were supposed to. They were upset that they decided to get the shots because they knew it was going to make their pain worse, but they wanted to try just in case they might've helped decrease their pain. This is mentally exhausting for individuals because they're constantly hearing about therapies that may be helpful, but they must weigh the risks of furthering their pain.

Cierra said, "I used to go to a lot of doctors appointments, but I have kind of given up on getting a diagnosis and proper help." They explained how they're currently in Physical Therapy, but still cannot get to a place where they can exist without pain. Cierra's spent a lot of energy attending appointments, but they still haven't received a diagnosis. They have little interest in attending more appointments other than physical therapy, which is one of the few things they've found helpful. But it's not helping as much as they'd like. Gina said, "I don't attend many appointments for my EDS anymore, as there's not much else doctors can do." Gina's experiences

with EDS are different from the other respondents in that some of her symptoms have been improving recently. It is very rare for any symptoms to improve over time. But even with some of her symptoms getting better, other new symptoms are developing. She explained that she's been to countless appointments over the last decade, so now she doesn't allocate energy towards attending appointments because she feels there is nothing more doctors can do for her symptoms.

Fatigue & Co-existing Conditions

Fatigue and sleep difficulties are both common effects of EDS (Domany et al., 2018) and they effect each other. Pain is inevitable, so many people have difficulties falling asleep because they cannot find a comfortable position that causes a manageable amount of pain. Once they do fall asleep, if they move into positions causing significant pain, they wake up throughout the night and can have very restless sleep. Beatrice said that "sleeping anywhere but a nice bed is miserable." Domany et al. also found that people with EDS are more likely to have sleep-disordered breathing, obstructive sleep apnea, or insomnia, which impairs their quality of sleep, causing excessive tiredness during the day (2018). Sydney mentioned that sleeping has become difficult and she's developing a "love/hate relationship with" it. In the past two years, she started using a CPAP machine to help what her doctors describe as a "floppy throat" that causes sleep apnea and affects her sleep. Although she said the CPAP has significantly benefitted the quality of her sleep the past couple years, she still struggles to get good sleep "because of shoulder and neck/head pain. I have to sleep in just the right position in order to prevent my shoulder from aching or shifting in/out of the joint, and the muscles in my back and neck are often tense. My neck is like the Princess and the Pea when it comes to pillows, and if things aren't just so, I will wake up with neck pain and or headaches." Sydney's experiences demonstrate the

interconnectedness of different sources of pain and comorbidities that affect people with EDS (Halverson et al., 2023a).

When talking about sleep difficulties, Cierra said “whether its my neck and shoulders in pain, or my hips feel weird, or my back is arched uncomfortably, I can’t get comfortable. Some mornings I wake up in extreme pain from whatever hyper-extended position I got into when I was sleeping. A lot of times I wake up from pain at 3-4am and can’t get back to sleep. It’s hard because I can’t sleep because of the pain, and lack of sleep exacerbates the pain. It’s a vicious cycle.” Sleep is necessary to repair damaged tissues, so without sufficient sleep their tissues cannot be repaired. Many people with EDS have comorbidities of insomnia and/or sleep apnea, which affects their ability to fall asleep and quality of their sleep, on top of their physical discomfort sleeping. Dibley et al. researched the vicious cycle of the effects of chronic illness on sleep and energy (2020). They studied the effects of irritable bowel disease on people’s energy levels, their need for sleep, and struggles resting. Although they were studying IBD, the results they found between the need for sleep and difficulty getting sleep with chronic illnesses is like what many respondents reported in my study.

Many respondents reported feeling fatigue as an effect of EDS. Sydney mentioned the continuous and overwhelming aspects of the physical and mental fatigue that she has from constantly adjusting her body to find more comfortable positions and planning out how to allocate her energy for essential tasks. Sydney explained how it’s difficult to find any comfortable positions because “some muscle or other it tired from trying to hold me upright or move me around.” She talked about her mental fatigue from constantly trying to understand what is going on in her body, how to make it feel better, and who, if there is anyone, she can contact for support. People with chronic illnesses use the “spoon theory” to represent how they allocate

their limited energy (Miserandino, 2013). For example, if someone only had 12 spoons of energy on average every day, this helps others conceptualize how they allocate their energy between getting out of bed, cooking, cleaning, and other tasks. Different tasks require different amounts of 'spoons of energy' to complete. Sydney explains how she tries to manage her energy and pain daily by limiting her time outside of her house, sleeping with her natural circadian rhythm, and resting during the day as she needs. Despite her efforts allocating her energy effectively, she stated, "I feel like [my fatigue] has gotten more intense as I have aged and my body seemingly falls apart." This emphasizes how exhausting it is to constantly alter her body positions and the tasks she does, depending on how her body feels in that moment.

