Sibling Experiences of Hypermobility Spectrum Disorder and Hypermobile Ehlers-Danlos Syndrome: An Interpretative Phenomenological Approach

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Portfolio for the Professional Doctorate in Counselling Psychology (DPsych)

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June 2025

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Acknowledgements

At times, I thought this day would not come. The last few years have been incredibly challenging, but throughout all of this, I have been supported by my wonderful family and friends who have kept me going on the days I wanted to give up and who believed in me even on the days I had little belief in myself.

I would like to dedicate this research to my wonderful, kind, strong and resilient mum Susan, who I sadly lost in 2023. Both of my parents in one, my best friend and my inspiration throughout life. Your kindness, support and love I will always take with me.

I would also like to thank from the bottom of my heart, everyone who participated in the study and who shared it far and wide. Without you, this study would never have been possible and I will be forever grateful to you all. To everyone who participated, your strength and humility is beyond admirable. Please continue to speak about your experiences and help others to understand and to raise awareness, so that we can continue to improve the support for everyone affected by the Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorder.

The Psychology department at City, University of London and my supervisor Dr. Fran Smith- you encouraged me to continue and supported me throughout; I am eternally grateful. I also express my gratitude to EDS-UK and HMSA for their unwavering support and willingness to share my research.

I feel now would be an appropriate time to mention that I also have Hypermobility Spectrum Disorder. I did not wish to mention this widely beforehand as I hoped to gain perspectives without this being a factor that could potentially impact the process, but I found it truly inspiring to hear the experiences of people who have a sibling with HSD or hEDS and found comfort in knowing that in some ways, some of my experiences were similar to your siblings'; we were never alone.

To my fellow Zebras, their resilient siblings, their families, friends and everyone affected;

I hear you and I see you always.

Preface

1424 Words

This portfolio, submitted for the Professional Doctorate in Counselling Psychology will consist of three separate pieces of work, but which can all be linked together. I will first explore the contents of this portfolio in turn, followed by the ways in which these can relate to each other and my overall experiences as a Trainee Counselling Psychologist conducting these portfolios.

i. Section A

Section A consists of my original piece of research on the experiences of people who have a sibling with Hypermobility Spectrum Disorder (HSD) or Hypermobile Ehlers-Danlos Syndromes; two interlinked chronic health conditions which are relatively unknown within the medical and psychological fields. This research was conducted using an analytical procedure which enabled rich data to be collected to truly gain a deeper understanding and justify the need for further research into this area, whilst raising awareness of the conditions.

ii. Section B

Section B entails a combined client study and process report. This specifically explores a therapy session with a previous client and my overall experience of working with them in addition to relevant theories, my abilities as a Trainee Counselling Psychologist and areas I recognised for improvement.

iii. Section C

Section C contains a proposed journal article to submit to the Journal of Disability and Rehabilitation, in line with their guidelines.

iv. The Underlying Links

I had already started the processes of collecting data for my research by the point of becoming aware of the requirements to consider how this could link with a publishable paper and a combined process report and client study. Surprisingly, the process report I had submitted as part of my third year of training and which I had initially thought of, appeared to be linked to the research topic I had chosen, suggesting that these appear to be particular areas of interest I have had throughout the doctorate.

My research uses the analytical procedure of Interpretative Phenomenological Analysis (IPA) as I was interested in understanding the lived experiences of people who have a sibling with two relatively unknown chronic health conditions. It is important to note that I do personally have a diagnosis of one of the conditions: HSD and that during the process of conducting this research, I have become aware that I may potentially have been misdiagnosed and in fact possibly meet diagnostic criteria for hEDS. My motivation for conducting this research was in part, due to my personal experience of the condition and whilst I was aware of my own diagnostic journey and experience of healthcare professionals, I was struck by the lack of research on these conditions; even more so on the lack of available guidance or literature for Psychologists. With this being a particular area of interest, I became curious around how we could incorporate the theory we learn throughout the doctorate as Trainee Psychologists, with the experiences of people who have a sibling with hEDS or HSD if they were to enter our services or private practice in the future.

As part of the analytical procedure for IPA suggested by Smith et al. (2022), I needed to consider through rigorous processes, how I made sense of my participants' experiences and to remain aware and curious around why I would make sense of their experiences in a particular way.

This can certainly be linked to the combined process report and client study. This report required me to consider my experience of my client within the therapy sessions and as a

whole, which can be related to what IPA enables us to do as researchers; understanding the unique and individual experiences of people and making sense of it as a whole when combined with other participants' responses.

Additionally, themes I chose to focus upon within the combined process report, included working with a client's guard, how their previous experiences impacted the experience within therapy and how we could make positive therapeutic change with these factors. Within my research, superordinate themes which were revealed during the analysis, included several of these factors. They considered how participants had noticed that their prior experiences of medical professionals due to having a sibling with hEDS or HSD, impacted their view of seeking further personal support for their mental and physical health in the future. In particular, mistrust experienced due to negative experiences of professionals, appeared to be a cooccurring theme between the research and the process report. Furthermore, these negative experiences reported by participants appeared to demonstrate a level of a guarded approach when encountering professionals. The combined process report considers how a guard was able to be decreased with warm and empathic behaviour which strengthened our relationship as it allowed for validation of my client's experiences. I adopted a similar approach within my role as researcher and subsequently found that participants appeared to feel able to openly talk to me about their experiences, including difficult emotions. Interestingly, the process report also considered difficult emotions and how it could feel to experience being understood and heard by others; elements which were also explored within the research study.

The findings from the research study and combined process report can equally reflect the importance of utilising and continuing to implement the skills we learn within our Counselling Psychology doctoral training, around empathy, effective listening, warmth and considering what may be occurring for the person in the background which is not always explicitly brought to sessions. Importantly, they demonstrate the importance of considering people as individuals first and foremost, before we consider diagnoses and symptoms.

v. Rationale around Journal Choice

I have chosen to prepare a publishable paper for the Journal of Disability and Rehabilitation. Initially, I had in mind that a psychological journal may be more appropriate, however it appears that many research articles on hypermobility have been published within this journal, including qualitative research and psychological papers. Upon further consideration, I felt that publishing in a journal that was not specifically and solely psychological, would allow for this research to reach a wider range of professionals who could benefit from the findings and clinical suggestions. As a multidisciplinary approach was suggested from previous literature and supported by the findings of my research, this felt of particular importance to consider; it is not exclusively rheumatologists and general practitioners who come across these conditions, therefore medical journals did not feel appropriate, but nor is it wholly psychologists. A journal which allows for the experiences of the participants in my research to be considered by varying professions, encourages critical thinking around the implications in their respective practices and how improvements can be made to benefit the lives of people who have a sibling with hEDS or HSD. Part of my training as a Counselling Psychologist, requires me to think openly and holistically about the wider picture for clients. This was noted in depth within my process report and also within the main research thesis, thus it felt particularly appropriate to consider how the choice in journal would fit with this.

vi. Experiences as a Trainee Counselling Psychologist

It would be remiss of me not to acknowledge my experiences of conducting three pieces of work as part of this portfolio for my doctoral training. As explored within my research study under reflexivity, not only did I have a diagnosis of one of these conditions for which I was learning how to manage during the doctorate, but I also unfortunately and suddenly became a carer for my only parent during the process, whilst trying to navigate a global pandemic. These experiences ultimately changed how I viewed my world and my practice as a Trainee

Counselling Psychologist, but when I sadly suffered a bereavement, I recognised the importance of placing both my health and equally my clients' needs first. This meant I needed to take the difficult decision to take a break from my studies, stepping away from the research study to navigate my new normal and upon returning to my studies, learning how to manage analysing and acknowledging data which at times reminded me of aspects of my own experiences as a carer. Despite chronic health conditions being a particular interest of mine, there were occasions where I considered whether I could ever return to working with this client group, however being reminded of the strength and resilience of my participants and of my client within my process report, supported me in learning how to adapt and use my previous, but still recent, experiences in a helpful way. Overall, my initial interest in HSD and hEDS was ultimately my motivating factor that has in part, enabled me to complete this portfolio.

Section A: Research Study

Sibling Experiences of Hypermobility Spectrum Disorder and Hypermobile Ehlers-Danlos Syndrome: An Interpretative Phenomenological Approach

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Submitted in fulfilment of the requirements for the degree of:

Doctor of Psychology

as part of the Professional Doctorate in Counselling Psychology

Department of Psychology

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44,680 Words

Abstract

Purpose: To understand how people experience and make sense of having a sibling with Hypermobility Spectrum Disorder (HSD) or Hypermobile Ehlers-Danlos Syndrome (hEDS) and the meaning they place on caring or supporting their sibling.

Methods: Six adults with a sibling diagnosed with HSD or hEDS, who did not personally meet formal diagnostic criteria, participated in semi-structured interviews. Interpretative Phenomenological Analysis was used to analyse data.

Results: Three superordinate themes were identified: i) emotional consequences of having a sibling with EDS, ii) interference with life, iii) absence of support. A transcending theme throughout was the conflict participants experience between having a caring and supportive role for their SWEDS versus being a sibling. Participants reported a lack of trust in professionals due to a perceived lack of knowledge on the conditions. As part of their caring and supportive role, they take on the roles of researcher, advocate and help the family to collectively cope, whilst experiencing a conflict between being a carer or sibling and little support is available for them.

Conclusions: Increased psychological and educational support is needed for siblings and clinicians should consider the views of siblings and the family during the diagnostic process and when considering treatment plans, as they can also be affected. It is imperative to consider rarer physical health conditions before making assumptions and for clinicians to willingly learn about conditions clients present with. This is the first study to date on the experiences of people who have a sibling with HSD or hEDS with previous research focusing on patients and parents and larger studies are warranted in this area.

1.0. Introduction and Critical Review of Literature

This literature review will start by exploring the definitions of Hypermobility Spectrum Disorder (HSD) and Hypermobile Ehlers-Danlos Syndrome (hEDS) and their diagnostic criteria and prevalence, in order to provide an understanding of these conditions for the reader. This will follow with an exploration of the literature around the impact of hEDS and HSD on the patient, family and siblings respectively, in order to truly understand how these conditions can affect not only the sibling, but the wider family. Psychological frameworks that could be applied to the study of people who have a sibling with a long-term condition will also be explored, followed by a summary of the literature identified within this chapter and the subsequent aims of this current study.

"Definitions" will include the meaning of the term *"hypermobility"* and will acknowledge the various types of Ehlers-Danlos Syndrome and how hypermobility is an important factor to consider. "Understanding Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorder" will delve into a deeper understanding of the relationship between these conditions and chronic pain, alongside the symptoms which can be experienced by patients and current recommended treatments. "Experience and Impact of Joint Hypermobility on Patients" examines available literature on how conditions comprising of joint hypermobility can affect the lives of patients, whilst the section "Impact of Chronic Health and Hypermobility on Families" will explore how this can impact the patient's family and also explore literature on chronic health conditions, due to the overall lack of research specifically on hypermobility in this area. Similarly, "Impact of Chronic Health Conditions on Siblings" explores other chronic health conditions and the impact this can have on siblings, due to the lack of research on people who have a sibling with HSD or hEDS. The "Psychological Frameworks" will in turn explore the theories of relationship to help and family systems theory, along with the relevance to the study of siblings. Lastly, the summary addresses

these findings and how these relate to the current study alongside gaps in the literature and closely followed by the subsequent aims of this research.

For this literature review, the various past and present terms will be used as it would be difficult to clarify whether each piece of research has been conducted on participants who would now meet a HSD or hEDS diagnosis.

Databases used for the search included Google Scholar, PsycINFO and researching further into journals, for example the American Journal of Medical Genetics and various journals on rheumatic diseases. Reference sections on papers were also utilised. No date restriction was used, due to the limited amount of research and various reclassifications and it was important to obtain as much literature as possible. Keywords used were previous names the conditions were known as, in addition to chronic pain, family, siblings, relationships, experience(s), support and care. Papers eliminated from the review were those on vascular EDS as there tended to be less of an emphasis on hypermobility as a symptom. In order to gain an understanding of the terms that will be used throughout this research, we will first explore the definitions.

1.1. Definitions

Hypermobility, a term used by Kirk, Ansell and Bywaters (1967) involves laxity of connective tissues, joint instability and the ability to move joints past the usual limits (Malfait et al., 2017). Hypermobility can also be a symptom of a heritable connective tissue disorder (HCTD): Ehlers-Danlos Syndrome (Castori, 2012), which affects collagen produced. There are 13 types of Ehlers-Danlos Syndromes (EDS) and whilst 12 are deemed to be rare conditions (EDS UK, 2017) for which we are aware of the genes responsible (EDS UK,

2017) the hypermobile type is viewed to be the most common type (EDS UK, 2017) and to date, the gene responsible has not yet been identified (EDS UK, 2017).

Since March 2017, the conditions have been reclassified by Malfait et al. (2017) in the American Journal of Medical Genetics as Hypermobility Spectrum Disorder (HSD), Hypermobile EDS (hEDS) or Ehlers-Danlos Syndromes (including hypermobile, vascular and classic EDS). They were previously known as EDS type three (EDS III), EDS-Hypermobility Type (EDS-HT), Benign Joint Hypermobility Syndrome (BJHS), Joint Hypermobility Syndrome (JHS), Joint Hypermobility (JH) and Hypermobility EDS (HEDS). These were terms used since the Beighton criteria (Beighton et al., 1998) and Brighton criteria (Grahame, Bird & Child, 2000), both methods of assessment and screening (Juul-Kristensen, Shmedling, Rombaut, Lund & Engelbert., 2017). Additionally, "the five-point questionnaire" (Hakim & Grahame, 2003) is also used. These conditions consist of a variety of symptoms patients experience, which are imperative to understand in order to make sense of how people who have a sibling with HSD or hEDS could understand their experiences, which will be explored in the next section.

1.2. Understanding Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorder

One of the many symptoms of hEDS and HSD is chronic pain (EDS UK, 2017). This appears to have been noted in many of the research papers available on the conditions. Scheper et al. (2015) noted that people with these conditions frequently report experiencing chronic pain, which Syx et al. (2017) and Tinkle and Levy (2019) corroborate with their similar findings.

Castori et al. (2013) paid particular attention to chronic pain and additional symptoms of hEDS and HSD and found that whilst HSD and hEDS are deemed to be genetic conditions of faulty collagen (Castori et al., 2013), the associated pain is not inherited and is in fact

affected by the environment of the participant. They provide examples of medical procedures, lifestyle choices and trauma and it poses an interesting insight as to how much influence outside influences can impact a genetic health condition. Trauma as an external factor is particularly noteworthy as in this case, Castori et al. (2013) were considering the physical traumas of sprains, strains, dislocations and subluxations, rather than psychological traumas, but the impact these experiences and the subsequent pain could have on an individual's psychological wellbeing, should not be dismissed.

There can be many comorbid conditions associated with HSD and hEDS, which have been highlighted in literature to date. Murray et al. (2013) used an online survey to investigate the lived experience of 466 people with EDS-HT. Interestingly, they note that approximately 90% of participants were women (Murray et al., 2013), suggesting a higher prevalence in females. They reported finding that as high as 99% reported hypermobility and joint pain, but in addition, 73% reported feeling anxious, 69% reported symptoms of depression and 82% reported experiencing chronic fatigue (Murray et al., 2013). Limitations of this research however, are that participants were recruited from the USA, therefore it may be necessary to replicate the research elsewhere, in order to compare findings and establish if this appears to be consistent between countries and different healthcare systems. Additionally, participants self-reported their diagnosis and whilst the study states participants needed a diagnosis from a professional and whilst it could be argued that patients could have a greater understanding of their own conditions considering the lack of knowledge from medical professionals that we have seen from studies such as Terry et al. (2015), De Baets et al. (2017), and Clark and Knight (2017), it is still not confirmed that every participant had received a clear diagnosis.

In addition to physical health comorbidities, links have been found with neurodiversity and mental health. Castori and Colombi (2015) created a flowchart to report their findings on comorbid conditions with hypermobility and in addition to chronic pain, noted a link with the

learning difficulty Dyspraxia, a variety of anxiety disorders and also Attention Deficit Hyperactivity Disorder (ADHD). Yew et al. (2021) also found a link, but noticed that a difference between hEDS and HSD. Whilst various physical health conditions, chronic fatigue and psychological difficulties such as anxiety disorders could be associated with HSD and hEDS, it was less likely to occur comorbidly with HSD in particular (Yew et al., 2021).

Management of the conditions has been debated in more recent years as we become to understand the psychological impacts of the condition. Rahman et al. (2014) had studied the efficacy of a CBT pain management programme for people with JHS who had reported pain and over six weeks, participants engaged in an intensive programme. A multidisciplinary approach was taken whereby both a physiotherapist and a psychologist, taking into consideration both areas of expertise, assessed for appropriateness for taking part in the study and collected pre and post measures, with a one and five month follow up (Rahman et al., 2014). They found that the mental health of participants improved, with reduced anxiety, depression and a deeper understanding of managing pain (Rahman et al., 2014).

However, Gazit et al. (2016) concluded that despite EDS-HT affecting multiple areas of mental and physical health, professionals remain unaware of the condition and therefore unaware of how to appropriately treat patients. They importantly note that this lack of knowledge could be easily improved upon which could reduce the chance of patients experiencing disabling effects from poor treatment management (Gazit et al., 2016). This is an aspect Counselling Psychologists should remain aware of, considering the positive impact we could have on patients by taking the time to increase our knowledge of both physical and mental health conditions our patients present with.

More recently, Yew et al. (2021) highlighted that a multidisciplinary approach is important to consider for people with HSD or hEDS. They noted that in addition to psychological

treatment and physiotherapy, that learning techniques to manage symptoms themselves would be beneficial in treatment plans due to being long-term conditions that need consistent management (Yew et al., 2021). Guedry et al. (2023) made similar conclusions from 353 participants in America, about the need for a multidisciplinary approach. They found that as people with hEDS or HSD seek a range of treatments to manage, such as medication to manage pain, physiotherapy and yoga and that many people with these conditions have low satisfaction with their healthcare due to seeing many professionals, that a multidisciplinary approach would be overall more effective for managing symptoms (Guedry et al., 2023). Despite the study being solely on participants living in America, we can take important lessons from these findings about he importance of a multidisciplinary approach which we generally use within the National Health Service (Carter et al., 2003).

Song et al. (2023) evaluated current psychological treatments recommended to manage HSD and hEDS. They included 10 studies on all ages of participants and ensured there were multiple reviewers to reduce bias (Song et al., 2023). Within the included studies which had fewer than 50 participants, two studies used psychoeducation, one used Dialectical Behavioural Therapy, one focused on Acceptance and Commitment Therapy, four on Cognitive Behavioural Therapy and two on Intensive Interdisciplinary Pain Treatment (Song et al., 2023). They critically appraised the available research and found that a majority of the literature does not note their participants demographic details, the treatment length or regularity (Song et al., 2023). They also noted that studies which reported the ethnicities of individuals, used samples which could not be applied to the wider population (Song et al., 2023) and made recommendations that for psychological therapy for people with HSD or hEDS to be assessed fully, randomised controlled trials with larger and more inclusive sample sizes are needed (Song et al., 2023).

Recent research by Clark et al. (2024) confirms these findings, demonstrating that the advised approach at present to manage hEDS and HSD is to incorporate psychological

approaches to help improve the experiences of patients. Clark et al. (2024) had noted that current treatments tend to have less of a focus on the psychological impacts of the condition and more on the musculoskeletal difficulties and therefore conducted a systematic review of the research. They found six appropriate studies which measured the outcome of psychological therapies on people with a diagnosis of hEDS or HSD and which were either measuring pre and post intervention or a randomised controlled trial (Clark et al., 2024). They concluded that although larger randomised controlled trials are unavailable, therefore there are limited samples available to make conclusions from, a multidisciplinary approach was most efficient, especially when psychological therapy was used in conjunction with physiotherapy as they found this was the most effective in reducing psychological and physical pain (Clark et al., 2024).

Both hEDS and HSD are widely underdiagnosed by health professionals, due to the lack of awareness and knowledge, contributing to them being referred to as rare conditions and Tinkle et al. (2017) and Baeza-Velasco et al. (2017) both describe hEDS as being possibly the most prevalent hereditary connective tissue disorder. It is important to note that an individual may have symptoms of joint hypermobility, but may not experience other symptoms which would lead to a diagnosis of HSD or hEDS (EDS UK, 2017). It may actually be quite usual to experience symptoms of hypermobility. Blajwajs et al. (2023) estimate that between 2-57% of the general population have some generalised joint hypermobility, but that only 10% have symptoms which may warrant a diagnosis of hEDS or HSD. Along with the Beighton Criteria (Beighton et al., 1998) and the reclassification literature by Malfait et al. (2017), we can understand that the ability to move joints past their usual limit is of course, a crucial element of HSD and hEDS, but it is the combination of a variety of symptoms in addition to hypermobility, that contributes to these conditions being deemed as rare. For the purpose of this study, there will be a focus specifically on research and individuals who have a diagnosis of hEDS or HSD, including both older and reclassified terms.

Guedry et al. (2023) conducted a survey in Canada and the United States of America on 353 adults who had a diagnosis of EDS or HSD, to further understand their experiences of having a chronic illness and how they experience the care they receive from health professionals. They concluded that these conditions were commonly underdiagnosed and that understandably, patients felt frustrated with the care they received.

In addition to frustrations with care, the lack of knowledge from both professionals and people with the conditions, has contributed to the average amount of time it takes for people to reach a diagnosis, with it being 10 years in the United Kingdom currently (EDS UK, 2017; Wang, et al., 2024).

Wang et al. (2024) noted that previous literature highlights that the wider population and healthcare professionals tend to have a lack of understanding around HSD and hEDS. This is of particular interest, as although there is generally limited research on the conditions, this appears to be an area that many are inclined to research and a common finding in the literature. For example, Bennett et al. (2021) conducted a thematic analysis on nine studies consisting of 17 adults with the conditions. Out of five themes they identified, “a lack of awareness of Joint Hypermobility and Ehlers-Danlos Syndrome (Hypermobility Type) among healthcare professionals” (Bennett et al., 2021) was noted. They reported that in addition to this, patients also found their support network of family and friends to be lacking in empathy and understanding and hypothesised that this was due to the conditions being less physically visible to others (Bennett et al., 2021). This was corroborated by De Baets et al. (2017) who also found that people reported limited understanding from others due to many of the symptoms seeming unapparent. Ironically, despite their findings noting limited understanding of the conditions from professionals, they chose to use the terms “JHS” and “EDS-HT”, both of which are older terms used before the 2017 reclassification. As this study was conducted after the reclassification, it is intriguing as to why older terms were used.

A lack of empathy and invalidation due to the invisible nature of the conditions, was also found by Berglund et al. (2010) who found this was the case with professionals and with support networks. This is also supported by Yew et al. (2021), who noted that the experiences of people with the conditions can be disregarded by professionals due to a lack of understanding. Similarly, Berglund et al. (2010) found participants reported feeling disrespected by healthcare professionals due to the range of symptoms they could experience and lack of clarity around these. Further research which supports these findings includes Clark and Knight (2017) who concluded that people with hypermobility, or what is now classified as hEDS, had reported feeling that their symptoms were questioned due to the complexity of the conditions.

We can be reminded of the quote “when you hear hoofbeats behind you, don’t expect to see a zebra” (Theodore Woodward, as cited in Ambardekar, 2019), regarding how medical professionals are trained to make sense of patients’ experiences with the most common reasons, rather than the rarer, more unexpected explanations. This approach to medical care is of great concern, as professionals have a duty of care (BPS, 2023) to their patients and this approach conversely suggests that the conditions which may be less common, are to be dismissed and not taken seriously; it does not take into account that whilst they may be more infrequent explanations of health, they do indeed exist and their symptoms are valid. It is of great importance to note for Counselling Psychologists also, as not only is there a risk that patients may be more reluctant to seek help (Clark and Knight, 2017) but equally, there is also a possibility that these experiences may need to be explored with patients if clinicians are in particular, working within a pain management or long-term conditions service.

Invalidation and a lack of compassion from others around these conditions specifically, can, rather understandably, contribute to emotional distress as De Baets et al. (2017) found. They interviewed 10 women, who had a diagnosis of what would now be reclassified as hEDS, on their experiences of motherhood and of having the condition. They used

Interpretative Phenomenological Analysis (IPA) to understand the data and found that every participant reported feeling fearful of negative reactions from their available social support if they were to speak about their experiences of having hEDS. This is striking; for every participant interviewed to report feeling this way after likely having experienced a lengthy diagnostic process, to then feel that they are unable to utilise the support they have available is of deep concern. We understand from previous research, such as De Ridder and Schreurs (1996), that when chronic health conditions are felt to be accepted by our support networks, this has a positive outcome on our mental health and well-being. Therefore if people who have a diagnosis of hEDS or HSD feel unable to seek support due to a lack of empathy, linked to a lack of understanding about these conditions, we can understand that this risks negatively impacting their mental health.

If people are feeling unsupported by their support networks and expecting rejection from those close to them if they disclose their concerns and symptoms, they may experience similar reactions from professionals and we can understand why they may be more reluctant to seek support, which can contribute to, but not fully explain, the lengthy diagnostic process.

Interestingly however, there appears to be little research available on the psychological link between disability and chronic pain in people with a diagnosis of hEDS (Baeza-Velasco et al., 2017). Bulbena et al. (2011) conducted a longitudinal study over 15 years in Spain, to ascertain whether anxiety disorders were more likely to occur in people with a diagnosis of Joint Hypermobility Syndrome (JHS). At the start of the study, participants were between 16-20 years old and living in a rural area and the researchers confirmed whether participants had hypermobility by using a standardised measure of Beighton's criteria (Bulbena et al., 2011). In order to evaluate psychological concerns, they utilised the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) (Bulbena et al., 2011). They

found that 21.1% of their participants had JHS and compared results to participants who did not have the condition (Bulbena et al., 2011). They found that people with JHS were more likely to have a diagnosis of an anxiety disorder, including phobias, social anxiety and panic disorder (Bulbena et al., 2011).

Although the study excluded people who already had an anxiety disorder and recruited from the wider population rather than specific hypermobility related services (Bulbena et al., 2011), it is important to consider that participants were from a rural area of Spain and it raises the question of whether external factors may have influenced the results; for example, are there fewer stressors in rural areas compared to large cities. Additionally, it is unclear whether participants remained in rural areas by the time of the 15 year follow up and external factors did not appear to be accounted for; considering the initial age of participants, they may have been completing higher education which undoubtedly would contribute to additional stressors and anxiety, as previous research, such as Robotham and Julian (2006) has found can be the case.

There are however, several studies which support these findings. Pasquini et al. (2014) also compared people with the conditions to individuals without, using anxiety and depression scales, the Brief Psychiatric Rating Scale and the Structured Clinical Interview for the DSM-IV. They found that people with a diagnosis of the conditions, had a higher risk of personality disorders and were more likely to develop a mental health condition (Pasquini et al., 2014).

Similarly, Smith (2014) conducted a meta-analysis on 14 papers with a total of 1006 patients with hypermobility and 2951 participants without the conditions. They found that people with the condition were more likely to develop panic disorder, anxiety and depression. Additional

studies who also shared similar conclusions are Hershenfeld et al. (2016), who found that out of 106 participants who either had a diagnosis of hEDS or Classical Ehlers-Danlos Syndrome (cEDS), 25.5.% reported depression and 23.6% reported anxiety, with 42.5% overall reporting a mental health condition. They concluded that there is a high prevalence of mental health conditions within people who have a hEDS or cEDS diagnosis (Hershenfeld et al., 2016). Additionally, Sinibaldi et al. (2015) concluded that there is a strong relationship between joint hypermobility and developing anxiety disorders and found that there may also be a relationship between Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD).

In addition to supporting the findings from these studies and also highlighting that Dyspraxia, substance misuse and eating disorders appear to have a relationship with hypermobility, Baeza-Velasco et al. (2015) concluded that their findings demonstrated the necessity of assessing symptoms of mental health disorders in people with hypermobility. They made recommendations that research therefore continues to investigate this apparent link (Baeza-Velasco et al., 2015).

Despite a large amount of the studies which investigate the link between psychological disorders and hypermobility focusing on participants from one specific country, they add to the overall literature available and appear to support each other's conclusions that there appears to be a link between having HSD or hEDS and developing mental health conditions. With this prevalence apparent, Counselling Psychologists need to remain aware, so that this can inform our practice as scientist-practitioners.

Literature has also explored how patients experience the healthcare system and made recommendations for professionals. Rather disappointingly however, research has found

that people with hEDS or EDS can be treated poorly by healthcare professionals (Berglund et al., 2009) or that psychological disorders are explored before the possibility of a chronic physical health illness is considered (Berglund et al., 2010; Sulli et al., 2018).

Berglund et al. (2010) asked people with EDS to complete a questionnaire related to their experiences with seeking healthcare. They used a narrative content analysis and found themes in their research relating to poor treatment by professionals, consideration of experiencing abuse by family members and symptoms being understood in the context of psychological disorders (Berglund et al., 2010). They understood their results to demonstrate that these negative experiences can have lasting impacts on patients including a mistrust of services and subsequently made recommendations for professionals to consider patients as being able and with differing needs and symptoms (Berglund et al., 2008). Whilst these findings are certainly concerning; Berglund et al. (2010) even titled their research to highlight the negative experience people with a diagnosis of EDS have; it is important to note limitations to this study. Berglund et al. (2010) acknowledged that the questionnaire used to collect data was specifically asking about experiences patients had when they felt they were not respected and that participants were attendees of an EDS conference. Subsequently, it is possible there may have been leading questions or participant bias. Additionally, participants had a range of EDS diagnoses, of which there are 13 types (EDS UK, 2017), therefore it was not specific to the hypermobile type and also did not include people with a diagnosis of what would now be referred to as HSD, for which we do not know if different responses would have been elicited had they been included in the study.

Sulli et al. (2018) also found that people with a diagnosis of EDS can experience mistrust from clinicians, with symptoms questioned and serious accusations of Munchausen-by-

Proxy and Munchausen (now respectively referred to as Factitious Disorder Imposed on Another, and Factitious Disorder Imposed on Self) and psychological disorders being explored by healthcare professionals before the rarer physical health conditions are considered. These are extremely concerning and disappointing findings which Counselling Psychologists need to remain aware of as we need to ensure we balance our duty of care, along with ensuring we are considering a holistic viewpoint of what may be happening for our service users. Sulli et al. (2018) also highlight that as these experiences can understandably impact a patient's mental health, that there should be further psychological interventions to support patients.

Literature on the conditions has suggested that there should be an emphasis in future research on how to increase professionals' awareness of HSD and hEDS (Bennett et al., 2021).

Whilst there generally appears to be rather limited research on hypermobility and Ehlers-Danlos Syndromes, research appears to have largely focused on explaining the conditions or patient experiences. rather than the experiences of the families of patients. There appear to be some studies on the experiences of parents of people with the conditions, such as Baeza-Velasco et al. (2011) and De Baets et al. (2017), but the people with hypermobility or EDS tend to be children or adolescents, rather than adults. To date, there do not appear to be any studies on other family members who have a caring and supportive role.

1.3. Experience and Impact of Joint Hypermobility on Patients

Previous research has examined patient experiences of JHS, including diagnosis and management, such as Terry et al. (2015). However, it has focused on patients who are

known to specialist hypermobility services (Palmer et al., 2016; De Baets et al., 2017), genetic clinics (Bovet, Carlson & Taylor, 2016), or who have been receiving physiotherapy for a substantial amount of time (Terry et al., 2015). Although Terry et al. (2015) recruited participants who had been receiving physiotherapy for a minimum of 12 months, Palmer et al. (2016) and Bovet et al. (2016) did not specify how long their participants had been aware of their diagnosis. It is important to note that patients who have a prior diagnosis for a substantial amount of time, could potentially have a deeper understanding as to their condition, compared to newly diagnosed patients. These studies also focused towards the experiences of physiotherapy, rather than alternative therapies, e.g. psychological interventions.

Castori et al. (2012) reviewed literature on JHS and EDS-HT and reported that as lethargy and pain is still not completely understood in individuals with these conditions, this has resulted in a lack of knowledge surrounding the most effective long-term treatment. They also concluded that there appears to be little evidence-based research demonstrating the effectiveness of treatments for lethargy and pain in JHS. However, the PubMed search conducted had only included the terms “hypermobility”, “pain” “fatigue” and “dysautonomia”, not considering terms related more specifically to JHS or EDS-HT, despite having referred to these conditions in the literature review. Therefore, this study may be more related to general hypermobility and may demonstrate a lack of literature reviews specific to JHS/EDS-HT.

Studies as recent as Bovet et al. (2016) have also recognised that research does not appear to identify the most effective treatment for patients, in order to manage their symptoms; rather research suggests that a range of treatments are used (Chopra, et al., 2017; Bovet et al., 2016), including physiotherapy, medication (Chopra, et al., 2017), pilates (Bovet et al.,

2016) and that rather than treatment focusing on specific joints, it could be more useful to focus on the entire body (Palmer et al., 2016). Castori et al. (2012) recommended using a multidisciplinary approach for patients to manage various areas of the pain experienced. This could be helpful in alleviating the concern that as JHS can be experienced in a variety of ways (Baeza-Velasco et al., 2011), one type of treatment may not be as effective for all individuals, therefore focusing on a variety of treatment methods could be more effective. However, it does raise the question of how the lack of clarity regarding the most effective treatment influences the patient's experience and whether this affects their mental health. Furthermore, could this decrease their quality of life? This does not yet appear to have been researched.

It is crucial to acknowledge that despite the clear negative impacts of the condition on an individual's life, there can be advantages. Although this has been identified for several decades, such as Grahame and Jenkins (1972) who studied 52 professional ballet dancers and a control group of student nurses using the Beighton criteria and a quantitative test of manoeuvring joints, there does not appear to be a large amount of research on the advantages; rather research focuses on the negative impacts. The advantages can include being able to engage in activities where a larger range of movements would be useful. This is corroborated by Castori (2012) who identified through a review on the factual knowledge on JHS/EDS-HT available, but without critically evaluating studies, that it be a strength for gymnastics. Furthermore, Larsson, Baum, Mudholkar and Kollia (1993) concluded from the reported experiences of 660 students and staff members, that JHS can also be a strength for playing musical instruments. Additionally, Foley and Bird (2013) explored the usefulness of JHS for ballet, by using a dancer's perspective and the standardised criteria for measuring JHS, concluding that JHS was an asset for success within the activity, provided management and support was available throughout training. It was an interesting to gain the viewpoint of the dancer in this instance as it highlights a need for further research to include

individuals' positive experiences of JHS, even if there may be fewer positive aspects. It also highlights that research specifically investigating the positive experiences of JHS has tended to use quantitative methods, such as questionnaires and whilst this can be useful for investigating larger sample numbers, such as Larsson et al. (1993), it does not necessarily provide open-ended questions or the opportunity for detail to be obtained.

Although a majority of research appears to have used qualitative methods when exploring patient experiences and quantitative methods for examining positive experiences, when quantitative methods have been used, such as Hagberg, Berglund, Korpe, and Andersson-Norinder (2004), questionnaires investigating the variety of ways the condition can impact an individual, were used. However, Hagberg et al. (2004) focused on individuals who had a diagnosis of EDS rather than JHS and although a control group was included, they used closed-ended questions which did not allow for in-depth detail to be obtained from participants regarding their experiences. Although this clearly identifies a gap in the literature for quantitative methods regarding patient and family experiences, it also justifies the need for qualitative methods so that detailed and rich information can be obtained, in order to further understand the impact of hEDS and HSD and to identify further methods of support for both patients and families. Using a qualitative method would also not allow for questions to be directive to participants and would allow for new themes and topics to be recognised and explored. These conditions also can affect the wider family which will be explored through the literature below.

1.4. Experience and Impact of Chronic Health and Hypermobility on Families

Overall, there appears to be a lack of research focusing purely on the experiences of families of individuals with JHS, particularly how they can manage and cope with the

condition, therefore the impact of chronic health conditions on families will also be explored in this section.

Gurley-Green (2001) identified that children of JHS patients could experience anxiety from viewing the difficulties their parents endure. They also identified that the partners of individuals with JHS can feel irritated due to the impact the condition can have on their partner's ability to engage with the family (Gurley-Green, 2001). Interestingly, Gurley-Green (2001) also identified that involving the family in the patient's interventions could aid their management, yet it does not explore what the impact of doing so would be on the family individually. They concluded that the conditions affect not only the patients but the family and caregivers and made recommendations that professionals should consider treating the family due to the impact (Gurley-Green, 2001). Interestingly, whilst Gurley-Green (2001) also identified that involving the family in the patient's interventions could aid their management, they does not explore what the impact of doing so would be on the family individually.

However, despite this research identifying several interesting ideas, the author was reporting on their own experience of being involved with the Hypermobility Syndrome Association and therefore patients were not directly interviewed or involved in the research. Furthermore, whilst it is interesting to gain the perspective and experience of professionals, the face validity of the research can be questioned as despite challenging the literature, no additional references were included.

Nevertheless, there is research available on the experiences of parents of individuals with EDS, linked to JHS. Although it is fairly limited and dated, it identifies important points to consider if investigating family experiences for hEDS or HSD, such as how parents with the

condition can experience anxiety surrounding transmitting JHS to their children (Berglund et al., 2000; Baeza-Velasco et al., 2011). This is corroborated by De Baets et al. (2017), who focused on the mother's experience and identified that parents with a child who also has JHS may experience guilt for passing the condition on to their child.

Whilst Gurley-Green (2001) and De Baets et al. (2017) did not focus on adult family experiences, there were a limited amount of studies which did consider the impact on parents and caregivers.

Bell and Pearce (2022) had found from their study on caregivers and parents, that caregivers take on additional roles, such as researcher, in order to support their children. Bell and Pearce (2022) explain that this is due to caregivers finding the understanding of healthcare professionals to be insufficient and therefore they have felt they need to take matters into their own hands by researching and improving their own understanding on the conditions. They also reported irritation felt by caregivers at what caregivers had perceived to be a necessity to improve the support available for their children and that they had identified that this could differ from their role as a caregiver (Bell & Pearce, 2022). Interestingly, this suggests that their participants experienced the role of researching the conditions to improve their personal understanding, to be separate from their role as a caregiver.

In support of this research, Somers et al. (2024) conducted semi-structured interviews on four people who have a child with hEDS and used Interpretative Phenomenological Analysis (IPA) to understand their experiences. They found that hEDS not only impacts patients physically but also psychologically and financially and these therefore share an impact on parents (Somers et al., 2024). They reported that participants noted communicating with

healthcare professionals to be a difficult experience, corroborating research by Terry et el. (2015), De Baets et al. (2017), Clark and Knight (2017) and Bell and Pearce (2022) respectively, and that this had meant there were challenges accessing appropriate care. It is important to note however, that this was a limited sample size of four parents and that they were specifically recruited from a specialist clinic, meaning that it may be difficult to generalise this to the wider population. We are also unaware as to whether these experiences were shared between both parents of the child and of the experiences of any further family members including siblings.

Bieniak et al. (2022) looked at the difficulties caregivers of children with a diagnosis of hEDS and the children themselves experience, using a mixed methods approach. They found that the ways in which patients and caregivers manage with the condition differs, but that they in general, agree on the difficulties the condition poses (Bieniak et al., 2022). Recommendations were made that healthcare professionals should consider the differences and the shared experiences in coping in order to inform treatment. et al. (2022) also compared the experiences of 36 patients aged between 10-20 years old with a confirmed diagnosis of either cEDS or hEDS and their caregivers using surveys, and found that whilst generally children and parents agreed with each other, there were still aspects they disagreed on. They made similar recommendations to Bieniak et al. (2022) that the views of parents should be considered as these may differ from the patients (Wang et al., 2022). Interestingly, Wang et al. (2022) excluded patients who had conditions such as Autism Spectrum Disorder (ASD), but as we understand from Sinibaldi et al. (2015), ASD may have a relationship with hypermobility and therefore by excluding this client group, they potentially could have excluded people who have a diagnosis of hEDS and whose experiences are still very much valid and important to consider as these may differ from the experiences of people without comorbid ASD.

Ojeda et al. (2014) looked at how chronic pain generally can affect families, but this did not specifically explore HSD or EDS. They found out of 131 family members of Spanish adults who experience chronic pain, that 51.2% of family members had felt there was an impact on their sleep and enjoyable activities and therefore concluded that treatment should consider the experience of all involved, as this would positively improve their quality of life and improve the outcome of treatment (Ojeda et al., 2014).

Birt et al. (2013) a year prior, had similar conclusions. They used semi-structured interviews on 28 families of children with hypermobility, to understand how families can impact whether children and adolescents engage with their treatment plans, specifically physiotherapy (Birt et al., 2013). This study had recruited families who had already been engaging in a randomised controlled trial for a multidisciplinary treatment plan (Birt et al., 2013). As they were taking part in NHS interventions, the results could be generalised to the wider population in the United Kingdom (UK). They analysed date using a thematic approach and found that families who understood the advantages of the treatment, who encouraged their children to engage in the treatment plan and who incorporated this within family life, had more positive outcomes overall with their children feeling motivated and completing treatment plans (Birt et al., 2013).

Russek et al. (2019) also conducted research focusing on physiotherapy for hypermobility and made recommendations to educate both the family and the patient to reduce injury risk and promote independence with managing symptoms. They specifically advised on educating people with the conditions and their caregivers about reducing stress and pain and noted the use of Cognitive Behavioural Therapy (CBT) techniques to manage (Russek et al., 2019). This further highlights the importance for Counselling Psychologists to be

aware of how theory and a holistic approach can support people with HSD or hEDS and their families and caregivers.

Somers et al. (2024) in a recent study, supported these findings by conducting a qualitative study on four parents and using Interpretative Phenomenological Analysis (IPA). Whilst participants were attendees of a specialist clinic and participants had a diagnosis of EDS, rather than specifically hEDS or HSD, they made sizable conclusions; they concluded there is an evident necessity for treatments that consider the patient and their families and that these treatments should focus on their education, mental and physical health (Somers et al., 2024). They also discussed the importance for professionals to be aware of how to support not only the patients but their families which they believe will overall help to support the patient (Somers et al., 2024).

Hypermobility is a chronic pain condition (Chopra et al., 2017; Baeza-Velasco et al., 2011) and whilst research has focused on the experiences of families of individuals with chronic pain, it does not directly investigate joint hypermobility syndrome, highlighting the lack of research surrounding this area. Palermo (2000) reviewed the literature and acknowledged that studies have not focused on how chronic pain influences the amount of burden parents experience or the impact on their emotions. Although the study reviewed literature on adolescents with chronic pain (not including JHS) and is fairly dated, it brings to attention the point that parents experience guilt, as corroborated by De Baets et al. (2017) and the impact could potentially be significant in a variety of ways which have not yet been researched in depth. Interestingly, it also concluded that parents reinforcing “the role of the sick” on their children helps the patient maintain these behaviours (Palermo, 2000). However, this again focused on additional chronic pain conditions, revealing the lack of research on the effect of specifically hEDS or HSD or the reasons why the family engage in this behaviour.

Edwards, Zeichner, Kuczmierczyk and Boczkowski (1985), conducted a study with 288 college students identifying whether individuals with family members reporting frequent pain, would be more likely to experience pain themselves. They concluded that families reporting pain do have an impact on each other by increasing the likelihood of other family members reporting symptoms of pain and subsequently learning avoidant behaviours from each other. It also identifies a gender difference, stating that females tend to report more pain than male familial members.

However, there appears to be a flaw in the methodology as the study had used a questionnaire containing symptoms of 10 pain conditions and had asked participants to report whether their family members had also complained of pain. The questionnaire did not allow for participants to report any additional pain symptoms that may not have been originally included and it relied on the subjective perspective of participants having noticed their family members reporting pain and self-report measures. Furthermore, the 10 common pain symptoms included may have now changed due to being a fairly dated study.

As there appears to be limited research on how HSD and hEDS can affect siblings, the impact of other chronic health conditions on siblings will be explored in the next section, alongside how this is relevant to the current research.

1.5. Experience and Impact of Chronic Health Conditions on Siblings

Chronic health conditions not only affect patients, but also those around them (Morlion et al., 2008; Rea et al., 2019; Soltani et al., 2022) and there is a potential that people with a caring and supportive role could be affected in particular.

There appears to be little research on the experiences of the wider family unit of people diagnosed with HSD or hEDS, with research seeming to focus on the patient and their parents. However, studies have certainly become more available in recent years on the experiences of people who have a sibling with a long-term condition unrelated to HSD or hEDS.

Research, although limited, is available on considering the experiences of people who have a sibling with a chronic health condition. To date, these have not included siblings of people with hEDS or HSD. Morlion et al. (2008) explored a treatment protocol to use in Europe to manage chronic pain. They noted that not only does chronic pain affect patients, but also their families (Morlion et al., 2008). Likewise, Rea et al. (2019) conducted a systematic review on the efficacy of recreation camps for siblings who have a chronic health condition and their families and noted families are also affected; they stressed that siblings of children who have a chronic health condition, can be more likely to develop challenges psychosocially. Similarly, Soltani et al. (2022) highlighted that the experiences of siblings of people who have a chronic pain condition have not yet been researched. They focused on gaining a further understanding in the context of the COVID-19 pandemic in Canada and noted that siblings experienced significant worsening of their mental health (Soltani et al., 2022).

This supports the importance of conducting further research into understanding the experiences of siblings, particularly around conditions that are already not fully understood, and for informing the practice of Counselling Psychologists who will be supporting siblings with their worsening mental health and will need to understand the context patients may be experiencing, in order to fully inform practice.

Recent research by Linimayr et al. (2025) identified 62 studies on the experiences of people who had a sibling with a chronic condition which started in childhood, These conditions included Autism Spectrum Disorder (ASD), Down Syndrome, Chronic Kidney Disease and Cancer. They concluded that participants had acknowledged their part in caring for their sibling and that this could entail increasing their knowledge around their sibling's condition, supporting with medical responsibilities to reduce the impact on their parents and providing emotional support. However, they noted that whilst siblings tended to have a range of views on whether they required a support group or felt this was unnecessary, some participants had not been informed of possible support available for them. Whilst a variety of databases were used within their search and it was clear they looked at research published over 23 years, they did not focus on studies with adult participants and only included studies in German or English, meaning not all relevant studies were included.

Similarly, Hilário (2022) conducted a thematic analysis on a narrative review and noted that people who have a sibling who is a child with a chronic illness, have reported increased responsibilities and care. This is further corroborated by Woodgate et al. (2016) who also conducted research on a variety of conditions, rather than focusing solely on one and considered the support needs. They interviewed 16 people who have a sibling who is a child with complex care needs. Woodgate et al. (2016) concluded that siblings placed importance on the needs of the wider family, suggesting there was less focus on their own. Additionally, they highlighted that it is imperative for professionals to consider the experiences of people who have a sibling with complex care needs in order to be able to fully support them (Woodgate et al., 2016). They used open-ended questions and participants were a mix of nine females and seven males, but they did not focus on adults and Woodgate et al. (2016) had noted there was a lack of variation with ethnicities which could pose difficulties for generalising elsewhere.

Kirk and Pryjmachuk (2024) who conducted a thematic analysis on 22 adults, noted that the experiences of people with a sibling who has a life-limiting condition, can develop throughout their life, and that this may change depending on what they perceive to be the needs of the family and of the person with a life-limiting condition. This is of particular importance as it is one of few studies that appears to identify the experiences of people who have an adult sibling and it allows for reflection around how this could impact the support they may require. Additionally, as reflexivity was included as part of their analysis, this would have reduced researcher bias strengthening the results of this study. These results should be noted when considering studies such as Hanvey et al. (2022), where a thematic analysis on 16 participants who had a sibling with a chronic illness identified a theme that participants lacked awareness of their own needs and that subsequently, they may not receive the support they require. This could be partially explained by findings from Kirk and Pryjmachuk (2024), as if their experiences change over time, this could potentially affect awareness of personal needs which may also be adjusting.

Studies have also considered the psychological impacts on people who have a sibling with a long-term condition. O'Brien et al. (2009) noted that at the time there seemed to be a lack of research on how to support people who were siblings of children with a long-term illness. Seventeen studies were reviewed and they found that research demonstrated people who have a sibling with Down's syndrome versus people who have a sibling with ASD or Cancer appeared able to adapt more effectively and experienced less of an impact on their mental health (O'Brien et al., 2009). They highlighted the importance for clinicians to be aware of the potential impact on siblings and the differences shown in this study between conditions demonstrate how vital it is that research is conducted on the experiences of people who have a sibling with hEDS or HSD. The natural variation in these two conditions suggests there could be a variation in experiences, which needs to be acknowledged, but is a strength

of this study ensuring that the psychological impacts were explored across a variety of conditions.

Conversely, Derouin and Jessee (1996) explored how fifteen participants understood how their sibling's illness of asthma or cystic fibrosis could have affected them using open-ended questions and a measure on self-esteem. Whilst they found participants experienced their relationships with their family as stronger due to the conditions, they also noted that there were significantly higher levels of worry around the condition (Derouin & Jessee, 1996). This is corroborated by Vermaes et al. (2012) who noted from a meta-analysis on ten studies that if a sibling's condition was deemed as life-threatening or if the participant was of an older age, they experienced a higher risk on their mental health being impacted.

Additionally, Limbers and Skipper (2018) conducted a systematic review and noted that people who have a sibling who is a child with a long-term condition, can exhibit more reserved behaviour. They understood this to be due to more of a focus from the wider family, being on their sibling (Limbers & Skipper, 2018). This could suggest a lack of support for participants, but as only nine studies were included, this warrants further research.

However McKenzie Smith et al. (2018) queried the efficacy of support aimed at improving psychological health using a systematic review of 17 studies and found that there were noticeable benefits on their mental health, although as studies included were only in French or English, it has not captured all relevant studies available. Martinez et al. (2022) supports these findings by concluding from a systematic review and meta-analysis on 34 papers, that there was a higher risk of depression if an individual had a sibling with a long-term conditions and that they recommended for support to focus on reducing the impact on their mental health. A wide variety of conditions and locations of studies were included, meaning this

could be more readily generalised to the wider population, however they only used research written in English meaning some relevant research could have been excluded.

There is also extensive research on the experiences of people who have a sibling with a form of neurodiversity, such as Developmental Coordination Disorder (DCD) or Autism Spectrum Disorder (ASD) with conclusions that are imperative to consider with this current study.

Cleaton et al. (2018) conducted research on the families of children in the UK who had a diagnosis of DCD using mixed methods including a survey. They noted that this affected their quality of life, particularly due to feeling unsupported by clinicians and siblings in particular experienced negative impacts on their mental health. However, as Cleaton et al. (2018) noted, it was biased due to convenience sampling and they did not obtain ethnicity, meaning it is difficult to generalise outside of this study.

Morris et al. (2021) conducted a thematic analysis on 10 adults in the United Kingdom who had a sibling with a diagnosis of DCD. One of their themes included a perceived lack of knowledge around DCD and they highlighted the importance of available support for people with a sibling with DCD. The study included siblings with DCD from a wide range of age groups, allowing for the experiences to be generalised to the wider population and a significant strength of the study was that it captured the varying experiences of people who have a sibling who is a child versus a sibling who is an adult. This allowed for different dynamics and roles between siblings to be explored.

Angell et al. (2012) conducted research on children aged 7-15 using grounded theory and found participants supported their siblings with their ASD and advocated for them. They also noted that participants experienced an increased ability to adapt to changing circumstances within the family, but that validation from others was important to them and recommendations were made to continue researching how best to support people who have a sibling with ASD (Angell et al., 2012). If there were multiple siblings of the same family member with ASD, they were eligible to take part which would have allowed for an interesting perspective on their subjective experiences of the same sibling, but it is unclear whether this did occur within participants. Additionally, tables included the age and gender of the sibling with ASD; it is unclear whether the sibling provided consent for their information to be shared, but given the young ages of siblings with ASD (6-15 years), it could be unlikely.

Leedham et al. (2020) also found that participants supported their sibling with ASD with their needs and they noted these were understood to be separate from what they experienced to be their usual role as a sibling. They conducted a thematic analysis on 18 studies from a systematic review of research available and highlighted that this additional support from participants towards their sibling meant what they needed emotionally and practically was not acknowledged (Leedham et al., 2020). They concluded that this subsequently affected their own mental health, but noted participants still reported positive emotions such as empathy (Leedham et al., 2020).

This conflict between positive and negative experiences of having a sibling with ASD was also acknowledged by Ward et al. (2016) Semi-structured interviews on 11 males and 11 females who had a sibling with ASD noted that positive emotions towards their sibling were experienced by participants, but that they had also experienced themselves as having

responsibilities for their sibling and less support from their parents (Ward et al., 2016). These findings support previous research by Green (2013) who concluded from 14 studies that it is imperative for the wider family to be acknowledged in treatment plans for people who have a diagnosis of ASD in order to reduce the potential negative impact on their psychological health. However, it is important to note that Green (2013) highlighted research included adolescents and children, which they viewed as meaning it was difficult to make conclusions due to the differences in life stages (Green, 2013); an area to consider for future research.

Due to the complexities around receiving a diagnosis for HSD or hEDS and the unpredictability of symptoms, in a more general sense, it is crucial for research to be conducted within this area, not only to increase awareness and understanding of the conditions, but in particular, how people with a caring and supportive role can be affected and the support they are able to receive. If we consider the importance for Counselling Psychologists, we need to be aware of how to consider the potential impact of these conditions on the people we see in our practices. Simmonds and Keer (2008) recommended that a holistic viewpoint is needed for JHS and it is here that Counselling Psychology can be linked, due to the holistic outlook throughout Counselling Psychology training and the opportunity to embody this throughout future research on the experiences of individuals related to the topic of hEDS and HSD. If psychosocial factors are to be considered within HSD and hEDS (Murray, 2006), Counselling Psychologists must be aware of this, not only for when people with the conditions enter our practice, but also for the people who have a caring and supportive role, so we can help prepare them for the possibility that symptoms may develop, let alone worsen and so we can support them in navigating a new normal and the impact this may have on the family dynamics.

Research on this area will also highlight additional ways professionals, including Counselling Psychologists can support patients and families with the symptoms of the conditions and mental health disorders associated with receiving the diagnoses and caring for people with the conditions. Research on people who have a caring and supportive role for someone with HSD or hEDS would also allow the opportunity to explore current support available and to highlight additional methods of support or changes to what is available.

It is important to remain aware that JHS can have an impact not only on the patient and health professionals, but also on the patients' family and friends. Gallant (2003) identified that social networks provide support for chronic illnesses and whilst participants included did not have an HSD or hEDS diagnosis, it is crucial to consider for these conditions due to the chronic nature. Research also found that patients with JHS can feel detached from friends and excluded due to their condition and surprisingly, that they sometimes socially isolate themselves (De Baets et al., 2017). This could be partly due to individuals fearing a negative reaction (De Baets et al., 2017), but also perhaps due to a lack of understanding of the condition from their social network.

As we understand the chronic nature of HSD and hEDS, but have no research on how people who have a sibling with these conditions could be affected, it is crucial that we acknowledge that current literature on other long-term conditions could be highlighting potential difficulties they could be facing. If we remain unaware of these challenges, we reduce our ability of being able to support and understand this client group not only within society, but also within our practice as Counselling Psychologists. Within our practice, we consider psychological frameworks to formulate and make sense of the experiences of our clients and two particularly relevant theories will be explored below.

1.6. Psychological Frameworks

Two particular psychological frameworks which are important to consider when understanding the experiences of people who have sibling with a chronic health condition, particularly hEDS or HSD, are the relationship to help and family systems theory, which will be explored in turn along with the relevance to this research.

1.6.1. Relationship to help.

The theory of relationship to help (Reder & Fredman, 1996) is of particular interest when studying the experiences of siblings. They state that early family experiences have shaped how we understand and seek help and that we come with expectations around how we want to provide help and how we want to be helped (Reder & Fredman, 1996). Reder and Fredman (1996) also considered that early experiences of support from previous caregivers who had a role in providing help, would shape future ways of understanding the relationship to help. They noted that if people had experienced being dismissed or their needs neglected, then they expected the same experience in the future from others who could provide help (Reder & Fredman (1996).

Interestingly, Reder and Fredman (1996) found that the therapeutic relationship can be greatly influenced by a personal understanding and beliefs about the process of help, from both clinicians and clients. They found that with their clients, they noticed this happening in the form of their suggestions in therapy being rebuffed and therefore feeling that clients were experiencing the therapist as not meeting their needs (Reder & Fredman, 1996). They confirmed from their findings that these early experiences influence how clients relate to their therapist and what they are able to bring to the session, or whether they are able to fully engage with support being offered (Reder & Fredman, 1996). Additionally, they noted that if there had been negative experiences of clinicians, these could impact how individuals

experience future help and that at times, this could lead to therapy interfering behaviours, such as not communicating to the therapist and non-attendance (Reder & Fredman, 1996). However, they note that clinicians also of course have their own beliefs and ways of understanding and that their way of making sense and responding will be based upon their own experiences and beliefs (Reder & Fredman, 1996). When conducting research on people who have a sibling with a chronic-health condition, these aspects can support the researcher to have a deeper understanding of participants' behaviours and not only the level of detail participants provide, but the experiences they describe.

It is important to consider the wider context to understand the behaviour (Reder & Fredman, 1996). Part of this context could be the shared beliefs between the family about how to support each other, e.g. seeking support elsewhere, which could be influenced by different cultural views (Reder & Fredman, 1996). They use the examples of "..you only see a psychiatrist or psychologist if you are 'mad', or that contact with social workers should be avoided because they 'take your children away'." (Reder & Fredman, 1996, p. 461) and the example of "most men still believe that they should not reveal themselves as vulnerable or needy and feel threatened if they experience emotional problems.." (Reder & Fredman, 1996, p.461). These examples are of particular interest when conducting research on physical health conditions which are widely misunderstood by medical professionals, as people involved in supporting the person with hEDS or HSD may have certain expectations of clinicians which may be shared between the family and these expectations may also impact whether they take part in research such as this current study and in how they may respond to the researcher.

1.6.2. Family systems theory.

Family Systems Theory is another important psychological framework to consider when studying the experiences of siblings. Bowen (1985) theorised that the family are a unit

together and focuses on how the emotions of one person will affect the family as a whole, rather than just individually. The collective expectations from the family around each individual's role, what the family require of each person emotionally and the shared understanding of boundaries within the family, can impact a person's wellbeing, but also contribute to how the family act as a unit (Watson, 2012). There are also direct and indirect influences on each member of the family unit (McGinnis & Wright, 2023) and their behaviours are a result of this (Bowen, 1985). Some people develop a low differentiation of self (Bowen, 1985) which may present itself as focusing more on the needs of others within the family, rather than their own and a heightened sense of responsibility at meeting the needs of others (Bowen, 1985).

He considers the family as creating triangles whereby there are two family members who may be aware of tension or stress and subsequently seek support from others either inside the family or externally, to reduce this and create a balance; creating the third person in the triangle (Bowen, 1985). If one person notices heightened anxiety, this can affect the family and rather than finding the family soothing, they can have a negative experience of feeling drained (Bowen, 1985) and when the family deem themselves as unable to manage the anxiety and stress felt within the family, they are more likely to seek support from others outside the family unit (Bowen, 1985). Interestingly, he also theorises that when the individual notices the heightened anxiety, they may adapt more than other members in order to balance out the needs of the family (Bowen, 1985). When attempting to understand the experiences of siblings, this could help to explain how the sibling behaves and makes sense of their world as part of the family unit and that if they are experiencing anxiety around having a SWEDS, we could consider their response to supporting their SWEDS and family in the context of the family systems theory.

The psychological frameworks of relationship to help and family systems theory are imperative to consider when attempting to understand the experiences of siblings. The

reminder that the participant is part of a wider family unit and the acknowledgement that their early experiences have contributed to how they understand and provide help, supports the researcher in remaining mindful of the wider experience. This is of particular use when trying to make sense of their experience as it could explain their behaviours and how they communicate their experiences to the researcher. We will therefore explore a summary of the current literature available to consider in the context of this study.

1.7. Summary

Literature provides a clear understanding that the impact on patients includes psychological factors e.g. anxiety, guilt, stigma, pressure on relationships and sleep disturbance and physiological e.g. pain and fatigue. The ability to engage in everyday activities is impacted as hEDS and HSD are experienced as chronic pain conditions and although a multidisciplinary approach is recommended for treatment, it is not yet known which approaches, if any, are more effective. A lack of specialist knowledge from professionals or understanding from partners can result in negative experiences for patients and misdiagnosis appears to be common. Nevertheless, hEDS and HSD can be an advantage for ballet, gymnastics and music. Research has focused on women and qualitative approaches have been used to investigate patient experiences to obtain rich information.

Reclassifications of hEDS and HSD and previous research suggest a multidisciplinary approach to treatment and a future focus on identifying if there is a gene responsible. Literature demonstrates that we have started to understand the impact on individuals, but that it is still widely underdiagnosed. Considering the impact on family members without the condition would be useful in furthering our understanding of how to support individuals involved.

Research has identified many difficulties patients can experience, including during motherhood, yet there is a lack of literature on the experiences of family members who do not meet criteria for the diagnoses, specifically siblings.

Research appears to have focused on the experiences of people who have a sibling with a long-term condition, yet these conditions are unrelated to HSD or hEDS and it is therefore difficult to draw conclusions for this group. Research clearly demonstrates that people who have a sibling with a chronic health condition can be closely involved with helping their sibling to cope with their diagnosis and that they can experience negative impacts on their overall mental health, further justifying the importance of conducting research focusing on the experiences of people who have a sibling specifically with HSD or hEDS, This would allow the opportunity to ascertain whether there are similarities or differences with the current literature.

The psychological frameworks of relationship to help and family systems theory allow for deeper consideration of how the experiences of siblings can be understood within the practice of Counselling Psychologists and can be useful for understanding the responses and experiences of people who have a sibling with HSD or hEDS.

A qualitative study using interviews with open-ended questions and a thematic analysis could allow for a holistic approach, embodying the aspects of Counselling Psychology and for detailed information to be obtained from family members including partners, children and extended family, to identify themes in the experiences and impacts of the conditions.

Investigating this clear gap in research would provide a clearer understanding of the current support available, improvements that could be made and whether additional support is required. It would also allow Counselling Psychologists to further their knowledge on how best to support patients with symptoms of the conditions and with mental health disorders associated with receiving the diagnosis and living with the conditions. This in turn could help to improve patients' quality of life. At an exciting time of reclassifications to highlight a spectrum disorder and clarify symptoms associated, continuing research on hEDS and HSD will justify the importance of needing to continually support all individuals involved and review diagnoses regularly.

Additionally, it is important to note, that there does not appear to date, to be research considering the impact and experiences of the conditions on family members who do not have a diagnosis and are not parents, specifically grandparents, adult siblings and extended family members. There appears to be a significant gap in research on these topics and it is a particular area of interest to research so that professionals, including Counselling Psychologists, can be aware of the experiences of the wider family which can inform their practice and to help identify whether further support is required for families which may not be currently available.

1.8. Research Aims

Due to these gaps in the literature, this research therefore aims to address the question of "how do people understand the experience of having a sibling with Hypermobility Spectrum Disorder or Hypermobile Ehlers-Danlos Syndrome?" The research had several aims for both the participants and professionals. It aimed to understand how people experience and make sense of having a sibling with hEDS/HSD, to explore their individual experiences and the meaning of supporting or caring for a sibling and to empower participants by creating a

space where their voices could be heard on a topic which has not yet been widely recognised. The research aimed to improve the quality of life for siblings by increasing awareness of the conditions to professionals, demonstrating the importance of understanding these conditions to professionals who may have been unaware, to inform Counselling Psychologists about their role in supporting siblings and to identify if there is additional support that needs to be available for siblings with a chronic pain condition. Furthermore, the researcher hoped this study would contribute to justifying the need for continual support for all individuals involved and the need for funding into support and research on the conditions.

2.0. Methodology

2.1. Introduction and Rationale

The rationale for this study involves several points. I will first consider the rationale from a research perspective. Firstly, both HSD and hEDS are chronic pain conditions underdiagnosed by health professionals, due to the lack of awareness and knowledge (Knight & Hakim, 2011). Secondly, whilst we are somewhat aware of the subjective experiences of both patients with Hypermobility Spectrum Disorder (HSD) or Hypermobility Ehlers-Danlos Syndrome (hEDS) and their parents through previous literature, there appears to be no previous research on siblings of individuals HSD or hEDS and subsequently, little acknowledgment of their own experiences. Thirdly, there appear to be few studies on siblings, chronic pain or on HSD/hEDS using the methodological approach of an Interpretative Phenomenological Analysis (IPA) which can be useful in understanding individual experiences. Lastly, there is limited research available more generally on the experiences of siblings of individuals with a chronic pain condition.

This study reflects the holistic aspects of Counselling Psychology (CP) outlined in the introduction and literature review and confronts these gaps in our knowledge, by focusing on the subjective experiences of siblings and approaching them as individuals, rather than generalising to a diagnosis. It is important to continue research into these conditions as they are being reclassified and updated frequently, thus it is imperative professionals remain informed of how individuals' subjective experiences may be changing over time, in order to enable professionals to gain an understanding of how they can support siblings and their families, which also enables a holistic view on a person's wider experience.

2.2. Research Aims

As explored in the previous chapter, this research aimed to understand “how do people understand the experience of having a sibling with Hypermobility Spectrum Disorder or Hypermobile Ehlers-Danlos Syndrome?”, focusing on the individual and unique experiences and the meaning they create around caring for a sibling with these conditions.

2.3. Theoretical Position

The chosen methodology for this thesis is Interpretative Phenomenological Analysis (IPA), which focuses on understanding the interpretations of an experience from a participant’s perspective and the meaning behind it (Dempster, 2011). It is regularly used in counselling psychology, allows for individual experiences to be explored and understood (Smith, Flowers, & Larkin, 2009) and has been used to study chronic pain (Biggerstaff & Thompson, 2008; Osborn & Smith, 1998).

IPA can allow us to understand how the participant has understood an experience which is subjectively significant to them or has created a substantial impact on their life (Smith et al., 2009). It means the researcher can recognise and comprehend the individual’s world (Smith et al., 2009) and offer alternative perspectives of the meanings through the analysis (Smith et al., 2009).

IPA had been chosen due to these factors, as the researcher was interested in understanding how participants understand the phenomena of having a sibling with the conditions and their perceptions of the experience, within the context of having a sibling with hEDS/HSD.

IPA consists of phenomenology, hermeneutics and idiography (Smith et al., 2009). Phenomenology is a philosophical method of studying experience (Smith et al., 2009). Within IPA, this is based upon the philosopher Husserl’s understanding of the

importance of a “phenomenological attitude” (Smith et al., 2009, p.12), which consists of understanding human experience (Smith et al., 2009). There was an emphasis on our consciousness; in particular, that our consciousness is based upon how we have perceived and made sense of an object in our outside world (Smith et al., 2009). He highlighted the importance of focusing on this rather than only on the objects themselves, so that we are able to fully understand our experiences in the world (Smith et al., 2009). Husserl also expressed the importance of bracketing, which we use within IPA; a way of acknowledging but simultaneously separating our perceptions (Smith et al., 2009).

Heidegger was a student of Husserl’s and took his ideas further, to express the importance of exploring what our experiences mean and the meaning we place around this. Hermeneutics, based on Heidegger’s philosophical ideas (Smith et al., 2009) involves interpreting how people understand and make meaning of their experience (Smith et al., 2009) and the researcher’s analysis of the participant’s interpretations may highlight additional aspects surrounding the topic to consider (Smith et al., 2009).

Hermeneutics, based on Heidegger’s philosophical ideas (Smith et al., 2009) involves interpreting how people understand and make meaning of their experience (Smith et al., 2009) and the researcher’s analysis of the participant’s interpretations, may highlight additional aspects surrounding the topic to consider (Smith et al., 2009). As part of Hermeneutics, Heidegger recognised that there can be meanings in our consciousness and unconsciousness which equally need to be acknowledged (Smith et al., 2009) and he subsequently understood phenomenology to require interpretation (Smith et al., 2009). This study is interested in the subjective experiences of participants that have not been focused upon in previous literature, rather than objectivity.

A hermeneutic circle (Smith et al., 2009) analysis as part of IPA, involves thinking about responses in varying ways, rather than working in a linear process (Smith et al.,

2009). Idiography focuses on particular people, contexts and phenomenon and ensures a detailed and systematic analysis by focusing on comprehending how the phenomenon being explored has been made sense of by the participant in certain situations (Smith et al., 2009). As IPA allows for a participant's interpretation of their experience to be interpreted by the researcher (Dempster, 2011), this was deemed as an important aspect when considering methodologies. As chronic health conditions, particularly rare conditions, may rely on donations for research (Chronic Disease Research Foundation, n.d.), the interpretations of others are important in justifying whether further research or support is needed. For funding and support to be justified, we need to understand the experiences of these individuals.

As the researcher aimed to understand the experiences of people who have a sibling with HSD/hEDS, it is important to consider that although the data had the potential to provide an insight into participants' experiences, we may never fully understand their experience, yet this does not decrease the importance of conducting this research. Rather, it further justified the need to research these underdiagnosed and under-researched conditions, to inform professionals' (including Counselling Psychologists) knowledge and practice and to contribute to the support available for siblings.

The researcher has aligned to a phenomenological epistemological position proposed in Willig (2012)'s classification system of epistemologies. A phenomenological epistemology attempts to produce information about the individual's subjective experience, rather than generalising an experience, identifying whether the experience is completely real or whether the experience is due to social constructs (Willig, 2013). It recognises "there is more than one world" (Willig, 2012, p.12), therefore each experience is individual. A phenomenological epistemology is interested in "what is the world like for this participant?" (Willig, 2012, p.12) and how it is to experience the phenomenon (Willig, 2012).

The focus within this epistemology on the individual subjective experience aligns closely with the methodology of IPA due to the idiographic and phenomenological aspects. The recognition of several worlds (Willig, 2012) links to IPA's recognition that experiences can differ within contexts (Smith et al., 2009).

This research was interested in attempting to understand the phenomenon of having a sibling with HSD/hEDS and participants' subjective experiences and was not aiming to identify whether the experience was real, as the researcher and IPA take the stance that the experience is important to the participant. A phenomenological epistemology recognises this and identifies that the researcher needs to understand that they will be unable to fully understand the participant's "world" (Willig, 2012, p.12) and that the researcher's interpretation will impact the participant's response (Willig, 2012). The researcher felt this was an important stance to adopt when considering epistemologies and methodologies, as they recognise each experience is individual, yet important to participants and it is imperative we attempt to understand what it is like for participants so we can attempt to consider methods of support participants may require and how they make meaning.
A phenomenological epistemology has been compared to a therapist adopting a person-centred approach, due to remaining non-judgemental, empathic and listening and positions the researcher as a counsellor (Willig, 2012). This leads back to how the research is related to CP as a person-centred approach is encouraged and taught within CP training and is a method which the researcher uses within therapeutic sessions.

Willig (2012) proposes IPA takes on a phenomenological epistemology, whilst Larkin and Thompson (2011) define it as an interpretative phenomenological epistemology (IPE). Larkin and Thompson (2011) place an emphasis on interpretation and state the researcher can access experience through the participant's meaning-making. They also emphasise the importance of comprehending how people make meaning of an experience, which the researcher identified more closely with, compared to Willig (2012), as this study was

concerned with understanding how people make meaning of the experience of having a sibling with hEDS/HSD.

In contrast, a critical-ideological epistemology would assume language and power are important factors in experiences and thus a focus is placed upon these (Ponterotto, 2005). The researcher considered at length, whether this would be appropriate for the current study and concluded that if the research was focusing on individuals with the conditions, perhaps the power aspect would be crucial to consider. However, as the research focused on the siblings, the researcher did not deem the power factor to be of particular relevance for this study to focus on. Furthermore, the researcher was more concerned with the subjective experiences, rather than language used.

2.4. Ontology

Ponterotto (2005) defines a relativist ontology as viewing the world as having several realities, which are subjective and which can be influenced by experiences and social factors. A relativist ontology also assumes there are several ways to make meaning and to interpret a phenomenon (Ponterotto, 2005). Smith et al. (2009) make a related point, in terms of IPA analysis, that the researcher can offer alternative perspectives of the meanings participants make. As the researcher recognised participants will have subjective experiences and will potentially be from varying backgrounds and contexts, a relativist ontology appeared to fit well.

In contrast, Willig (2012) states adopting a realist approach would require using individuals responses “at face value” (Willig, 2012, p.8) and states interpretative phenomenology does not engage in this as the researcher would look further for meanings within the psychological and social contexts (Willig, 2012). Furthermore, IPA recognises we may not achieve a “pure

description" (Willig, 2012, p.15) and an IPE aligns with a relativist ontology, due to the focus on subjective experiences.

2.5. Alternative Methodologies

Alternative methodologies considered included a descriptive phenomenology and grounded theory. Descriptive phenomenological methodologies may use a critical-realist theoretical position (Willig, 2012), which assumes a realist ontology (that the world includes entities that have a causal connection with each other [Willig, 2012]) and a relativist epistemology (that data will allow the researcher to understand how meaning is made [Willig, 2012]). Descriptive phenomenology does not attempt to explain experience, acknowledge psychological and social meanings, or require the researcher's preconceptions to be used for analysis (Willig, 2012). The researcher felt it was important to attempt to understand the data's external meanings of having a sibling with HSD/hEDS within society and psychology and to attempt to understand the individual's world and how they make sense of the particular phenomenon of having a sibling with the conditions; meaning that for the researcher to comprehend the experience, they are required to provide connotation to the data first (Willig, 2012). Research shows qualitative methods for chronic pain allows this and while IPA has been used for research on chronic health conditions (Smith et al., 2009), there is a lack of research using IPA specifically for chronic pain, the experiences of siblings and in hEDS/HSD. Therefore IPA was felt to be the most appropriate methodology which would still allow an IPE.

Grounded theory was considered, but the research question would have focused on the impacts of having a sibling with HSD/hEDS and the factors involved. Whilst this is interesting, Smith et al. (2009) recommend understanding subjective experiences, before establishing a scientific explanation and due to the lack of research on this topic, the researcher felt it was important to first attempt to understand how people experience and make meaning, before attempting to establish a theory about their experience. Grounded

theory adopts a different epistemological position to the researcher: a constructivist position (Smith et al., 2009), which would impact the research question. The researcher recognised however, that this may be a useful methodology for future research. These reasons are also why the researcher felt a qualitative methodology would be appropriate versus a quantitative approach, as it would allow rich data to be obtained from subjective experiences and was aligned with the researcher's epistemological and ontological positions.

Therefore, the researcher adopted an IPE, in line with the position proposed by Larkin and Thompson (2011) and supported by Willig (2012), with a relativist ontology.

The research question related to the IPE and methodological approach of IPA, by asking how people understood the experience of having a sibling with HSD/hEDS. This embodied the sense-making and meaning aspect of a phenomenon, essential for IPA and aimed to produce information about the individual's subjective experience, a fundamental part of an IPE.

2.6. Research Procedures

2.6.1. Recruitment.

Smith et al. (2009) emphasise the importance of using fewer participants to obtain detail through analysis and reflection and recommend up to six for an undergraduate or master's thesis and several more for a doctorate. As the current study is for a doctorate, 8-12 participants initially felt appropriate to recruit. Participants were recruited from support groups affiliated with the conditions: Hypermobility Syndromes Association (HMSA), Ehlers-Danlos Support UK (EDS-UK) and the social media group on Facebook "Hypermobility UK Support Group". Participants were also recruited via the researcher sharing on Facebook and asking people to share the research advert to reach a larger amount of people and via

the researcher's university City, University of London where posters were placed across campus. The researcher had considered recruiting from NHS settings and support groups as previous research appears to only focus on only one of these at a time, but time constraints resulted in choosing one option for the purpose of this research.

2.6.2. Permissions.

Permissions to advertise through the support groups and at City, University of London were obtained. The HMSA and EDS-UK newsletters, social media pages and websites advertised the research, whilst posters (appendix B) were placed around the researcher's university and a post placed with the advertisement attached on the social media support group and researcher's personal page on Facebook. Permissions to use rooms for interviews at City, University of London were obtained and initially there was an intention to seek permission for meeting rooms within particpants' local areas before agreeing on a date for the interview with participants, but throughout recruitment, the researcher found participants were agreeable to meet at City, University of London or virtually via Zoom.

2.6.3. Participants.

The researcher intended to recruit a mix of participants who were males and females over the age of 18 from the UK, who had a sibling with a diagnosis of Hypermobility, HSD or hEDS. Older terms such as EDS type three (EDS III), EDS-Hypermobility Type (EDS-HT), Benign Joint Hypermobility Syndrome (BJHS), Joint Hypermobility Syndrome (JHS) and Joint Hypermobility (JH) and reclassified terms such as HSD or hEDS were all included.

Interestingly, the participants all had a sibling with hEDS rather than HSD. Exclusion criteria included not typically residing in the UK (to create a homogenous sample), being well-known to the researcher or meeting formal diagnostic criteria for the conditions. The rationale for the latter is that the researcher was interested in understanding how these conditions affect individuals who do not personally experience symptoms of hEDS/HSD but who have a

sibling who does have a diagnosis. It was assumed participants' siblings would have been symptomatic at some point to receive their diagnosis, therefore this was not outlined in the information sheet or inclusion criteria. Participants would have been excluded if they experienced an acute mental health episode or distress at the time of the study as, regardless of whether they have a formal mental health diagnosis, it would not be ethically appropriate to include them in the study. The information sheet (appendix D) and screening protocol informed participants of exclusion criteria and they were supported by the researcher to make an informed decision about their participation.

Table 1 displays participants who took part in the current study, along with demographic information collected. This included the age range of the participant at the time of the interview, the participant's gender, their ethnicity if specified and the amount of siblings they had with EDS. As siblings were identified as having a diagnosis of EDS rather than HSD, this has been identified in the below table as "SWEDS" meaning "Sibling With EDS".

Table 1: Demographics of Participants

Name of Participant	**Age Range of Participant at Time of Interview:** 18-30 30-40 40-50 50-60 60+	**Gender of Participant**	**Participant's Ethnicity**	**Amount of Siblings with EDS (SWEDS)**
Amelie	18-30	Female	White British	1
Jasmine	18-30	Female	Not Disclosed	1
Jake	18-30	Male	White British	2
Isaac	18-30	Male	Not Disclosed	1
Michael	18-30	Male	White British	1
Felicity	40-50	Female	Not Disclosed	1

2.6.4. Data Collection.

Interested participants were provided with the information sheet and allowed a minimum of 24 hours to consider before receiving a telephone call from the researcher to establish their interest and before being screened via a telephone call from the researcher to ensure they met inclusion criteria.

Suitable participants were invited to a face-to-face interview with the researcher, lasting between 60-90 minutes, initially, to take place within the participant's local area or at the researcher's university. If participants were unable to meet face-to-face, Skype was to be considered. During recruitment, the world entered into a pandemic of COVID-19 and recruitment had to be reconsidered with further risk assessments for both the researcher and participants. It was agreed that further interviews with participants would take place virtually over Skype to mitigate risk.

Interviews took place at City, University of London within a meeting room, a location convenient for the participant or they took place virtually via Skype. This was to ensure that interviews were within a public environment to reduce risk to the researcher and in a location deemed suitable by the researcher and participant where they felt able to speak confidentially and openly. Interviews consisted of 13 open-ended questions (appendix C) concerned with understanding the individual's subjective experience as guiding points for participants. Prompts were provided throughout, as recommended by Smith et al. (2009). Written informed consent was obtained from participants before the interview occurred. The researcher explored the consent form (appendix E) with participants, to check their understanding and to offer a chance to ask questions or express concerns. Participants were reminded they could ask questions throughout the interview or via email after the interview had occurred.

Participants were debriefed after the interview and allowed an opportunity to ask the researcher questions. They were informed that the researcher would send them a one-off follow-up email after the interview which they would not need to reply to but which would offer them a further opportunity to ask questions. Although the debrief sheet provided information for participants to contact the researcher if they chose to, the follow-up email offered the opportunity to provide contact information for relevant services that participants could seek further support from. These included Samaritans, Hypermobility Syndromes Association (HMSA), Ehlers-Danlos Support UK (EDS-UK) and a reminder that they could also contact their GP. This was to ensure participants felt supported with their experiences as a sibling with a caring and supportive role and also with their mental health. An information sheet for the study was also provided, for participants to pass onto anyone they felt may be interested in taking part which could have aided recruitment.

Over time, due to difficulties recruiting, the worldwide pandemic and time constraints, the researcher made the decision with their supervisor to aim to collect a smaller sample size of six participants which was achieved. When the study had reached its target sample size, people who had been interested in taking part received an email thanking them for their interest, explaining that recruitment had ended and attaching the same list of useful contacts for further support.

A pilot study was conducted on the first participant of the sample group. This was to provide an opportunity to practice asking the proposed interview questions, gain feedback and allow the researcher to refine questions. As questions posed no major concerns, this interview was included in the main study. Participants were informed via the information sheet that if they were one of the first people to be interviewed, the researcher may not be able to use all information disclosed if it was collaboratively felt between the participant and researcher that there was a large concern with the questions and that this would be used as a pilot study. Participants were also able to let the researcher know whether they would like to be involved

in the pilot and were given the option that if they preferred not to be, they could be interviewed later in the study.

2.6.5. Analytic Process.

The researcher used the analytic strategy for IPA outlined by Smith et al. (2009), which comprised of six steps and which kept in mind the hermeneutic circle: (1) re-reading transcripts, (2) making notes, (3) searching for themes within the data, (4) connecting data with themes (5) repeating the process with the next interview transcript and (6) identifying patterns between transcripts. These steps will be described below.

The researcher considered the idiographic aspect of IPA by focusing on each interview in turn to fully examine the detail. Step one required reading the transcripts several times before making notes, to start identifying how the participant talked about their experience to the researcher (Smith et al., 2009). Step two involved paying attention to the context spoken about by participants and their language and creating descriptive notes on the transcript of the aspects which were important to the participant and interpretative notes on the researcher's thoughts of why these aspects were of importance to the individual and the potential meaning behind them (Smith et al., 2009). The researcher considered what the expressions and language used meant to them and used their own knowledge of the words or experiences to assist interpreting, whilst considering the meaning for the individual (Smith et al., 2009). The researcher incorporated Smith et al. (2009)'s recommendation of additionally documenting thoughts and feelings for particular words and phrases. The researcher also listened to audio-recordings, as they were not involved with the transcription and needed to familiarise themselves with the interview and ensure transcriptions had captured all details. As recommended by Smith et al. (2009), the researcher documented their primary thoughts and opinions about the interview separately, in order to allow bracketing and focus on the transcript. Step three required detecting emerging themes and considering the relationships and themes between notes made from step two (Smith et al.,

2009). Comments from steps two and three were made on opposite sides of the margin, to separate them. Step four involved considering the research question and the importance of themes identified from step three, before looking for connections between the themes (Smith et al., 2009). This process involved looking for similarities, differences, relationships and patterns between themes, whilst always considering the context of the data, the amount of times a theme occurs and their purpose (Smith et al., 2009). Step five involved repeating the analytic process with the next interview transcript but ensuring that previous themes and notes from the previous transcripts were held to one side, so this did not impact the initial thoughts and themes on subsequent transcripts and each transcript remained its own individual experience. Lastly, step six involved identifying patterns between transcripts (Smith et al., 2009). Throughout the analysis, the researcher aimed to connect parts of the data to the whole as part of the hermeneutic circle (Smith et al., 2009), whereby the researcher aimed to make sense of how the participant made sense of the situation; in this case, the situation was of having a sibling with a diagnosis of hEDS or HSD.

2.7. Many Different Lenses

There were three different lenses in play that could influence the data and how the data is understood and interpreted. These consisted of the researcher's lens, the participant's lens about themselves and the participant's lens about their SWEDS and these will be explored here in turn.

2.7.1. The researcher's lens.

The researcher took part in this study with several perspectives: a researcher, a patient, a sibling and over the course of the study a carer. These perspectives were interchanging throughout and meant that there were different ways in which the researcher viewed how to conduct the study and the data that was collected.