Inconsistent sleep affects people's energy and healing for the following days. This isn't the only factor influencing fatigue, but it does have a large effect on people's energy and their well-being for the following days. It is cyclical because when people have difficulties falling, or staying, asleep, this affects their body's ability to rest and heal during sleep. Therefore, this effects their energy levels when they're awake. Sydney said "fatigue makes literally everything feel like a slog. Full stop. I've been on ADHD stimulation medication for nearly 2.5 years, and being on the medication (as in the 4-8 hours it is in my system) are the only times in my memory when I haven't felt fatigued." Sydney expresses the chronic physical and mental exhaustion from the co-occurrence of ADHD, EDS, and POTS. Fatigue makes everything more difficult, especially for people who have chronic conditions (Dibley et al., 2020).

In a study conducted by Halverson et al., they found that the average number of co-diagnoses for people with EDS is 10.45 (2023a). They found that the most common co-diagnoses included anxiety, depression, migraines, POTS, and IBS. From the responses I received to my questionnaire, I found these results to be accurate. Almost every participant reported having co-

occurring conditions, even though there was no question about co-existing conditions on the questionnaire. When talking about fatigue, Gina said that her daily life has significantly changed since developing EDS, however she is unsure how much this is due to EDS versus other comorbid health conditions, including "severe POTS, chronic fatigue, sleep apnea, insomnia, and also Rumination Syndrome." The list of co-existing conditions Gina has is extensive, and the interconnectedness of the symptoms she experiences is important to note when understanding her situation. She wrote "my fatigue makes most everyday activities difficult—attending class, grocery shopping, multitasking, showering, doing my self-care, sometimes even hanging out with friends. Recently I've been able to shower and do my self-care better" because she's been drinking significant amounts of electrolyte water which have helped her experience less dizziness when doing these tasks. Cierra also mentioned their experiences with fatigue. They said "everything is more difficult when you're in constant pain. I think one of the hardest things is motivation, when you're in pain you don't want to do anything, but you don't have a choice." Dibley emphasized the need to understand the impact of multiple symptoms of chronic conditions, to better understand their fatigue and difficulties with sleep (2020).

Gina's sophomore year of college, she had difficulties managing all the work necessary for her classes as well as attending class because of her pain and fatigue, so she had to switch to a less intensive major her junior year. Additionally, she "received accommodations for both attendance exemptions and deadline extensions" as well as priority registration, which she said have all been beneficial, but that "sometimes even these accommodations are not enough, as I experience severe fatigue and dizziness flares that can last 1-3 weeks and [her school] will only give me 3 day deadline extensions." Because of the physical and mental energy required for school, Gina cannot work because her "fatigue and dizziness is too severe." This year, she tried

to join her first college extracurricular activity, but “it hasn’t been very successful because of the severity of my fatigue and dizziness.” Even though some of Gina’s symptoms have improved over the past couple years, she still does not have enough energy to do schoolwork, take care of herself, and attend many social events.

Misunderstood by Peers and Family Members

Many people in this study emphasized the lack of understanding from their peers and family members. They must spend significant time resting and healing their bodies, which further isolates them from social events and spending time with their peers and family members. Beatrice said she doesn’t think anyone “understands the severity of the pain you experience with EDS unless they’ve experienced some sort of chronic pain themselves. People often don’t have compassion for people with such significant chronic pain because they don’t understand all the ways it affects their lives.” It’s not just medical professionals that lack empathy, but also people’s close friends and family. On top of all the pain and other symptoms of EDS, being dismissed by friends and family members is incredibly isolating. This makes it difficult for people to talk with others about their experiences because no one understands the extent of their symptoms. Beatrice also explained how her family did not understand how significantly EDS impacted her “until they saw me hit rock bottom, unable to work, unable to have any emotional composure, and nearly unable to move.” It’s so frustrating for people to experience these significant life changes, and their families do not even believe their experiences until they “hit rock bottom.”

Many participants explained how being misunderstood by family members and peers is isolating because no one understands the extent of their experiences. Once family members and friends begin understanding the extent and severity of people’s symptoms, they continue making

small, ableist comments about the expected ability of people. For example, Gina explained how someone said, “why didn’t you run and catch the door?” This upset Gina because she was limping and could barely walk from her pain, and her friend didn’t even think about the pain she was experiencing or the impact of her comment. Since then, she’s talked to her high school friends, and they’ve all confirmed that they didn’t believe her pain was severe in high school. It must be incredibly difficult to experience these levels of pain, and to not be believed by the people you’re closest to.