As a researcher, a focus was to collect rich and detailed data for this particular research question. The researcher was also aware that this would be the first study to date on the experiences of people who have a sibling with hEDS or HSD. Due to their interest and investment in this topic, they noted subsequent pressure they felt from themselves to make sense of and thoroughly report findings, with the hope that this study would help support people who have a SWEDS and to provide a starting point for further research into this area. This therefore meant the researcher's lens had a focus on perfecting the data collection and analysis processes, meaning a perhaps extensive amount of time was spent on this.

Additionally, several assumptions were brought to the study. The researcher assumed that recruitment would be straightforward, due to a perceived lack of opportunities for people with a sibling who has HSD/hEDS to speak about their experiences. The researcher also had brought assumptions that participants would highlight that they felt they needed further support around having a SWEDS, as it was assumed that there is little support available currently for people with a SWEDS who have a caring and supportive role. This created the risk that the researcher could be searching specifically for information to validate these assumptions and could therefore misinterpret the data or miss key information relating to other themes.

Their assumptions were influenced by their own experiences of having HSD and having in the past few years, been through the diagnostic process of understanding whether symptoms fell into a category of HSD or hEDS. They held in mind that their personal diagnosis was relatively quick, compared to suggestions made by current research of approximately 10-12 years to reach a diagnosis (EDS UK, 2024) and that their own experience of becoming aware of their symptoms could differ greatly from when participants noticed their sibling's symptoms or became aware of a diagnosis. The researcher fluctuated

between being visibly “well” versus experiencing a flare-up of their symptoms of HSD and co-morbid conditions, whilst collating and analysing data. The researcher was therefore able to have the knowledge that asking questions around whether participants noticed symptoms in their SWEDS could be valuable in understanding the fluctuations in the participants’ experiences.

The researcher’s experience as a patient was particularly important to consider with the chosen analysis being IPA, which focuses on the hermeneutic circle of the researcher attempting to make sense of how participants make sense of a particular experience. As the researcher had personal thoughts, feelings and motivations which could create personal perspectives and assumptions, these could have impacted how the research was advertised, questions asked or data interpreted and it was an important aspect to consider how to manage.

Additionally, new diagnostic criteria was confirmed at the time the researcher was submitting their proposal for this study, the researcher’s own understanding of the conditions was changing over time. Their perspective of being somewhat knowledgeable about the conditions and symptoms as part of their lens as a patient and as a researcher, was temporarily affected whilst they needed to spend time to understand the change in diagnostic criteria and what the impacts could be, whilst also remaining aware that this could subsequently affect participants who would also be navigating these changes and could look to the researcher as someone with significant knowledge around the conditions.

The researcher was aware that at the same time, they were a sibling, but of people who do not have the conditions, therefore they were researching people who could have been in their own sibling’s positions. Along with their own understanding of their personal

experience of having siblings but being a patient, this could have increased the chances of unconscious biases from the researcher whilst analysing data.

During the study, the researcher became a carer for their only parent and subsequently made the conscious decision to step away from the research. Upon returning after their parent had passed away and they were suddenly no longer a carer, the researcher's lens had evolved over this time. Whilst the researcher's lens could have been influenced by emotions around their personal circumstances, they may have simultaneously had a greater understanding of how to make sense of participants' experiences of being a carer and been able to notice elements within language and attitudes to life that perhaps the researcher may not have beforehand.

The researcher entered this role with their own narrative influenced by what they personally experienced in life as a patient, sibling and carer. Their unconscious biases from these experiences could have affected their overall lens as a researcher and how they made sense of the data.

2.7.2. The participant's lens about themselves.

The participant's lens about themselves could have been influenced by their views around mental health, which could be further impacted by their family's views on this. Their attitude towards mental health and talking about their emotions could have impacted their willingness to take part in the study and their openness in interviews. This could be the difference between obtaining rich data or minimal data. Participants' views on their approaches and attitudes towards their SWEDS, along with how they view others around them, e.g. whether

people would be judgemental, could have also influenced what they disclose to the researcher.

Their own physical health and that of their family's could shape the lens they have about how they cope and make sense of having a SWEDS. If participants generally had fewer physical health difficulties, they may have a different understanding compared to participants with their own experience of physical health concerns and this could adjust the importance they place on support.

Participants may not view themselves as having enough knowledge about the conditions and this could impact the detail they provide in responses in addition to possibly increasing worries around whether they are articulating their answers in a way that makes sense. Unconscious biases and desires to support the researcher as part of their lens could further shape their responses.

2.7.3. The participant's lens about their SWEDS.

Participants may not view themselves as a carer for their SWEDS and may have varying understandings of what being a carer entails. Varying ways they make meaning around being a sibling can also impact their responses; what one participant views as part of their role as a sibling may differ to another participant who may view this in a more caring role. Subsequently, there could be variations in whether they view themselves as struggling or needing support and this could be further influenced by whether they viewed themselves as being the main person involved in their SWEDS' care or whether they lived with their SWEDS.

As the conditions fluctuate and change over time, so could their lens about their relationship with their SWEDS; what they view is needed from them, whether they require further support, how they make sense of the fluctuations. Additionally, due to the frequent variations in their SWEDS' conditions and the visibility of symptoms, the possibility that participants' views could change from the point of recruitment to the interviews is feasible.

Participants may not have had an opportunity to speak about their experiences which mean the level to which they have reflected upon their experiences previously could greatly vary and could impact how open they are with responses. This could also contribute to whether participants feel able to separate out their own experiences compared to their SWEDS' experiences.

2.8. Researcher's Impact on the Study

In addition to the many different lenses that could influence the data, the researcher also brought further assumptions which changed over time. The researcher had assumed participants would be a mix of males and females and that there would be a mostly balanced mix of siblings with HSD and siblings with EDS. Whilst there was a mix of genders, all participants had siblings with hEDS. This could be due to chance, but it is important to note that at the time of recruitment, the diagnostic criteria had recently been reviewed and people who may have met criteria previously for Joint Hypermobility or Benign Joint Hypermobility Syndrome, may now meet criteria for hEDS.

It is also important to note that whilst treatment does not differ for HSD and hEDS, the researcher had included both reviewed and older diagnostic terms as the researcher queried whether there would be themes arising from receiving particular diagnoses. Importantly, the researcher, perhaps naively, assumed it would be extremely possible to separate their own experiences and assumptions from the research through the use of self-interviews.

Additionally, the researcher's assumptions about the ease of recruitment was challenged; recruitment was in fact, difficult. Whilst there was interest from people who typically resided abroad and were therefore not eligible to take part in the study, it took a significant amount of time to recruit from the UK. This could be potentially due to decreased awareness of the conditions in the UK; therefore fewer SWEDS and fewer potential participants. When there were difficulties with recruitment and the researcher's family had offered to be interviewed, the researcher needed to ensure that they persevered with recruitment rather than being tempted by a more convenient option which could have created bias within the research.

In order to manage the researcher's lens and potential impact on the study, the self-interviews conducted by the researcher included an amended version of the interview questions used for participants (appendix I) and a reflexive interview (appendix J) The reflexive interview was based on Langdridge (2007) and enabled thoughtful responses around the importance of this study, personal motivations, expectations, potential ways the research could be influenced by personal experiences and hopes for the impact of the study. Particularly notable was the perceived way that this study could impact participants. The researcher hoped this study highlighted how effective current available support was for people with a sibling with the conditions and that it allowed for further thought and consideration around how the availability and content of the support could be improved if needed, in order to create a more supportive environment for participants.

The amended interview for the researcher was an important element of the research. Part of the researcher's experience as a Trainee Counselling Psychologist had been as a client within personal therapy sessions; a core part of the training which allowed space to process but also enabled trainees to experience being a client, which further informs our approaches and practice. Partaking in the amended interview aligned with the researcher's core training as a Trainee Counselling Psychologist; providing the experience of being a participant and

allowing opportunity to consider the wording and emotions questions could bring. The researcher's answer to "have there been any positive or negative aspects of your experience?" contained some negative aspects the researcher was mindful to explore further in the reflexive journal, however the positive aspect was how this had led the researcher to developing this current study and being motivated to support change in how we support people who have a SWEDS, with their caring and supportive role. The researcher's answers highlighted assumptions made about the possible answers from participants which was also explored further in supervision and in the reflexive journal.

2.9. Reflexivity

Reflexivity recognises that the researcher can influence individuals' answers and how data is construed, therefore they need to acknowledge how they have created their own prior knowledge, as this will naturally be brought into the research (Finlay, 2002). The researcher acknowledged their own lived experience and attempted to be aware throughout the research process (Finlay, 2002). Preconceptions were bracketed to enable the researcher to attempt to understand the participant's own experience (Finlay, 2002). This is closely related to IPA due to the subjective experience aspect and hermeneutic circle, therefore the researcher deemed this to be of importance. Reflexivity occurred at each stage of the research.

Using Finlay (2003)'s methods of reflexivity, this researcher engaged in reflexivity as introspection; looking at personal meanings and understandings of the researcher's experience. The researcher felt this was appropriate considering their epistemological position and methodology.

Challenges in the reflexive process included the researcher becoming aware of difficult aspects they had either been unaware of or purposely not acknowledged (Finlay, 2002). This researcher was aware their own experiences of the conditions could potentially

influence the data, particularly without reflexivity and it may bring up unpleasant aspects about the researcher's experience. However, this further justified the need for reflexivity; for the researcher to acknowledge their thoughts, feelings and preconceptions before collecting and analysing data, so it would not influence participants' responses or analysis. As the research topic was somewhat related to the researcher, the researcher engaged in an amended version of the interview schedule (appendix I) before conducting interviews with participants so the researcher could identify and understand their own preconceptions and assumptions about participants' answers, without impacting the interview questions for participants or the data analysis. They also engaged in a reflexive interview (appendix I), based on the reflexive questions by Langdridge (2007), which allowed identification of why this topic was significant to the researcher and what they hoped to discover and achieve from the study.

Finlay (2002) highlights the importance to recognise a potential power difference between the individual and researcher. This relates to how the researcher within an IPA methodology is similar to a person-centred counsellor (Willig, 2012) and therefore needing to remain aware of power differences. Reflexivity allowed the researcher to acknowledge this (Finlay, 2002) and the researcher drew upon their skills as a person-centred therapist, by embodying the core conditions of unconditional positive regard and empathy (Mearns & Thorne, 2013). A further challenge was that the researcher's views of the research could change, due to reflexivity and engaging in the hermeneutic circle (Smith et al., 2009). A reflexive journal was kept to document the researcher's role throughout the study, the research process, challenges, changes and influences. The researcher also documented their preconceptions and thoughts before and after interviews and throughout the analysis, in addition to having documented feelings and thoughts upon reading the transcripts separate to the analysis, in order to temporarily bracket these.

It is important to note the researcher's personal motivation for this study. The researcher was diagnosed with HSD shortly before starting the doctorate and was attempting to navigate the new diagnosis and lack of knowledge from others. The researcher had also needed to understand the conditions at great length, in order to inform friends and family. These experiences led to the consideration of what it may be like for the researcher's siblings to transition from understanding their sibling to be healthy and to look "well", to suddenly having a condition which can present with a variety of symptoms. Upon looking into the available research, it was evident that this had not been considered at the time of deciding on a research topic. Whilst the researcher was initially offered a different topic for their thesis on an area of significant interest to them, also related to physical health, the researcher felt that the opportunity to study a topic that had not yet been considered and the opportunity to create a space for people who have a sibling with HSD or hEDS was in line with their personal values of empowering others and improving knowledge in an area that may otherwise continue to be forgotten.

In addition to the researcher's change in physical health and caring responsibilities throughout the research process, there was also a worldwide pandemic which resulted in unforeseen circumstances and difficulties accessing university resources, interviewing participants and negatively affecting the researcher's physical health further.

Continuing to engage with the reflexive journal proved invaluable in grounding the researcher and enabling a space to process, without bringing these experiences to the study. The researcher also unfortunately became a full-time carer for their only parent who became unwell during the pandemic. This later became terminal and the researcher suffered a devastating bereavement affecting both the mental and physical health of the researcher. Whilst the researcher at first attempted to continue with the study, utilising the reflexive journal and checking in with support from the university, it became clear after time that it would be more beneficial to postpone the research until the researcher had been able

to recover and feel able to separate personal experiences from the study. The researcher found several factors difficult upon returning: analysing comments about mortality after suffering a bereavement and finding the motivation to continue the research whilst struggling to adapt to a "new normal". The researcher was able to reflect during the research upon how their personal experience and motivation has changed over time. The researcher was mindful that the person they had a caring role for did not have an official HSD/hEDS diagnosis, but experienced symptoms. It had therefore been part of the researcher's experience to learn to navigate the medical field, whilst advocating and informing on the conditions. New additional motivations were around ensuring that the experiences of people who have a caring and supportive role have a space to process and that it is explored as to whether there is sufficient support available. The researcher was reminded of participants' experiences they had shared in interviews, including advocacy, improving knowledge both personal and of others and considering the mortality of the person they have a caring and supportive role for.

Whilst the self-interviews were conducted prior to interviews taking place, due to the researcher's personal experiences during the study, they felt it was crucial to re-read the self-interviews before resuming the analysis and writing up stages. This was to ensure that personal experiences would not influence or negatively impact the study and that the researcher could remain aware of how they could otherwise impact the research. As data had already been collected, the researcher felt completing the self-interviews twice would unlikely have shown anything further in motivations to conduct the research and the researcher would have been unable to answer questions around what they anticipate results to be as these had already been gathered. Re-reading previous answers however, were invaluable to the researcher not only to ensure the study could continue without bias, but also to enable the researcher to return to the study after a significant break and to be reminded of the researcher's perceived importance of conducting this research.

The data analysis allowed for open-ended questions to be asked, guaranteeing that participants could freely answer without any unconscious bias from the researcher and audio recording the interviews ensured the researcher could listen on repeat to the recordings, which enabled the researcher to analyse over time, thus reducing the chance of unconscious bias.

2.10. Ethical Considerations

Participants were informed that the research had been approved by City, University of London's research ethics committee (please see appendix A for ethics form).

2.10.1. Informed consent.

Written informed consent was obtained from participants. They were provided with an information sheet and allowed a minimum of 24 hours to consider before being screened. The information sheet advised participants that they could express concerns about the study to the researcher's university ethics committee if required and provided contact details. Concerns and formal complaints were not expected, but it was essential participants were aware of their rights.

The researcher explored the information sheet and consent form with participants before they signed and checked participants' understanding by asking whether they had questions or concerns. Participants were informed they could withdraw from the study at any time until one week after the interview had taken place. This ensured data was not withdrawn after analysis had occurred or after submission of the thesis.

2.10.2. Debrief.

Participants were briefed about the research, before written informed consent was obtained and they informed that they could ask questions throughout and after the research. They were debriefed (appendix F) after the interview. As the research topic had the potential to

bring up difficult emotions and memories for participants which they may have needed time to process, a brief follow-up email was sent after the interview to allow the researcher to check in and the participant to ask questions and be provided with contact details for further support if required. Participants were made aware they did not need to reply to the email.

2.10.3. Researcher-therapist.

Participants could have assumed the researcher was acting as a therapist during the study. The information sheet clarified the researcher was a Trainee Counselling Psychologist but that the interview would focus on understanding their experiences for research purposes and would not be a therapy session. Participants were signposted to further support if they felt it was something they required. Russo and Thompson (2012) highlight researchers can experience conflict between therapist and researcher roles and state supervision is important to identify and understand the conflicts. The researcher was in personal therapy in periods throughout their training and had regular contact with their research supervisor.

2.10.4. Risks to researcher.

Please see appendix G for an overall risk assessment. Distressed or violent clients during the interview could have posed a risk to the researcher. Therefore interviews were conducted in a public location where the participant and researcher deemed there to be an appropriate opportunity for confidentiality so the participant could speak openly, whilst also ensuring that individuals were nearby should violence or an accident have occurred. During the COVID-19 pandemic, Skype was also utilised to mitigate risks to the participant and researcher's physical health. Safety checks were conducted by informing the researcher's supervisor and another individual known to the researcher of the interview location and start/end times. The researcher checked in with their supervisor and additional person via a telephone call before and after interviews. A phone number for research purposes was used to contact participants.

2.10.5. Distress.

If participants were experiencing an acute mental health episode or were in distress, they would have been encouraged to self-exclude from the study before signing the consent form as it would have been ethically inappropriate to include them. They would have been supported by the researcher to make an informed choice about their participation and made aware of the exclusion criteria via the information sheet before providing written informed consent.

Although it was not anticipated, participants could have experienced slight distress due to the sensitive nature of the topic or disclose illegal behaviour, or emotional, psychological or health concerns. The information sheet, written informed consent and being informed of their ability to decline to answer questions or to leave the study if preferred aimed at reducing chances of distress. The researcher also had the training to detect distress and if participants became distressed, the researcher would have asked participants if they would like to terminate the interview, have a break or continue and would have stayed with the participant whilst checking the following: if the researcher could call someone on their behalf to meet them, if there was anyone they could talk to afterwards, what they felt the researcher could do to help and the participant's plans for after the interview.

The researcher would have conducted a risk assessment if required, to ensure the participant's safety and deem whether they required further support. If the participant was unable to guarantee their safety, the researcher would have contacted their research supervisor and the participant's GP or taken them to the nearest A&E and stayed with them. The researcher would have remained empathic throughout and had experience in counselling and managing situations where people experience emotional distress. The researcher's supervisor would have been made aware of the incident and participants would have been provided with contact details for relevant organisations e.g. HMSA. Samaritans and EDS-UK.

2.10.6. Pressure.

If participants had been informed of the research by a family member with the conditions, they may have experienced pressure to take part. This was part of the screening process and interested participants needed to clarify who's idea it was to participate. Participants were informed it was their choice, that they did not need to take part and no one would be informed of their decision. They were informed that their decision would not impact the care or support their sibling received.

2.10.7. Transparency.

As a support group on social media (Facebook) had been considered for advertising the research, it is important to note the researcher had been a member of the group and had previously posted (without identifying information) that they have the condition. The researcher's link to the conditions were not expressed beforehand, but the potential meaning to participants to know the researcher's link was considered, as participants were exploring their experiences as a sibling of someone with the condition. The researcher felt being transparent, honest and open if asked by participants about their link, was important, particularly as transparency is enmeshed within CP training and ethical guidelines (BPS, 2014).

2.10.8. Confidentiality.

The researcher and their supervisor had access to the data and were bound by professional practice codes outlined by the BPS (2014). The transcription service had access to the recording and adhered to confidentiality and anonymity guidelines. Participants were informed via the information sheet that exceptions to maintaining confidentiality were if they reported abuse, criminal activity, violence or harm to themselves or others. The information sheet informed participants the researcher would need to inform their supervisor and possibly the participant's GP for further support in this instance, to ensure their safety.

2.10.9. Anonymity.

Participants from the researcher's university were screened via telephone to allow anonymity for if they were unable to or decline to take part in the study. The researcher considered that if they were suitable and took part, the researcher could come into further contact with them at university, but the researcher adhered to ethical guidelines of respect, anonymity and confidentiality (BPS, 2014).

The information sheet and consent form informed participants of the use of a transcription service and that direct quotes would be used, but identifying information of themselves or others would be changed to maintain anonymity, whilst enabling them to withdraw from the study if required. The information was replaced by a code, kept separately to the main data in a secure location which the researcher and their supervisor had access to. The analysis referred to participants by a pseudonym.

2.10.10. Data storage.

Digital data including audio recordings of interviews, transcripts and the thesis were stored on a password-protected computer. Digital audio recordings were sent to a transcription service, who were bound by confidentiality. Recordings were password-protected, with a password agreed between the researcher and transcription service. Digital audio recordings of interviews will be erased after the thesis has been reviewed. Hard data was stored in a folder in the researcher's locked home, which only the researcher would have access to.

2.10.11. Validity.

The researcher recognised that as they have chosen a qualitative methodology, data could be influenced by the researcher as part of the hermeneutic circle in IPA (Smith et al., 2009), which is explored further in the section "many different lenses" and therefore the research is not objective and may not be consistent across researchers. However, this research aimed

to attempt to understand participants' experiences within the particular context, rather than to generalise. Furthermore, a small sample size is in line with IPA due to the level of detail and reflection required (Smith, et al., 2009), but results in it being ungeneralisable or representative of the wider population.

Yardley (2000) identify four criteria for qualitative research, including a set of skills the researcher needs to adopt. The criteria requires the researcher to be skilled with their methodology, committed to the topic, to conduct detailed analyses, to adhere to ethical issues and to examine participants' perspectives, whilst remaining reflexive throughout (Yardley, 2000). The criteria expresses the importance of the researcher understanding the philosophical approach for their methodology and states that to maintain validity, consistent reflexivity is crucial (Yardley, 2000). To adhere to these criteria, the researcher carefully considered ethical issues as detailed above, considered other methodologies and epistemologies and had informed themselves of their chosen methodology and its philosophical approach, before deciding on an interpretative phenomenological epistemology with a relativist ontology and therefore an IPA methodology. This was to ensure that the research and decisions would fit well within the researcher's theoretical stance. Yardley (2000) states phenomenological methodologies are usually transparent and committed, due to length and open reflections and interpretations, which fits well with IPA, adding to the validity of this research and methodology. Due to the importance of reflexivity to increase validity, the researcher engaged in reflexive tasks throughout, as detailed previously in this chapter. Therefore, the researcher felt confident that the chosen methodology, epistemology and ontology fitted well with the research question and would help maintain validity throughout.

3.0. Analysis

"When you hear hoofbeats behind you, don't expect to see a zebra"- Theodore Woodward

3.1. Introduction

I will be exploring three superordinate themes and their related sub-themes throughout this chapter which have been obtained through the process of Interpretative Phenomenological Analysis (IPA).

For the purpose of this thesis, I will refer to the participant who took part in the research as "participant" (e.g. within the names of the themes) or by their name (e.g. in quotes). I will refer to the participant's siblings as "Sibling With Ehlers-Danlos Syndrome" in the abbreviated format of "SWEDS". Although the study initially set out to understand the experiences of people who have a sibling with a form of Hypermobility or EDS including former and newer terms, people who took part in the study all had siblings with a diagnosis specifically of a type of EDS, rather than a diagnosis of Hypermobility Spectrum Disorder for example. The reader should keep in mind that the diagnostic process and treatment which is recommended, remains the same for HSD and EDS (EDS UK, 2017), therefore the results could be considered for people who have a sibling with either condition.

The superordinate themes which I will explore in turn are:

- Emotional consequences of having a sibling with EDS
- Interference with life
- Absence of support

A transcending theme throughout, is the conflict participants experience between having a caring and supportive role for their SWEDS, versus being a sibling. This will be identified further in the context of each theme and all superordinate themes with related subthemes are shown in the theme table below:

Table 2: Themes Identified in Analysis

Transcending Theme	**Superordinate Themes**	**Subthemes**
The Conflict Between Having a Caring and Supportive Role for a SWEDS versus Being a Sibling	Emotional Consequences of Having a Sibling with EDS	• Frustration • Increased Responsibility • Worsening mental health
	Interference with Life	• Increased awareness • Changed attitude to life • I need to care for my SWEDS
	Absence of Support	• Experiencing Scarcity in Support • Searching for Support • Advice for others with a SWEDS: support yourself

3.2. Emotional Consequences of Having a Sibling with EDS

This theme focuses on the emotions having a sibling with EDS can evoke, and how the related responsibilities can affect participants' mental health. Three subthemes were identified: frustration, responsibility and worsening mental health, which will be explored in turn, with a transcending theme of the conflict for participants of being a sibling versus having a caring and supportive role for their SWEDS.

3.2.1. Frustration.

The most common emotion that appeared to be expressed by all participants, was frustration. Whilst some participants openly expressed their frustration, others were less explicit but understood by the researcher to be implied. This perhaps suggests both a wariness around directly expressing negative experiences due to their siblings being involved, but also suggesting that perhaps participants may not have had the opportunity to reflect upon their emotions and their own understanding of their experiences.

All participants appeared to have a negative experience of the diagnostic process. In addition to their new siblings being misdiagnosed or given inappropriate treatments, participants appeared to notice their siblings being sent to a variety of medical professionals who they experienced to have little knowledge or awareness of the conditions. This appeared to evoke strong feelings of frustration from participants.

Michael highlighted three elements of the diagnostic process: the amount of appointments, the amount of time to obtain an appointment with a medical professional, and the lack of knowledge he perceived professionals to have, which will be explored in turn. Whilst

Michael does not explicitly use the word “frustration”, we are able to gain a sense of his emotions whilst he tells the researcher about his experience.

> Michael page 34, lines 9-13 – page 35, lines 1-3
>
> *“..it just took way too long for them and all- all these pointless appointments you have to go to, just sort of jumping through hoops, even to get to someone who’d heard of it and was able to go, oh look, these are all the things that..”*

He describes the appointments as “pointless”, suggesting he does not feel they achieved much and goes on to describe the experience he felt his sister went through as “jumping through hoops”; suggesting he felt it was an unnecessary part of the process to reach someone who has heard of EDS and suggesting he experienced this to be negative. Michael’s language here demonstrates his frustration with the process and suggests that he may have initially expected a different outcome; a shorter process and shorter waiting times for appointments, with more professionals aware of the condition. It suggests that the difference with his expectations may have exacerbated his feelings of frustration. This is further explored below when Michael addresses the amount of appointments involved in the process:

> Michael page 37, lines 4-10
>
> *“..we’ve got to go to it so we can get this other appointment in another few months’ time and it’s like, well, what’s the..? You know, it’s- it’s wasting everyone’s time and money trying to get through to it um.”*

Whilst Michael appears to demonstrate that he understands the process of supporting his sibling to understand their physical health symptoms, he stresses that he experiences there to be a necessity to attend appointments in order to unlock the ability to attend one in the

future with a professional who may hold the answers. He also explains that he understands the current diagnostic process as wasting the time and money of everyone involved and we can sense the frustration he feels around this by the use of his language, such as “wasting” and by stopping and starting his sentences, as if attempting to communicate to the researcher how difficult the process can be. The use of “we’ve got to” also suggests that at the same time, Michael may be experiencing a sense of helplessness and acceptance; whilst he does not necessarily agree with the process, he understands that he must accept it in order to support his sibling. This along with the use of “we’ve” and “everyone’s”, further suggests that he experiences himself as being involved in the process and that he may be purposely placing his own emotions aside in order to continue being able to care for his SWEDS. This suggests that Michael may experience the ability to acknowledge his own frustration around the diagnostic process as being incompatible with how he experiences himself as being able to care for his SWEDS.

We can also see that Michael appears to communicate frustration around the approach of medical professionals as part of his SWEDS’ diagnostic journey:

> Michael page 38, lines 1-8
> *“..they’d have to keep going back and seeing these same people and it was like, why haven’t you learned (pause) why haven’t you gone well, I can’t do anything about this. She’s not- she’s just doing the same things over and over again, isn’t it?..”*

He seems to struggle to understand why his sister is having to see so many people to obtain a diagnosis and to understand why professionals were unable to fit the puzzle pieces together around her symptoms. We can see that Michael feels professionals should have been able to learn from the process and from his sister’s symptoms, and appears to be expressing frustration and incredulity at this. Perhaps Michael experiences himself as learning from the experience and subsequently wondering why professionals do not appear

to be learning, but also perhaps experiencing professionals as having a deeper knowledge and expertise that he feels should already be present. His question around why professionals are not openly admitting they cannot help suggests that he feels they are being dishonest and that he experiences feelings of frustration around this and perhaps invalidation for both himself and for his SWEDS. The amount of frustration he appears to experience suggests his emotional involvement with the diagnostic process and that this also affects him regardless of his sibling or carer role.

Similarly, Jasmine shares frustration at what she perceives to be a lack of knowledge from professionals:

> Jasmine page 49, lines 7-9
> *"..I feel like as soon as collagen doesn't work properly, it is unpredictable and I think that's why, like the unpredictability for scientists and medics is just like not okay for their brain, I guess."*

Whilst she considers how she understands EDS to be unpredictable and that this may impact the readiness of scientists and doctors to understand, her use of the language with "not okay for their brain" suggests concurrent exasperation and frustration. It suggests Jasmine may be managing her frustration, but upon speaking in detail about her experiences, she feels able to acknowledge these emotions. It suggests she may have little opportunity to do so usually. It appears that knowledge is seen as important amongst participants; both for the SWEDS to understand their condition and for the participant to feel able to manage their own expectations and emotions around having a sibling with EDS.

Isaac's frustration seems to be around the amount of diagnoses and treatments experienced by his sister before an EDS diagnosis:

Isaac page 2, lines 7-10

"..Um, yeah so there's all sorts of different disorders that she's been labelled with, different operations and treatments which we now know that maybe aren't that appropriate."

He considers how his sister's treatments and operations may have been inappropriate given his present knowledge about her condition, which seems concerning. Additionally, he has experienced his sister as being "labelled" with a multitude of disorders; his language here, suggests a frustration around the process but the use of "maybe" suggests an element of passivity in his expression. Perhaps this could be an uncertainty in whether the treatments were solely inappropriate or possibly in what my response as a researcher could be.

Amelie however, understood her frustration as being linked to her own experience of her SWEDS' diagnostic process:

Amelie page 10, lines 4-5 (about her sister not receiving a diagnosis):

"..A: Yeah, it was infuriating, I think more, you know. It was upsetting, but more for me it was more infuriating. Because we all just wanted answers."

She communicates a shared desire between the family for answers around her SWEDS' symptoms and expressed that whilst she understood this is upsetting, it contributed to these feelings of infuriation, suggesting the impact a delayed diagnosis can have, not just on patients but also emotionally for their siblings. In contrast to Michael and Isaac, Amelie explicitly communicates her infuriation, perhaps initially suggesting that the level of frustration she experiences around this is high, but it is also important to consider that it may suggest she feels comfortable enough with the researcher to openly express herself and that she may also be more used to communicating her emotions around this topic to others.

Participants' perceived lack of knowledge from others also appeared to exacerbate feelings of frustration. Michael expressed this around a lack of knowledge from medical professionals:

> Michael Page 34, lines 1-9
>
> *"..I think, the main problem I have with it is the fact that it just took that long to figure out what it was um (pause) and it just seemed like it was almost- and uh the whole NHS system just seemed to be just s- so poorly set out to deal with any- that- all that kind of thing.."*

His frustration around the NHS' ability to recognise and diagnose hEDS and the time this took, seems to be related to him perceiving the NHS as poorly designed. We can see how he experiences few people as having heard of the condition and therefore few people able to make the connections. He appears to experience himself as being involved in the process and along with his use of the word "problem", Michael's response implies his frustration around this part of his experience and also highlights that this may be part of a caring and supportive role for his SWEDS.

Isaac also shared concerns around how he perceives medical professionals to understand his SWEDS' condition:

Isaac (page 83), page 60, lines 9-11

> *"..Yeah it's not her being stubborn, it's her knowing herself better than an A&E nurse, a doctor would do and realistically what expectations she has from that she's not really gonna get I think, what she needs."*

He reflects upon how he feels his sister is unlikely to get the care he feels she needs from medical professionals. We can sense his frustration and his protectiveness over his sister,

by him expressing that he does not experience her as “stubborn”, suggesting he holds assumptions that others may view her in this way. Rather, he appears to view her as self-aware and knowledgeable. We can gain a sense of how viewing his SWEDS’ struggles with medical professionals has also led to a distrust in professionals, which appears to be adding to the protectiveness of his role for his sister and possibly part of a caring role.

Participants appear to experience there as being a variety of diagnoses being considered, which they understand as being due to a lack of knowledge from professionals, but this can upset participants and lead to increased frustration:

> *Amelie page 8, lines 6-11*
> *“..for example, they said she had polycystic ovaries at one point and then said, actually maybe not, we’re not really sure. And after having to kind of prepare her with that situation, we prepared her this might mean it’s more difficult to have children and things like that, so it was quite a difficult environment to be in. Um, so yeah it was more like just upsetting seeing her go through that.”*

We can see from Amelie’s understanding of her sister’s experience, that there appears to be a lack of understanding from medical professionals which they were able to at times acknowledge. Amelie expresses that she felt there was a responsibility to explain to her sister what the condition doctors were originally diagnosing could mean and goes on express how difficult and upsetting it was to be in this position and see her sister go through multiple diagnoses. I am struck by how Amelie appears to have experienced this as being part of the caring role Amelie and her family were in, rather than as a sibling, in order to support her sister with the potential diagnosis, rather than medical professionals doing so.

Participants expressed that a lack of knowledge extended to others around them, not just medical professionals and these experiences subsequently added to feelings of frustration.

Jake communicated that his frustration and anger was around experiencing people reacting negatively to his younger sister and their judgements around what his sister feels able or unable to do:

> Jake page 53, lines 8-10 – page 54, lines 1-5
> *"..she doesn't let it limit her where it can, but sometimes she does have to draw a line in the sand and say, look, this is something I shouldn't or cannot do. Um and people that have reacted negatively to that I do find myself very, very frustrated and sometimes I do get really angry with them because, you know, when you're sat and watched someone spend their teenage years unwell, you know, ailing across the board and they just go, no, it's not real, you're just being a drama queen is, you know, it's quite difficult to actually stomach that really."*

Jake remarks that he has experienced others as reacting negatively to his sister. It suggests others experience his sister as exaggerating symptoms or have a lack of understanding, perhaps due to the less visible aspects of EDS. He explicitly highlights the intensity of his frustration when people react in a negative manner or dismiss his SWEDS' symptoms. This could be understood in several parts: it could suggest his role as a protective sibling, it could demonstrate how involved he feels in the process and it could also indicate that he may be experiencing a sense of invalidation. If others are dismissing that his SWEDS experiences symptoms, but he experiences himself as viewing the impact on his sister's physical health, he may understand their responses as dismissing his own experiences, which may explain an increased level of anger and frustration.

Jasmine notes a lack of understanding from people not involved in their everyday life, such as journalists who interviewed Jasmine's mother about the conditions:

> *Jasmine page 12, lines 3-10- page 13, line 1*

"..lot of people said like my mum as well when she got interviewed on like [redacted] and stuff they're like, "Oh, was it an absolute sense of relief, like we're you kind of overjoyed, was it a positive experience when she got diagnosed," and it's like it's only positive in the fact that you're like, this is her ticket out of this like psychiatric unit. It's not like, "Oh, I'm overjoyed that she's ill." Like I think a lot of people like mixed up that question whenever—like journalists, whenever they asked mum about it and she's like, well no, like it was horrible because it's like, oh, like we're in a situation with the stuff and like (pause) there's no cure for this."

She highlights an assumption from others that the diagnosis would provide a sense of relief and a positive experience. Jasmine appears to understand the diagnosis to only be positive in terms of allowing her sister to leave mental health inpatient services and that she finds it important to consider how the siblings and families are not finding the SWEDS being ill as a positive experience. Importantly, Jasmine expresses that she understands there to be no cure for the condition and that this adds to a negative experience and along with what can be perceived as sarcasm, this suggests feelings of frustration around others' lack of awareness or consideration for Jasmine and her family's experiences.

We can see that feelings of frustration appear to increase when there are also feelings of hopelessness and a sense of helplessness. Jasmine implies that she experienced helplessness and to some extent, a level of acceptance after time with how her SWEDS and the family were treated by medical professionals:

Jasmine page 35, lines 6-8

"..And it's always, like especially in the beginning when we didn't have a diagnosis, you always just waited for them to like get the social workers involved and like, you know, all that kind of stuff.."

Jasmine explains that whilst waiting for a diagnosis, the family expected social workers to become involved, as if there was no medical explanation for her sister's symptoms. This implies helplessness, as though there was nothing Jasmine or her family could do to stop this from happening and a sense that others would view her SWEDS' symptoms as a concern from a safeguarding view. It is concerning that families expect this to be the case and highlights the importance of professionals considering rarer physical health conditions.

In addition to expectations around social workers involvement, Jasmine perhaps shockingly, highlighted how Jasmine and her family were aware that her sister had EDS and yet felt they did not have a choice in her SWEDS' treatment:

> Jasmine (page 71), page 11, lines 2-4
> *"So, she was taken into a psychiatric unit in [redacted], um, we knew before she went in there that she had EDS but we didn't have a choice in her going there."*

Her expression of not having a choice and the use of "we" suggests she experienced helplessness as a shared view between the family around her sisters' treatment and a suggestion that their choices were not taken into consideration. It further suggests Jasmine perceived there to be nothing she could do to stop her sister entering a unit for her mental health despite being aware of the true cause. It appears that whilst Jasmine may experience herself to have more of a role as a carer, the helplessness may be affecting her chances of this. I am reminded of the process of admissions into inpatient mental health services, e.g. reduced capacity and insight into the condition, and a concern about keeping themselves safe, in addition to the importance of seeking the family and/or caregiver's views. I am also reminded of the importance of considering the physical symptoms of EDS and how this may have better explained Jasmine's sister's symptoms and to consider the views of the family.

This feeling of helplessness and hopelessness is shared by Felicity:

Felicity page 15, lines 605-607

"..it was quite a horrendous journey really because you're just ferried from pillar to post.."

It is crucial we consider how people who have a sibling with these conditions are also involved in the diagnostic process and what their experiences may be. As we have been able to see here, it does not appear to be a positive experience and once which is understood by Felicity as being a negative experience due to being sent from place to place without answers.

3.2.2. Increased responsibility.

Having a sibling with EDS appears to evoke many emotions, but this seems to be exacerbated by how much responsibility for their SWEDS that participants perceive themselves to have. This can create feelings of disgust and annoyance, demonstrated by Jasmine and Felicity. Jasmine reflects upon how she experienced her sister before a diagnosis:

Jasmine page 8, lines 6-9

"Since she was younger, she would be like sick quite a lot, um, and like would ask to be carried all the time and I was just like, "Ugh." She just wants to be carried because, you know, she's little, but like now we understand her symptoms more because her joints were in pain like even when she's like five.."

The use of "ugh" suggests disgust and annoyance at her experience of her sister wanting to be carried so frequently when she was younger and suggests she experienced herself as having an element of responsibility to do so. The use of "ugh" implies Jasmine assumes I will

understand and possibly empathise with her experience and also suggests she feels comfortable sharing these emotions with me as a researcher. Jasmine reflects upon how she initially understood her sister's requests as being due to her age but that she now understands them being due to joint pain at a young age. This shows the process of Jasmine understanding her responses to her sister's condition changing over time.

Felicity also expressed negative feelings around aspects of her sister's symptoms. She reflects upon her sister having taken part in Cancer Research UK's Race for Life:

> Felicity page 4, lines 23-24
> *"..then seeing the kind of impact on her body, you just think God, that was a bit stupid really.."*

It suggests that with what Felicity is now aware of regarding hEDS, she finds the impact Race for Life caused on her sister's body was "stupid", showing annoyance at her sister's actions and implying she does not agree with her sister's decisions. It also shows a caring perspective and role as she considered how this would have negatively impacted her sister.

We can also see that participants can at times be dismissive of their SWEDS; not intentionally, but rather as a consequence of the amount of responsibility and pressure they experience themselves as having for their SWEDS in a caring and supportive role, versus as a sibling. This is highlighted in Michael's response when reflecting upon the physical symptoms he noticed his sister had before her diagnosis:

> Michael Page 21, lines 9-12 – page 22, lines 1-3
> *"Um (pause) but I mean, it was always just kind of like early on it's just like, oh, she's just clumsy and stuff like that, so that's when we were noticing them and she'd always tape her arm in plaster or whatever, so."*

Michael understood his sister to be clumsy before her diagnosis and we can sense an dismissive tone around the possibility of her injuries due to his understanding at the time with the use of “just clumsy”, “stuff like that” and “or whatever”. When explaining that his sister’s symptoms became more visible due to the frequency in which they occurred, he uses “we”, suggesting he experienced this view as being shared between Michael and his family. Furthermore, his heightened awareness of his sister’s symptoms and how she managed it suggests a caring aspect to his relationship with his sister.

These feelings of disgust, annoyance and subsequent dismissiveness could be further explained by participants feeling exhausted. Felicity acknowledges not only her sister’s energy levels, but her own:

> Felicity Page 16, lines 629-637
> *“..it’s tiring, it takes a lot out of them, you know, and so that whole kind of medical pathway obviously isn't there at the moment in terms of that so, hearing sometimes who she was seeing, where, when and all that I didn’t really take it all in. I just thought oh my gosh I’m just exhausted thinking about all the appointments you’ve got to go to..”*

As participants at times seemed to focus their responses more on their sibling’s experiences rather than their own, it is important to acknowledge that Felicity has openly acknowledged how exhausting it can feel thinking about what her SWEDS has to endure as part of the diagnostic process. She acknowledges that it is at times difficult to take in all the information she receives around this and it suggests a sense of perceived responsibility that she feels she needs to be aware of the process and demonstrates the impact on siblings, suggesting that she enters into the caring role when this is needed.

Perceived responsibility for participants' SWEDS can also contribute to feelings of nervousness. Jasmine notes feeling nervous around her sister's treatment:

> Jasmine (page 99) Page 101 line 10- page 102, lines 1-2
> *"..her doctor at the [redacted] Hospital, um, we have to go and see him and we're like nervous, we was like oh what is he going to say, is it going to be psychological again.."*

In particular, Jasmine notices that her feelings of nervousness are around whether other professionals will view her SWEDS' difficulties as psychological rather than physical. It suggests that she experiences mistrust in professionals and the use of "we" suggests she experiences nervousness as shared between Jasmine and her family. This implies that the diagnostic process can also affect people who have a SWEDS and further showing the conflict Jasmine experiences between being a sibling and having a caring role with responsibilities to protect her sister.

Jasmine's perceived responsibilities and struggle between her caring and supportive role and her role as a sibling is further explained below:

> Jasmine page 93, lines 7-9 - page 95, line 1
> *"..EDS can mean that you're on artificial nutrition, that I feel like a lot of it in the media is to do with like, um, I'm going to be a wheelchair user and like, like more… more joint stuff. But actually, like Lauren is like reliant on something that is like killing her liver, you know? Like that kind of thing is like madness for me to like understand. Like, I just like, cause I forget about, like I try to forget about it, I don't want to think about it all the time. But like, yeah, I feel like if you are prepared and you knew what TPN was, it would be like less of a shock when you learn like, oh god, like a line is*

something that gets pulled out and like could get air in it, like… you know, all the dangers of being like fed through a central line.."

She highlights how she would have wanted to know how EDS can affect people in different ways, including specific symptoms and how the media can also impact others' understanding. Jasmine expresses how she attempts to forget about her sister being "reliant on something that is like killing her liver", suggesting this is understandably a difficult aspect for her to cope with knowing. Importantly, she considers how knowledge about the conditions and specifically artificial nutrition, would have allowed for less of a "shock" during her sibling's treatments and the potential side effects. This suggests she feels further knowledge would have enabled her to feel able to manage this more effectively. The use of "you are prepared" suggests that she experiences herself as having the responsibility around physically caring for her SWEDS' health, highlighting the conflict between her role as a sister. Jasmine's responses suggest she may have felt overwhelmed and that she has considered what she would have found more helpful in order to cope with having a SWEDS whilst in a caring role.

We can see that the level of responsibility participants perceive themselves to have, can also increase how much they advocate for their sibling, perhaps as a way of coping with difficult emotions around having a SWEDS and having a consistent way of offering support for a condition that is otherwise largely unpredictable. Michael reflects upon how the treatment suggested for EDS generally, may cause a negative impact on a SWEDS:

Michael Page 38, lines 12-13- page 40 line 1:

"..they're given all these like exercises and stuff to do, and to be fair, she wasn't exactly receptive to them, but then it was hard to do most of them because (pause) she- she'd be doing it for a month and then she'd have a knee pop or something and then it kind of sets you back, and she can't do anything about that for a while to do

with them. So it's like- it's like, what's her motivation really to keep doing all these things if she's then just going to dislocate it, that not being her fault and it just sets her all the way back so she's wasted her time.."

Whilst he experienced his sister as not being "receptive" to the suggested treatment and understands this as due to the physical impact of the treatment and the need to pause treatment to recover, he appears to find it important to express that it is not his sister's fault and that he experienced the exercises provided as difficult. Along with highlighting that he felt this meant his sister "wasted her time", this suggests that he views his sister's time as precious and that he has a perceived importance to advocate for his SWEDS and to protect her, which could be understood in the context of both his caring role and as a sibling.

Jasmine also acknowledged what she experienced her part was in her SWEDS' experience:

Jasmine page 24, lines 1-2 (about the hospital)

"..I know that I did the very best I could to set her free from there."

She describes a protective element of her relationship with her SWEDS and explains that she tried her hardest to help her sister leave hospital. The use of "set her free" suggests that Jasmine experienced her sister's stay in hospital as unpleasant and negative and that she experienced her SWEDS as trapped; needing rescuing. We can see that Jasmine appears to have taken on the responsibility of ensuring her SWEDS' wellbeing and to advocate for her as part of a caring role.

However, a focus from participants on increased advocacy also appears to contribute to self-invalidation. There was an element of "keep calm and carry on" identified by Jake:

Jake page 18, lines 1-2

"..Um but we are all of the kind of opinion that you crack on and (pause) get over it.."

Jake explains with the use of “we” that he experiences there to be a shared opinion within his family that there is an expectation to carry on and accept the roles they have related to his SWEDS, This suggests a dismissive and invalidating approach to his own emotional responses in order to ensure the wellbeing of his SWEDS due to a possible perceived sense of responsibility for them in a caring role and suggests he has experienced there to be little choice in how to manage with having a sibling with this condition.

The increased level of responsibility can add to a difficult dynamic of balancing the amount of care and support for their SWEDS and Michael noted in particular how he experiences the support he provides for his SWEDS to be part of the role he expects to play as a sibling:

> Michael page 72, lines 7-11 – page 73, lines 1-9
> *“..I think it’s just a lot of it’s just being uh a big brother rather than looking after her do- doing something for my- I- I think of it as more as doing it- just doing it because I'm her big brother um rather than (pause) caring for my disabled sister or something, do you know what I mean? Yeah. It's just, yeah, it’s- it’s not- it’s not- I don’t see it as a big deal really. Not- not- not- not- not- not the condition itself may yeah, the role I- yeah, the role I play, yeah.”*

This suggests he experiences the responsibilities around care and support for his SWEDS to not be a separate role, but one he incorporates as a brother which perhaps would be unchanged if his sister did not have this condition. It suggests that there are times where he does not necessarily view it as a conflict to care for his sister versus being a sibling, because he has come to understand that he would support her regardless of her condition, as part of him being a brother to her. It further demonstrates his own values and intent to see his sister as more than having a disability.

3.2.3. Worsening mental health.

The emotional consequences of having a sibling with EDS appear to have also contributed to overall worsening mental health for participants. We could understand this in the context of the above explored varying emotions that participants experience and the related perceived levels of responsibility they have within their caring and supportive roles and as a sibling.

Participants noted increased levels of anxiety and worry:

> Jasmine page 41, lines 10-11
> *"Like mental health is still like a problem, like a legit problem, and I feel like I [inaudible 00:30:36] have like my own anxiety issue and it mainly started from when Lauren was poorly."*

Jasmine reflects upon where she experiences her anxiety difficulties to have stemmed from and appears to have made sense of having increased anxiety due to her experiences of having a SWEDS; particularly from the period of time when she experienced her sister to be unwell. It suggests she experienced this as a particularly distressing time and a main aspect of her experience and demonstrates how having a SWEDS could contribute to increased anxiety.

Jasmine and Michael reported that they have found their worrying increases particularly when considering their SWEDS' future post diagnosis:

> Jasmine page 79, lines 9-10 – page 80 line 1
> *"..like that big worry of like maybe one day having to live life without her, I think like trickles down into like everyday activity, becoming more anxious.."*

She notes that this has affected her psychologically, increasing her anxiety and having a significant impact on her daily life due to an overwhelming sense that she may outlive her sister due to EDS. It suggests she experiences EDS as life limiting and a factor she considers in her behaviour and approach to having a SWEDS, such as appreciating having her sister, which shows a strong relationship between them. It also therefore appears her worries are perhaps stemming from her concerns as a sibling rather than a carer; in contrast to Michael:

Michael page 102, lines 4-7

"..it's just worrying about how it's going to affect her in the future and how she's going to be able to cope with that."

Michael expresses feeling worried about how EDS would affect his sister in the future and how she would cope. It suggests a protective and caring role as a sibling, but also shows how often he thinks about this aspect and with the lens of a carer in this instance.

It may come as no surprise that stress levels were also reported to be elevated amongst participants. Jake experienced increased levels of stress which he understood to be around EDS both pre and post his SWEDS' diagnosis:

Jake page 70, lines 1-4

"..So I think you know (pause) general, the stress of not knowing has definitely diminished. But then you get the stress of knowing and then how to deal with it and there's not a great deal…. It's- it's a very difficult balance to find, I think."

He addresses that being unaware of the reasons for his sister's symptoms increased his stress but that he experiences this as having decreased following a diagnosis, reminding us of how important he perceives knowledge. Interestingly, he considers his stress to have

increased post diagnosis due to needing to know how to manage his sister's EDS, suggesting that knowledge does not necessarily reduce overall levels of stress and can perhaps highlight more aspects to consider that may seem worrying to people who have a SWEDS.

In contrast however, Jasmine reflects upon her perceived increase in self-confidence:

> Jasmine page 76, lines 2-5
> *"..all of these things like I balanced them well and like I did them well, like when I look back and I kind of think like even though like I had all these things that's happened, like I overcame it and I know that like now I've been that strong, like I know I'm in a position to like be there for her again."*

It suggests Jasmine has been reflecting upon this previously and that she experiences her responses to having a SWEDS to be well-balanced and positive, also suggesting a sense of pride and accomplishment. She seems to understand her behaviours to mean that she has been strong and that this therefore sets her up to being able to support her sister again if needed. It suggests Jasmine experiences the ability to support her sister as needing inner strength.

We can see overall that the transcending theme of the conflict between having a caring and supportive role for a SWEDS versus being a sibling is evident within the emotional consequences of having a SWEDS. There can be a significant impact on participants' mental health, which could be understood in the context of the wide variety of emotions they experience throughout their SWEDS' diagnostic journey and their own experiences navigating how to support and care for their SWEDS. Frustration and elevated protectiveness were experienced, alongside a perceived heightened sense of responsibility to advocate for their sibling, understand information and ensure their sibling's wellbeing

which demonstrates a caring role. However participants attempted to reduce the emotional consequences by attempting to forget about upsetting information of their SWEDS' condition. This conflict differs between participants as part of their subjective experiences.

3.3. Interference with Life

This theme focuses on how having a sibling with EDS can impact the participant's everyday life. "Interference" was chosen to describe this in further detail as it appears that having a SWEDS tends to have a significant negative impact on life for participants, but there are some positives to participants' experiences, which will be explored towards the end of this theme.

Three subthemes were identified: increased awareness, changed attitude to life and I need to care for my SWEDS. These will each be explored, alongside the transcending theme throughout of the conflict between being a sibling versus having a caring and supportive role for participants' SWEDS.

3.3.1. Increased awareness.

There was a general sense of increased awareness for participants around the everchanging symptoms of EDS and the complexities that can arise. Participants appeared to make sense of this being related to their SWEDS' symptoms becoming visible over time and following their SWEDS receiving a diagnosis which was able to explain symptoms that were previously otherwise explained. Amelie reflected upon a connection being made between her sister's symptoms:

Amelie page 4, lines 9-11

"..along the line we realised that other things kind of connect to each other, that were probably visible earlier but just never, we never kind of picked up on it being an issue.."

The use of "we" suggests she felt this was a shared experience between the family and that she was part of her SWEDS' diagnostic journey. She reflects that symptoms were visible previously but that they had initially not known of a connection to therefore understand it as being a concern or to make sense of symptoms. The invisible was becoming visible and it shows the process of Amelie considering the steps she experienced with her sister to understand symptoms.

Amelie also reflected upon how she experienced herself to have little knowledge of EDS prior to her SWEDS' diagnosis and the impact this had on her life:

Amelie page 31, lines 9-11

"..I mean I wish I knew, known more about the disorder first, because it just wasn't something that was part of our mind. It was one of those things that, once we'd heard about it, um, we'd noticed it.."

She appears to have experienced herself as noticing symptoms more often once EDS was mentioned, which implies that it helped Amelie to make sense of her SWEDS' symptoms. Amelie's expression that symptoms were not a part of their mind suggests she may have experienced invalidation from others and can explain why she expresses that she would have preferred to have known more about EDS previously. Her response further suggests that attempts to make sense of her SWEDS' symptoms were a significant factor in her experience and that these had a substantial impact on her life.

Felicity also reflected upon several occasions where she supports her sister now that she is more aware of the condition due to symptoms becoming more visible:

> Felicity page 4, lines 1-3
> *"..I think sometimes I'd forget that she couldn't really walk very easily, so you'd park because you didn't have the mobility, um, Disability Badge or something, um, whereas now I'm much more aware of that.."*

She admits that she would at times forget about how the condition could contribute to mobility difficulties for her sister when it did not appear visible and through lack of a Disability Badge and that subsequently, she would park further away. Felicity considers how this has now changed due to her awareness of her sister's mobility difficulties and that the impact on her life is her increased awareness of how to support her sister by parking nearer than she usually would. Felicity further expresses the usefulness of the condition being visible:

> Felicity page 3, lines 33-34
> "..I think it's just easier seeing somebody that clearly isn't, um, so physically mobile – you're able to help more, if you see what I mean.."

She reflects upon how she experiences seeing a visual reminder that someone is not as physically mobile as enabling her to support the individual more. It implies that when Felicity applies this to her sister, she is perhaps likely to support her SWEDS more than she otherwise would without a visual reminder. This could be understood that Felicity does not consider these aspects when she is not around her SWEDS, suggesting that she tries to reduce the impact having a SWEDS has on her everyday life and that she goes between the role of a sibling and the role of a carer; considering when to enter these roles.

In order to cope with an initial perceived lack of knowledge and understanding of EDS, Isaac attempted to improve his personal knowledge:

> Isaac page 14, lines 4-6
> *"..Um, so I've only been aware of EDS itself and it being an actual condition for the past year. But I'm reading more about it so it's like okay these all do kind of fit."*

He highlights how recently he has become aware of EDS and that he has taken the time to read about the conditions, which in turn has furthered his understanding of how the diagnosis can be understood in the context of his sister's symptoms. This suggests that he experienced EDS as having enough of an impact on his life that it warranted understanding EDS further.

Jasmine unfortunately appeared to have an eye-opening increase in her awareness around how medical professionals can make sense of EDS:

> Jasmine page 33, lines 7-9
> *"..I think the lucky thing about our situation is that we weren't like a typical textbook Munchausen's EDS situation because I was so involved at that point.."*

We can see that Jasmine felt professionals were suggesting there were elements of Munchausen's and FII and that this was occurring frequently. What is perhaps even more concerning, is that Jasmine experiences there to be a "typical textbook Munchausen's EDS situation"; suggesting that she understands this to occur frequently with other individuals with EDS. This suggests a disturbing impact that a lack of information and understanding around EDS from medical and mental health professionals can have on people with EDS and their families. She continues to explain her experiences around this and the impact this had on her:

Jasmine page 33, lines 9-11

"..because I was there and like fighting as well, I think that the usual like structure of that just didn't really fit so they weren't able to like completely like diagnose us with Munchausen's.."

Jasmine experienced herself as needing to fight for her SWEDS and appears to have experienced her active and clearly significant involvement with her SWEDS' care as being directly linked to medical professionals not diagnosing with Munchausen's. This suggests she understands that it would have been a concern had she not been involved as a sibling, but seems to show that she is entering into a caring role. The use of "us" implies that she experienced the family as a unit and that if one had been diagnosed with Munchausen's, this would have been a shared experience between them all. We can understand from this that Jasmine likely has a strong relationship with her SWEDS and that the question of Munchausen's and subsequent need for advocating for her sibling had a large impact and interference on her life.

It appears that Jasmine also had an increased awareness of how EDS can affect others and that this was an element she had reflected upon prior to this interview, suggesting the interference on her life:

Jasmine page 43, lines 6-9

"My mum, I remember her like picking up being a living-donor for livers, because obviously your liver like packs up if you're on TPN for a long time. So like (pause) it's had an impact on my mum as well, like she has no life really."

Jasmine highlights how she experienced her mother as a "living-donor" for her sister, due to the impact of artificial nutrition on her sister's liver, which Jasmine experienced as a direct

impact of EDS. She expresses feeling that it is not just her sister who is impacted by artificial nutrition, but also her mother and experiences her mother as having little freedom in her life.

Isaac had reflected upon how his awareness of other people's health conditions has changed over time:

> Isaac page 36, lines 2-4
> *"..Just because it's not something you can always see. Um, like I'm very aware, like, anyone for instance could have any underlying physical or mental condition.*

He reflects that physical and mental health conditions are not always visible and that anyone could have a condition, but interestingly he appears to attribute this understanding directly to having a SWEDS, demonstrating a subsequent increased awareness and consideration of others which could suggest that he experiences these aspects as carrying high importance.

3.3.2. Changed attitude to life.

Participants noted in particular that having a SWEDS changed their attitudes to various aspects of their lives. Some reported an increase in their self-awareness of their own difficulties, such as Michael:

> Michael page 98, lines 3-10
> *".. I'm definitely more aware of a lot of the struggles that I have to go through um because of it and so and then- and then and how frustrating it can be um (pause) in terms of like a lack of sup- potential lack of support and stuff like that um yeah."*

Michael expressed that he felt his attitude to life has changed due to having a SWEDS and understands this to mean he is aware of how frustrated he can feel and the perceived lack of support available that he experiences around this. His response stresses that he

experiences having a SWEDS as being directly related to increased struggles within his life that he may feel he would unlikely experience without EDS being present.

Jake noticed that having a SWEDS impacted his thought process around his own actions and around what might be going on for others:

> Jake page 21, line 11- page 22, lines 1-5:
> *"..So it's (pause) it's more raised a point of concern that there's things without you can't see or don't actually appear to be ailing you that a slight knock reveals that another part useful and another part it's…. (pause) So does put a bit of a question mark over you know, what's going on and you- you know, you seem fine until you're not fine.."*

He expresses that he experiences his sister as having symptoms which may be invisible to others but could still be affecting her and that this is not necessarily recognised until further injury occurs. He appears to experience this as partly useful and hesitates over explaining fully how he feels about this. It appears as though he has spent time thinking about this previously but not necessarily expressed this to others beforehand. He highlights that this creates a question around what might be occurring for someone and expresses a sense of his sister and others seeming well initially until they are not. We get a sense of there being a sudden change in his sister's symptoms without warning and his response suggests how he has learnt to cope with the unpredictability.

Jake also noticed that having a SWEDS appears to have led to him changing how he views his everyday life by risk assessing his actions beforehand. This is demonstrated in the below quote where Jake responds to a question about what EDS means to him:

> Jake page 89, lines 3-5

"..it's constantly having to kind of risk evaluate your whole life (pause) which gets a bit tiresome."

He expresses that he experiences EDS as meaning he needs to consistently risk-assess his life and that he experiences this to negatively impact his energy levels. It suggests he experiences EDS as regularly changing and an element of the unknown which he experiences as needing to be considered in order to manage. His perceived necessity for risk-assessing his life due to having a SWEDS, seems to also factor into how he approaches his physical health:

Jake page 65, lines 7-10 – page 66, lines 1-5

"..SN: (laughs) And has it changed about how you view your own physical health?

J: Um (pause) yes, I think it probably has. Um I make more of a conscious effort to um- because I uh I try and- if it's within reason, I try and do a lot more light exercise and stuff. Um so I cycle to work every day where I can uh if I need to go into town I walk. Because I think overexertion can be a problem that will make it worse in the future if I am a carrier of it. But (pause) with my younger sister especially, I've seen the effects of, you know, doing nothing. Because once that muscle and the- everything's atrophied, it's a lot, lot harder to bring it back.."

Jake experiences himself as making a conscious effort to consider the impact particular daily activities and exercise could have on his body and that he considers the negative consequences of overexerting himself. He understands this to be due to an increased awareness that if his sister has EDS, that he may potentially be genetically predisposed to also having EDS. He also seems to relate his changed outlook on his physical health as being due to seeing what he views as negative impacts of reduced exercise on people with EDS, such as his SWEDS. It suggests he now experiences himself as having a higher risk to poor physical health and a sense of responsibility to change his behaviours to reduce this

risk, despite not having a diagnosis, in addition to being knowledgeable about the effects EDS can have on physical health.

This awareness of EDS having genetic components and a willingness to change an attitude towards personal physical health is shared by Michael:

> Michael page 92, lines 3-12- page 94 line 1
>
> *"SN: Okay. And since Jennie's had this condition, has it changed how you think about yourself?*
>
> *M: Um (pause 8s) I mean- I mean, if the fact because it is something that is genetic is there anything that- that you know (pause) say, I'll like I have- I get- I get injured a lot, like because I- I had to quit rowing because I was like, got injured all the time.*
>
> *SN: you had to quit?*
>
> *M: Rowing.*
>
> *SN: Okay.*
>
> *M: Yeah, because I got injured all the time and I was like, oh, is this- is it maybe some little things from it that also affects me? Is that- is that part of it? But um (pause) I- I wouldn't say it- it- it massively, I would think that's more just me being annoyed at the time that my back hurt or something, you know what I mean, so?"*

Michael shares his awareness that EDS can be genetic and his reflections and increased awareness around the frequency in which he becomes injured. He shares that he needed to stop a particular physical exercise due to recurrent injuries and whilst he expresses annoyance at this, he seems to consider that his SWEDS' diagnosis could have a part to play in the amount of injuries he experiences, showing how Michael has been linking knowledge around his experience of having a SWEDS, to his everyday life.

Jake appears however, to not only consider the genetic components of EDS and whether his own health could be affected, but also whether his child could be impacted:

Jake page 63, lines 8-10 – page 65, lines 1-2

"..I (pause) just had a newborn baby.

SN: Yeah.

J: And because we're now finding out there's- that there's uh a such a 50/50 probability that if I'm a carrier, she's a carrier. Um and I think the most it's played on my mind has been since then, because- and why I've looked into different case studies and try and get as much information as what put me on to doing this really, um is the thought of, I think a lot of the damage my sisters are suffering with (pause) is because we didn't know and just were kids. So now I've got a kind of an internal conflict of she might not have it, but if she does, what is the correct balance I need to find to let her still be a child but stop her doing things you know, not stop her experiencing life, but stop her doing things that will- I know because I've seen my sisters in their later life- well, not even in later life, in their 20s all of a sudden become this greater issue. So it's finding a good balance with that is how I probably noticed it's affected me the most since, which uh I- wasn't something I expected until it came about, really."

His attempts to further his knowledge around EDS and the genetics, suggest an element of worry and fear around EDS and a desire to have a better outcome for himself and his child than what he experienced his sister as having. The use of "damage" shows how negatively Jake experiences his sister's symptoms to be. He describes an ongoing conflict around how to obtain what he deems to be an appropriate balance for his child to experience life, demonstrating how frequently he considers this and the potential impact it could have on his child's life due to his hypervigilance. Interestingly, he seems to experience difficulties related to EDS as not necessarily presenting themselves at an early age, but from the age of 20

onwards. This demonstrates that having a SWEDS has significantly impacted Jake's life and that this may be passed onto future generations as a result.

Conversely, some participants noted feelings of acceptance around having a SWEDS. Isaac made sense of this in the context of his sibling having symptoms and a diagnosis for an extended period of time and that he now feels unable to recall life before EDS:

> Isaac page 22, lines 5-8
>
> *"..it's always been a presence since I was very young anyway, to me it seems like the norm. Whereas like if I introduce, I introduced to my partner last year and he was quite taken aback by how debilitating it was, whereas I think that's normal.."*

He recognises however that this is not the case for others who are introduced to it at a later age, such as his partner and notes his partner experienced EDS as "debilitating", whereas Isaac felt the debilitating aspects were "normal" parts of his life and not an aspect which stood out to him. It suggests Isaac has spent time previously reflecting on this interaction and on how he views his life with a SWEDS. Furthermore, we can understand the importance of considering when participants were made aware of EDS and how the impact on participants' lives may differ due to this factor.

Jasmine also acknowledged her acceptance around having a SWEDS, focusing on her sister's mortality:

> Jasmine page 101, lines 3-9
>
> *".. I could sit here and like cry every day, probably if I thought about like what could actually happen to her. But then like, you know, like you can't live like that. Like I can't probably live like that, like that would be no kind of life for me, let alone anyone else in our family, so, like… like everyone has to kind of make it a positive. "*

Whilst she considers that she could be tearful around what she fears and understands will happen to her sister due to EDS, she shares a positive perspective on life, including reframing thoughts and it seems, living in the present moment. She seems to understand her perspective as being due to considering how this would not be a life she nor her family would want to live and that she feels there is a shared approach between the family of reframing EDS into being something positive. This demonstrates Jasmine has thought at length about this prior to this interview and that she is trying to acknowledge the negatives whilst reducing the interference with her life.

Jake noticed that it affected the time he spent with others when he was mainly in a caring and supportive role:

> Jake page 49, line 10 – page 50, lines 1-6
> *"..when I was looking after my sister um especially when it was just while I was the only one at home to look after her. Um I would sometimes put off going out with some people just because making sure she was all right was of a great concern to me.."*

He notes this was the case when he experienced himself as being the only one available to care for his SWEDS, suggesting this was perhaps outside of what he would usually experience their relationship to be and highlights that he would choose to care for his SWEDS and ensure her wellbeing, rather than to spend time with people and leave the house. It suggests the closeness of their relationship and that he may experience a heightened sense of responsibility, whilst also highlighting the interference with his other relationships; reducing time with others.

3.3.3. I need to care for my SWEDS.

Participants identified how they cared for their SWEDS and it appears that this changes depending on whether participants experience themselves as needing to engage with a more caring and supportive role and whether they view this as separate from their usual relationship as a sibling.

Jasmine's experiences with medical professionals involved in her SWEDS' care appear to have contributed to how she made decisions around how to care for her sister. In the above subtheme of "increased awareness", we noted that Jasmine had identified that she experienced advocating for her SWEDS as having a direct impact on whether they were diagnosed with Munchausen's or not. She reflects in various ways around how she continued to support her sister with medical professionals:

> Jasmine page 32, lines 9-10
>
> *"..every Friday we got an hour and a half battle of like fighting against like opinions that we just didn't agree with."*

Jasmine expresses that there were differing opinions between medical professionals and Jasmine and the use of "we" suggests she felt this was a shared experience within the family; suggesting the family were a united front and that she experienced there as being two sides: family and doctors. She appears exasperated at the experience of feeling she needs to fight for her sister every Friday and it is striking that she appears to have felt this was a necessity weekly, understandably having a significant interference with her life. Jasmine appears to have felt advocating was separate to her sibling relationship:

> Jasmine page 18, lines 3-6

"..Like in the beginning, when she was in the hospital for all that time, like I feel like our relationship was (pause) opening up that extra dimension of me not just being a sibling, like I was like fighting for her as well.."

She attributes her relationship with her SWEDS changing when her SWEDS had a significant hospital stay and understands this to be due to her perceived need to fight for her sister's medical treatment and that this is a separate aspect of being a sibling. However, she has mixed feelings about the care she experienced herself as being expected to provide and the subsequent impact this had on her life:

Jasmine page 18, lines 8-10 – page 19, lines 1-7

"..because the three years I was at uni was when she was in hospital. Like, a lot of my energy went into saving her, or trying to anyway. So, I feel like that kind of—I'm happy about it because it brought us closer together, but I'm not happy about it because it kind of like added this extra dimension to a sibling relationship that I don't think really should be there. Like more of like a caregiver relationship, which kind of… I don't know, yeah, like… uh, I wasn't giving her care because we didn't have her at home, but kind of like fighting for her adds like extra pressure. But like overall, like at that time, I was really… I was happy because I got to see her all the time because I have to be there for her. Does that make sense?"

Jasmine reflected upon feeling that her time and energy was around her SWEDS' care and a heightened responsibility to protect and rescue her SWEDS from the treatment she was receiving, rather than focusing on her own needs. She appears conflicted around how she feels about this situation and compares the pros and cons: a closer relationship due to increased time spent around each other, but with the caveat that she would also be a caregiver. Jasmine appears to experience this caregiver role where she would be

advocating for her SWEDS' needs as separate from her sibling relationship and an aspect she felt increased pressure and should not have been present.

There is an important element that participants noted, around the difficulty of creating a balance between a caring and supportive role for their SWEDS and carrying on with their everyday life which they seemed to view as separate experiences at times.

> Jake page 79, lines 1-10
>
> *"..Um (pause) if you try to it's like what I called bubble wrapping, it can fall and then become slightly controlling and that will cause animosity between you and your siblings. Though everyone knows it comes from a good place, it's- it's not a healthy way to live essentially. Um so it's, do things to care for your sibling, but this- again, that's- I think everything with this seems to revolve around finding a balance of you know, you can't be too overbearing, but if you do nothing, then you know, you have got to prepare yourself- you'd probably feel guilty for- either you see uh something that could go wrong or be detrimental and do nothing, then prepare to live with regret over it. Yeah."*

Jake explains how he perceives caring and supporting for his SWEDS to be important but how he can see too much support could be controlling and overbearing for his SWEDS, despite good intentions and that this could impact the strength of his relationship with his sister. He views this approach as unhealthy and recognises that by not caring and supporting, he would likely experience feelings of guilt and regret. It suggests he has weighed up these options and is reflecting upon how to balance them in a way that benefits his sister, rather than considering his own boundaries, proposing that he may focus less on his own needs in their relationship in order to fit with his current values.

Jasmine shares her perspectives on siblings who have a caring and supportive role:

Jasmine page 70, lines 10-11 – page 71, line 1

"..I feel like maybe siblings who show their support are then like relied upon. I feel like such kind of awful for saying that."

She expresses guilt around disclosing to me that she feels siblings who have this role may be relied upon by others. This suggests it is more an admission and that she may not have had an opportunity to mention this previously. It also suggests she experiences others as having expectations around siblings and caring responsibilities. We can see that Jasmine is weighing up the impact on her life being a sibling versus being a sibling who has more of a supportive role for a SWEDS could have. This can sometimes feel difficult to separate out for Jasmine:

Jasmine page 7, lines 7-9

"..it's hard to kind of, um, separate the two things because we don't really let like the EDS get in the way, it's not like trying to think of like specific EDS stuff and specific normal stuff like we kind of—it's just like one big life, you know?"

Her response suggests she makes a conscious effort to ensure she reduces the interference EDS can have on her everyday life and that this could be explained by acceptance around her situation of having a SWEDS. It suggests she tries to balance these aspects and that she ensures it does not stop her living her everyday life outside of the caring role she has with her SWEDS.

She notes the conflict she experiences between wanting to support her mum who she seems to experience as her SWEDS' main caregiver and also not wanting to be seen solely as a caregiver, but with the opportunity to be seen as a sibling.

Jasmine page 58, lines 7-10 – page 59, lines 1-4

"..mum is basically her TPN nurse at home, I guess for her. Um, and like I will help my mum out so she gets a break but also, like I don't want it to become like, "Oh, I'll do it Wednesday, Thursday, Friday," because then that moves me back into the other category. Like I want to be like… like we're best friends now she's older, you know, like we were watching Friends together, like we're going out like… Yeah, like I want it to stay like that because I want to carry on like the positive things that we built on when she was poorly and have like a normal sibling relationship.."

Jasmine experiences her mother as taking on a role of a nurse in their home and needing a break, but also seems to experience that increasing the amount she offers to support her mother, would lead to fewer activities with her sister that she enjoys as a sibling and which she feels are positive and which she understands to be part of a usual sibling relationship. It suggests she feels caregiving roles are not something other siblings experience and that she finds the caregiver role negative in comparison.

Isaac also notes increased responsibility and a step away from a sibling relationship:

Isaac page 17, lines 2-5

"..I don't think it's a typical brother/sister relationship, just in terms of I think I feel more responsible for her than I would with my little sister and a lot more, um, invested in say, her wellbeing and things.."

Isaac page 16, lines 7-11

"..I'm the younger brother but I've kind of taken a bit more of a parental role with her. She was that kind of role for me when I was growing up and now it's flipped around a little bit because she will push herself a lot more than she should, and then end up bed bound for a week and I'm like very strict.."

He notes experiencing himself as taking on a parental role, suggesting he feels caregiving aspects may not be part of what he feels a sibling relationship should entail. Interestingly, he recognises that his sister had a similar caregiver role for him during childhood which he now feels is not the case due to his SWEDS' pushing her boundaries around the condition. He notes himself as not having a typical sibling relationship and recognises being "strict", suggesting a protective element to his relationship and a perceived need to reduce harm to his sister due to her condition, compared to his younger sister where he does not appear to recognise this need.

Part of Isaac's caregiving role, is considering her needs and the impact EDS may have on her ability to take care of herself:

> Isaac page 55, lines 6-9
> *"..if she comes over I will cook for her, um and send her back with a load of food to put in the freezer (laughs) which is like fresh and healthy because she obviously doesn't necessarily have the time or the energy to be able to cook, like as fresh as she'd like to all the time.."*

He manages this by cooking for her and ensuring she has healthy meals available without needing to cook, due to the amount of energy he perceives his sister to have due to EDS. It shows consideration and choosing to spend his time supporting his sister. Isaac seems to go above and beyond for his sister:

> Isaac page 30, lines 6-9
> *"..if it's a case of sitting down in a seat for a couple of hours it isn't the best for her. So, we've got around that by picking the disabled seats and we go to the pub and*

play bingo or something and we're just very aware so we take extra pillows so she can get comfortable.."

He considers how to ensure his sister remains comfortable and how to spend time together in an enjoyable way whilst responding to her needs; ultimately showing care and respect for his SWEDS and that he has adapted his everyday approach to ensure she is included.

Amelie shared concerns around her caregiving role:

Amelie page 17, line 11- page 18, lines 1-7

"..SN: Okay, and what does this mean for you to, for example, be an ally and a friend, and also as well a care, you know a caring, care-giver?

A: Yeah, um (pause) I dunno, it feels great, you know, we have a really, you know, a really strong, um, relationship and it's very equal in the sense that we both feel that we can talk to each other and confide in each other and help each other. Um, but I don't, like the caregiving is very much more one way, towards me to her.."

Although she expresses feeling she has an equal relationship with her SWEDS due to shared emotional support, she expresses not liking her role as caregiver as she perceives this aspect to be one sided from Amelie to her SWEDS.

One of the pressures of having a SWEDS, was felt was by Jake who noted feeling he was in a full-time carer role:

Jake page 15, lines 6-9

"..Um I made all her food, all her drinks. Uh she used to have to shower with the door open- like the bathroom door open and we'd have to set time if she passed out in the shower. Um (pause) I basically became a full-time carer.."

He notes that when he was off work with his own injury, he was expected to support his SWEDS by preparing her food, drinks and ensuring she did not pass out when showering. This suggests he was needing to place her needs above his own despite also having his own injury and that he took on the main caregiving role. This appeared to influence the decisions he would make around his social life:

> Jake page 51, lines 3-10
>
> *"..So if it was a case of choose to stay and make sure if she was all right or go out for an afternoon or an evening or something, I would…. You know, to me, it seemed a negligible choice, it was. It seemed the right, you know, it wasn't the right thing to do, it was the smart thing to do. It was leave your sister that could pass out at any time and swallow her tongue or just for a couple hours of enjoying yourself or…. So I mean, we used to have a good laugh anyway, doss about and watch films really, it was good (laughs)."*

He explains the choices he made between leaving his SWEDS for his own social life or staying at home to support her and explains that he found this choice to be smart given the situation and therefore a small decision for him to make. This appears to have been influenced by what he perceived to be potential harmful consequences to leaving his SWEDS alone, compared to adjusting his plans to ensure she remained safe and still have a positive experience spending time together.

Part of the difficulty with keeping a balance between roles, is that plans were seen to be affected at times by the conflict between wanting to support their SWEDS and their family and also not wanting to always change plans:

> Felicity page 5, lines 4-5

"..organising things were always quite tricky because you didn't know, obviously it was always subject to her being well enough to be there, sort of thing.."

Felicity explains that she found it difficult to make plans as she felt it was reliant on her SWEDS being well enough to attend. The use of "obviously" suggests she experienced me as being aware this would be a factor to consider and that I may share a similar opinion to her family that her plans would need to be reliant on her sister's health. This could suggest how Felicity experiences others outside of her family also and highlights how others' opinions have impacted on her own expectations and values.

Conversely, Jasmine's fear around her SWEDS' mortality meant that Jasmine increased how often she would see her sister and reduced the balance in her life:

Jasmine page 50, lines 9-10 – page 51, lines 1-2

"..I think like I couldn't say this to her, but she talks about it all the time, but I know that she's not probably going to live as long as I would like. So, you know, it's about… I don't think about that all the time but like, probably subconsciously that's why I like going to see her all the time or like do fun stuff.."

Whilst she feels unable to say this directly to her sister, she acknowledges that her SWEDS is aware of the impact EDS may have on her own mortality. Jasmine reflects upon how she experiences herself as likely to live longer than her SWEDS and is aware that she may be subconsciously considering this, which she experiences as impacting how often she chooses to see her SWEDS and the shared experiences they have together. It suggests she views her relationship and time left with her sister as more important.

The conflict between others opinions on participants' caring roles and their own values ad boundaries, appear to have contributed to participants feeling that they at times need some

independence and time away from the conflict between the caring and supportive role they appear to feel a responsibility around and the subsequent guilt if they choose to place their needs first. Isaac noted that he experienced himself as taking on an agony aunt role:

> Isaac page 33, lines 2-5
> *"..I think I take on a bit of an agony aunt sort of role, because she's obviously going through all of this stuff and there's a mental aspect to it as well and it's obviously gonna do a lot to your mental health.."*

He explains how he understands his conscious effort to remain in this role as a way of supporting his SWEDS due to the impact he experiences his sister to have from EDS on her mental health. The use of "obviously" suggests he experiences me as understanding that this would be the case. He reflects upon how he feels around this role:

> Isaac page 35, lines 4-9
> *"SN So, what does being an agony aunt, in sort of your relationship with your sister mean to you?*
> *I Um, (pause) I mean in an ideal world I wouldn't be because she wouldn't have this condition and she'd have a normal life. But I don't mind it because it brings us closer as siblings. It's good that she's got someone to confide in. Um and I think I help her with certain things so I'm there to help so it's good."*

Whilst he feels it has improved his relationship with his SWEDS, he admits that he would prefer not to be an agony aunt and that he experiences there to be ideal world where he would not need to enter this role, suggesting the significant interference it has with his life. Isaac focuses more upon the positive aspects of how it helps his SWEDS, suggesting he is focusing on her needs rather than how he feels and somewhat invalidating himself. It is

perhaps unsurprising, given his experiences within his caring and supportive role, yet it suggests he may not have had many opportunities to focus solely on how this affects him.

However, there appears to be an overall sense between participants that their relationships with their SWEDS have improved due to EDS, which they understood as partly due to their knowledge of the condition and due to their caring and supportive role bringing them closer together:

> Isaac page 35, lines 7-8
>
> *"..I don't mind it because it brings us closer as siblings.."*

Isaac shares he does not mind his experience as he feels his relationship with his SWEDS has improved, which shows he feels this is a positive factor outweighing any negative aspects. Jasmine shared a similar experience:

> Jasmine page 102, lines 7-9
>
> *"..but like overall, like the way our story panned out, is like positive because like me and mum and Lauren have like such an amazing bond now because of it."*

The use of "our story" suggests she finds this to be a shared experience between the family and that the current ending of the story is that the relationship has greatly improved between Jasmine, her SWEDS and her mother and that she experiences this as positive.

Felicity notes that her relationship with her SWEDS has improved due to EDS becoming more visible to Felicity and the family:

> Felicity page 3, lines 26-29
>
> *"..so probably our reactions to her have changed a little but I imagine. For her, I suspect it may have made it easier for her in a way because we've got something*

visual rather than her just looking unwell and just sitting there not being able to move very much. There's a more, sort of, tangible, kind of thing to see."

She relates this to a shared understanding between the family due to there being visible aspects of EDS and perhaps due to having more understanding around what EDS entails. Felicity notes that this has contributed to reactions to her SWEDS changing between the family and understands this to make her SWEDS' life likely easier due to more positive reactions.

The transcending theme of the conflict between a caring and supportive role for a SWEDS versus being a sibling is demonstrated here by participants' views that they need to fight and advocate for their SWEDS to reduce psychosomatic conditions being suggested by clinicians, which they felt as separate to their sibling relationship and which needed time allocated by participants to do so. Additionally, participants adapted their lives to ensure their sibling felt supported as they viewed spending time with them as more important; demonstrating the caring role to ensure there are adjustments but a desire for the sibling role to spend time together, suggesting the caring role allows for this to occur. Expectations from others however around how participants should be caring for their SWEDS and an experienced conflict of wanting to help other family members involved, but not wanting to be seen purely as a caregiver, appears to lead to a desire for independence and time away which would have an effect on both being a sibling and a caregiver.

3.4. Absence of Support

This theme focuses on the absence of support felt by participants and how they manage this. Three subthemes will be explored in turn: experiencing scarcity in support, searching for support and advice for others with a SWEDS: support yourself. The transcending theme of the conflict between having a caring and supportive role versus being a sibling for participants' SWEDS will be explored alongside.

3.4.1. Experiencing scarcity in support.

This subtheme explores in particular how participants experienced little support to be readily available or offered. Whilst participants were able to reflect upon their experiences of available support for themselves, their family and their SWEDS, it has been striking how they perceive there to be so little support available for themselves:

Amelie page 24, lines 9-11- page 25, line 1

"..SN: Okay. What's your personal experience of support for you?

A: There was never really, there wasn't really any, I don't think. Um, yeah, I don't think, I mean nobody reached out. Like my family were supportive in general.."

The use of "I don't think" suggests Amelie is considering her answer and suggests she may have not previously thought about this. Amelie explains that within her experience of having a SWEDS, there was no support for her outside of her family, but notes that she experienced her family as being supportive towards her, suggesting a family unit and potentially strong relationships. Amelie's emphasis on the support she receives from her family suggests she has expectations that she should have been offered support from elsewhere, although does not explicitly state where she feels this should come from.

Jasmine page 65, lines 7-10

"..Um, support for me? (Laughs), nothing. Like, (laughs) I think this is the most helpful thing I've ever done. Like talking this through right now, like I'm going to take this with me like (pause) for ages, like today has been so helpful for me, like [inaudible 00:50:22] it or like thinking about how it affects me."

Her laugh here suggests sarcasm rather than finding the topic amusing and Jasmine's reflection that she has not experienced and support for herself as a sibling without EDS, could explain why she then informs me that she has found this interview so helpful. She informs me of the impact she feels this interview has had on her, explaining that she will take the benefits with her, in particular being able to think about the effect EDS and having a SWEDS has had on her. It should be noted that Jasmine experiences this interview as supportive and as her first experience of support purely for herself.

Jasmine continued by reflecting upon how she experiences others' perspectives on who needs support for having a SWEDS:

> Jasmine page 66, lines 4-10 – page 67, line 1
> *"..I think it's so hard because a lot of people think about like, oh, how are the younger siblings going to cope in terms of not getting the same attention? And I feel like that's as far as it goes, like knowing things about the impact on like… Like I was a grown-up, like I was 20, and it's still like it wasn't great, you know? Like, there needs to be like even if like someone gets diagnosed when they're 80 and they've got like an 82-year-old like brother, like there needs to be support, uh, there as well, like it needs to be like, like siblings need to be recognised as a category of people who are affected by it.."*

Jasmine had experienced others as considering how younger siblings would be able to cope in the context of receiving attention from others, but notes that she experiences siblings who may be older in comparison to the SWEDS and older generally, may not receive that support from others. She considers how when she felt she needed support, she was an adult and that she experienced herself as requiring more support than what she felt was available. Jasmine explains that she feels support needs to be available for siblings without EDS regardless of their age when their SWEDS receives a diagnosis. As she powerfully sums up

in the last sentence, she feels siblings need to be recognised as being affected by EDS; suggesting that she feels this is not currently the case and suggesting that she feels siblings are not considered by others as needing support.