Many people with EDS note how significantly it affects their social lives (De Baets et al., 2022b). They spend ample time and energy taking care of their bodies so they have little energy to spend with friends. Additionally, since very few people understand the extent of their experiences, many people reported feelings of frustration when hanging out with people because they do not know how significantly every task affects their bodies. Ray emphasized how every day her body feels different, so she structures her days around managing her symptoms, which takes away almost all her time to socialize with peers or do things she enjoys. If she does find time and has the energy to make plans with someone, she must plan everything out ahead of time to minimize her recovery afterwards. Lane also talked about how social settings have become more difficult because she’s “constantly nervous that [her symptoms are] going to flare up or get really bad.” This constant stress and anxiety of flare ups affects people’s mood and how they feel during social events. Additionally, since people turn down offers to hangout or cancel their plans last minute, peers often invite them less often (De Baets et al., 2022b). All these factors combine and result in individuals with EDS having fewer social interactions compared to before they had significant symptoms. This is emotionally difficult because people with EDS need a lot of support, but everyone reports feeling isolated from peers and family members.

Daily Life stressors

On top of all the pain, discomfort, and stress of the direct effects of EDS, people have additional stressors including financial, educational, and emotional effects that are affected by EDS. For example, Ray talked about the "daily concerns about if I will be able to complete what I need to, what symptoms it will cause, and if it is worth it." People with EDS are constantly weighting the costs and benefits of different tasks in their lives, to decide what is necessary and what isn't necessary. This is difficult because with limited energy and constant pain, these individuals only have a specific amount of time and energy for necessary tasks. Also, they can't predict how their body will feel a couple hours after doing different tasks, like sometimes there's not a huge effect on their body, but sometimes there's significant pain or fatigue.

Beatrice reported having to "drop out of massage school" following her longest flare up to date because she couldn't perform massages without "excruciating pain." She is now working from home, which allows her more time and flexibility to take care of her body. She said that "EDS definitely comes with a financial burden as well as emotional. I've had several flare up's in the last two years that have put me out of work, unable to pay rent, and back into my parent's houses. Even when seeking treatment the bare minimum for me costs around $300/month and the maximum care costing closer to $1,000+." The cost of medical bills racks up quickly because doctor's refer people to many different specialists to receive diagnoses. From there, individuals often visit many different doctors and therapists to maintain their current pain levels and symptoms, so they reduce the progression of their symptoms. Managing the cost of appointments takes time away from working and is nearly impossible when you're in school and paying your own rent.

Gina mentioned that her family is well-off, so she hasn't had significant financial repercussions, but that she "would probably be experiencing severe financial hardship due to the cost of appointments and my inability to work." The treatments she's been able to access for her EDS and mental health are expensive, which is a significant barrier for people. This emphasizes the monetary barriers within the healthcare system that affects people's ability to receive diagnoses and try beneficial treatments. But she's still facing significant barriers within the education system because they don't understand the extent of her symptoms. Gina said she has had difficulties completing all the requirements for college. She noted that after walking to classes or the grocery store, she knows she'll need a few hours to recover. It is difficult for people to balance everything in our fast-paced world when they need significant time to rest and recover. It is impossible for individuals to allocate their time in ways that allows success in school, work, a social life, and taking care of their bodies. Within a society that emphasizes capitalism and is structured for able-bodied individuals, people with chronic pain are omitted from many social and work-related things.

Difficult Daily Activities

Many people in my study mentioned difficulties with household work and aspects of self-care. These tasks are difficult because they happen on an almost daily basis, are repetitive muscle movements, and take a significant amount of energy. Sydney stated that everyday activities are "absolutely" affected by EDS, and that "at this point, I don't think there are any everyday activities that aren't impacted." Four out of the six participants listed grocery shopping as a difficult task, and all have alternatives for getting groceries. Sydney said mobility is a significant issue while grocery shopping and she "feel[s] increased fatigue, get[s] tachycardia, and

sometimes get[s] lightheaded and nauseated when out standing/shopping for too long." She also talked about how POTS and ADHD affect her experiences in grocery stores, making her sensitive to the lights and sounds of the stores. She feels over stimulated "trying to take everything in, make decisions, [and] stay on task" which uses a significant amount of mental and physical energy. But luckily, her husband enjoys shopping, so he does most of their grocery shopping. Also, with improved online ordering, she's able to place pharmacy, clothing, and household orders online, so she can purchase the items from home. Gina is thankful that she can frequently use Instacart to order groceries, so that she does not have to go into the store to get her groceries. Beatrice mentioned that she completely avoids going to malls or grocery stores because they are "overstimulating as well as draining when you only have so much energy to spare." She tries to avoid doing anything that can be avoided.