We can see however that she experienced hopelessness within her life, which she understood as being related to her sister's condition:

> Jasmine page 37, lines 6-7
> *"..at the time, like it literally felt like your life was like never going to get better.."*

By stating that she had felt previously that her life did not have a chance of improving, this suggests she experienced a lack of support available and that she felt the condition and experience of having a SWEDS would not become more manageable for her as a sibling. Hopelessness and an experience that there was no support available, appears to have contributed to Jasmine viewing her experience of having a SWEDS as largely negative:

> Jasmine page 25, lines 4-7
> *"..the negative experiences that stand out, I definitely like how at the time, like I didn't really get the support from the people in my life that like should have been there really."*

She expresses that she felt she should have received support from particular people within her life and that this was not available for her, which stands out as a negative experience. It suggests perhaps a lack of understanding from others around knowing how to support Jasmine and a lack of services being readily available for people who have a SWEDS.

Amelie however, acknowledges a slightly different experience within her family:

> Amelie page 23, lines 10-11

"..Family I supposed was, a lot of people that wanted to support but didn't really know what was needed or what was necessary."

Amelie notes that her family tended to want to offer support but did not know how to. There is no suggestion here that Amelie or her SWEDS were able to advise the family on the support needed, suggesting an overall uncertainty between the family.

Participants noted that they not only experienced a lack of support around having a SWEDS, but that they noticed the wider family unit was not offered support:

Felicity page 20, lines 784-790

"No, I don't think, I'm not aware of anyone having any support, um or being offered any support, but I could be wrong. It certainly not something that's been discussed or come up in conversation or been put out there so my assumption is that it hasn't but I could be wrong (laughs)."

Felicity reflects upon how she is unaware of support being offered or discussed within her family but considers that it may have been the case and that she may not have been informed. This implies that even if support was offered to the wider family, it did not reach Felicity as a sibling of someone with EDS.

Jake also reports that little support was offered for his family, particularly his parents:

Jake page 61, lines 4-5

"..Um and my parents, I don't think they were ever offered much in the way of support.."

This is echoed by Jasmine:

Jasmine page 73, lines 2-3

"SN: Good. And what about support for your family?

J: They have nothing.."

Jasmine page 73, lines 7-8

"..never have anyone like come over to stay or help or anything"

She highlights that not only have her family not been offered support, but they do not currently have any support. By informing me that no one stays or helps the family, this implies that she feels this would be a particularly helpful way of supporting the family that she would value and suggests that there is perhaps pressure within the family to help her SWEDS overnight. She reflects upon how this impacts her family:

Jasmine page 91, lines 1-3

"..that's what's missing is like people in a single parent family, like you just think, "Oh, the mum and dad will take it in turn each night," but like no, like it's mum every night. Like I think that's like the biggest thing there."

Jasmine makes an important point that families do not always involve two parents and experiences others as making assumptions about hers. It suggests that the family have not been asked what kind of support would have been helpful and also suggests she experiences her mother as being the main and consistent caregiver without a break, in comparison to how she views other families coping. Interestingly, she explains how she understands support to be related to visible disabilities:

Jasmine page 74, lines 3-5

"..if you look at her in the street, you'll have no idea she has a disability, like mum doesn't get that same amount of support. Um, and I don't think that's right.."

She seems to feel visible disabilities have increased support, compared to EDS which she views as an invisible disability. Jasmine links this to the amount of support she feels her mother does not receive and expresses that she does not feel this is acceptable.

Jasmine had identified where she would make improvements on the support available for people with a SWEDS from her own experience, suggesting that she has considered this previously and deems it to be an important matter:

Jasmine page 68, lines 3-5

"..EDS UK have been like really, really helpful and I enjoyed working for them but obviously there's no like section of that like for me. Um, (pause) yeah, I don't even know where to begin. Like it would be nice to like have a group going.."

Whilst she notes that she has experienced the national organisation EDS-UK as being helpful generally and that it shows she has spent her time supporting others with EDS, she highlights that she is not aware of there being any form of support for people with similar experiences to her. There is a sense of overwhelm when she explains about her perceived lack of knowledge of how to access support for herself, but also a sense that she would experience group support as positive if it were available. She further explains this in the form of a social media group:

Jasmine page 83, lines 7-10 – page 84, lines 1-3

"..I love the Facebook group, I'm a big fan of those. So, I'd love it if there was like loads of siblings that I could just like… I could… the thing that I was kind of struggling with at the moment is like how much I help my mum with stuff like… Um, I

mean I couldn't help her that much that's why I'm struggling at the moment so I'm like, I'm worried—like, it's like a duty versus like selfishness, like should I, um… like I'd love to be able to like message and would be like, "What do you guys think of this?""

She expresses how useful she would feel a social media group of people who have a SWEDS would be and uses the example of seeking advice, validation and reassurance from others when she feels it is important to set boundaries and consider her own needs rather than others. It suggests this is a frequent conflict Jasmine is needing to manage, without much support. Jasmine explains that the conflict she enters around considering her own needs can be experienced by her and others as selfishness which highlights that Jasmine may not have been supported by others previously in order for her to invalidate her own emotions. Additionally, her choice of language here around a hope to access "loads of siblings" for increasing the support available to her, suggests she experiences there as being many others in a similar situation with a SWEDS who also would be open to supporting each other.

Participants also noted that they found there to be a lack of support for their SWEDS which they seem to acknowledge as a significant element of their experience of having a sibling with EDS:

Isaac page 47, lines 1-7

"..I think there's a kind of two-fold kind of emotional support network around her – partner, me, her daughter sometimes if she's (laughs), um, being particularly helpful that day, um, (pause) but then support around her in terms of, um, medically and benefits and things I think has very much failed her, just in terms of with a lot of misdiagnoses, for instance um and all of these different operations and treatments, which she should never have done in the first place.."

He recognises there is emotional support available for her through Isaac and the family, but that benefits and medical support have resulted in treatments he deems inappropriate and highlighting that he feels it "failed her", strong words suggesting he views it as inadequate and that this evokes powerful emotions of perhaps anger or frustration for him. He continues to explain how capability to work assessments, which are designed to support people with chronic needs, were actually unsupportive and unhelpful:

> Isaac page 47, line 11- page 48, lines 1-5
> *"..She's gone through all of the capability to work assessments and that was a very dark time for her, like mentally, um, just because they basically questioned whether she was disabled. She went in with all of her medical notes from the past 20 years and they challenged it and it's a case of they're not medical professionals, the people who are judging her on there and they challenge her on it, they ignore all the medical advice.."*

He explains how he experienced a capability to work assessment as judgemental around his sister's symptoms and reports experiencing them as questioning if his sister had a disability despite being able to provide evidence. This suggests a wider judgemental response from others, invalidation and a deeper lack of understanding, in addition to the impact this can have on others. As Isaac talks about his experience of little support being available for his SWEDS, strong emotions remain present throughout expressed through his language:

> Isaac page 49, lines 5-11
> *"..so yeah I think the support there has really, really failed her. She was very worried about it, she ended up having to pay back a lot of money just because they'd miscalculated what they should have paid her, um, which is very stressful.."*

The use of “failed” repeated here and the emphasis of “really, really” shows that he experiences strong emotions of perhaps anger and frustration and a possible need to protect his SWEDS due to how he experienced a lack of support for his sister from services. Isaac expected there to be more support for his sister. He notes the impact he experienced the assessment to have had on his sister, such as being housebound without her car which he understands as a mistake from the assessors and considers how he understands disability to have a direct negative impact on income.

Michael also noted that he has noticed support for his SWEDS as changing post her diagnosis but that what was available was generally limited:

> Michael page 87, lines 7-10
> *“..I think there’s obviously more now once she’d been diagnosed, but there's not- there’s not a lot kind of thing..”*

Whilst Michael highlights that there is more support available post diagnosis, he confirms that there is little available, suggesting he expected support to increase after the diagnostic process. He reflected upon the support he felt would be useful for his sister and the family:

> Michael page 109, lines 9-12 – page 111, lines 1-11
> *“Um honestly, financial would- that- that’d be- because uh there’s- there’s a lot of just…. I mean uh stuff like she’s- she’s been given- you get like the standard disability things which is they give you like a laptop and sometimes- like a- sometimes you get a like a printer or whatever, but (pause) there’s not really enough specific. Yeah, she’s got like a million different leg braces and you know, and you know, all the- all the splints and stuff like that and um I think that- that- I think now that- that- that would be um the most useful but um (pause) but I think maybe- I think maybe like my mum also because she's the one that deals with her the most my-*

maybe she'd appreciate um being able to see someone to talk to about it. Um not even (pause) maybe- maybe just to sort of check up on you know, personalise it so they could talk about the condition itself, but then also how (pause) it's affecting her, so kind of um like a double…."

His focus on support for his sister and family rather than for himself initially, suggests that he feels they need support more than he feels he may do in comparison. He notes that his sister has had access to equipment adapted for her needs and lots of mobility aids which he experiences as useful, but also considers how financial support for his sister and emotional support for his mother would be helpful. He justifies the need for emotional support with his understanding that his mother has more contact with his sister. Interestingly, he notes how the emotional support could be teamed with having the space to talk about EDS, suggesting he feels time to process and understand the condition is useful for people with a caring and supportive role.

Conversely, despite largely negative views around medical professionals, participants reported that they had on occasion experienced support from medical professionals. Felicity draws upon how she experiences there to be more support for her SWEDS post diagnosis, now that she understands her sister's symptoms as visible to Felicity and to others:

Felicity page 3, lines 19-23

"..she's gone from someone that spent a lot of time in bed to somebody that's now in a wheelchair, braced up, um, with a mobility scooter. So what does that mean really? Um, just means that she's getting support now, which is great as well, cos she's now got a Disabled Badge she can use, she's got a Motability car, so it's really nice that she's now getting some support that enables her to go out and live a bit more easily.."

This suggests that she did not experience her SWEDS' symptoms as visible prior to a diagnosis and that she understands there to be increased support now that others can see there are difficulties and have visual reminders. She compares the differences between her sister needing to spend time in bed, to now using mobility aids which she feels contribute to more independent living.

Jasmine also noted that her SWEDS had access to further support post diagnosis, in the form of psychological therapy:

> Jasmine page 72, lines 7-10 – page 73, line 1
> *"..there's a Psychologist at [redacted] who is supporting Lauren now not because of, um, (pause) not because of like mental health in terms of like, "Oh, you make it all up in your head," but she's there to talk about like, um, Post-Traumatic Stress Disorder cause that's the diagnosis now for being like put in that unit for so long."*

She ensures that she is clear about how psychological support is not in place due to anyone feeling that EDS is psychosomatic, but due to PTSD from experiences within services where symptoms were misunderstood and misdiagnosed. It highlights the impact these mistakes can have on SWEDS.

Jake found that support for his SWEDS was possible depending on the professional:

> Jake page 61, lines 2-4
> *"..once we- she'd moved and referred to a new doctor um the level of support for her has been really good. Uh (pause) uh my sister was- got some good support from that side.."*

As we can see from Jake, support tends to come from professionals who are knowledgeable and accepting around EDS, suggesting this may be inadequate with other professionals and demonstrating how the knowledge of professionals can play a significant part in the experiences of people who have a SWEDS.

There were various ways in which participants experienced themselves as supporting their SWEDS and this changed over time.

Isaac's support appeared to be offering emotional support, perhaps from a heightened sense of responsibility due to experiencing there as a lack of support from others:

> Isaac page 34, lines 2-4
> *"..I think a lot of it, um, my role in it is, kind of, always picking up the pieces, helping her see through to the light at the (pause) or whatever the phrase is.."*

He views himself as supporting his sister to seek a positive attitude and know that her situation will improve, whilst also offering support when her situation may feel difficult, but his language of "picking up the pieces" suggests he experiences himself as being a main source of support or his sister instead of her being able to access this elsewhere and demonstrates a perceived level of responsibility to support his SWEDS and to provide her with hope.

Michael reflected upon how his support for his SWEDS has changed post diagnosis:

> Michael page 115, lines 9-13 – page 116, lines 1-9
> *"..you just kind of have to understand that a lot of times you're just going to have to kind of get along with it yourself, um when you know, when something happens and then just understand that you know, that that- that right now, and it's probably- it's*

probably the same with any disability realistically is that, is that- that there's a lot of the time where they just they need your- they need the attention and the support just more than you do, so."

He expresses that there will be frequent occasions where people with EDS need attention and support more than he experiences he would as a sibling and that he feels it is important to understand this. His response shows he considers EDS to be a disability and that he reflects upon how his response to EDS would be in his opinion, similar to a response with another disability.

Michael explains that when someone has a SWEDS they need to understand their SWEDS' needs, implying they must maintain acceptance around the situation. The use of "have to" suggests he experiences there as being little choice with his responses to his sister's condition and explaining that he experiences people with EDS as needing support more than their siblings might suggests he places his sister's needs first and understands this to be important in the context of a disability. The change in his caring response to his SWEDS is demonstrable of the change in symptoms of EDS over time and highlights how participants may need to consistently adapt.

Felicity however, appears to worry about supporting her SWEDS sufficiently:

Felicity page 18, lines 708-710

"..sometimes I feel a bit oh gosh I don't feel I can support as much as maybe I'd like to because I don't know enough about it.."

Felicity admits that there are times where she feels unable to support her SWEDS or that the support she is able to offer is insufficient and attributes this to a perceived lack of personal knowledge. It shows that Felicity attributes increased knowledge around EDS to an

increased ability to support her SWEDS. However, sometimes participants made a conscious effort to increase their knowledge with the aim of being able to support their SWEDS effort to increase their knowledge, with the aim of being able to support their SWEDS, as we can see with Amelie:

> Amelie page 19, lines 3-5
> *"..I think, when I hear her the term Ehlers-Danlos now I understand a lot more about it and therefore, um, feel that I sometimes can give a bit more support than I would have before.."*

She notes that she feels able to provide more support that she would have before improving her understanding of EDS. It shows an effort by participants to attempt to make their SWEDS' lives more manageable and a level of compassion and thoughhtfulness.

3.4.2. Searching for support.

Whilst the support available for participants was certainly limited, participants identified where they were able to obtain a form of support. The wider family unit was a main source for Jake and Jasmine:

> Jake page 62, lines 3-5
> *"..I think we- we're- as a family, we're very, very open, you know, there's essentially no topic we won't discuss. So we do form our own kind of insular support network.."*

He acknowledges that his family act as their own support network for each other and explains that they will talk about everything, suggesting a close bond between them all and supportive environment for Jake. He explains that the support is not purely emotional:

Jake page 41, lines 8-10

"..if someone's nursing an injury, we won't- we'll go out of our way to help them out or (pause) I don't know, typical family stuff really (laughs)."

Jake experiences a shared approach within the family that they will go above and beyond to help someone if they are injured, demonstrating that there is physical support between the family in addition to emotional support. He appears to experience this as something to be expected within a family unit which could explain why he has not considered support outside of his family as his needs may be being met.

Jasmine also reported a reciprocal environment within her family; namely between Jasmine and her mother:

Jasmine page 20, lines 7-9

"..mum is her like TPN provider, like mum is basically her TPN nurse at home, I guess for her. Um, and like I will help my mum out so she gets a break.."

She experiences herself as offering support for her mother, who she deems as having more of a nurse's role at home with her sister's artificial nutrition and for her SWEDS, by providing the TPN care when her mother needs a "break". The use of "break" suggests the toll it takes upon the family and Jasmine's acknowledgement that she will do so to help her mother suggests the reciprocity of the support experienced between Jasmine and her mother.

Isaac however, noted that he did share a level of reciprocity with his SWEDS:

Isaac page 45, lines 6-11- page 46, lines 1-4

"..I don't necessarily think that's something I need because it's not a terminal illness, it's something that they've [inaudible] manage, however in terms of er like emotional

support, erm, I kind of I think I can talk to her about things like that, she knows I'm not gonna like pour out my heart and say this is really difficult for me, we're gonna do this because that's being insensitive anyway and I don't think it is that way, it can be difficult sometimes to know that your sibling is in a lot of pain and there's nothing you can do for them, especially when they're getting bad news with diagnoses and they don't really know how to handle it and you're trying to make sense of it for them.."

He reports that he feels able to speak to his SWEDS and obtain emotional support to some extent, but that he is more careful around choosing what to disclose in case it comes across as "insensitive" to his SWEDS' difficulties. Isaac explains that he finds being a sibling is "difficult", with a sense of helplessness around his SWEDS' symptoms and experiences. It suggests that he feels his emotions may have less value in comparison to his SWEDS' struggles and that he may be invalidating his own experiences and emotions, but that he understands EDS as not being a terminal illness and seems to feel that subsequently, additional support is not needed for this reason. We can also see that Isaac takes on the role of sense-maker for his SWEDS as a form of support for them, but it seems that no one can fully offer him this in return.

Some participants sought support from their partner but did not appear to find this helpful:

Isaac page 46, lines 6-8

"..Erm I'll talk to my partner about it, erm (pause), but even then they're in the same position that I'm in with her whereas they can't suggest anything that's gonna help, just keep on listening I guess.."

Isaac acknowledges that as his partner is supporting his sibling equally, they are unable to offer Isaac support, further than listening to his difficulties. His response however suggests that he feels listening as a form of emotional support is insufficient for his needs and that he

requires support in other ways. It also suggests that Isaac may be experiencing hopelessness around others having helpful suggestions for improving his situation of having a SWEDS and therefore to some extent, hopelessness for his partner being in a similar situation.

Jasmine however, experienced her partner as criticising her support for her sister:

> Jasmine page 22, lines 3-6
>
> *"..my relationship with my boyfriend at uni was quite strained because, um, he'd be like, "Look, I know you love her but like you can't keep fighting for her because it's not really your job." And at the time I was furious because everyone in my life kept telling me that"*

Jasmine noted that she experienced others within her life as questioning her approach to caring for her SWEDS due to advocating for her sister. Additionally, she experienced her boyfriend at a particular time in her life as sharing these views, which she felt created a strain and negative impact on their relationship. This suggests others viewed Jasmine's support for her SWEDS as significantly impacting her life and that whilst they may have been coming from a caring perspective for Jasmine, she may have experienced invalidation around her own feelings and capability around making decisions. Jasmine expressed anger towards these attitudes which she is able to recognise now alongside the impact on her relationships and these seem to be an important element of her experience.

It is also important to note that participants experienced medical professionals as being supportive if their SWEDS' symptoms were validated and believed.

> Jasmine page 30, lines 2-4

"..one of the nurses who was kind of like on our side at this point had disconnected Lauren's TPN and she was like go, like get out of here, like she was like, "Go on your nice day trip," but like I think secretly like they knew where we were going."

When Jasmine was talking about a trip the family had planned to take her SWEDS out of an inpatient mental health unit to visit an EDS specialist without the support of the wider team, she noted that she felt professionals took sides and that one in particular, supported the family in being able to leave the service for the appointment. Jasmine recalling this to me, demonstrates how important Jasmine perceived these actions towards her and her family to be and shows the positive impact validation can have not just on people with EDS but on their siblings without the conditions also.

Interestingly participants noted that they tended not to ask for support from others. Jake noted that he has not previously been offered support:

Jake page 62, lines 5-8

"..So partly, I think we don't seek help because it hasn't been offered and we won't go out of our way to look for it and to other things that you'd speak to people to get said help is spoken about quite openly, that's…. So I think it's kind of mitigated by that fact."

He highlights that he experiences people with a SWEDS as not actively searching for support and the use of "we" suggests he experiences others who have a sibling with EDS as sharing similar experiences of not being offered support from others. Jake notes that he understands people who have a SWEDS as being able to speak "openly" about other difficulties which he experiences as a contributing factor to not seeing further support for himself. This suggests that he feels people are less likely to talk about their specific experiences of having a SWEDS and therefore less likely to seek support for this.

Jake also reflected upon how he learnt over time that EDS was part of his life and that he understood this as another reason to not actively seek support:

> Jake page 58, lines 4-7
> *"So, um within my family good- with- outside of the family (pause) I've never really actively- support- uh, you know, sort out any help or support for anything along those lines, I just (pause) carried on as I have (laughs)"*

There appears to be a sense of "keep calm and carry on". Whilst Jake acknowledges his family were supportive, he notes that he has not sought support outside of his family and has continued with his life. It may suggest that he feels he did not require additional support due to how his family manage, but could also suggest that he has not thought about what support he may need in addition or been given the opportunity previously to consider this.

Amelie shared a similar reflection:

> Amelie page 24, lines 3-6
> *"..her diagnosis came after a lot of the issues had already been almost dealt with, but we all just kind of learned to cope with, like the stomach issues and things like that. So, by the time the diagnosis came we weren't like actively like desperate for support or help from the medical side of things.."*

She notes that by the time her sister received an EDS diagnosis, many of her symptoms had been managed. The use of "we" suggests she felt there was a shared understanding between the family that they felt able to manage with her sister's symptoms and that they did not need to actively seek additional help outside the family. This highlights that siblings may

be needing to adapt and accept due to a lack of support and the length of time it takes for them to witness their SWEDS receive a diagnosis.

In addition to accepting that having a SWEDS was simply part of their lives, there was also a sense that there was a duty to support their SWEDS as part of their role as a sibling and that they would do so regardless of the diagnosis:

> Jake page 58, lines 9-10- page 59, lines 1-2
> "..I've never considered it uh (pause) something I've needed support for, really, you know. Uh you look after your sister because she's your sister, it's…. (pause) Um (pause) I don't know, this had been my job to support them, I don't need the support."

Jake expressed that he has not considered support for himself as he deems it as part of his everyday life due to being a sibling. It shows a level of acceptance around the condition and his role in his sibling's life and subsequently, an understanding that he does need support around an everyday factor.

Amelie even noted that she has not previously had a chance to consider her experiences of having a SWEDS or the role she has:

> Amelie page 34, lines 1-4
> *"..I feel like it's something I've never really had to talk about or ever talked about. Um, so it's an interesting experience..."*

Highlighting that she has not "had to" talk about her experience, suggests she has not been asked about it by anyone before this interview. She describes being asked to think and talk about her experiences as "interesting" and it appears Amelie is processing being able to talk about her experiences and valuing the opportunity to do so.

Likely with the lack of support in mind, participants considered the support they would have liked to have available and how this could help people with a SWEDS and their families in the future:

> Michael page 107, lines 9-12 – page 108, lines 1-2
> *"..just something you know, just to- to understand it a bit more and you know, if there's anything I'm doing wrong or something that I have to be doing differently um with regards to it.."*

Michael notes that furthering his understanding would have been of use and feels this would have supported him to know how to support his SWEDS which he clearly feels is important. He also considers other forms of support for him as a sibling without EDS:

> Michael page 105, lines 1-13
> *"..maybe would've been useful is like if there was just something we could get like, massage not even just myself to just something like uh like a- like a workshop or a presentation just to explain it all to us, like in like, well, like a Q&A or something and just- just to- um maybe just to understand it bit more from the most. I mean, obviously, there's- there's just a lot of other things that I'm still- I'm still not sure about um."*

He initially considers the usefulness of a massage, suggesting he experiences stress and would like time to himself, but goes on to explain how a workshop or presentation with opportunities to ask questions would have supported his understanding of EDS, demonstrating how he views knowledge to be important.

Jasmine however, highlights the usefulness of this particular interview as an opportunity for her to process:

> Jasmine page 1-5, lines 2-9
>
> *".. And how is it—lastly, how is it been to talk to me about this?*
>
> *J: Like, one of the most positive experiences of like for a long time, like I actually feel like (pause) like I feel like I'd like piece my mind together by like putting it all out there. Um, and like it's really helped me particularly with like the guilt that I feel about not helping as much, like it taught me a few today kind of like justifying my reasons for that even though I still feel a bit guilty, like just like talking about it is really helpful. So, thank you."*

She expresses that the interview had been a positive experience due to providing an opportunity for her to process her experiences by talking about them. Jasmine also notes that she has found talking about her experiences helpful in understanding her feelings of guilt around how often and when to support her family and SWEDS and to help her to validate her own emotions and boundaries. This suggests the positive impact we could see from increasing opportunities for siblings to speak about their experiences. The way in which participants understand their experiences, may explain the role they perceive themselves to take in their SWEDS lives and therefore the type of support they would find helpful in order to cope.

3.4.3. Advice for others with a SWEDS: support yourself.

During the interviews, participants considered if there was any advice they would want to give to others who may have a SWEDS. This interestingly presented in the analysis as being related to how participants perceive having a SWEDS to have impacted them and appears to largely be around different ways participants would like to support their SWEDS or others with the condition. Throughout participants' responses, we can see their conflict

between having a caring and supportive role versus purely having a role of a sibling where they can support as needed rather than as expected by others.

Jasmine's focus was around considering the mental health of people who have a SWEDS, I addition to reducing guilt and creating a balance with their care and support:

> Jasmine page 92, lines 5-10 – page 93, lines 1-3
> *"..I'd feel like if it's affecting like your mental health, like go and speak more about it. Like it's—it is okay to… I feel like it's okay to change your opinion as well. Like also back then I was, "Oh, you know, why is everyone cross that I'm supporting mum, why is everyone thinking that I'm not living my life right by giving up things for my family? Whereas now I look at it with like a more balance view, and I feel like you shouldn't have to feel guilty about that. Like, like I shouldn't feel guilty about like not being there every single night and like that's fine, like you can live your own life, like learn what your balance is in terms of like just having a balance with like shopping and like being there for them."*

She highlights that she wants to communicate to other participants that if they find having a SWEDS is affecting their mental health, that it is important to seek help for themselves. This suggests how important she views mental health to be and that she has considered within her answer how her own mental health was affected. Jasmine also expresses that it is acceptable to change opinions throughout their experience as someone who has a SWEDS. She understands this in the context of her changing how she perceives others' perspectives on the amount that she is caring and supporting her family and that she now understands a balance to be necessary. Jasmine also highlights the importance to reduce feelings of guilt, particularly around striking a balance in a caring and supportive role and encouraging others who have a SWEDS to understand that they can be there for their SWEDS and also live their own life.

Amelie also highlighted the importance of seeking support for others who have a SWEDS:

> Amelie Page 30, lines 5-11 – page 31, lines 1-2
>
> *"..SN: Okay. And, what advice would you give to other siblings who have a sibling with Joint Hypermobility, Hypermobility Spectrum Disorder or Hypermobile Ehlers-Danlos Syndrome?*
>
> *A: Um, to reach out for support if they feel that they need it. Um, (pause) to just be there to support their sibling as much as possible, and really try and understand what they need from you, because, you know, some people might really want their sibling at every single doctor's appointment and others might not want them at any, so it's very much just about being, like directly listening to what your sibling wants and needs.."*

Similarly to Jasmine, it suggests she views mental health as important and that she has considered her own experiences within her response. Amelie highlights that she finds it important to ask SWEDS what support they need: emotional, physical or practical and stresses the usefulness of directly listening to a SWEDS.

Participants identified that an additional way to support themselves with having a SWEDS, was to increase their knowledge around the condition.

Felicity considered that participants will have different relationships with their SWEDS compared to her own relationship and that this needs to be considered when thinking about advice for others:

> Felicity Page 77, lines 1045-page 78, line 1052

"Well I suppose it depends on people's relationships with their siblings as to what works for them, but I think um, (pause) I think understanding, you know linking in with a charity organisation or looking up information about it, if there's a really good book about it, I think that that can help in terms of at least you have some knowledge about it. But also I think the sibling that's got it will feel more supported by them doing that as well.."

She chooses to focus on the importance of increasing personal knowledge around the condition to support SWEDS and increasing involvement with local support networks. Felicity seems to understand these aspects to help SWEDS feel more supported also but acknowledges that this will differ depending on the relationship someone has with their SWEDS and highlighting the individual and unique experiences.

Jake also expressed his perceived importance around increasing personal knowledge to support SWEDS:

Jake page 77, lines 3-10

"..Um (pause) especially if they're themselves not a carrier, that they- just understanding that (pause) the body doesn't work essentially the same as- well, it does work the same, but (pause) just saying, oh, come on, pull your bootstraps up, isn't helpful, it's. Sometimes you know, the- them being your own family, you know when they need a to kick up the arse and sometimes you know when you need to give a helping hand, it's…. (pause) Um it's, push them to do things, so don't let them shut down and do nothing, but don't expect them to run a marathon.."

He explains that knowledge around how the condition may affect SWEDS can be useful to know how to respond in a supportive way and describes seeking a balance. It appears he understands this to be between being a supportive sibling with an element of tough love and

being understanding around when particular responses can be more damaging to SWEDS and that SWEDS also need to seek a balance in their lives which participants can support them with.

Isaac however, highlights the importance of considering the various emotions SWEDS may experience, in order to know how to support them effectively:

> Isaac page 65, lines 2-11 – page 66, lines 1-2
> *"..appreciate that there's probably a whole range of emotions they're going through, they're not just depressed, they're going to go through things like having to accept like addictions, grief for what they can't do and like limits at like points in their lives and then they can go through all of these things multiple times; it's not like you accept it once and then it's done. There's like a lot of different triggers, whereby it can then send you into a bit of a downward spiral, um, um which is understandable it's huge kind of stress and pain to actually put a person through so, you just I guess listen, try to understand, don't make any judgements, like kind of accommodate when you can and don't make any don't have too high expectations of someone because then they're going to feel like they can't reach that and it makes them feel more disabled I guess.."*

His response demonstrates he has thought about what may have helped him in hindsight and what he understands to be important through his experiences of having a SWEDS in knowing how to support them. Throughout his response, he continually validates each emotion and communicates his understanding of how SWEDS may be feeling. He acknowledges that emotions will change and that he understands SWEDS to experience grief for what they may be unable to do physically and acceptance around the condition which may present itself more than once. Isaac specifically highlights that he feels participants should lower expectations of their SWEDS, be non-judgemental and to actively

listen. It suggests he views the role of a participant to need to include emotional and practical support for SWEDS.

Participants' responses suggest they are consistently focusing on how to improve the life of their SWEDS and suggests this may be second nature given the length of their experiences and that they may feel the way to improve their life is by improving their SWEDS' lives.

The transcending theme of the conflict between a caring and supportive role for a SWEDS versus being a sibling is evident when participants note that they experience pressure from others to support their SWEDS overnight, suggesting they are aware of entering into a caring role. Single parent families could potentially add to pressure experienced by participants to enter into this caring role away from their role as a sibling, whilst conversely, others questioning how much participants support their SWEDS, contributes to increased feelings that they need to support their sibling as people do not understand the importance, adding to a protective element. Interestingly, participants noting that they would appreciate support from others, suggests they have an understanding that they have a caring role which requires support.

4.0. Discussion and Conclusions

In this final chapter, the reader will be reminded of the research aims of this current study, before discussing the findings of the current study. These include the transcending theme of The Conflict Between Having a Caring and Supportive Role for a SWEDS versus Being a Sibling and three superordinate themes of Emotional Consequences of Having a Sibling with EDS, Interference with Life and Absence of Support. They will each explore their relation to the current, limited literature available on HSD, hEDS and siblings of people with these conditions, and to the aims of this research. In addition, the relevance to Counselling Psychologists and our colleagues within a multidisciplinary team will be considered, with reference to relevant psychological frameworks. Limitations of the study will be addressed, along with clinical implications of the findings and recommendations for future research. Due to the researcher's connection to the topic, a concluding reflective statement will be included followed by conclusions about the current study.

4.1. Research Aims

The research aimed to make sense of how people who have a sibling with hEDS or HSD understand their experiences, with the intention of ensuring individuals' unique responses were addressed and that participants had a non-judgemental space to explore their experiences in detail. The research also aimed to explore what it means to have a sibling that requires care and support due to these conditions. As to date, there appears to be no previous literature on this topic, the researcher hoped that this study would contribute to empowering participants and encouraging them to speak about their experiences. By doing so and having the opportunity to make recommendations for services and future research, the aim was to contribute to improving the quality of life for people who have a sibling with hEDS or HSD and to continue to raise awareness of these conditions to healthcare

professionals, subsequently contributing to the support available for participants and justifying the importance of continuing further research.

4.2. The Conflict Between Having a Caring and Supportive Role for a SWEDS versus Being a Sibling

The transcending theme throughout the findings, was the conflict participants experienced between having a caring and supportive role for a SWEDS, versus being a sibling. This will be discussed in relation to current literature and theory.

This conflict was exacerbated by a perceived sense of responsibility from participants to care for their SWEDS. At times this presented as participants explaining doctors' explanations of medical symptoms to their sibling, but there was also an understanding amongst participants that they needed to ensure the wellbeing of their SWEDS. In order to do so, participants took it upon themselves to acknowledge the physical health needs of their sibling in order to manage the condition and considered what could exacerbate symptoms.

This heightened sense of responsibility could also explain why participants took on an advocation role for their siblings, despite them not necessarily acknowledging this explicitly. They do not seem to allow their SWEDS to give up but take an overwhelmingly humble approach to explaining their caring and supportive role. A potential explanation for these modest responses is that participants felt this was to be expected of them by others as part of being a sibling and that therefore these additional caring elements were not noteworthy; some indeed did note that they felt they had a duty to support their SWEDS. This could be understood in the context of their relationship to help which would suggest their perceived expectations are related to how they expect to be helped and to help others.

Part of this duty is reflected in their acknowledgement of having a protective role of their SWEDS; protecting them from what could exacerbate symptoms, from what participants deem to be a threat of their SWEDS' symptoms being understood as mental health conditions by others and protected from their perceived threat of not being believed. They note that this can feel as though they are fighting for their sibling against opposing views from professionals, which is a concerning aspect professionals should be aware of if we wish to truly manifest a healthy and therapeutic relationship with caregivers and patients, in order to achieve the outcomes we hope for.

This heightened sense of responsibility can be understood using the family systems theory (Bowen, 1985), who noted that if there is a low differentiation of self, this may present as a focusing more on the needs of others within the family and perceived importance of meeting the needs of others (Bowen, 1985). However, this responsibility to ensure the wellbeing of their SWEDS can be at the expense of their own emotions and needs, which supports Woodgate et al. (2016) and Leedham et al. (2020) who found siblings place less importance on their own needs, but there is instead an emphasis on the wider family's needs.

As part of this conflict between roles, the analysis shows that participants also felt they constantly needed to adapt to the situation, which we can understand in the context of the family systems theory (Bowen, 1985), who noted that when there is heightened anxiety noticed by an individual as part of the family triangle, they may adapt to balance out the needs of the family. This supports O'Brien et al. (2009) who acknowledged that people who have a sibling with Down's syndrome were needing to adapt but this is in contrast to their findings that this was not the case in people who have a sibling with ASD or Cancer. This demonstrates how unique the experiences of people who have a sibling with a long-term condition can be and the importance of ensuring adequate research is conducted

addressing the wide variety of conditions so that support can sufficiently address the needs of people who have a sibling with a long-term condition, which further supports similar recommendations made by O'Brien et al. (2009).

Participants acknowledged the difficulty of maintaining a balance between supporting their SWEDS and overwhelming them and when the role of caring and supporting a SWEDS is seen as separate from what they may otherwise expect as part of their usual role as a sibling, this can affect how they care for their SWEDS and how they seek support.

Subsequently, we noted in the analysis that there was a conflict of deliberating supporting their sibling and family and wanting to reduce the chances of being seen by others as purely a caregiver. There was a sense of fear amongst participants that being seen as a caregiver would negatively impact their relationship with their SWEDS, in that they would no longer enjoy mutual non-HSD/hEDS related activities, be seen in a parental role and would therefore not have what they deemed to be a normal sibling relationship.

As a result of these fears, participants expressed that they noticed at times reducing the amount of care for their SWEDS in order to protect their sibling relationship and avoid uncomfortable emotions such as guilt. This suggests that siblings and the wider families of people with HSD or hEDS may not feel equipped with skills to cope with the situation or have an understanding that there is a shared responsibility between the family. Not only were family relationships affected, but participants also found their relationships with partners and friends strained due to the pressures of having a caring and supportive role for their SWEDS.

Subsequently, they appear to search for acceptance in relationships with the aim of building stronger connections around this and otherwise experience anger and frustration when others do not understand why they deem caring for their SWEDS to be an important aspect of their life. These are all elements which could be addressed within psychological therapy with siblings and within systemic psychological therapy, but would also be useful to address with the family when a diagnosis is reached.

4.3. Emotional Consequences of Having a Sibling with EDS

Findings demonstrated that the emotional consequences of having a SWEDS can involve frustration, increased responsibility and worsening mental health. The findings consistently highlighted that SWEDS were diagnosed with a different condition before hEDS or HSD were considered and these were noticed by participants. Poignant aspects of their experiences were that until their SWEDS reached a medical professional who had knowledge of HSD or hEDS, other physical health or even psychological conditions were suggested as an explanation for their SWEDS' symptoms, understandably increasing the frustration felt by participants. Not only does this suggest that only professionals with knowledge of HSD and hEDS are able to make sense of the symptoms and make accurate links, but it also suggests that there is some element of a health lottery; that there are potentially so few professionals with this understanding, that patients are somewhat bound to experience a lengthy diagnostic process unless they have a professional in their local area and service who can make sense of their experiences.

For SWEDS to receive multiple diagnoses, this suggests a level of desperation by professionals to explain symptoms and participants appeared to understand this as a lack of knowledge from others. This therefore supports previous research such as Baeza-Velasco et al. (2011), Terry et al. (2015), Bennett et al. (2021) and Wang et al. (2024), which have all

concluded that the conditions tend to have a longer diagnostic process due to the lack of understanding from others. Participants had made sense of this in the context that professionals struggle to understand HSD and hEDS due to the unpredictability of the condition and how it differs within patients, with many participants expressing a feeling of exasperation around this.

As Berglund et al. (2010) noted that there was a sense of disrespect by professionals due to the amount of symptoms, it is possible that the experiences the current participants noted could indeed contribute to feeling disrespected further and increased frustration, which would support these findings. This demonstrates the importance of medical professionals striving to improve their knowledge, so they can reduce the impact and disruption this has on both patients and people who have a SWEDS.

It is interesting that alternative conditions not usually comorbid with hEDS or HSD were considered, as whilst professionals were not necessarily aware of HSD of hEDS being options to consider, they were evidently still noticing particular symptoms, demonstrating some awareness, but perhaps suggesting a lack of active listening to the patient, their siblings and their respective views.

Participants had shared in interviews, that they had either been informed of or experienced professionals being dismissive towards their SWEDS' symptoms, experiencing them as being unconcerned when they do not have a valid explanation. Whilst research by Berglund et al. (2010) and Yew et al. (2021) each found that professionals dismissed these conditions due to a lack of understanding, these findings demonstrate that sadly these experiences do not appear to have improved. These findings, along with the concerning experience one participant noted of their SWEDS not being informed that a diagnosis was previously made

on their medical notes, suggest a lack of communication between professionals, patients and their families or caregivers, which undoubtedly prolongs the diagnosis and increases the impact this has on families as a result. If we consider this in the context of the relationship to help proposed by Reder and Fredman (1996), we can understand that participants' experiences of future help could be significantly impacted by witnessing professionals dismissiveness towards their SWEDS and this could discourage them from seeking support for their own health.

Participants noted that they felt the diagnostic process consisted of their SWEDS attending more appointments and procedures than participants felt were necessary and concerningly viewed some of these as inappropriate. They also noted feeling frustrated about the amount of time, money and resources they felt the process entailed and whilst they understood this as not being the fault of the individual clinicians and more a lack of awareness amongst professionals, we must consider the potential impact this has on people with a SWEDS in witnessing the process but feeling as though they have no input. The responses from participants demonstrated that this led to an overall sense of dismay, disappointment and frustration around the process and the National Health Service (NHS) and understandably contributed to a lack of trust of professionals within participants. We previously noted that Guedry et al. (2023) found patients felt frustrated with the care they received due to a lack of knowledge and that Bell and Pearce (2022) concluded that caregivers expressed the importance of professionals being aware of the conditions. These current findings not only support these studies, but also share a similar perspective from the viewpoint of the siblings of patients.

In addition, participants felt similarly around the exercises their SWEDS were provided with from clinicians; they experienced these as being challenging for their SWEDS and noted

they felt their sibling's symptoms were not taken into consideration when treatment plans were considered. Their heightened sense of awareness to their SWEDS' experiences meant they reported noticing how this can feel disheartening for their siblings' and lead to a decrease in motivation, which subsequently felt frustrating for participants to view. This continues to demonstrate the importance of professionals creating trusting, therapeutic relationships with patients and to include the family or caregivers within their considerations and treatment reviews, which, as Ojeda et al. (2014) concluded, can subsequently allow for greater mutual trust from all involved and as Bird et al. (2013) noted in particular, can contribute to more effective outcomes in treatments.

As we saw in the analysis of interviews that the overall experience of healthcare professionals was seen as inadequate and poor by participants, this was able to be explained by participants understanding others involved in their SWEDS' care as having a lack of knowledge and awareness of the conditions. These findings further support several previous studies which all noted limited understanding and knowledge of hEDS and HSD (Baeza-Velasco et al., 2011; Terry et al., 2015; Bennett et al., 2021 & Wang et al., 2024).

Their responses suggested that they viewed their SWEDS as being more knowledgeable of their condition compared to professionals and whilst this can understandably be justified as patients have a lived experience, therefore able to understand their own bodies, we could consider that training could better equip professionals and prepare them more adequately, creating a less pressured environment for professionals, patients and their families. We must also remain aware that despite people with HSD and hEDS being referred to as Zebras, this does not mean people with the conditions do not exist.

This lack of knowledge extends itself to the NHS services available post diagnosis also. Participants noted experiencing a sense of irony, in that their SWEDS who have mobility issues and symptoms such as chronic fatigue, are being asked to attend multiple appointments at varying locations, where there are limited parking facilities, making it feel inaccessible and exhausting for their SWEDS. Participants noted that they personally felt exhausted and drained thinking about the processes they understood their SWEDS had to experience.

Services could benefit from considering alternatives for supporting patients in attending their appointments and making the experience more bearable for siblings who have a caring role for their SWEDS, such as video-calls or phone-calls or liaising with the hospitals and clinics to advocate for increased or reserved parking for appointments, if funding allows. Whilst we could suggest considering increased accessible parking, we need to hold in mind the difficulties patients experience in gaining a diagnosis in the first place and the length of time this takes, thus having access to a blue badge may not be possible. This could overall create a more positive experience for people with a SWEDS who may have the responsibility of accompanying their SWEDS to appointments.

The media was noted within the analysis, to have a lack of knowledge perceived by participants. They highlighted that despite journalists having the opportunity to research the condition before conducting interviews, focus is on joint problems and mobility aids, rather than additional symptoms, such as gastrointestinal. Participants also noted that assumptions were made by the media and others, around how the family may view receiving a diagnosis as positive, which can be experienced by siblings as somewhat invalidating; although an accurate diagnosis can certainly be valuable, it does not mean the symptoms the SWEDS experiences or the challenges siblings face daily dissipate. Whilst using

platforms to increase awareness of the conditions can be helpful, it is imperative to ensure research is conducted beforehand to reduce the chances of false or inadequate information being dispersed.

These experiences, along with others viewing chronic pain as being explained psychologically, have understandably contributed to feelings of frustration amongst participants. There was a sense that psychosomatic explanations meant reduced help for SWEDS and that this was a shared view amongst the family. These experiences understandably contribute to participants viewing their overall experience of the diagnostic process as largely negative and these concerns appear to stay with participants after diagnosis has been reached. When participants need to seek support for their own health, these negative experiences and views of the health services available could potentially prolong the time it takes for them to seek medical treatment and could ultimately increase their risk depending on the health concern, which further supports similar findings by Clark and Knight (2017). When early intervention is key for so many conditions we have the ability as healthcare professionals to change the perception people have, to encourage them to seek treatment earlier.

Interestingly, participants throughout their responses, appeared to assume the researcher's knowledge, suggesting a level of trust in the researcher and perhaps an element of comfort in feeling that the researcher will understand them due to providing the opportunity to speak about experiences; suggesting participants may not have had this opportunity before.

Frustration appeared to be increased when participants felt helpless or hopeless. An unsettling finding was that participants did not feel they were involved in decision making around their SWEDS' treatment. This contributed to participants feeling helpless and

understanding that this was a shared view between the family, demonstrating the impact these decisions can make and how many people can be affected. For one participant, this was explained in the context of their SWEDS being admitted to a psychiatric unit, despite already having a diagnosis of hEDS with related physical difficulties with food consumption. Whilst it is not the purpose of this research to comment on individual cases, it would be remiss of the researcher not to highlight that the processes of admissions into mental health services include, but are not limited to, considering the patient's insight into their condition, being able to keep themselves safe, having reduced capacity to make decisions and seeking the views of caregivers. It worryingly allows questions to be made as to whether these were adequately adhered to as part of good practice and as we can see from findings, it appears the family did not understand the rationale for the treatment plan. This suggests a lack of communication between professionals and the family and perhaps a lack of opportunities given to the family to ask questions. It is also imperative to note the importance of clinicians considering the views of siblings and the wider family or caregivers who have a caring and supportive role and in taking a holistic approach in considering both physical and mental health explanations.

The increased responsibility that participants felt to care for their SWEDS led to them understanding themselves as needing to advocate, particularly when they experienced their SWEDS' symptoms as not being believed by clinicians or instead being seen as psychosomatic. Some participants had noted that doctors had expressed not believing SWEDS, despite alarming symptoms, whilst others had experienced their SWEDS as being told their symptoms are psychological and that there is a purpose of obtaining drugs. Not only is this invalidating towards the patient and their family who have taken the time to seek a diagnosis but it also seeks to cause further distress to all involved.

This author noticed that an increase in responsibility that participants perceived themselves to have appeared to increase these feelings of frustration and lead to feelings of disgust and annoyance. Participants could subsequently at times become dismissive towards their SWEDS due to the pressure they felt around what they experienced others as expecting from them and from exhaustion.

There were several disturbing findings, the first being that Factitious Disorder Imposed on Self was considered by professionals to explain SWEDS' symptoms. Disappointingly, these findings support Sulli et al. (2018) who also found that Factitious Disorder Imposed on Self was considered by professionals and that this understandably contributed to a mistrust around clinicians; a view which was shared by the current participants. Whilst it is imperative that we consider our duty of care, it suggests that Factitious Disorder Imposed on Another could also be queried by professionals which could have a direct impact on people who have a sibling with HSD or hEDS. Furthermore, it is equally important that we consider all avenues, both in mental and physical health and do not ignore the possibility that symptoms could be explained by rarer medical conditions before we make assumptions. Whilst we can acknowledge that clinicians are human and mistakes may indeed be made, clinicians complete sufficient rigorous training to know that we have an equal duty to remain knowledgeable about conditions or be willing to improve our knowledge. This is a shared responsibility across all disciplines and professionals involved in their care and clinicians must remain open to questioning decisions if we disagree with the outcome or process.

Adding to this sense of responsibility rather interestingly, is that participants seem to experience themselves as being involved in their SWEDS' diagnostic process and view this as a shared experience between the family; that it is not just the patient waiting for a diagnosis, but also the family so they can make sense of what is going on and start to

understand how to move forward with their lives. They seem to experience themselves as noticing symptoms long before professionals do and there actually appears to be less acceptance from participants around alternative conditions being diagnosed, yet when HSD or hEDS is suggested, participants appear to research the conditions and accept that they accurately explain their sibling's symptoms. Interestingly, this appears to support Bell and Pearce (2022) who noted that this research role tends to occur in caregivers due to viewing professional's knowledge as insufficient.

In addition to supporting their SWEDS with attending appointments, they also appear to take on the role as "sense-maker" for their SWEDS but find that they do not have this role reciprocated for them. Subsequently, along with how important they seem to view knowledge of the conditions, they take matters into their own hands by researching the conditions to further their personal understanding, concurrently recognising that much of their knowledge of the conditions comes from their relationship with their sibling, accompanying their siblings to appointments and the communication around the conditions between them, all of which demonstrate strong relationships. It has also interestingly manifested itself as a sense of heightened responsibility in participants to further understand the conditions and to prepare their siblings, rather than relying on medical professionals. This can further be explained by previous literature that concluded the perceived importance caregivers have on personally increasing knowledge about the conditions (Bell & Pearce, 2022) and supports Linimayr et al. (2025) who noted that people who had a sibling with a chronic condition which started in childhood, increased their knowledge around the condition in order to support their sibling.

With several participants noting that they experienced themselves as making active choices to care for their SWEDS to ensure they feel supported, at times meaning this was instead of

socialising, further demonstrates a heightened sense of responsibility amongst siblings. Placing their SWEDS' and wider family's needs above their own in order to help the family to cope with the situation, can be seen as admirable, but this could be due to a low differentiation of self if considering family systems theory (Bowen, 1985). This is concerning as this could increase the sibling's risk of burnout, which could negatively impact their own mental health and their abilities to care for their SWEDS and therefore the wider family's ability to cope, as Bowen (1985) suggests. This was recognised amongst participants and there appears to be a conflict around caregiving roles they experience themselves as being involved in which can create a closer relationship with their SWEDS, or considering their own health first.

These findings highlight the importance for professionals to gather history from the family in addition to truly acknowledging the views of the family which could ultimately contribute to a more prompt diagnosis. As family views are considered when assessing for mental health conditions such as Autism Spectrum Disorder and the 2017 criteria for HSD and hEDS (Malfait et al., 2017) highlights that a diagnosis of hEDS can be made after considering whether the family share symptoms or have a personal diagnosis, clinicians should therefore be choosing to do within their practice, whether they are treating a patient or their sibling.

Rather unsurprisingly, these emotional difficulties contributed to participants reporting worsening mental health. Participants quite aptly summarised that being a sibling of someone with hEDS or HSD can be a difficult experience and many reasons were identified throughout the interviews. The main impact appeared to be on the mental health of participants, supporting Rea et al. (2019) who noticed psychosocial difficulties in siblings of people with a chronic health condition, but who did not specifically explore this impact on siblings with HSD or hEDS. Participants noted high levels of stress pre and post diagnosis,

which is unsurprising given how they experience and witness the diagnostic process and the symptoms their SWEDS experience daily and which supports Russek et al. (2019) who noted that family members of people with hEDS or HSD experience levels of stress significant enough to warrant psychological therapy. A somewhat consuming level of frustration was felt by participants regarding the diagnosis, especially regarding viewing the process as needing to meet certain requirements to have a chance at reaching a diagnosis, despite participants largely having little faith that this would be achievable. It appears as though the diagnosis is not solely the experience of the patient, but is felt by people who have a SWEDS and at times, the wider family which participants are able to sense as part of their experience. As part of their caring and supportive role whereby participants accompany their SWEDS to appointments and care for them at home, they are required to take time off work or change their own plans in order to support their SWEDS.

Additionally, they developed anxiety disorders originating from their SWEDS becoming unwell and being affected by concerns around how their SWEDS will cope and an awareness of their SWEDS' mortality. There appeared to be a heightened awareness of their SWEDS' ill health and one participant in particular, noted that they may outlive their sibling which subsequently impacted their decision making regarding spending time and caring for their SWEDS. This likely exacerbated the amount participants felt they needed to risk assess their lives, especially their own physical health and suggests a hyperawareness. It appeared to contribute to participants choosing to pace themselves or reduce activity, suggesting they may have been aware of techniques such as pacing that their SWEDS may have been taught within their treatment, which could conversely, be beneficial for their mental health. However, their awareness of the potential genetic implications and risk to their children appeared to increase from their understanding of the conditions and this was mentioned by several participants, suggesting the impact this has on people who have a sibling with the conditions. The current research confirms previous findings from Gurley-

Green 2001 who considered hypermobility specifically, Morlion et al. (2008) who focused on chronic health conditions as a whole and Derouin and Jesse (1996) who noticed higher levels of worry in people who had a sibling with asthma or cystic fibrosis. This suggests that findings from the current study could have broader implications for chronic health conditions that may not necessarily be related to HSD or hEDS.

4.4 Interference with Life

Participants also noted that they experience hEDS and HSD as invisible conditions, due to the range of symptoms that may not always be as visibly evident to others and that over time, participants become aware of the symptoms and difficulties their SWEDS experience. They appear to experience symptoms as suddenly changing, on occasion, with the use of mobility aids that they may need to assist their SWEDS with, demonstrating the level of debilitation people with these conditions can experience and the subsequent impact on siblings who have a caring and supportive role. Interestingly, the use of mobility aids supported participants in being reminded of the difficulties their SWEDS faced. Whilst some participants reflected that they would at times not recall their SWEDS' needs, they noted that witnessing mobility aids had a positive impact on their awareness and in knowing how to support their SWEDS. Previous literature has acknowledged the lack of understanding from the family due to the invisible nature of these conditions (Berglund et al., 2010; De Baets et al., 2017 & Bennet et al., 2021), and the current findings support these conclusions, acknowledging the viewpoint of multiple separate family members who indeed recognise the impact the condition becoming visible can have on their perceived knowledge.

Participants appeared able to start making sense of their experiences in viewing their SWEDS as unwell when a diagnosis was made and interestingly, they appear to feel this is a shared experience between the family. However, they noted others being unaware of their

SWEDS' symptoms until they were informed verbally, due to the at times invisible nature of some of the symptoms. Feelings of annoyance were reported amongst participants, particularly when they experienced symptoms as being visible but having no explanation or when they noted their SWEDS requiring more support from either the participant or the wider family, without an understanding as to why. This annoyance tends to dissipate when a diagnosis is obtained and participants understand the SWEDS to not be at fault. Interestingly, they reflected upon how they have found their experience of having a SWEDS to change how they view other people; considering that someone may be suffering but their symptoms may not always be visible to others.

These findings demonstrate the unpredictability and changeable nature of these conditions which participants appear to be aware of. An important aspect to consider when working with people who have a sibling with hEDS or HSD, is the difficulties they may face needing to navigate their new normal when symptoms can suddenly worsen and improve and that it would be careless of professionals not to acknowledge that they may be affected in different ways by this. It is imperative to take from this that invisible conditions do not mean patients, their siblings or the wider family are suffering less.

Not only was the mental health of participants impacted by having a SWEDS, but their physical health also took a toll due to having less overall time to take care of themselves. This supports previous research by Chang et al. (2010) who noticed similar results in people who care for someone with a chronic health condition. Further challenges were identified which centred around the negative aspects of being a caregiver. In addition to feeling pressure to take care of their SWEDS and therefore focusing on the needs of their SWEDS rather than their own, they also seem to struggle with a heightened awareness of the risks that may befall their sibling if they take care of them or engage in medical support. There is

also a sense that participants view themselves as needing to become nurses without feeling they have adequate training and thus learning how and where to set boundaries with their families. Interestingly, participants seem to view this pressure as coming from the wider family rather than their SWEDS, suggesting that pressure is a shared experience between the family and that they are seeking support from participants who are perhaps viewed as responsible and knowledgeable enough to take on this role.

The experience of having a caring and supportive role for a sibling with HSD or hEDS could be positive on occasion, however. Participants noticed an increased understanding of their sibling's symptoms which they felt was important for them to know how to support their SWEDS and reduce feelings of helplessness. They were also pleased for siblings to receive a diagnosis as they found this to validate their own experiences in addition to their SWEDS'. Participants highlighted the personal importance of their SWEDS receiving a diagnosis, which suggests a diagnosis is the focus and that they view this to create opportunities for their SWEDS to have a better quality of life, which in turn means participants can refocus on other aspects of their own respective lives. It is also important to note that participants' strength was evident throughout; they noted feeling that they needed to be strong due to having perceived that there was little other choice and therefore learnt how to reframe negative thoughts into positives.

A "keep calm and carry on" approach suggested participants felt they were unable to change the situation of having a sibling with these conditions and suggests a way siblings manage and demonstrates the other part of the conflict participants experience with learning how to balance caring for their sibling and maintaining their strong relationships with their SWEDS. The psychological framework on the relationship to help (Reder & Fredman, 1996) suggests

experiences such as these could be impacted by the individual's environment and cultural ideas around whether they seek help.

It also appears to support previous research by Payne (2007) who noted that people who have a caring role seem to refrain from recognising their position, perhaps out of fear that it will detract from their identity. This approach appears to contribute to emotional dissonance and perhaps a viewpoint of there being little point in acknowledging their emotions if they are unable to change the outcome longer-term. Unfortunately, this could significantly increase their risk of burnout, as we have seen from several studies such as Kenworthy et al. (2014) and Fiabane et al. (2019).

4.5. Absence of Support

An element of this research was to explore how people who have a sibling with HSD or hEDS experience available support. Participants generally felt the support available was poor; they expressed that visible disabilities have more support options available and that there were few opportunities to obtain emotional support around their experiences or to consider the impact of these conditions on them, which they viewed as a shared experience between the family. This supports findings in recent research by Linimayr et al. (2025) who found that people who have a sibling with a chronic condition of ASD, Down Syndrome, Chronic Kidney Disease or Cancer had also not been informed of support available for them and that some felt this was unnecessary as they deemed themselves able to cope. Findings from Harvey et al. (2022) could provide an explanation that participants in this current study may not have accessed support as they may lack awareness of their own needs.

This was evident in participants' responses, where they appeared to be processing their experiences and initially focusing within their responses, on the emotional, financial and psychological support that would benefit their SWEDS, rather than for themselves, suggesting the rarity that they can spend time considering their own needs. Interestingly, responses suggested participants had previously thought about some of the topics covered, but had not necessarily had a chance to verbalise these thoughts. Participants opening up to the researcher demonstrated that they trusted the researcher to understand and respect their perspectives, possibly due to being aware that the researcher had chosen to research this particular topic and also suggests that they would benefit from emotional support that they do not appear to have obtained elsewhere.

When considering the support available to them, participants shared the view that they were not offered support from professionals after their sibling's diagnosis and that subsequently the family strengthen as a unit and work to offer this support for each other which could be explained by their relationship to help, due to their expectations of how to help and to be helped (Reder & Fredman, 1996). They acknowledged feeling supported by professionals only when their SWEDS' symptoms were recognised and validated, highlighting the importance of all professionals involved with people who have a sibling with HSD or hEDS to make a conscious effort to validate. This also supports suggestions by Courtois and Ford (2009) that psychological therapists should ensure they implement active listening skills and of remaining empathic.

This could in turn, support people with a SWEDS to gain trust with professionals and be more likely to seek support for themselves when required. Crucially, they noted that they have not actively sought support for themselves as they did not know what is available, suggesting that services could be more proactive in informing the families of patients of the

support they can obtain, such as psychological therapy. The usefulness of psychological therapy in supporting people who have a sibling with these conditions further supports previous research that identified the importance of a multidisciplinary approach for patients and carers, such as Yew et al. (2021) and Guedry (2023) which is implemented within the NHS (Carter et al., 2003).

It is imperative that we consider the recommendations of participants of the support they would find beneficial. Knowledge was a continual focus point within responses and participants felt that if workshops or further information was provided to people with a SWEDS, they would feel better equipped in supporting their sibling and in validating their experiences, which they view as an important aspect of being a sibling and having a caring and supportive role. Participants reported feeling forgotten about by others; there was a sense that when considering the siblings of people who have a diagnosis of HSD or hEDS, that siblings were assumed to be more affected if they were of a younger age. They stressed the importance to the researcher of ensuring others acknowledge that adults can continue to be impacted and that it is imperative that support is available for all ages. They acknowledged that one of the main organisations offering support and information around hEDS and HSD, does not offer support specifically for siblings and expressed that they felt support groups for siblings and social media support networks would be of significant benefit to their mental health and offer non-judgemental spaces to process their emotions and experiences.

A main piece of advice from participants, was that they would hope others who have a sibling with HSD or hEDS can learn that it is acceptable to have a balance between living their own life and caring for their SWEDS and that it is vital to seek support for themselves.

4.6. Clinical Implications

It is also of interest to consider these findings in the context of the relationship to help (Reder & Fredman, 1996). Reder and Fredman (1996) explore how people tend to develop a relationship to help based on childhood family relationships and cultural factors. This theory could potentially explain the frustration some participants express around the diagnostic process. As Reder and Fredman (1996) noted within their work, if people have had disappointing prior experiences within their relationships which have been unreliable and not met their needs, they could pre-empt that this would be the case in future relationships, such as with medical professionals and this could in turn, become a pattern in responses to professionals and in this case, specifically when their sibling is seeking a diagnosis for HSD or hEDS. As they suggest that we all develop our own relationship to help, this of course would mean that professionals may have opposing ways of relating (Reder & Fredman, 1996). It is crucial therefore, that as professionals, we identify and remain aware of what we may be bringing to appointments, particularly therapeutic sessions and how this may clash with what our clients are bringing.

This current study highlights how people who have a SWEDS experience themselves in a caring role, the relationship with their sibling and the impact on their mental health and supports the theory of the Informal Caregiving Integrative Model (ICIM), proposed by Gérain and Zech (2019). By considering this theory, we can understand how to support people who have a sibling with these conditions and are experiencing burnout from having a caring and supportive role, and we can implement this within our practice. As part of their model, they suggest exploring how elements of their social environment in addition to their caring role, impact them psychologically, considering how they understand their role as a carer and understanding the relationship they have with who they care for (Gérain & Zech, 2019); in this case, their SWEDS.

The clinical implications of these findings are invaluable in the practice of Counselling Psychology. This study aimed to explore the experiences of people who have a sibling with HSD or hEDS, considering the previous focus in literature on patients and their parents, and this appears to be the first study conducted on this topic. Subsequently, we can consider how to effectively work with and support people who have a sibling with these conditions and how we can significantly improve services and offer consultation to our colleagues within a multidisciplinary team.

We have seen that the mental health of people who have a sibling with HSD or hEDS can be significantly impacted by a variety of factors in their internal and external worlds. Not only do the family systems contribute to added pressure, heightened responsibility and increased anxiety for participants, but the unpredictable nature of these conditions and the lack of knowledge from those around them, add to heightened emotions which participants have little opportunity to explore or to learn effective coping mechanisms. Participants experience the dismissive approach of professionals towards their SWEDS and witness the alarming experience of mental health being used as an explanation for their SWEDS' symptoms, with their SWEDS subsequently being reprimanded with disrespectful comments from professionals or being placed in psychiatric units. As Counselling Psychologists, it is of upmost importance that we consider how this can negatively impact participants seeking support for themselves and in having a trusting, therapeutic relationship with clinicians. This could indeed partially explain why participants do not actively acknowledge the extent of their caring and supportive role for their sibling with HSD or hEDS; after all, if participants are witnesses to their SWEDS being dismissed, why would participants be willing to actively seek support for themselves.

Furthermore, we should be aware that if patients with HSD or hEDS are described in the medical world as “Zebras” due to the rare nature of these conditions then surely, the siblings of these patients are also to some extent Zebras; they are not always recognised by others as existing, let alone having a caring and supportive role and it is crucial we bring this into the awareness of all healthcare professionals.

The benefits of considering this aspect as Counselling Psychologists, means we can maintain a holistic viewpoint on what our clients may be experiencing; a crucial element of the Counselling Psychology doctoral training which enables us to consider the multiple ways in which these experiences can affect our clients. As part of the Counselling Psychology doctoral training, there is an emphasis on treating clients as individuals and focusing on their experiences, rather than focusing on a diagnosis. Whilst many Counselling Psychologists do work in health settings such as pain management clinics and therefore may expect to see clients who have a SWEDS or even the patient themselves, other Counselling Psychologists may be less aware of these possibilities. It is vital that when assessing clients and starting treatment with them, that we consider asking whether they view themselves as having a caring and supportive role for others as they may not readily feel this information is of importance if attending for reasons they feel are unrelated. By remaining aware of these factors, we can understand barriers to therapy that clients may face, such as needing to reschedule or miss appointments to take care of their SWEDS- sometimes at late notice, distractions from the outside world if receiving a phone-call from their sibling or family, difficulties being able to ensure that therapy remains their protected time for their well-being and ensuring they prioritise engaging in home practice of skills learnt during therapy sessions. This awareness ensures we can consider how to effectively support our clients, such as being aware of the unpredictable nature of their sibling’s condition and how this may affect service cancellation protocols, setting realistic expectations with clients and modelling

how to set boundaries whilst maintaining unconditional positive regard and support, engrained in Counselling Psychology training.

Systemic therapy could be remarkably beneficial for the families of people who have HSD or hEDS. As Wampler and Patterson (2020) highlight, the family operate together and this should be considered within psychological therapy, rather than solely considering their individual experiences. As we have seen from the findings of this current study, hEDS and HSD do not appear to be conditions located in one individual but become conditions experienced within the family system. Whilst the analysis chosen for this study of IPA focuses indeed on individual experiences, the purpose of this is to gather a greater understanding of what siblings go through daily, which can be considered alongside the limited amount we already know of how parents or other caregivers manage. It does not however, diminish the importance of considering how their experiences may be influenced by shared family views and approaches to coping but may also differ due to their own individual experiences in life.

Systemic Family Therapy (SFT) allow the opportunity to acknowledge these aspects as a whole and work with the family to understand and support each other (Wampler & Patterson, 2020). It also allows the space to explore potential cultural differences between the family and professionals (Goldenberg et al., 2008), which may allow a greater understanding of how to reduce feelings of frustration around the experience of medical professionals and identify specific coping mechanisms the family can adopt together. Systems Theory (Stanton & Welsh, 2012) would be important to consider within psychological therapy as the idea that collective rules are created within the family and that these could explain behaviours, are elements that may need to be acknowledge and at times, challenged within the family if rules are contributing to undesirable effects.

As part of our training as psychologists, we learn about the importance of seeking the views of the family and this subsequently should be part of our continual practice. Within our roles, we are also able to support siblings to process their difficult and challenging experiences, understand the challenges their loved ones face when they have a caring and supportive role, which may share similarities or have differences, and we are able to support siblings in learning about shared responsibilities and setting helpful boundaries. Considering the family systems theory (Bowen, 1985), we are aware that the emotions felt by one within the family unit will have an impact on others involved, in this case, a family triangle between the participant, SWEDS and a parent.

This subsequently could reduce the amount of pressure the family feel and the level to which they feel supported and could therefore have a positive impact on their own mental and physical health. With greater control over their own health, the family are less likely to experience burnout and more able to effectively support the person with HSD or hEDS.

In individual psychological therapy, elements of thinking systemically can also be utilised and there is more opportunity to work with clients to understand the impact on the relationships around them and how they can create more meaningful relationships which align with their values. Cognitive Behavioural Therapy (CBT) allows the opportunity to work on understanding the link between thoughts, emotions, physical reactions and behaviours, in addition to challenging and reframing negative automatic thoughts. Understanding unhelpful thinking styles which could negatively impact their behaviours and challenging core beliefs around themselves, the world and others, could allow for improvements in their own mental health and in their ability to continue to care for their SWEDS, whilst reducing the negative impacts.

Counselling Psychologists should consider that people with a SWEDS may also benefit from learning skills to manage stressful situations, supporting Russek et al. (2019) who also noted the benefits of CBT for reducing stress in family members of people with hEDS or HSD. Additionally, learning skills to reduce anxiety and low mood, which they appear likely to face as part of having a SWEDS, can be addressed with CBT techniques. People with a SWEDS may indeed seek trauma focused therapy due to having witnessed their sibling's symptoms which can certainly alarm participants, their subsequent treatment and the difficulty in being aware of their sibling's potential mortality depending on the severity of the condition.

This research is not only the first to acknowledge the experiences of people who have a sibling with HSD or hEDS and therefore adds to our understanding of the impact of these conditions, but can also be useful when considering the impact of chronic health conditions on people who have a caring and supportive role when the condition may not be HSD or hEDS.

4.7. Limitations

The researcher identified potential limitations of this study. Due to the analytical procedure chosen of IPA, a small sample size was obtained in order to gather rich, detailed data. Additionally, an inclusion criterion was that participants typically reside in the United Kingdom (UK), therefore the experiences of participants is focused on their experiences of the NHS. Due to the limited sample size, it was not possible to ensure that a range of participants who had siblings who sought medical support through the NHS and siblings who sought support privately were included, yet this would be an interesting aspect to explore in future research.

In order for participants to hear about the study, they needed to either be a member of social media support groups, to check the EDS-UK or HMSA websites, to hear via word of mouth, or to be a student at City, University of London. Due to time constraints of the current study, the researcher was unable to consider gaining NHS ethical approval and therefore was unable to recruit in specialist clinics and services. In addition, recruitment became more challenging due to the outbreak of the COVID-19 pandemic and thus this could have affected the participants choosing to take part in the research. Furthermore, whilst recruitment did include having a sibling with a diagnosis of either HSD or hEDS, interestingly, all participants had a sibling with hEDS. Although HSD was not represented within these findings, we can make the assumption that findings would not necessarily differ due to the similarities in conditions and the identical diagnostic processes and treatments that HSD and hEDS share (EDS UK, 2017).

Nevertheless, this does mean that whilst these current findings widen our knowledge into this area and identify significant gaps within the available literature, larger studies on this topic are needed in order to be able to make generalisations to others who have a sibling with HSD or hEDS, including people who do not typically reside in the UK. Additionally, this study needs to be replicated in different client groups to ascertain whether these findings can also be generalised to people who have a caring or supportive role for a sibling with a different chronic health condition.

As part of IPA, the researcher makes sense of how participants make sense of an experience, as part of the hermeneutic circle (Smith et al., 2009). It is possible that other researchers may gather alternative meanings and understanding of responses, but the importance of using an analytical procedure whereby unique responses could truly be

acknowledged and made sense of in a topic that has not previously been explored in literature, was imperative in order to start gathering an understanding around this area.

As explored within reflexivity in the methodology chapter and also below in the concluding reflective statement, despite the researcher's attempts to reduce this risk, such as using a reflexive questionnaire and keeping a reflexive journal throughout, the researcher's own experience of the condition could have impacted how they made sense of the participants' responses. It is important to note however, that the researcher's experience of the condition and their experiences as a Trainee Counselling Psychologist could have contributed to creating a non-judgemental environment for participants, thus allowing richer responses from participants due to feeling comfortable with the researcher, an unexpected finding due to participant's largely negative experiences of healthcare professionals and therefore a particular strength of this study. It would be of interest to replicate this study with a researcher who has no affiliations with the conditions, but due to the lack of knowledge amongst professionals of these conditions, future researchers may indeed have an affiliation if choosing to conduct further research into this area.

4.8. Recommendations for Services and for Future Research

Recommendations can be made regarding the care of both people who have a sibling with HSD or hEDS and the patients themselves. If a chronic health condition such as these is left without adequate treatment, there is a potential risk that treatment options to manage the condition may take a greater amount of time to see results thus it is imperative that healthcare professionals remain aware of the importance of connecting symptoms when necessary and considering all options, rather than making assumptions. Part of the practice of the multidisciplinary team that work with siblings and patients, should readily include seeking the views of siblings and the wider family, in addition to keeping updated with

current literature around the conditions our clients present with or bring to sessions, which can contribute to creating a trusting, therapeutic relationship. Psychologists could offer consultation to the wider multidisciplinary team regarding the potential psychological impacts on clients within this group and could consider the various ways in which their practice as Psychologists could be improved as part of being scientist-practitioners. It is imperative that we remain aware of and acknowledge that people who have a caring and supportive role for a sibling with HSD or hEDS are significantly impacted by the conditions and this is important to note in the wider context of people who have a sibling with a chronic health condition generally.

Crucially, we must consider the impact on siblings, patients and the wider family of explaining physical health conditions as psychological and of our own assumptions we bring to our work with clients and must be willing to acknowledge this within supervision and by furthering our personal understanding.

As this study highlights that there appears to be little support accessible for people who have a sibling with these conditions and as funding may not be readily available for services catered to offering further support, it would be beneficial for voluntary organisations such as Ehlers-Danlos Syndrome UK (EDS-UK) and the Hypermobility Syndromes Association (HMSA) to consider whether support groups specifically for siblings and information booklets catered for people who have a sibling with HSD or hEDS could be offered within their remit.

Replication of this current study with a larger and more diverse participant group would greatly benefit our understanding further around the experiences of people who have a sibling with HSD or hEDS. Future research would also be useful on the perspectives of health professionals on working with people who have a caring and supportive role for

someone with HSD or hEDS but who do not personally meet formal diagnostic criteria for the conditions. Lastly, the researcher recommends a pilot study on support groups and information groups for siblings and the wider family, to support the justification of further funding into these conditions and the services that could be available.

4.9. Concluding Reflections from the Researcher

Whilst the researcher has acknowledged reflexivity in depth in earlier chapters of this thesis, it felt of importance to share concluding reflections on the experience of conducting this study. The researcher has already addressed their personal experiences of the conditions, the potential impact on the research process and the ways in which these were managed, particularly after becoming a carer for their only parent, suffering a bereavement and returning to the research.

Since documenting these factors, the researcher suffered their own personal flare ups at various points of the condition they have a diagnosis of. There were many occasions in which the researcher could have chosen not to progress further with the study, but the potential clinical implications and the awareness that this is to date, the only study on this topic, continued to be a motivating factor for the researcher to continue. In addition, during this time, the researcher became aware that they may have personally experienced a misdiagnosis of their condition and experienced an internal conflict of deliberating whether to re-enter the diagnostic process. The awareness of this, along with the internal conflict of deliberating whether to re-enter the diagnostic process, whilst making sense of how participants made sense of their sibling experiencing misdiagnoses, further justified the importance of the reflexive journal and taking time, where appropriate and possible, away from the study to ensure the results were not affected by personal experiences.

Being aware of the possible clinical implications of this study and the opportunity to make recommendations from this research is an aspect the researcher cannot take for granted. The opportunity to acknowledge that people who have a sibling with the conditions may also to some extent be considered as Zebras and do require validation of their experiences.

4.10. Conclusions

This research has certainly furthered our understanding as to how people who have a sibling with hEDS or HSD make sense of their experiences; identifying their unique experiences and exploring how this relates to others and to the current literature available. Whilst participants had largely expressed that they had not had the opportunity to discuss their experiences previously, the non-judgemental environment created by the researcher, allowed for participants to start making sense of their caring and supportive role and of the impact of these conditions on both their lives and their relationships with others.

A caring and supportive role had negative impacts on participants' mental health and created a deeper awareness of their own physical health, yet participants appeared to be battling with an internal conflict of whether to reduce the amount they support their sibling and the wider family, in order to allow self-care and focus on other, unrelated aspects of their lives. The findings support previous research that recommends a multidisciplinary approach for HSD and hEDS and professionals should include as part of their practice, considering the possibilities of rarer physical health conditions to explain symptoms, before making assumptions. Additionally, as professionals, we need to remain open to improving our knowledge on the conditions our clients present with and to having open discussions with our colleagues as part of a multidisciplinary team. Psychologists should consider the benefits of systemic approaches and theory when working with people who have a sibling with hEDS or HSD and to incorporate exploring with clients as to whether they view

themselves as having a caring or supportive role for others, as part of our assessment and treatment approaches.

Whilst further research is needed in this area to hopefully replicate findings so that generalisations can be made to others who have a sibling with hEDS or HSD and to people who have a sibling with a chronic health condition, this study increases the awareness of these conditions to healthcare professionals and further justifies the need for continuing research into a relatively unknown, yet fascinating area.

In conclusion, this current study has found that amongst people who have a sibling with hEDS or HSD, they appear to experience a transcending theme of the conflict between having a caring and supportive role for a SWEDS versus being a sibling, alongside three superordinate themes of the emotional consequences of having a sibling with EDS, the interference with life and an absence of support. These findings support previous research on the experiences of people who have a sibling with a chronic health condition and psychological frameworks such as the relationship to help and family systems theory can support our understanding of their experiences. This appears to be the first study to date on the experiences of people who have a sibling with hEDS or HSD and therefore warrants further research on this area in addition to improving the support available for people who have a sibling with HSD or hEDS.

5.0. References

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6.0. Section B: Combined Client Study and Process Report

[redacted]

7.0. Section C: Publishable Paper for the Journal of Disability and Rehabilitation

7.1. Title Page

Sibling Experiences of Hypermobility Spectrum Disorder and Hypermobile Ehlers-Danlos Syndrome: An Interpretative Phenomenological Approach

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Abstract: 199 Words

Research Paper: 7796 Words

7.2. Abstract

Purpose

To understand how people experience and make sense of having a sibling with Hypermobility Spectrum Disorder (HSD) or Hypermobile Ehlers-Danlos Syndrome (hEDS) and the meaning they place on caring or supporting their sibling.

Methods

Six adults with a sibling diagnosed with HSD or hEDS, who did not personally meet formal diagnostic criteria, participated in semi-structured interviews. Interpretative Phenomenological Analysis was used to analyse data.

Results

Three superordinate themes identified: i) emotional consequences of having a sibling with EDS, ii) interference with life, iii) absence of support. A transcending theme was the conflict participants experience between having a caring and supportive role for their SWEDS versus being a sibling. Participants reported a lack of trust in professionals due to a perceived lack of knowledge. Within the caring role, they become researcher, advocate and help the family to collectively cope, whilst experiencing a conflict between being a carer or sibling and little support is available.

Conclusions

This is the first study to date on the experiences of people who have a sibling with HSD or hEDS; larger studies are warranted. Increased psychological and emotional support is

needed for siblings and clinicians should consider views of siblings during diagnosis and treatment.

7.3. Keywords

Hypermobility

Ehlers-Danlos Syndromes

Carers

Hypermobilty Spectrum Disorder

Siblings

7.4. Research Paper

7.4.1. Introduction

The research aimed to make sense of how people who have a sibling with Hypermobility Spectrum Disorder (HSD) or Hypermobile Ehlers-Danlos Syndrome (hEDS) understand their experiences and the meaning they place on caring for their sibling. To date, there appears to be no previous literature on this topic.

Hypermobility, a term used by Kirk, Ansell and Bywaters (1967) involves laxity of connective tissues, joint instability and the ability to move joints past the usual limits (Malfait et al., 2017). Hypermobility can also be a symptom of a heritable connective tissue disorder (HCTD): Ehlers-Danlos Syndrome (Castori, 2012), which affects collagen produced.

The conditions were reclassified by Malfait et al. (2017) in the American Journal of Medical Genetics as Hypermobility Spectrum Disorder (HSD), Hypermobile EDS (hEDS) or Ehlers-Danlos Syndromes (including hypermobile, vascular and classic EDS). They were previously known as EDS type three (EDS III), EDS-Hypermobility Type (EDS-HT), Benign Joint Hypermobility Syndrome (BJHS), Joint Hypermobility Syndrome (JHS), Joint Hypermobility (JH) and Hypermobility EDS (HEDS). Both hEDS and HSD are widely underdiagnosed by health professionals, due to the lack of awareness and knowledge, contributing to them being referred to as rare conditions and Tinkle et al. (2017) and Baeza-Velasco et al. (2017) both describe hEDS as being possibly the most prevalent hereditary connective tissue disorder.

There can be many comorbid conditions associated with HSD and hEDS, which have been highlighted in literature to date. Management of the conditions has been debated in more

recent years as we become to understand the psychological impacts of the condition. Gazit et al. (2016) concluded that despite EDS-HT affecting multiple areas of mental and physical health, professionals remain unaware of the condition and therefore unaware of how to appropriately treat patients. They note that this lack of knowledge could be easily improved upon which could reduce the chance of patients experiencing disabling effects from poor treatment management (Gazit et al., 2016). Recently, Yew et al. (2021) highlighted that a multidisciplinary approach is important to consider for people with HSD or hEDS. Clark et al. (2024) support these findings, demonstrating that the advised approach to manage HSD and hEDS is to incorporate psychological approaches to help improve the experiences of patients.

Rather disappointingly, research has found that people with hEDS or EDS can be treated poorly by healthcare professionals (Berglund et al., 2009) or that psychological disorders are explored before the possibility of a chronic physical health illness is considered (Berglund et al., 2009; Sulli et al., 2018).

Sulli et al. (2018) also found that people with a diagnosis of EDS can experience mistrust from clinicians, with symptoms questioned and serious accusations of Munchausen-by-Proxy and Munchausen (now respectively referred to as Factitious Disorder Imposed on Another, and Factitious Disorder Imposed on Self) and psychological disorders being explored by healthcare professionals before the rarer physical health conditions are considered. These are extremely concerning and disappointing findings which clinicians need to remain aware of, to ensure we balance our duty of care, along with ensuring we are considering a holistic viewpoint of what may be happening for our service users. Sulli et al. (2018) also highlight that as these experiences can understandably impact a patient's mental health, that there should be further psychological interventions to support patients.

Research, although limited, is available on considering the experiences of people who have a sibling with a chronic health condition. To date, these have not included siblings of people with hEDS or HSD.

Linimayr et al. (2025) identified 62 studies on the experiences of people who had a sibling with a chronic condition which started in childhood. They concluded participants had acknowledge their part in caring for their sibling and this could entail increasing their knowledge around their sibling's condition, supporting with medical responsibilities to reduce the impact on their parents and providing emotional support.

Morlion et al. (2008) explored a treatment protocol to use in Europe to manage chronic pain. They noted that not only does chronic pain affect patients, but also their families (Morlion et al., 2008). Likewise, Rea et al. (2019) conducted a systematic review on the efficacy of recreation camps for siblings who have a chronic health condition and their families and noted families are also affected; they stressed that siblings of children who have a chronic health condition, can be more likely to develop challenges psychosocially.

This supports the importance of conducting further research into understanding the experiences of siblings, particularly around conditions that are already not fully understood, and for informing the practice of Counselling Psychologists who will be supporting siblings with their worsening mental health and will need to understand the context patients may be experiencing, in order to fully inform practice.

7.4.2. Methodology

The research aimed to understand “how do people understand the experience of having a sibling with Hypermobility Spectrum Disorder or Hypermobile Ehlers-Danlos Syndrome?”, focusing on the meaning of supporting or caring for a sibling with these conditions. Data was analysed using Interpretative Phenomenological Analysis (IPA) using Smith et al. (2009) proposed analytical strategy. It is regularly used in counselling psychology, allows for individual experiences to be explored and understood (Smith, Flowers, & Larkin, 2009) and has been used to study chronic pain (Biggerstaff & Thompson, 2008; Osborn & Smith, 1998). IPA can allow us to understand how the participant has understood an experience which is subjectively significant to them or has created a substantial impact on their life (Smith et al., 2009). It means the researcher can recognise and comprehend the individual’s world (Smith et al., 2009) and offer alternative perspectives of the meanings through the analysis (Smith et al., 2009). IPA was appropriate as the researcher is interested in understanding how participants understand the phenomena of having a sibling with the conditions and their perceptions of the experience, within the context of having a sibling with hEDS/HSD.

The researcher aligned to a phenomenological epistemological position proposed in Willig (2012)’s classification system of epistemologies. It attempts to produce information about the individual’s subjective experience, rather than generalising an experience, identifying whether the experience is completely real or whether the experience is due to social constructs (Willig, 2013). A relativist ontology was adopted as it assumes there are several ways to make meaning and to interpret a phenomenon (Ponterotto, 2005).

Participants were over 18 years old who typically reside in the UK and have a sibling with a diagnosis of HSD or hEDS. Older terms used for diagnoses before the reclassification

(Malfait et al., 2017) were included. Participants were recruited from support groups affiliated with the conditions: Hypermobility Syndromes Association (HMSA), Ehlers-Danlos Support UK (EDS-UK) and the social media group on Facebook “Hypermobility UK Support Group”, through the researcher sharing on their personal Facebook page, word of mouth and through placing posters around the researcher’s university campus in London. Time constraints meant NHS ethical approval was not possible, therefore did not include NHS recruitment. Ethical issues were considered and mitigated; for example participants were not included if they were experiencing an acute mental health episode or in distress and were not informed of the researcher’s own diagnosis of one of the conditions before the interview, but if asked afterwards, would disclose if appropriate to remain transparent but not influence their experience taking part.

Interested participants were provided with an information sheet and allowed 24 hours to consider before receiving a telephone call from the researcher to establish interest and engaging in screening via telephone to ensure inclusion criteria were met. Written informed consent was obtained before participants attended a 60-90 minute semi-structured interview either in person or, when the COVID-19 pandemic occurred, over Skype which mitigated risk. Interviews were audio recorded on password protected devices and debriefed after the interview and allowed an opportunity to ask the researcher questions. A one-off follow up email was sent afterwards expressing that a reply was not needed and offering contact information for relevant services participants could seek further support from. Data was anonymised using pseudonyms and redacting identifying information to ensure confidentiality.

The researcher engaged with reflexive interviews and journals to ensure they were able to separate their own experience of having the condition.