Many people reported having significant pain with household cleaning tasks as well as self-care. Beatrice noted that "mopping, vacuuming and shower scrubbing are some of the most antagonizing activities" in her everyday life, and if she's in a flare up "showering, cooking, driving, and cleaning are the hardest tasks to complete." Sydney noted that house care is harder now because of her pain, but her family contributes to household chores, which is helpful. She recently developed a chronic shoulder injury, which has significantly affected her ability to do household chores, including "emptying the dishwasher (reaching above [her] shoulder), vacuuming, swapping laundry from top-loading washing machine to dryer, as well as folding laundry." She usually waits to do these tasks when one of her family members is around. Sydney also explained how her self-care is impacted, especially because of her shoulder injury. She said that doing her hair is a challenge because the motions aggravate her shoulder, especially because she does it right after showering, which also aggravates it. If her energy is low or she has

significant pain, she allocates her available energy towards her children before taking care of herself beyond her basic needs of food, water, caffeine, and medications. It's frustrating for individuals knowing the self-care care and cleaning they want to accomplish but cannot because they must monitor their body's energy and pain that day. People's day-to-day structure changes as their symptoms progress, and many people report these changes significantly impacting their household routines.

Helpful Treatments

As I stated earlier, there aren't currently treatments that are known to help EDS. Many people report a balance between massages, physical therapy, and heating pads to be the most beneficial in managing the progression of their symptoms. Progression of EDS symptoms is inevitable, so these therapies aren't taking away their pain, they just help to slow the progression of their pain.

Beatrice found massage therapy and physical therapy in moderation are beneficial and she avoids most stretching techniques. She has tried "sensory deprivation tanks, cupping therapy, rolfing, reiki, and tens machines," none of which seemed to improve her symptoms. Massages are beneficial, but over massaging muscles makes her pain worse because it takes substantial time to rebuild her muscles and tissues after they're massaged. She also reported beneficial improvements from chiropractic work, that moves her ribs from their subluxed positions to their correct positions. Gina found Physical therapy helpful for her pain and joint subluxations as well. If she needs additional support to hold her joints in place, she uses KT tape, which she's found helpful. Sydney noted that one or two massages a month has been beneficial to her, but they're

only short-term benefits. They help manage current pain, but they do not provide long lasting benefits.

Everyone reported therapies they tried that were not beneficial or made their symptoms worse. Lane said she hasn't found any treatments beneficial. Cierra has found "ice packs, biofreeze, tiger balm, and heating pads" to be the most helpful. They used to take Celebrex, for almost a year, before realizing it's not supposed to be taken for long periods of time. No doctor told them the cardiovascular effects it can have if taken for long periods of time. This is another example of medical professionals lacking the knowledge of treatments for chronic pain because they prescribed them a long-term medication that is only supposed to be taken in moderation. Each treatment works differently for every individual, so everyone has specific treatments that don't benefit them or even make their symptoms worse. Because of this, individuals have to try countless treatments, many of which increase their pain, before possibly finding a therapy that helps them maintain their current pain levels.

Some people undergo surgeries for their most significant injuries. Some people report positive experiences with surgery, but there are also many risks. One risk is the substantial time it takes for people's wounds to heal (Gensemer et al., 2021). Since people with EDS have decreased collagen production, it takes a long time for their tissues, including their skin, to heal from wounds (Castori, 2012). Another risk of surgery is the amount of time individuals must be sedentary after surgery. Since they are not using their stabilizing muscles while they're recovering, their other joints have a higher probability of subluxing or dislocating (Castori, 2012). For example, Ray said "it seems that most treatments that are more invasive such as strong pain medication and major surgeries do more harm than good for me as it can set me back further in the long run." Lastly, it would take years for individuals to have all the surgeries

necessary to decrease their pain, but people in my family have found surgery on their most severe joints has been beneficial.

Conclusion

The experiences of people with EDS are painful, life altering, and chronic. Their experiences deserve validation and empathy, which they infrequently receive. With better medical understanding of EDS, doctors would be able to sooner identify symptoms of EDS, so people can be referred to beneficial therapies early on, to slow the progression of their symptoms. Early care is important because EDS is progressive, meaning the symptoms continue to get worse with time.

My purpose in doing this research is to better understand the impacts of EDS, and share people's experiences with EDS. I hope to educate people about how serious and life altering the symptoms are. I hope, if nothing else, after reading this research paper, you listen with empathy to the experiences of people with chronic pain, instead of approaching them with judgement and criticism. My sibling, Katie, explained their efforts trying to be seen and understood as "Speaking into the Wind" because they put in so much energy into understanding what is going on in their body and trying to manage it, just for doctor's, family members, and peers to dismiss their experiences and believe they were overreacting. The pain for people with EDS is constant, and they have limited energy, so the least you can do is listen to them, to better understand their situation.

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Appendix

Recommended Readings

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