7.4.3. Results

Individuals who took part in the research will be referred to as “participant” or via their pseudonyms and their siblings as “Sibling With Ehlers-Danlos Syndrome”, abbreviated to “SWEDS”, as all participants noted their sibling had a hEDS diagnosis. The reader should keep in mind that the diagnostic process and treatment recommended remains the same for HSD and hEDS (EDS UK, 2017), therefore results can be considered for either condition.

Three superordinate themes were identified: 1) emotional consequences of having a sibling with EDS, 2) interference with life, 3) absence of support. A transcending theme throughout is the conflict participants experience between having a caring and supportive role for their SWEDS, versus being a sibling. This will be identified further in the context of each theme.

Emotional Consequences of Having a Sibling with EDS

This theme focuses on the emotions having a sibling with EDS can evoke and how the related responsibilities can affect participants’ mental health. Three subthemes were identified: frustration, responsibility and worsening mental health, with a transcending theme of the conflict for participants of being a sibling versus having a caring and supportive role for their SWEDS.

Frustration.

The most common emotion that appeared to be expressed by all participants, was frustration and this appeared to increase when there were also feelings of hopelessness and a sense of helplessness.

All participants appeared to have a negative experience of the diagnostic process. In addition to their new siblings being misdiagnosed or given inappropriate treatments, participants appeared to notice their siblings being sent to a variety of medical professionals who they experienced to have little knowledge or awareness of the conditions. This appeared to evoke strong feelings of frustration from participants.

Michael's frustration was around the amount of appointments, the amount of time to obtain an appointment with a medical professional, and the lack of knowledge he perceived professionals to have.

> Michael page 37, lines 4-10
>
> *"..we've got to go to it so we can get this other appointment in another few months' time and it's like, well, what's the..? You know, it's- it's wasting everyone's time and money trying to get through to it um."*

Whilst Michael appears to demonstrate that he understands the process of supporting his sibling to understand their physical health symptoms, he stresses that he experiences there to be a necessity to attend appointments in order to unlock the ability to attend one in the future with a professional who may hold the answers. He also explains that he understands the current diagnostic process as wasting the time and money of everyone involved and we can sense the frustration he feels around this by the use of his language, such as "wasting" and by stopping and starting his sentences, as if attempting to communicate to the researcher how difficult the process can be.

The use of "we've got to" also suggests that at the same time, Michael may be experiencing a sense of helplessness and acceptance; whilst he does not necessarily agree with the process, he understands that he must accept it in order to support his sibling. This along with the use of "we've" and "everyone's", further suggests that he experiences himself as

being involved in the process and that he may be purposely placing his own emotions aside in order to continue being able to care for his SWEDS. This suggests that Michael may experience the ability to acknowledge his own frustration around the diagnostic process as being incompatible with how he experiences himself as being able to care for his SWEDS.

Increased responsibility.

Having a sibling with EDS appears to evoke many emotions, but this seems to be exacerbated by how much responsibility for their SWEDS that participants perceive themselves to have and can increase how much they advocate for their sibling, perhaps as a way of coping with difficult emotions and having a consistent way of offering support for a condition which is largely unpredictable.

Jasmine also acknowledged what she experienced her part was in her SWEDS' experience:

Jasmine page 24, lines 1-2 (about the hospital)

"..I know that I did the very best I could to set her free from there."

She describes a protective element of her relationship with her SWEDS and explains that she tried her hardest to help her sister leave hospital. The use of "set her free" suggests that Jasmine experienced her sister's stay in hospital as unpleasant and negative and that she experienced her SWEDS as trapped; needing rescuing. We can see that Jasmine appears to have taken on the responsibility of ensuring her SWEDS' wellbeing and to advocate for her as part of a caring role.

However, a focus from participants on increased advocacy also appears to contribute to self-invalidation. There was an element of "keep calm and carry on" identified by Jake:

Jake page 18, lines 1-2

"..Um but we are all of the kind of opinion that you crack on and (pause) get over it.."

Jake explains with the use of “we” that he experiences there to be a shared opinion within his family that there is an expectation to carry on and accept the roles they have related to his SWEDS, This suggests a dismissive and invalidating approach to his own emotional responses in order to ensure the wellbeing of his SWEDS due to a possible perceived sense of responsibility for them in a caring role and suggests he has experienced there to be little choice in how to manage with having a sibling with this condition.

Worsening mental health.

The emotional consequences of having a sibling with EDS appear to have also contributed to overall worsening mental health for participants.

Jasmine and Michael reported that they have found their worrying increases particularly when considering their SWEDS’ future post diagnosis:

Jasmine page 79, lines 9-10 – page 80 line 1

“..like that big worry of like maybe one day having to live life without her, I think like trickles down into like everyday activity, becoming more anxious..”

She notes that this has affected her psychologically, increasing her anxiety and having a significant impact on her daily life due to an overwhelming sense that she may outlive her sister due to EDS. It suggests she experiences EDS as life limiting and a factor she considers in her behaviour and approach to having a SWEDS, such as appreciating having her sister, which shows a strong relationship between them. It also therefore appears her worries are perhaps stemming from her concerns as a sibling rather than a carer; in contrast to Michael:

Michael page 102, lines 4-7

"..it's just worrying about how it's going to affect her in the future and how she's going to be able to cope with that."

Michael expresses feeling worried about how EDS would affect his sister in the future and how she would cope. It suggests a protective and caring role as a sibling, but also shows how often he thinks about this aspect and with the lens of a carer in this instance.

We can see overall that the transcending theme of the conflict between having a caring and supportive role for a SWEDS versus being a sibling is evident within the emotional consequences of having a SWEDS. There can be a significant impact on participants' mental health, which could be understood in the context of the wide variety of emotions they experience throughout their SWEDS' diagnostic journey and their own experiences navigating how to support and care for their SWEDS. Frustration and elevated protectiveness were experienced, alongside a perceived heightened sense of responsibility to advocate for their sibling, understand information and ensure their sibling's wellbeing which demonstrates a caring role. However participants attempted to reduce the emotional consequences by attempting to forget about upsetting information of their SWEDS' condition. This conflict differs between participants as part of their subjective experiences.

Interference with Life

This theme focuses on how having a sibling with EDS can impact everyday life. Three subthemes were identified: increased awareness, changed attitude to life and I need to care for my SWEDS, alongside the transcending theme of the conflict between being a sibling versus having a caring and supportive role for participants' SWEDS.

Increased awareness.

There was a general sense of increased awareness for participants around the everchanging symptoms of EDS and the complexities that can arise.
Amelie reflected upon how she experienced herself to have little knowledge of EDS prior to her SWEDS' diagnosis and the impact this had on her life:

> Amelie page 31, lines 9-11
> *"..I mean I wish I knew, known more about the disorder first, because it just wasn't something that was part of our mind. It was one of those things that, once we'd heard about it, um, we'd noticed it.."*

She appears to have experienced herself as noticing symptoms more often once EDS was mentioned, which implies that it helped Amelie to make sense of her SWEDS' symptoms. Amelie's expression that symptoms were not a part of their mind suggests she may have experienced invalidation from others and can explain why she expresses that she would have preferred to have known more about EDS previously. Her response further suggests that attempts to make sense of her SWEDS' symptoms were a significant factor in her experience and that these had a substantial impact on her life.

Jasmine unfortunately appeared to have an eye-opening increase in her awareness around how medical professionals can make sense of EDS:

> Jasmine page 33, lines 9-11
> *"..because I was there and like fighting as well, I think that the usual like structure of that just didn't really fit so they weren't able to like completely like diagnose us with Munchausen's.."*

Jasmine experienced herself as needing to fight for her SWEDS and appears to have experienced her active and clearly significant involvement with her SWEDS' care as being directly linked to medical professionals not diagnosing with Munchausen's. This suggests she understands that it would have been a concern had she not been involved as a sibling, but seems to show that she is entering into a caring role. The use of "us" implies that she experienced the family as a unit and that if one had been diagnosed with Munchausen's, this would have been a shared experience between them all. We can understand from this that Jasmine likely has a strong relationship with her SWEDS and that the question of Munchausen's and subsequent need for advocating for her sibling had a large impact and interference on her life.

Changed attitude to life.

Participants noted that having a SWEDS changed their attitudes to various aspects of their lives, such as self-awareness of their own difficulties, risk assessing and prioritising spending time with their SWEDS:

Jake noticed that it affected the time he spent with others when he was mainly in a caring and supportive role:

> Jake page 49, line 10 – page 50, lines 1-6
> *"..when I was looking after my sister um especially when it was just while I was the only one at home to look after her. Um I would sometimes put off going out with some people just because making sure she was all right was of a great concern to me.."*

He notes this was the case when he experienced himself as being the only one available to care for his SWEDS, suggesting this was perhaps outside of what he would usually experience their relationship to be and highlights that he would choose to care for his

SWEDS and ensure her wellbeing, rather than to spend time with people and leave the house. It suggests the closeness of their relationship and that he may experience a heightened sense of responsibility, whilst also highlighting the interference with his other relationships; reducing time with others.

I need to care for my SWEDS.

Participants identified how they cared for their SWEDS and it appears that this changes depending on whether participants experience themselves as needing to engage with a more caring and supportive role and whether they view this as separate from their usual relationship as a sibling.

Jasmine appears to have felt advocating was separate to her sibling relationship:

> Jasmine page 18, lines 3-6
>
> *"..Like in the beginning, when she was in the hospital for all that time, like I feel like our relationship was (pause) opening up that extra dimension of me not just being a sibling, like I was like fighting for her as well.."*

She attributes her relationship with her SWEDS changing when her SWEDS had a significant hospital stay and understands this to be due to her perceived need to fight for her sister's medical treatment and that this is a separate aspect of being a sibling.

Isaac also notes increased responsibility and a step away from a sibling relationship:

> Isaac page 17, lines 2-5
>
> *"..I don't think it's a typical brother/sister relationship, just in terms of I think I feel more responsible for her than I would with my little sister and a lot more, um, invested in say, her wellbeing and things.."*

His responses suggest he feels caregiving aspects may not be part of what he feels a sibling relationship should entail. Isaac notes himself as not having a typical sibling relationship and recognises a heightened sense of responsibility, suggesting a protective element to his relationship and a perceived need to reduce harm to his sister due to her condition, compared to his younger sister where he does not appear to recognise this need.

The transcending theme of the conflict between a caring and supportive role for a SWEDS versus being a sibling is demonstrated here by participants' views that they need to fight and advocate for their SWEDS to reduce psychosomatic conditions being suggested by clinicians, which they felt as separate to their sibling relationship and which needed time allocated by participants to do so. Additionally, participants adapted their lives to ensure their sibling felt supported as they viewed spending time with them as more important; demonstrating the caring role to ensure there are adjustments but a desire for the sibling role to spend time together, suggesting the caring role allows for this to occur. Expectations from others however around how participants should be caring for their SWEDS and an experienced conflict of wanting to help other family members involved, but not wanting to be seen purely as a caregiver, appears to lead to a desire for independence and time away which would have an effect on both being a sibling and a caregiver.

Absence of Support

This theme focuses on the absence of support felt by participants and how they manage this. Three subthemes include: experiencing scarcity in support, searching for support and advice for others with a SWEDS: support yourself. The transcending theme of the conflict between having a caring and supportive role versus being a sibling for participants' SWEDS will be explored alongside.

Experiencing scarcity in support.

This subtheme explores in particular how participants experienced little support to be readily available or offered. Whilst participants were able to reflect upon their experiences of available support for themselves, their family and their SWEDS, it has been striking how they perceive there to be so little support available for themselves:

Amelie page 24, lines 9-11- page 25, line 1

"..SN: Okay. What's your personal experience of support for you?

A: There was never really, there wasn't really any, I don't think. Um, yeah, I don't think, I mean nobody reached out. Like my family were supportive in general.."

The use of "I don't think" suggests Amelie is considering her answer and suggests she may have not previously thought about this. Amelie explains that within her experience of having a SWEDS, there was no support for her outside of her family, but notes that she experienced her family as being supportive towards her, suggesting a family unit and potentially strong relationships. Amelie's emphasis on the support she receives from her family suggests she has expectations that she should have been offered support from elsewhere, although does not explicitly state where she feels this should come from.

Participants noted that they not only experienced a lack of support around having a SWEDS, but that they noticed the wider family unit was not offered support:

Felicity page 20, lines 784-790

"No, I don't think, I'm not aware of anyone having any support, um or being offered any support, but I could be wrong. It certainly not something that's been discussed

or come up in conversation or been put out there so my assumption is that it hasn't but I could be wrong (laughs)."

Felicity reflects upon how she is unaware of support being offered or discussed within her family but considers that it may have been the case and that she may not have been informed. This implies that even if support was offered to the wider family, it did not reach Felicity as a sibling of someone with EDS.

Jake also reports that little support was offered for his family, particularly his parents:

Jake page 61, lines 4-5

"..Um and my parents, I don't think they were ever offered much in the way of support.."

This is echoed by Jasmine:

Jasmine page 73, lines 2-3

"SN: Good. And what about support for your family?

J: They have nothing.."

Jasmine page 73, lines 7-8

"..never have anyone like come over to stay or help or anything"

She highlights that not only have her family not been offered support, but they do not currently have any support. By informing me that no one stays or helps the family, this implies that she feels this would be a particularly helpful way of supporting the family that she would value and suggests that there is perhaps pressure within the family to help her SWEDS overnight.

Searching for support.

Support available for participants was limited and they identified where they sought support, including the wider family unit:

Jake page 62, lines 3-5

"..I think we- we're- as a family, we're very, very open, you know, there's essentially no topic we won't discuss. So we do form our own kind of insular support network.."

He acknowledges that his family act as their own support network for each other and explains that they will talk about everything, suggesting a close bond between them all and supportive environment for Jake.

Some participants sought support from their partner but did not appear to find this helpful:

Isaac page 46, lines 6-8

"..Erm I'll talk to my partner about it, erm (pause), but even then they're in the same position that I'm in with her whereas they can't suggest anything that's gonna help, just keep on listening I guess.."

Isaac acknowledges that as his partner is supporting his sibling equally, they are unable to offer Isaac support, further than listening to his difficulties. His response however suggests that he feels listening as a form of emotional support is insufficient for his needs and that he requires support in other ways. It also suggests that Isaac may be experiencing hopelessness around others having helpful suggestions for improving his situation of having a SWEDS and therefore to some extent, hopelessness for his partner being in a similar situation.

Jasmine however, highlights the usefulness of this particular interview as an opportunity for her to process:

Jasmine page 1-5, lines 2-9

".. And how is it—lastly, how is it been to talk to me about this?

J: Like, one of the most positive experiences of like for a long time, like I actually feel like (pause) like I feel like I'd like piece my mind together by like putting it all out there. Um, and like it's really helped me particularly with like the guilt that I feel about not helping as much, like it taught me a few today kind of like justifying my reasons for that even though I still feel a bit guilty, like just like talking about it is really helpful. So, thank you."

She expresses that the interview had been a positive experience due to providing an opportunity for her to process her experiences by talking about them. Jasmine also notes that she has found talking about her experiences helpful in understanding her feelings of guilt around how often and when to support her family and SWEDS and to help her to validate her own emotions and boundaries. This suggests the positive impact we could see from increasing opportunities for siblings to speak about their experiences. The way in which participants understand their experiences, may explain the role they perceive themselves to take in their SWEDS lives and therefore the type of support they would find helpful in order to cope.

Advice for others with a SWEDS: support yourself.

During the interviews, participants considered if there was any advice they would want to give to others who may have a SWEDS.

Jasmine's focus was around considering the mental health of people who have a SWEDS, I addition to reducing guilt and creating a balance with their care and support:

Jasmine page 92, lines 5-10 – page 93, lines 1-3

"..I'd feel like if it's affecting like your mental health, like go and speak more about it. Like it's—it is okay to… I feel like it's okay to change your opinion as well. Like also back then I was, "Oh, you know, why is everyone cross that I'm supporting mum, why is everyone thinking that I'm not living my life right by giving up things for my family? Whereas now I look at it with like a more balance view, and I feel like you shouldn't have to feel guilty about that. Like, like I shouldn't feel guilty about like not being there every single night and like that's fine, like you can live your own life, like learn what your balance is in terms of like just having a balance with like shopping and like being there for them."

She highlights that she wants to communicate to other participants that if they find having a SWEDS is affecting their mental health, that it is important to seek help for themselves. This suggests how important she views mental health to be and that she has considered within her answer how her own mental health was affected. Jasmine also expresses that it is acceptable to change opinions throughout their experience as someone who has a SWEDS. She understands this in the context of her changing how she perceives others' perspectives on the amount that she is caring and supporting her family and that she now understands a balance to be necessary. Jasmine also highlights the importance to reduce feelings of guilt, particularly around striking a balance in a caring and supportive role and encouraging others who have a SWEDS to understand that they can be there for their SWEDS and also live their own life.

The transcending theme of the conflict between a caring and supportive role for a SWEDS versus being a sibling is evident when participants note that they experience pressure from others to support their SWEDS overnight, suggesting they are aware of entering into a caring role. Single parent families could potentially add to pressure experienced by participants to enter into this caring role away from their role as a sibling, whilst conversely, others questioning how much participants support their SWEDS, contributes to increased

feelings that they need to support their sibling as people do not understand the importance, adding to a protective element. Interestingly, participants noting that they would appreciate support from others, suggests they have an understanding that they have a caring role which requires support.

7.4.4. Discussion

The research aimed to make sense of how people who have a sibling with hEDS or HSD understand their experiences, with the intention of ensuring individuals' unique responses were addressed and that participants had a non-judgemental space to explore their experiences in detail. The research also aimed to explore what it means to have a sibling that requires care and support due to these conditions. The findings of this study will be explored within the transcending theme of The Conflict Between Having a Caring and Supportive Role for a SWEDS versus Being a Sibling and the three superordinate themes of Emotional Consequences of Having a Sibling with EDS, Interference with Life and Absence of Support.

The Conflict Between Having a Caring and Supportive Role for a SWEDS versus Being a Sibling

This transcending theme demonstrated that conflict was exacerbated by a perceived sense of responsibility from participants to care for their SWEDS. At times this presented as participants explaining doctors' explanations of medical symptoms to their sibling, but there was also an understanding amongst participants that they needed to ensure the wellbeing of their SWEDS. In order to do so, participants took it upon themselves to acknowledge the physical health needs of their sibling in order to manage the condition and considered what could exacerbate symptoms.

This heightened sense of responsibility could also explain why participants took on an advocation role for their siblings, despite them not necessarily acknowledging this explicitly. They do not seem to allow their SWEDS to give up but take an overwhelmingly humble approach to explaining their caring and supportive role. A potential explanation for these modest responses is that participants felt this was to be expected of them by others as part

of being a sibling and that therefore these additional caring elements were not noteworthy; some indeed did note that they felt they had a duty to support their SWEDS. This could be understood in the context of their relationship to help which would suggest their perceived expectations are related to how they expect to be helped and to help others.

Part of this duty is reflected in their acknowledgement of having a protective role of their SWEDS; protecting them from what could exacerbate symptoms, from what participants deem to be a threat of their SWEDS' symptoms being understood as mental health conditions by others and protected from their perceived threat of not being believed. They note that this can feel as though they are fighting for their sibling against opposing views from professionals, which is a concerning aspect professionals should be aware of if we wish to truly manifest a healthy and therapeutic relationship with caregivers and patients, in order to achieve the outcomes we hope for.

This heightened sense of responsibility can be understood using the family systems theory (Bowen, 1985), who noted that if there is a low differentiation of self, this may present as a focusing more on the needs of others within the family and perceived importance of meeting the needs of others (Bowen, 1985). However, this responsibility to ensure the wellbeing of their SWEDS can be at the expense of their own emotions and needs, which supports Woodgate et al. (2016) and Leedham et al. (2020) who found siblings place less importance on their own needs, but there is instead an emphasis on the wider family's needs.

Participants acknowledged the difficulty of maintaining a balance between supporting their SWEDS and overwhelming them and when the role of caring and supporting a SWEDS is seen as separate from what they may otherwise expect as part of their usual role as a sibling, this can affect how they care for their SWEDS and how they seek support.

Emotional Consequences of Having a Sibling with EDS

Findings demonstrated that the emotional consequences of having a SWEDS can involve frustration, increased responsibility and worsening mental health.

Participants shared they had experienced professionals being dismissive towards their SWEDS. Whilst Berglund et al. (2010) and Yew et al. (2021) each found that professionals dismissed these conditions due to a lack of understanding, these findings demonstrate that sadly experiences have not improved and there remains a lack of communication between professionals, patients and their families, which undoubtedly prolong the diagnosis and increase the impact this has on siblings as a result. When considered in the context of the relationship to help proposed by Reder and Fredman (1996), we can understand that participants' experiences of future help could be significantly impacted by witnessing professionals dismissiveness towards their SWEDS and this could discourage them from seeking support for their own health.

Unsurprisingly, these emotional difficulties contributed to participants reporting worsening mental health. Participants summarised that being a sibling of someone with hEDS or HSD can be a difficult experience and many reasons were identified throughout the interviews. The main impact appeared to be on the mental health of participants, supporting Rea et al. (2019) who noticed psychosocial difficulties in siblings of people with a chronic health condition, but who did not specifically explore this impact on siblings with HSD or hEDS.

Participants noted high levels of stress pre and post diagnosis; unsurprising given how they experience and witness the diagnostic process and the symptoms their SWEDS experience

daily and which supports Russek et al. (2019) who noted that family members of people with hEDS or HSD experience levels of stress significant enough to warrant psychological therapy.

A consuming level of frustration was felt by participants regarding the diagnostic process. It appears that the diagnosis is not solely the experience of the patient, but is felt by people who have a SWEDS. As part of their caring and supportive role whereby participants accompany their SWEDS to appointments and care for them at home, they are required to take time off work or change their own plans in order to support their SWEDS.

Interference with Life

Participants also noted that they experience hEDS and HSD as invisible conditions, due to the range of symptoms that may not always be as visibly evident to others and they experience symptoms as suddenly changing.

Not only was the mental health of participants impacted by having a SWEDS, but their physical health also took a toll due to having less overall time to take care of themselves. This supports previous research by Chang et al. (2010) who noticed similar results in people who care for someone with a chronic health condition. Further challenges were identified which centred around the negative aspects of being a caregiver. In addition to feeling pressure to take care of their SWEDS and therefore focusing on the needs of their SWEDS rather than their own, they also seem to struggle with a heightened awareness of the risks that may befall their sibling if they take care of them or engage in medical support. There is also a sense that participants view themselves as needing to become nurses without feeling they have adequate training and thus learning how and where to set boundaries with their

families. Interestingly, participants seem to view this pressure as coming from the wider family rather than their SWEDS, suggesting that pressure is a shared experience between the family and that they are seeking support from participants who are perhaps viewed as responsible and knowledgeable enough to take on this role.

A “keep calm and carry on” approach suggested participants felt they were unable to change the situation of having a sibling with these conditions and suggests a way siblings manage and demonstrates the other part of the conflict participants experience with learning how to balance caring for their sibling and maintaining their strong relationships with their SWEDS. The psychological framework on the relationship to help (Reder & Fredman, 1996) suggests experiences such as these could be impacted by the individual’s environment and cultural ideas around whether they seek help.

Absence of Support

Participants generally felt the support available was poor; they expressed that visible disabilities have more support options available and that there were few opportunities to obtain emotional support around their experiences or to consider the impact of these conditions on them, which they viewed as a shared experience between the family. This supports findings in recent research by Linimayr et al. (2025) who found that people who have a sibling with a chronic condition of ASD, Down Syndrome, Chronic Kidney Disease or Cancer had also not been informed of support available for them and that some felt this was unnecessary as they deemed themselves able to cope. Findings from Harvey et al. (2022) could provide an explanation that participants in this current study may not have accessed support as they may lack awareness of their own needs.

Crucially, they noted that they have not actively sought support for themselves as they did not know what is available, suggesting that services could be more proactive in informing the families of patients of the support they can obtain, such as psychological therapy. The usefulness of psychological therapy in supporting people who have a sibling with these conditions further supports previous research that identified the importance of a multidisciplinary approach for patients and carers, such as Yew et al. (2021) and Guedry (2023) which is implemented within the NHS (Carter et al., 2003).

Knowledge was a continual focus point within responses and participants felt that if workshops or further information was provided to people with a SWEDS, they would feel better equipped in supporting their sibling and in validating their experiences, which they view as an important aspect of being a sibling and having a caring and supportive role. Participants reported feeling forgotten about by others; there was a sense that when considering the siblings of people who have a diagnosis of HSD or hEDS, that siblings were assumed to be more affected if they were of a younger age. They stressed the importance to the researcher of ensuring others acknowledge that adults can continue to be impacted and that it is imperative that support is available for all ages.

A main piece of advice from participants, was that they would hope others who have a sibling with HSD or hEDS can learn that it is acceptable to have a balance between living their own life and caring for their SWEDS and that it is vital to seek support for themselves.

Limitations

The researcher identified potential limitations of this study. Due to the analytical procedure chosen of IPA, a small sample size was obtained in order to gather rich, detailed data. Additionally, an inclusion criterion was that participants typically reside in the United Kingdom (UK), therefore the experiences of participants is focused on their experiences of the NHS. Due to the limited sample size, it was not possible to ensure that a range of participants who had siblings who sought medical support through the NHS and siblings who sought support privately were included, yet this would be an interesting aspect to explore in future research.

In order for participants to hear about the study, they needed to either be a member of social media support groups, to check the EDS-UK or HMSA websites, to hear via word of mouth, or to be a student at City, University of London. Recruitment became more challenging due to the outbreak of the COVID-19 pandemic and thus this could have affected the participants choosing to take part in the research. Furthermore, whilst recruitment did include having a sibling with a diagnosis of either HSD or hEDS, interestingly, all participants had a sibling with hEDS. Although HSD was not represented within these findings, we can make the assumption that findings would not necessarily differ due to the similarities in conditions and the identical diagnostic processes and treatments that HSD and hEDS share (EDS UK, 2017).

As part of IPA, the researcher makes sense of how participants make sense of an experience, as part of the hermeneutic circle (Smith et al., 2009). Other researchers may gather alternative meanings and understanding of responses, but the importance of using an analytical procedure whereby unique responses could truly be acknowledged and made

sense of in a topic that has not previously been explored in literature, was imperative in order to start gathering an understanding around this area.

The researcher's own experience of the condition could have impacted how they made sense of data, but the use of reflexivity and the researcher's clinical experiences could have contributed to creating a non-judgemental environment, allowing richer responses from participants.

It would be of interest to replicate this study with a researcher who has no affiliations with the conditions, but due to the lack of knowledge amongst professionals of these conditions, future researchers may indeed have an affiliation if choosing to conduct further research into this area.

Recommendations for Services and Future Research

This study has found that amongst people who have a sibling with hEDS or HSD, they appear to experience a transcending theme of the conflict between having a caring and supportive role for a SWEDS versus being a sibling, alongside three superordinate themes of the emotional consequences of having a sibling with EDS, the interference with life and an absence of support. These findings support previous research on the experiences of people who have a sibling with a chronic health condition and psychological frameworks such as the relationship to help and family systems theory can support our understanding of their experiences.

Clinicians should actively seek the views of siblings and remain updated with current literature around conditions clients present with to contribute to creating a trusting, therapeutic relationship. Psychologists could offer consultation to the wider MDT regarding psychological impacts. Clinicians must consider the impact on siblings, patients and the wider family of explaining physical health conditions as psychological and remain aware of the assumptions we bring to work which can be explored in supervision. Funding may not be available for services to offer further support, thus voluntary organisations such as EDS-UK or HMSA could consider if voluntary support groups and information booklets for siblings are within their remit. Replication of this study with a larger and more diverse participant group would greatly benefit our understanding. This appears to be the first study to date on the experiences of people who have a sibling with hEDS or HSD and therefore warrants further research on this area, perhaps replication with a larger and more diverse participant group, to increase our understanding and help improve the support available for people who have a sibling with HSD or hEDS.

7.5. Acknowledgements

This study was conducted as part of the requirements for the researcher's portfolio submission, for the fulfilment of the Professional Doctorate in Counselling Psychology at City, University of London.

The researcher would like to extend their gratitude to their doctoral supervisor Dr. Fran Smith and the psychology department at City, University of London, for their unwavering support, and to The Ehlers-Danlos Support UK and the Hypermobility Syndromes Association for their support in advertising the research for participant recruitment.

7.6. Declaration of Interest

The authors report there are no competing interests to declare.

7.7. References

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7.8. Implications for Rehabilitation

- Having a sibling with Hypermobility Spectrum Disorder (HSD) or Hypermobile Ehlers-Danlos Syndrome (hEDS) can negatively impact mental health
- The views of siblings and the wider family should be considered during the diagnostic process and treatment considerations for HSD and hEDS
- There is a need for greater support in the form of psychological therapy and education on the conditions for people who have a sibling with HSD or hEDS
- Further research is needed on a larger sample size of siblings

8.0. Appendices

Appendix A: Ethical Approval

Psychology Department Standard Ethics Application Form:

Undergraduate, Taught Masters and Professional Doctorate Students

This form should be completed in full. Please ensure you include the accompanying documentation listed in question 19.

Does your research involve any of the following? ***For each item, please place a 'x' in the appropriate column***	**Yes**	**No**
Persons under the age of 18 *(If yes, please refer to the Working with Children guidelines and include a copy of your DBS)*		X
Vulnerable adults (e.g. with psychological difficulties) *(If yes, please include a copy of your DBS where applicable)*		X
Use of deception *(If yes, please refer to the Use of Deception guidelines)*		X

Questions about topics that are potentially very sensitive *(Such as participants' sexual behaviour, their legal or political behaviour; their experience of violence)*		X
Potential for 'labelling' by the researcher or participant (e.g. 'I am stupid')		X
Potential for psychological stress, anxiety, humiliation or pain		X
Questions about illegal activities		X
Invasive interventions that would not normally be encountered in everyday life (e.g. vigorous exercise, administration of drugs)		X
Potential for adverse impact on employment or social standing		X
The collection of human tissue, blood or other biological samples		X
Access to potentially sensitive data via a third party (e.g. employee data)		X
Access to personal records or confidential information		X
Anything else that means it has more than a minimal risk of physical or psychological harm, discomfort or stress to participants.		X

If you answered 'no' to <u>all</u> the above questions your application may be eligible for light touch review. You should send your application to your supervisor who will approve it and send it to a second reviewer. Once the second reviewer has approved your application they will submit it to psychology.ethics@city.ac.uk and you will be issued with an ethics approval code. <u>You cannot start your research until you have received this code.</u>

If you answered 'yes' to any of the questions, your application is NOT eligible for light touch review and will need to be reviewed at the next Psychology Department Research Ethics Committee meeting**.** You should send your application to your supervisor who will approve it and send it to psychology.ethics@city.ac.uk. The committee meetings take place on the first Wednesday of every month (with the exception of January and August). Your application should be submitted at least 2 weeks in advance of the meeting you would like it considered at. We aim to send you a response within 7 days. Note that you may be asked to revise and resubmit your application so should ensure you allow for sufficient time when scheduling your research. Once your application has been approved you will be issued with an ethics approval code. You cannot start your research until you have received this code.

Which of the following describes the main applicant? ***Please place a 'x' in the appropriate space***	
Undergraduate student	
Taught postgraduate student	
Professional doctorate student	X
Research student	
Staff (applying for own research)	
Staff (applying for research conducted as part of a lab class)	

1. Name of applicant(s). (All supervisors should also be named as applicants.)

Sharina Nathan Dr. Zoe Boden (supervisor year 2) Dr. Fran Smith (supervisor year 3)
2. Email(s).
Sharina.Nathan@city.ac.uk bodenz@lsbu.ac.uk Fran.Smith.1@city.ac.uk
3. Project title.
Sibling Experiences of Hypermobility Spectrum Disorder and Hypermobile Ehlers-Danlos Syndrome: An Interpretative Phenomenological Analysis
4. Provide a lay summary of the background and aims of the research. (No more than 400 words.)

Hypermobility Spectrum Disorder (HSD) and Hypermobile Ehlers-Danlos Syndrome (hEDS) are underdiagnosed chronic-pain conditions which involve a laxity of the joints and subsequent psychological and physiological symptoms which can impact every-day life. These symptoms include anxiety, sleep disturbances, guilt and chronic pain. Whilst research has looked at the experiences of patients and the experiences of mothers, research does not currently explore the experiences of siblings (of an individual with the conditions) who do not personally meet formal diagnostic criteria. There also appears to be few studies on siblings, HSD/hEDS or on chronic pain, using the particular methodological approach of an Interpretative Phenomenological Analysis, which can be useful in understanding individual experiences. This study is particularly interested in how siblings experience a caring and supportive role that they are offering to the individual with the conditions. One-to-one interviews will be conducted with participants, lasting between 60-90 minutes and consisting of open-ended questions. This study aims to understand siblings' individual experiences and increase awareness of the condition to professionals, inform Counselling Psychologists about how they can support siblings and their role in future support. In addition, it aims to empower participants and provide a voice for them.

5. Provide a summary of the design and methodology.

The study will use one-to-one semi-structured interviews, using 13 open-ended questions as guiding points for the participants. Interviews will be audio-recorded and, with appropriate permissions, conducted in local universities e.g. City, University of London, or in a meeting room in the participant's local community. The proposed methodology is Interpretative Phenomenological Analysis, which allows the researcher to understand an individual's unique experience, by interpreting the participant's interpretation of an experience which has a significant impact on them. The analysis also allows the researcher to reflect upon their own perspectives and the process and to understand the experience from both individual's perspectives and identify themes which connect the experiences.

A pilot study will be conducted on two participants beforehand from the target population. These interviews will be conducted in the same manner as above and will be audio recorded. If the interview schedule does not require large changes, the data from the two pilot participants will be used within the main sample. The pilot interviews will provide an opportunity to practice asking the proposed questions, obtain feedback on answering the questions and allow for the researcher to refine the interview questions if needed.

6. Provide details of all the methods of data collection you will employ (e.g., questionnaires, reaction times, skin conductance, audio-recorded interviews).

Data will be collected by one-to-one semi-structured interviews, which will be audio-recorded and last for approximately 60-90 minutes. Where possible these will be conducted face-to-face but Skype may also be used.

7. Is there any possibility of a participant disclosing any issues of concern during the course of the research? (e.g. emotional, psychological, health or educational.) Is there any possibility of the researcher identifying such issues? If so, please describe the procedures that are in place for the appropriate referral of the participant.

It is not expected, but it is still possible that participants could disclose emotional, psychological or health concerns during the interviews, due to the nature of the topic being discussed. The researcher has the ability to detect psychological distress and the procedures in place are ending the interview, informing the participant of contact numbers for relevant organisations (e.g. Samaritans, Hypermobility Syndromes Association, Ehlers-Danlos Support UK, or advising them to contact their GP). The researcher will also make the supervisor aware of the incident immediately and if

interviewing within an NHS setting, a Clinical or Counselling Psychologist will also be informed immediately so that further support can be provided.

8. Details of participants (e.g. age, gender, exclusion/inclusion criteria). Please justify any exclusion criteria.

Participants will be males and females over the age of 18 from the UK, who have a sibling with a diagnosis of Hypermobility (including both new and old terms), Hypermobility Spectrum Disorder or Hypermobile Ehlers-Danlos Syndrome and who wish to share their experiences. Participants will be excluded if they meet formal diagnostic criteria for these conditions (JHS/hEDS/Joint Hypermobility) and/or if they are well-known to the researcher (e.g. within family or close friends). They will also be excluded if they are currently distressed e.g. experiencing mental health difficulties. Furthermore, participants will also be excluded from the study if they do not typically reside in the UK. This is to create a homogenous sample.

9. How will participants be selected and recruited? Who will select and recruit participants?
The researcher will select and recruit participants from support groups affiliated with the conditions (Hypermobility Syndromes Association and Ehlers-Danlos Support UK), social media (Facebook) and universities (e.g. City, University of London). The support groups (Hypermobility Syndromes Association and Ehlers-Danlos Support UK) have agreed to advertise the research on their websites, social media pages and within their newsletters. Advertisements directed at siblings will also be placed within universities, with appropriate permissions and on a social media (Facebook) support group for the conditions. Interested participants will be screened via a telephone call from the researcher and if suitable for the study, will be sent the information sheet to read through. Participants will be allowed a minimum of 24 hours to read through the information sheet before receiving a telephone call from the researcher to establish whether they are interested in taking part. Participants who wish to take part and are suitable will arrange with the researcher via telephone a date, time and location for the interview to take place. If participants from universities are interested, particularly the researcher's own university, they will still be contacted via telephone so that they do not feel pressured from having met the researcher in person beforehand and possibly seeing the researcher at university if they decline to take part in the study.

10. Will participants receive any incentives for taking part? (Please provide details of these and justify their type and amount.)
No. It is hoped that the incentive will be the opportunity to contribute to research on underdiagnosed conditions.
11. Will informed consent be obtained from all participants? If not, please provide a justification. (Note that a copy of your consent form should be included with your application, see question 19.)
Written informed consent will be obtained from all participants.
12. How will you brief and debrief participants? (Note that copies of your information sheet and debrief should be included with your application, see question 19.)

Participants will be provided with an information sheet before the study so that they can make informed consent. They will also be debriefed after the study. The information and debrief sheets are attached to this application.
13. Location of data collection. (Please describe exactly where data collection will take place.)
Data will be collected from interviews conducted at universities, or within a meeting room in the participant's local community.
13a. Is any part of your research taking place outside England/Wales?

No	**X**	
Yes		If 'yes', please describe how you have identified and complied with all local requirements concerning ethical approval and research governance.

13b. Is any part of your research taking place <u>outside</u> the University buildings?

No		

Yes	X	If 'yes', please submit a risk assessment with your application or explain how you have addressed risks.
13c. Is any part of your research taking place <u>within</u> the University buildings?		
No		
Yes	X	If 'yes', please ensure you have familiarised yourself with relevant risk assessments available on Moodle.
14. What potential risks to the participants do you foresee, and how do you propose to deal with these risks? These should include both ethical and health and safety risks.		
Potential risks to the participants could be slight distress due to the sensitive nature of the topic being discussed, although this is not anticipated as participants will be made aware of the topic and their ability to decline to answer questions if they feel it is distressing or to leave the study, via the information sheet, before providing written consent. If distress occurs, the researcher will ask participants if they would like to terminate the interview, have a break or continue. The researcher has experience in counselling and managing situations where people are experiencing emotional distress. In addition, the supervisor will be made aware of the incident, participants will be provided with contact details for relevant organisations (e.g. Samaritans, Hypermobility Syndromes Association, Ehlers-Danlos Support UK) and/or a Clinical or Counselling Psychologist will be informed to be able to provide further support, if interviews are taking place within an NHS setting. Confidentiality and anonymity will		

be respected, by identifying information being taken out and adhering to the BPS guidelines. Audio-recordings will be deleted after submission of the thesis. Potential health and safety risks include accidents within the meeting place e.g. universities or a meeting room within their local community. A risk assessment would be conducted and relevant steps taken as per the procedures of each building/service the interviews take place in. Participants may also experience more pressure to take part in the study if they have been informed of the study by a family member or sibling with the conditions. This will be part of the screening process and interested participants will be asked "who's idea was it to participate in this study?" and "how do you feel about participating?" Participants will be informed that it is important that they wish to take part rather than feeling pressured to do so and it will be made clear to participants that they do not need to take part and that no one would be made aware if they decide to take part or not.

As a social media support group has been considered for obtaining data, it is important to note that the researcher has been a member of the group and has posted previously. The researcher did not post identifying information apart from stating that they have the condition. The researcher has considered what it will mean to participants to know that the researcher has the condition, particularly if participants are talking about their experiences as a sibling of someone with the conditions. The researcher has considered that being honest and open if asked by participants whether the researcher has hEDS or HSD is important, but this information will not be advertised by the researcher beforehand; the researcher would be open and honest if asked directly.

15. What potential risks to the researchers do you foresee, and how do you propose to deal with these risks? These should include both ethical and health and safety risks.

Potential risk to the researcher are clients becoming distressed or violent during the interview, or accidents within the building or service where the interviews are taking place. The researcher proposes to deal with these risks by conducting interviews in a public location (but within a meeting room) and informing a relevant person e.g. supervisor of when interviews are due to start and finish if there are concerns. Regarding the potential accidents within the building or service, a risk assessment would be conducted and steps taken in accordance with the procedures of the building/service the interviews are taking place in. As the topic of the study is somewhat related to the researcher, the researcher will be engaging in a reflexivity interview, by answering the proposed interview schedule to become aware of the researcher's own ideas and preconceptions, so that these ideas and preconceptions do not impact the questions for participants. A reflexive journal for the researcher will also be kept throughout.

16. What methods will you use to ensure participants' confidentiality and

anonymity? (Please note that consent forms should always be kept in a separate folder to data and should NOT include participant numbers.)	
Please place an 'X' in all appropriate spaces	
Complete anonymity of participants (i.e. researchers will not meet, or know the identity of participants, as participants are a part of a random sample and are required to return responses with no form of personal identification.)	
Anonymised sample or data (i.e. an *irreversible* process whereby identifiers are removed from data and replaced by a code, with no record retained of how the code relates to the identifiers. It is then impossible to identify the individual to whom the sample of information relates.)	**X**
De-identified samples or data (i.e. a *reversible* process whereby identifiers are replaced by a code, to which the researcher retains the key, in a secure location.)	
Participants being referred to by pseudonym in any publication arising from the research	
Any other method of protecting the privacy of participants (e.g. use of direct quotes with specific permission only; use of real name with specific, written permission only.) ***Please provide further details below.***	
Direct quotes will be used but identifying information about the participant or others will be removed. This is outlined on the participant information sheet before they provide written consent.	

17. Which of the following methods of data storage will you employ?	
Please place an 'X' in all appropriate spaces	
Data will be kept in a locked filing cabinet	
Data and identifiers will be kept in separate, locked filing cabinets	
Access to computer files will be available by password only	**X**
Hard data storage at City University London	
Hard data storage at another site. *Please provide further details below.*	
18. Who will have access to the data?	
Please place an 'X' in the appropriate space	
Only researchers named in this application form	
People other than those named in this application form. *Please provide further details below of who will have access and for what purpose.*	**X**

In addition to the researchers named in this application form, a transcription service will also have access to the audio recordings, in order to transcribe the data. A transcription service will only be used if they adhere to formal confidentiality and anonymity guidelines.

19. Attachments checklist. *Please ensure you have referred to the Psychology Department templates when producing these items. These can be found in the Research Ethics page on Moodle.

Please place an 'X' in all appropriate spaces

	Attached	**Not applicable**
***Text for study advertisement**	**X**	
***Participant information sheet**	**X**	
***Participant consent form**	**X**	
Questionnaires to be employed		**X**
Debrief	**X**	
Copy of DBS	**X**	
Risk assessment	**X**	
Others (please specify, e.g. topic guide for interview, confirmation letter from external organisation)	**X**	

Interview schedule (8 questions to guide participants if needed)		

20. Information for insurance purposes. **(a) Please provide a <u>brief</u> abstract describing the project**		
Research has not yet been conducted on the experiences of siblings of individuals with a diagnosis of Hypermobility Spectrum Disorder or Hypermobile Ehlers-Danlos Syndrome. This study is interested in understanding how siblings experience the conditions. Participants will be interviewed on a one-to-one basis with the researcher, in either a university or meeting room in their local community, for approximately 60-90 minutes on their experiences. Participants will be informed that they are able to leave the study at any point up to one week after the interview has taken place and that their data will be anonymised and confidentiality will be respected. Data will be transcribed and analysed using an Interpretative Phenomenological Analysis, which allows the researcher to attempt to understand the individual's experiences.		
Please place an 'X' in all appropriate spaces		
(b) Does the research involve any of the following:	**Yes**	**No**

Children under the age of 5 years?		**X**
Clinical trials / intervention testing?		**X**
Over 500 participants?		**X**
(c) Are you specifically recruiting pregnant women?		**X**
(d) <u>Excluding</u> information collected via questionnaires (either paper based or online), is any part of the research taking place outside the UK?		**X**

If you have answered 'no' to all the above questions, please go to section 21.

If you have answered 'yes' to any of the above questions you will need to check that the university's insurance will cover your research. You should do this by submitting this application

to insurance@city.ac.uk, <u>before</u> applying for ethics approval. Please initial below to confirm that you have done this.

I have received confirmation that this research will be covered by the university's insurance.

Name …….. Date……

21. Information for reporting purposes.		
Please place an 'X' in all appropriate spaces		
(a) Does the research involve any of the following:	**Yes**	**No**
Persons under the age of 18 years?		**X**
Vulnerable adults?		**X**
Participant recruitment outside England and Wales?		**X**
(b) Has the research received external funding?		**X**

22. <u>Final checks.</u> Before submitting your application, please confirm the following, noting that **your application may be returned to you without review** if the committee feels these requirements have not been met.	
Please confirm each of the statements below by placing an 'X' in the appropriate space	
There are no discrepancies in the information contained in the different sections of the application form and in the materials for participants.	**X**

There is sufficient information regarding study procedures and materials to enable proper ethical review.	**X**
The application form and materials for participants have been checked for grammatical errors and clarity of expression.	**X**
The materials for participants have been checked for typos.	**X**

23. Declarations by applicant(s)	
Please confirm each of the statements below by placing an 'X' in the appropriate space	
I certify that to the best of my knowledge the information given above, together with accompanying information, is complete and correct.	**X**
I accept the responsibility for the conduct of the procedures set out in the attached application.	**X**
I have attempted to identify all risks related to the research that may arise in conducting the project.	**X**
I understand that **no** research work involving human participants or data can commence until ethical approval has been given.	**X**

	Signature (Please type name)	**Date**
Student(s)	**Sharina Nathan**	**10/07/2017**
Supervisor		

Reviewer Feedback Form

Name of reviewer(s).			
Email(s).			
Does this application require any revisions or further information?			
Please place an 'X' the appropriate space			
No Reviewer(s) should sign the application and return to psychology.ethics@city.ac.uk, ccing to the supervisor.		**Yes** Reviewer(s) should provide further details below and email directly to the student and supervisor.	
Revisions / further information required			

To be completed by the reviewer(s). PLEASE DO NOT DELETE ANY PREVIOUS COMMENTS.
Date: Comments:
Applicant response to reviewer comments To be completed by the applicant. Please address the points raised above and explain how you have done this in the space below. You should then email the entire application (including attachments), **with changes highlighted** directly back to the reviewer(s), ccing to your supervisor.
Date: Response:

Reviewer signature(s) To be completed upon FINAL approval of all materials.		
	Signature (Please type name)	**Date**
Supervisor		
Second reviewer		

Appendix B: Advert

Department of Psychology,
City University, London

Do you have a sibling with Joint Hypermobility, Hypermobility Spectrum Disorder or Hypermobile Ehlers-Danlos Syndrome?

Would you like to talk about your experiences?

We are looking for volunteers to take part in a study on *sibling experiences of Hypermobility Spectrum Disorder and Hypermobile Ehlers-Danlos Syndrome (formerly Joint Hypermobility)*.

You would be asked to: *take part in a one-to-one interview on your experiences as a sibling of someone who has these conditions.*

Your participation would involve *1* session which would last approximately *60-90* minutes. Interviews will be conducted in English and you will remain anonymous.

Your time will be greatly appreciated.

For more information about this study, or to take part, please contact:
Sharina Nathan or Dr. Zoe Boden
Psychology Department
at
020 7040 4564 or [Work phone number to follow]

Email: *Sharina.Nathan@city.ac.uk*

This study has been reviewed by, and received ethics clearance through the *[insert committee name here]* Research Ethics Committee, City University London [*insert ethics approval code here*].

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee on 020 7040 3040 or via email: Anna.Ramberg.1@city.ac.uk

Appendix C: Interview Questions

1. Can you tell me a little bit about you and your sibling?
2. Can you tell me a little bit about when you first became aware of their symptoms?
3. Can you tell me a bit about what it has been like for you to have a sibling with Joint Hypermobility/Hypermobility Spectrum Disorder/Hypermobile Ehlers-Danlos Syndrome
   PROMPT: Which aspects of your experience stand out to you?
   PROMPT: Is there a specific time that springs to mind?
   PROMPT: Have there been any positive or negative aspects of your experience?
4. What is your relationship with your sibling like in light of their condition?
   PROMPT: What role do you take?
   PROMPT: Do you play a particular part in their life?
   PROMPT: What does this mean for you?
5. Since you became aware of your sibling's condition, has it changed how you relate to other people?
   PROMPT: Has it changed the nature of your relationships?
   PROMPT: Has it changed how much time you spend with people?
   PROMPT: Has it changed how you act around people?
   PROMPT: Has it changed how you feel about other people?
6. What is your personal experience of support around your sibling's condition?
   PROMPT: Support for you
   PROMPT: Support for them
   PROMPT: Support for the family
7. Since your sibling has had this condition, has it changed how you think about yourself?
   PROMPT: Has it changed how you view your physical health?
   PROMPT: Has it changed how you think about yourself psychologically?
   PROMPT: Has your attitude to life changed as a result of the conditions?
8. How has the experience changed for you over the years?
9. What advice would you give to other siblings who have a sibling with Joint Hypermobility/Hypermobility Spectrum Disorder/Hypermobile Ehlers-Danlos Syndrome?
   PROMPT: Please describe your reason for giving this advice
   PROMPT: Is there anything you wish you would have known?
10. After everything you have said about your experience, if you were to summarise, what do you feel these conditions mean to you?
11. Is there anything else you would like to add?
12. If you were the researcher, is there anything you would have asked that I didn't?
13. How has it been to talk to me about this?

Appendix D: Information Sheet

Title of study: Sibling Experiences of Hypermobility Spectrum Disorder and Hypermobile Ehlers-Danlos Syndrome: An Interpretative Phenomenological Analysis

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Hypermobility Spectrum Disorder (HSD) and Hypermobile Ehlers-Danlos Syndrome (hEDS), (recently reclassified from Joint Hypermobility and Ehlers-Danlos Syndrome, Hypermobility Type) are conditions which are widely underdiagnosed due to a lack of awareness and knowledge by professionals. Research is available on the experiences of people with the conditions, but we are not yet aware of the experiences of siblings of people with HSD or hEDS. This study is interested in sibling experiences of the conditions. This research aims to increase awareness of the conditions, understand siblings' experiences and inform professionals from various fields, how they can support siblings, in addition to giving siblings a voice. The study will involve approximately 60-90 minutes of a one-to-one interview, which will be audio-recorded. Recordings will only be used for the purpose of analysing data and will be deleted upon submission of the researcher's thesis. The study will be undertaken as part of the requirements for the Professional Doctorate in Counselling Psychology at City, University of London.

Why have I been invited?

You meet the inclusion criteria of the study, which includes being over the age of 18, typically residing in the UK, being a sibling of someone with Hypermobility Spectrum Disorder or Hypermobile Ehlers-Danlos Syndrome (including new and older terms) and not personally having received a diagnosis of the conditions. The study aims to interview between 8-12 people.

Do I have to take part?

Participation in the project is voluntary, and you can choose not to participate in part or all of the project. You can withdraw at any stage of the project up to one week after the interview has taken place. You will not be penalised or disadvantaged in any way and you can avoid

answering questions which are felt to be too personal or intrusive. This will not affect any future treatment for yourself or your sibling(s) and if you are a student, it will not affect your grades.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time up to one week after interviews have taken place and without giving a reason.

What will happen if I take part?

- You will be required to attend a semi-structured one-to-one interview, lasting approximately 60-90 minutes
- You will meet the researcher once
- Meetings with the researcher will last approximately 60-90 minutes
- The interviews will be exploring your experience as a sibling
- The research will take place within your local community- locations will be discussed on an individual basis

What do I have to do?

You will be required to attend a one-to-one interview with the researcher, lasting approximately 60-90 minutes. This will take place within your local community, with locations being confirmed on an individual basis.

What are the possible disadvantages and risks of taking part?

The interview may bring up topics you might find difficult to talk about. You will be able to decline answering any question you find difficult and details of relevant services where you can obtain further information and support will be provided after the interview. No further risks are expected.

What are the possible benefits of taking part?

The benefits include being part of research which could contribute to our understanding of the impact of these conditions on siblings and potentially influence future support available for siblings and families of people with Hypermobility Spectrum Disorder or Hypermobile Ehlers-Danlos Syndrome. The research also allows participants to voice their experiences.

Will my taking part in the study be kept confidential?

Yes. The researcher will guarantee that the information you provide will not identify you or your sibling.

- The researcher will have access to the audio recording of the interview and following transcripts.
- Direct quotes may be used, but data will be anonymised and any identifying information of yourself or others will be removed.
- Audio recordings will be destroyed once the research has been submitted as part of the researcher's doctoral thesis. If the project is abandoned before completion, data will be destroyed.
- The researcher will be adhering to the ethical guidelines of the British Psychological Society, including confidentiality and anonymity.
- Restrictions on confidentiality include any reports of violence, abuse, self-inflicted harm, harm to others or criminal activity

In the instance of risk of harm to yourself or to others, the researcher will be required to inform their supervisor for further support. The supervisor and researcher are bound by professional practice codes to ensure your safety. Please note that this may mean contacting your GP.

What will happen to the results of the research study?

Results will aim to be published as part of the researcher's doctoral thesis. Additional potential publications may be in newsletters, journals or websites of support groups affiliated with the conditions. Anonymity will be maintained throughout.

What will happen if I don't want to carry on with the study?

You will be free to leave, without explanation or penalty. You will be able to withdraw your data from the study up to one week from the interview date.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: *[insert project title here]*

You could also write to the Secretary at:
Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: Anna.Ramberg.1@city.ac.uk

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?
This study has been approved by City University London *[insert which committee here]* Research Ethics Committee, [*insert ethics approval code here*].

Further information and contact details

Sharina Nathan: Sharina.Nathan@city.ac.uk

Dr. Zoe Boden: bodenz@lsbu.ac.uk

Thank you for taking the time to read this information sheet.

Appendix E: Consent Form

Title of Study:
Sibling Experiences of Hypermobility Spectrum Disorder and Hypermobile Ehlers-Danlos Syndrome: An Interpretative Phenomenological Analysis

Ethics approval code: [*Insert code here*]

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve: • being interviewed by the researcher • allowing the interview to be audiotaped	
2.	This information will be held and processed for the following purpose(s): To answer research questions To analyse information for doctoral thesis I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	

	I consent to the use of sections of the audiotapes in publications.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	
4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

Name of Participant	Signature	Date
Name of Researcher	Signature	Date
Sharina Nathan	S. Nathan	10/07/2017

When completed, 1 copy for participant; 1 copy for researcher file

Note to researcher: to ensure anonymity, consent forms should NOT include participant numbers and should be stored separately from data.

Appendix F: Debrief Information

Sibling Experiences of Hypermobility Spectrum Disorder and Hypermobile Ehlers-Danlos Syndrome: An Interpretative Phenomenological Analysis

DEBRIEF INFORMATION

Thank you for taking part in this study. Now that it's finished we'd like to tell you a bit more about it.

The research aimed to understand the unique experiences of siblings of an individual with Hypermobility Spectrum Disorder or Hypermobile Ehlers-Danlos Syndrome. These conditions are widely underdiagnosed and this research hopes to increase awareness into the conditions and understand the impact faced by siblings, in addition to informing our knowledge of how professionals, including psychologists, can support siblings.

If you feel the study has raised concerns, please find below contact details of relevant organisations:

Samaritans: 116 123

Hypermobility Syndromes Association: 03330 116 388 or http://www.hypermobility.org/

Ehlers-Danlos Support UK: 0208 736 5604/ 0800 907 8518 or https://www.ehlers-danlos.org/

You can also contact your GP.

We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

Sharina.Nathan@city.ac.uk and *Zoe Boden bodenz@lsbu.ac.uk*

Ethics approval code: *[Insert ethics approval code here.]*

Appendix G: Psychology Department Risk Assessment

Psychology Department Risk Assessment Form

Please note that it is the responsibility of the PI or supervisor to ensure that risks have been assessed appropriately.

Date of assessment: 22/11/2017

Assessor(s): Sharina Nathan

Activity: Research: one-to-one interviews

Date of next review (if applicable): September 2018

Hazard	**Type of injury or harm**	**People affected and any specific consideration**	**Current Control Measures already in place**	**Risk level** Med High Low	**Further Control Measures required**	**Implementation date & Person responsible**	**Completed**
Slight distress due to sensitive nature of topic	Emotional or Psychological	Participants	Information sheet for participants before providing written consent, outlining the topic of the study, what they will be required for (one-to-one interviews), their ability to decline to answer questions if they feel distressed and their ability to leave the study.	Low	Supervisor will be informed of the incident, participants will be provided with contact details for Samaritans and support groups (Hypermobility Syndromes Association and Ehlers-Danlos Support UK). If interviews take place within an NHS setting, a Counselling or Clinical	November 2017 Sharina Nathan	

					Psychologist will be informed to provide further support.		
Confidentiality and anonymity being broken	Anonymity /Confidentiality	Participants	Participants are informed on the information and consent sheet, before providing written consent, that interviews will be audio-recorded and that identifying information of themselves or others will be removed.	Low	Interviews will be transcribed by a transcription service which adheres to confidentiality and anonymity guidelines. Identifying information will be removed. Audio recordings and transcripts will be password protected and deleted upon submission of doctoral thesis.	November 2017 Sharina Nathan	
Potential accidents in the	Physical harm	Participants and researcher	Interviews will be conducted in a building/service which adheres to health and safety regulations.	Low	A risk assessment would be carried out and the	November 2017	

building/service where interviews take place: for both researcher and participant e.g. trips hazardous environments					supervisor would be informed.	Sharina Nathan	

Risk to researcher: participants could become distressed or violent during the interview	Physical, emotional or psychological harm	Researcher	Interviews will be conducted in a public location where the participant and researcher deemed there to be an appropriate opportunity for confidentiality (including meeting rooms) at either a university, NHS clinic or meeting room in the participant's local community.	Low	The researcher will inform someone e.g. supervisor when conducting interviews particularly within a participant's local community of start/end times of the interviews, if there are concerns. A risk assessment would be carried out.	November 2017 Sharina Nathan	

Contacts

School Safety Liaison Officer: Chantal Hill, chantal.hill.1@city.ac.uk

University Safety Manager: Mohammad Torabi, safetyoffice@city.ac.uk

Appendix H: DBS

Enhanced Certificate

Page 1 of 2

Disclosure & Barring Service

DBS Fee Charged

Certificate Number 001539733814

Date of Issue: 01 AUGUST 2016

Applicant Personal Details

Surname: NATHAN

Forename(s): SHARINA LORETTE

Other Names: NONE DECLARED

Date of Birth: 04 NOVEMBER 1991

Place of Birth: LONDON

Gender: FEMALE

Employment Details

Position applied for:
ADULT/CHILD WORKFORCE DPSYCH COUNSELLING PSYCHOLOGY

Name of Employer:
CITY UNIVERSITY LONDON

Countersignatory Details

Registered Person/Body:
CITY UNIVERSITY

Countersignatory:
DAMIAN WILLIAMS

Police Records of Convictions, Cautions, Reprimands and Warnings

NONE RECORDED

Information from the list held under Section 142 of the Education Act 2002

NONE RECORDED

DBS Children's Barred List information

NONE RECORDED

DBS Adults' Barred List information

NONE RECORDED

Other relevant information disclosed at the Chief Police Officer(s) discretion

NONE RECORDED

Enhanced Certificate

This document is an Enhanced Criminal Record Certificate within the meaning of sections 113B and 116 of the Police Act 1997.

THIS CERTIFICATE IS NOT EVIDENCE OF IDENTITY

Continued on page 2

DBS Disclosure and Barring Service, PO Box 165, Liverpool, L69 3JD Helpline: 03000 200 190

Appendix I: Amended Interview for Researcher

1. Can you tell me a little bit about you and your sibling(s)?
2. Can you tell me a little bit about when you first became aware of your symptoms?
3. Can you tell me a bit about what it has been like for you to have Joint Hypermobility/Hypermobility Spectrum Disorder/Hypermobile Ehlers-Danlos Syndrome?

   PROMPT: Which aspects of your experience stand out to you?

   PROMPT: Is there a specific time that springs to mind?

   PROMPT: Have there been any positive or negative aspects of your experience?
4. What is your relationship like with your siblings?
5. Has your diagnosis changed your relationship with your siblings?
6. What role do you feel your siblings take?

   PROMPT: What does this mean for you?
7. Since you became aware of your condition, has it changed how you relate to other people?

   PROMPT: Has it changed the nature of your relationships?

   PROMPT: Has it changed how much time you spend with people?

   PROMPT: Has it changed how you act around people?

   PROMPT: Has it changed how you feel about other people?
8. How do you think your siblings would respond to knowing you are conducting research on this topic?
9. How do you think your siblings would respond to this interview?
10. What is your personal experience of support?

    PROMPT: Support for you

    PROMPT: Support for your siblings

    PROMPT: Support for the family

11. Since you have had this condition, has it changed how you think about yourself?

    PROMPT: Has it changed how you view your physical health?

    PROMPT: Has it changed how you think about yourself psychologically?

    PROMPT: Has your attitude to life changed as a result of the conditions?

12. How has the experience changed for you over the years?
13. What advice would you give to your siblings?

    PROMPT: Please describe your reason for giving this advice

    PROMPT: Is there anything you wish you would have known?

14. After everything you have said about your experience, if you were to summarise, what do you feel these conditions mean to you?
15. Is there anything else you would like to add?
16. How has it been to talk about this?

Appendix J: Reflexive Interview

Reflexive Interview (based on Langdridge, 2007)

1. Why is this study important to me?
2. Why have I chosen this topic? Why did I choose this topic over my other possible topics?
3. How will people respond to my research? (friends, family, peers)
4. What is my link to the topic?
5. How could I influence the data?
6. What are key areas I think participants (siblings) will identify?
7. How do I expect participants will respond?
8. What are my preconceptions about what will be shown within the data?
9. What do I expect/hope this research will achieve?
10. How could this study impact participants?

Appendix K: Sample Theme Table: Jasmine

Theme	Pages/Lines	Quotes Related to Theme
Participant's changing relationship with SWEDS over time	Page 55, lines 10-11	"..She's so supportive and like, with things like how selfless she is when she's got her own stuff going on.."
	Page 52 lines 9-10 – page 53, lines 1-3	"Um, I'd say like the role I have is just like aimed to just be like normal siblings even though I'd say we're a lot closer than other siblings might be, partly because of what's happened but also because it's always been like me, my mum and my sister, and like I feel like if you don't have a man in the house, like you just like become like a lot closer, I don't know."
	Page 54, lines 5-6	"Um, yeah, no, I don't play a particular role in terms of her condition, I'd say like a role like normal [inaudible 00:40:47]."
	Page 61, lines 7-9	"..I'm having to fight for a well-known condition, I'm to support on this, like what must Lauren feel like, like fighting for this, you know, the EDS."
	Page 73, lines 5-9	"..I don't want it to have to be like, "Oh, I'm Lauren 's caregiver on Wednesday," like if I want to go over on a Wednesday and watch Friends re-runs, great, like that's what I'll do but I think having that structure that she has, that means me and mum are both in that rigid structure, she doesn't have anyone who's like separate from it and I don't think that's great for anyone."
	Page 23, lines 10-11	"..I didn't have the typical uni experience but I wouldn't… I wouldn't give that up because now I have her back.."
	Page 7, lines 7-9	"..it's hard to kind of, um, separate the two things because we don't really let like the EDS get in the way, it's not like trying to think of like specific EDS stuff and specific normal stuff like we kind of— it's just like one big life, you know?"

	Page 50, lines 8-12	"..I do put more energy into building a relationship with her. I think like I couldn't say this to her, but she talks about it all the time, but I know that she's not probably going to live as long as I would like. So, you know, it's about… I don't think about that all the time but like, probably subconsciously that's why I like going to see her all the time or like do fun stuff.!
	Page 6, line 10-page 7, lines 1-2	"..the older she's got like the more we have in common. We spend like quite a lot of time together. She's just started watching Friends, which is very good because I get to watch all the re-runs as well."
	Page 18, lines 8-10- page 19, lines 1-7	"..because the three years I was at uni was when she was in hospital. Like, a lot of my energy went into saving her, or trying to anyway. So, I feel like that kind of—I'm happy about it because it brought us closer together, but I'm not happy about it because it kind of like added this extra dimension to a sibling relationship that I don't think really should be there. Like more of like a caregiver relationship, which kind of… I don't know, yeah, like… uh, I wasn't giving her care because we didn't have her at home, but kind of like fighting for her adds like extra pressure. But like overall, like at that time, I was really… I was happy because I got to see her all the time because I have to be there for her. Does that make sense?"
	Page 36, lines 2-3	"..I think she would have always been amazing but like I think she's probably got extra layer of resilience now.."
	Page 52, lines 9-10- page 53, lines 1-3	"..I'd say like the role I have is just like aimed to just be like normal siblings even though I'd say we're a lot closer than other siblings might be, partly because of what's happened but also because it's always been like me, my mum and my sister, and like I feel like if you don't have a man in the house, like you just like become like a lot closer.."
	Page 62, lines 2-6	"..compared to what it was like in the beginning and compared to what it's like now, it's very different. Like in the beginning, when she was in the hospital for all that time, like I feel like our relationship was (pause) opening up that extra dimension of me not just being a sibling, like I was like fighting for her as well.."

	Page 58, lines 7-10- page 59, lines 1-4	"..mum is basically her TPN nurse at home, I guess for her. Um, and like I will help my mum out so she gets a break but also, like I don't want it to become like, "Oh, I'll do it Wednesday, Thursday, Friday," because then that moves me back into the other category. Like I want to be like… like we're best friends now she's older, you know, like we were watching Friends together, like we're going out like… Yeah, like I want it to stay like that because I want to carry on like the positive things that we built on when she was poorly and have like a normal sibling relationship.."
	Page 50, lines 1-2	"..it's hard to distinguish EDS and like normal life because we're just kind of like trying not to like let it get in the way."
	Page 53, lines 8-9 and page 54, lines 2-3	"..a particular role, like I think just like… like we were so close and we say like we're each other's best friend.." "..Um, yeah, no, I don't play a particular role in terms of her condition, I'd say like a role like normal.."
	Page 54, lines 4-8	"..SN: Yeah. Thank you. And what does this mean for you that, you know, that you are best friends and that you just want to be able to spend time with each other? What does that mean for you? J: Um, it's like the best thing ever because she literally gets me better than like anyone else, like… And she's so—like I find this aspect so like beautiful."
	Page 33, lines 9-11	"..because I was there and like fighting as well, I think that the usual like structure of that just didn't really fit so they weren't able to like completely like diagnose us with Munchausen's.."
	Page 75, lines 5-7 and page 76, lines 1-4	"..I am proud of myself for what I did at the time. Like, I literally got a degree at the same time that this was happening. So yeah, like in a weird way, like what happened kind of have boosted my own self-confidence.."

		"..all of these things like I balanced them well and like I did them well, like when I look back and I kind of think like even though like I had all these things that's happened, like I overcame it and I know that like now I've been that strong, like I know I'm in a position to like be there for her again."
	Page 38, lines 6-10 – page 39 lines 1-2 and page 39, lines 4-7	"..in the beginning, because she was in [redacted] and I was in [redacted] at uni, I kind of like kept away from it for a bit because like for five weeks she'd been in hospital with this tonsil infection, um, and I don't think I visited her in that time because she'd always been like a sickly child, like up and down [redacted] all the time with like different, you know, gastro and things like that. "Well, you know, it's just the same old…" I was quite like blasé about it because like she had had that medical input for a while.."
		"..when she went back in in the October, that's when I really like started getting like invested in saving her because like, that's like six months and nothing had been done and she was like have her NG tube, NG tube like all of that and I was like, what's actually happening here, like no one's actually given us answers. "
	Page 20, line 10 – page 21, lines 1-4	"..I want to be like… like we're best friends now she's older, you know, like we were watching Friends together, like we're going out like… Yeah, like I want it to stay like that because I want to carry on like the positive things that we built on when she was poorly and have like a normal sibling relationship, I guess.."
How experience of having a SWEDS changes attitudes to life over time	Page 63, lines 7-10	"..still at the back of my mind like if you do something, that like the most normal people would just be like, "Oh, they're just being annoying," and I'd be like "Hmm, I wonder what this means, like is he like going back to not being supportive?""
	Page 23, lines 8-10	"..like I can—like I try, like I still go out clubbing and I still do like uni stuff but she's always like in the forefront of my mind that year."

	Page 80, lines 7-10- page 81, lines 1-8	"..I don't like it when people are like, "Oh, live every day like it's your last," like I hate that because you're constantly then thinking that every day needs to be like above average and you need to like live amazing days to be fulfilled. And then you—not every day, it wouldn't be like that, but then you become upset and you're like, oh, so my life isn't as good as someone else's, or I'm not fulfilling this aspect because I'm not living every day like it's my last. I genuinely just live by the rule like just live every day. Like have a normal like life, don't try and like super exceed like expectations were like lived by other people's expectations because like that's just not—that's just like not a feasible way to live and I think you'll just constantly feel disappointed. Like if I didn't take Lauren to Florida Disney every summer I'd be like, "Oh, I failed." Like, you know, like you just felt like finding that enjoyment in like every aspect of that. Does that make sense?"
	Page 92, lines 5-10 – page 93, lines 1-3	"..I'd feel like if it's affecting like your mental health, like go and speak more about it. Like it's—it is okay to… I feel like it's okay to change your opinion as well. Like also back then I was, "Oh, you know, why is everyone cross that I'm supporting mum, why is everyone thinking that I'm not living my life right by giving up things for my family? Whereas now I look at it with like a more balance view, and I feel like you shouldn't have to feel guilty about that. Like, like I shouldn't feel guilty about like not being there every single night and like that's fine, like you can live your own life, like learn what your balance is in terms of like just having a balance with like shopping and like being there for them."
	Page 97, lines 4-10 -page 98, lines 1-3	"..Um, so for my PGCE that I've just started, you have to do an assignment called "How Successfully is Learning X integrated into Learning", and a lot of the examples I've read, a lot of the things that always talk about Autism and Dyslexia and like, they're probably easier to do my assignment on because there's so much literature out there, that I wasn't to pick someone like a child with a medical needs and like how they're integrated into school. And I'm like, I have to pick someone who like actually, fits, so like I might have been able to get like someone like Lauren in the school that I'm going to, but, um, I think just like people need to be like more aware of like artificial nutrition but I just think the like probably like the impact it has on like every part of your life."
	Page 101, line 10- 102, lines 1-7	"..her doctor at the [redacted] Hospital, um, we have to go and see him and we're like nervous, we was like oh what is he going to say, is it going to be psychological again, but he was like, "I think the best advice I can give you is, yeah, you've been through a horrible timeline but like what they did to you was wrong, but you can't live your life holding onto that." Yeah, like these conditions for me, at

		the back of my mind, mean that like I have to think about things differently with my sister, like you can't just jet set to New York for the weekend, like there's a lot of thinking to be done before that.."
	Page 40, lines 7-10	"..I remember going with like a really positive attitude. I think partly because I was naïve, but also because I was like if I was gonna breakdown, mum's going to breakdown, so like I'd go in here, into this scary unit and like pretend I'm okay with it.."
	Page 21, lines 7-10 – page 22, lines 1-7	"..Yeah, so, I feel like when she's at hospital, the caring aspect was like this little teeny girl is being neglected, like she had her artificial nutrition taken away for a month so she got really poorly. Um, because they said, oh, you know, we're taking it away kind of thing so you just eat if you got hungry kind of thing. I think that was like a really, really terrible time. Um, (pause) yeah, and then now, now, I kind of tried to move away from that because I could see how it was affecting like my mental health, my relationship with my boyfriend at uni was quite strained because, um, he'd be like, "Look, I know you love her but like you can't keep fighting for her because it's not really your job." And at the time I was furious because everyone in my life kept telling me that. And now looking back, I can see why they said what they said but also, I'm like, I'm glad I did it, if that make sense."
	Page 77, lines 7-9	"Um, so I wouldn't say like I look on myself now and I'm like, oh well, she's got EDS, I must have it," like… Like it hasn't changed in that respect, I'm not like, "Oh well, you know, we must all have it," no, it isn't like—this is not like that."
	Page 79, lines 1-6	"..but like mentally and psychologically, yes, it's made my anxiety worse than it has—like it's better than it was, but it's like it's not [inaudible 01:00:33] was like well. I don't know if that's because my brain maybe like, because there's like such a big issue of like I might lose my best friend, my brain then like telling me not to worry turns it into like oh yeah the light switch is on, well, do you know what I mean?"
	Page 51, lines 5-7	"..I think like probably at the back of my mind I'm like, "Well, maybe this is her last Christmas so maybe I better do this advent calendar blooming well""

	Page 79, lines 9-10 – page 80 line 1 Page 85, line 10- page 86 line 1	"..like that big worry of like maybe one day having to live life without her, I think like trickles down into like everyday activity, becoming more anxious.." ".if I'm asleep and like something goes wrong with her line, that's my fault.."
Participant's perceived helpfulness of social media as a form of support for siblings	Page 85, lines 3-8 Page 83, lines 7-10 – page 84, lines 1-3	"..I'd love to be able to post on a social media group and be like, "Oh guys, what do you think I should do? Like should I be helping my mum more? What do you guys do?" Um, but I'd love other people like experience of that, and I like… Sometimes when like—I mean, it's quite rare now so I'm going to like pushing it to the back of my mind, but if somethings I'm feeling like, oh my god, like she might die one day, like I'd love to be able to talk to somebody about that.." "..I love the Facebook group, I'm a big fan of those. So, I'd love it if there was like loads of siblings that I could just like… I could… the thing that I was kind of struggling with at the moment is like how much I help my mum with stuff like… Um, I mean I couldn't help her that much that's why I'm struggling at the moment so I'm like, I'm worried—like, it's like a duty versus like selfishness, like should I, um… like I'd love to be able to like message and would be like, "What do you guys think of this?""
Impact of EDS on participant's mental health and managing this	Page 78, lines 6-9 Page 55, lines 1-2 Page 79, lines 1-6	"..people will automatically think like, oh, it's Lauren you're anxious about, like I completely understand like how that's kind of come to the forefront, but like actually it just makes my anxiety about everything worse.." "..I suffer with anxiety .." "..mentally and psychologically, yes, it's made my anxiety worse than it has—like it's better than it was, but it's like it's not [inaudible 01:00:33] was like well. I don't know if that's because my brain

		maybe like, because there's like such a big issue of like I might lose my best friend, my brain then like telling me not to worry turns it into like oh yeah the light switch is on, well, do you know what I mean?"
	Page 55, lines 5 and 10-11	"..she's so helpful whenever I'm like anxious.." "..she's so supportive and like, with things like how selfless she is when she's got her own stuff going on.."
	Page 75, lines 6-8	"..I am proud of myself for what I did at the time. Like, I literally got a degree at the same time that this was happening. So yeah, like in a weird way, like what happened kind of have boosted my own self-confidence.."
	Page 76, lines 2-5	"..all of these things like I balanced them well and like I did them well, like when I look back and I kind of think like even though like I had all these things that's happened, like I overcame it and I know that like now I've been that strong, like I know I'm in a position to like be there for her again."
	Page 41, lines 10-11	"Like mental health is still like a problem, like a legit problem, and I feel like I [inaudible 00:30:36] have like my own anxiety issue and it mainly started from when Lauren was poorly."
	Page 42, lines 2-4	"Um, so like I spend a long time understanding mental health, so I feel like I have like a good understanding like; not appreciation, appreciation is the wrong word but like an empathy like for any kind of mental health issue really."
	Page 67, lines 3-9	"I had CBT for [redacted] when I was at uni because when Lauren got ill, that's when it kind of like came to surface and like things are getting like really bad with my own mental health. Um, that was a really good mix of CBT and also like counselling and she's in hospital at that time, so like that was like a good mixture, like she helps me. She wasn't meant to be helping with that, she's meant to be doing like CBT for [redacted] but it just turns to like both. So, like that was- that was great, like that really helped me."

	Page 70, lines 7-10 – page 71, lines 1-4	"I don't want to get into a routine of helping and then feel guilty for leaving, because I shouldn't feel that guilt for leaving, like that's not a situation I want to get into because that affects my mental health, the guilt of going. Like you should just feel like, "Oh, you know, I'm going now, like I'll see you guys in a couple of weekend's time," and that'll stay with me like it shouldn't be like, "Oh god, can I leave this area, like if Mum wants to go to bingo on a Wednesday?" She doesn't go to bingo, but you know what I mean (laughs)."
	Page 78, lines 3-4	"..I think I've always been like quite an anxious person, because when she was ill like that's when it got like unbearable."
Understanding of EDS changing over time	Page 38, lines 1-3	"..her tonsils taken out, we just thought she had like reflux like, like you know, like most kids have that, you know, that's normal."
	Page 61, lines 3-9	"..I knew I had this condition, like there's no way with the sym—that symptoms that I had that I didn't have it. Um, I was literally like in agony and I was just like, I- I need some like diagnosis for this so that I can like move on. And to get that diagnosis for me was like so long, and that was such like a drop in the ocean from what Lauren had experienced and then she's there like, I'm having to fight for a well-known condition, I'm to support on this, like what must Lauren feel like, like fighting for this, you know, the EDS."
	Page 94, lines 5-8	"But actually, like Lauren is like reliant on something that is like killing her liver, you know? Like that kind of thing is like madness for me to like understand. Like, I just like, cause I forget about, like I try to forget about it, I don't want to think about it all the time."
	Page 12, line 11-page 13, line 1	"Like at least with mental health, there are like structures of support whereas now, it's like, oh, it actually is true, yeah."
	Page 100, lines 4-7	

	Page 43, lines 6-9	"..a few years ago, like people don't really know about the condition whereas now, like people were like posting on [redacted group] and like messaging me like, "Oh EDS, yeah, I'm so glad you mentioned that. All my friends actually got that I didn't know.""
	Page 94, lines 3-7	"My mum, I remember her like picking up being a living-donor for livers, because obviously your liver like packs up if you're on TPN for a long time. So like (pause) it's had an impact on my mum as well, like she has no life really."
	Page 98 line 10- page 99, lines 1-2	"..I feel like a lot of it in the media is to do with like, um, I'm going to be a wheelchair user and like, like more… more joint stuff. But actually, like Lauren is like reliant on something that is like killing her liver, you know? Like that kind of thing is like madness for me to like understand."
	Page 100, lines 7-9	"..the more times it comes up in the media, like things that happened, like other people's understanding, it helps bring like a web and like a network of understanding, like the more people that know about it."
	Page 103, lines 7-10 – page 104, lines 1-2	"..all these links like with the media getting more like on-board with having positive trails off this condition, like I feel like it's just like helping loads."
	Page 12, lines 3-10- page 13, line 1	"..I really just one like to get a message out there that like most people with EDS like do just live normal lives and aren't like completely encapsulated with like living in a drug life and like having all of these like different interventions. Like, I feel like that's the message that you'll come across a lot on social media because the people on social media who have EDS are the people who bother to put that stuff on there, you know?"
		"..lot of people said like my mum as well when she got interviewed on like [redacted] and stuff they're like, "Oh, was it an absolute sense of relief, like we're you kind of overjoyed, was it a positive experience when she got diagnosed," and it's like it's only positive in the fact that you're

	Page 8, lines 3-4	like, this is her ticket out of this like psychiatric unit. It's not like, "Oh, I'm overjoyed that she's ill." Like I think a lot of people like mixed up that question whenever—like journalists, whenever they asked mum about it and she's like, well no, like it was horrible because it's like, oh, like we're in a situation with the stuff and like (pause) there's no cure for this." "..there's so much to say, where should I begin to be clear.."
The impact of EDS on participant's relationships with others	Page 63, lines 3-5 Page 63, lines 7-10 Page 62, lines 3-5 Page 64, lines 10-11 – page 65, lines 1-3	"..my boyfriend, definitely like it caused some problems because I was like, it doesn't matter what you do, I'm never going to be able to forgive you for not supporting e during that time.." "..at the back of my mind like if you do something, that like the most normal people would just be like, "Oh, they're just being annoying," and I'd be like "Hmm, I wonder what this means, like is he like going back to not being supportive?.." "..yeah, it's definitely the way I relate to like medical professionals unless like they build their trust back up with me. Um, yeah, like I just… I just don't really have that trust anymore." "..yeah, it does put like massive strain on that because you need to be able to trust other people in your life that you care about are going to be there for you when times get hard, but if I've already been in that time when things got hard, and they weren't there for me, like what does that mean for me?.."

	Page 59, lines 5-9	"..SN: Yeah. And has it changed how much time you spend with other people? J: Um, (pause) when she was really ill, yeah. Like I would go to Mum and Lauren's, like I go to one of the girls house, like [redacted] Hospital like every day basically. Um, so yeah, that… that impacted on like the time I spend with other people"
	Page 60, lines 1-3	"..now, I don't think that has an impact like I'll see her when I can, like after work or after uni or whatever, but like now it's like now a lot more settled, I can have a lot more balanced life."
	Page 60, lines 8-10 – page 61, line 1	"… it's awful but it's completely changed like my trust in people. Like especially… I don't know if it's, like especially like medical professionals, like I'm often quite like, I don't know, like… (pause) do I trust them? Should I? I don't know."
	Page 22, lines 3-6	"..my relationship with my boyfriend at uni was quite strained because, um, he'd be like, "Look, I know you love her but like you can't keep fighting for her because it's not really your job." And at the time I was furious because everyone in my life kept telling me that."
	Page 53, lines 5-7	"..I think because the three of us spent so long, just like crying in the [redacted] car park and like all those experiences kind of like bring you together more, I guess.."
	Page 57, lines 3-9	"SN: Sure. Um, so for example, has it changed the nature of your relationships with other people since you became aware of her condition? J: Yes, in terms of like [inaudible 00:43:06] about my dad and my boyfriend. SN: Yeah. J: Like, (pause) kind of balancing that, I guess, like… like I'm in a good place now where I see where they were coming from at a time when I'm so invested in it all, but also I'm like no, like she's always have this issue, like I want you to be aware of it.."
	Page 102, lines 7-9	"..overall, like the way our story panned out, is like positive because like me and mum and Lauren have like such an amazing bond now because of it."
Perceived support for SWEDS	Page 32, line 9- page 33, line 5	"..every Friday we got an hour and a half battle of like fighting against like opinions that we just didn't agree with. And like at times, we were like supportive and annoyed when they said that we

		weren't because we even sat with Lauren and like try to help her eat Wotsits even though we knew it wouldn't make a difference and I was saying to her, you know, like sit up straight, like let's give it the best shot we can, like follow it and see what happened. Like just like playing the game really, and also hoping that like it would work."
	Page 91, lines 1-2	"..that's what's missing is like people in a single parent family, like you just think, "Oh, the mum and dad will take it in turn each night," but like no, like it's mum every night."
	Page 72, lines 2-7	(about TPN nurse): "..like so supportive and like… at the TPN clinics, like you go to like the gastro, like, um, that's like the gastro ward, you know, all there, um, you see all the other like kids with TPN and all their pick lines and everything and like she fosters a really good relationship with all of them but as soon as Lauren walks in, she like gives her a hug and then like, like they build up such a good bond, I feel like Lauren's support was there."
	Page 72, lines 7-10	"And there's a Psychologist at [redacted] who is supporting Lauren now not because of, um, (pause) not because of like mental health in terms of like, "Oh, you make it all up in your head," but she's there to talk about like, um, Post-Traumatic Stress Disorder.."
	Page 11, lines 2-4	"So, she was taken into a psychiatric unit in [redacted], um, we knew before she went in there that she had EDS but we didn't have a choice in her going there."
	Page 30, lines 2-4	"..one of the nurses who was kind of like on our side at this point had disconnected Lauren's TPN and she was like go, like get out of here, like she was like, "Go on your nice day trip," but like I think secretly like they knew where we were going."
	Page 24, lines 1-2	"..I know that I did the very best I could to set her free from there."
Lack of understanding around EDS from others	Page 97, lines 2-3	"People's understanding is poor, like… Oh God. And particularly for the artificial nutrition side of things…"

	Page 74, lines 2-4	"..Lauren is like, um, mentally and like verbally able and like if you look at her in the street, you'll have no idea she has a disability.."
	Page 86, lines 8-9	"..I think the worst thing you can do is group them all together. That's what I've seen at the EDS support group.."
	Page 103, lines 7-9	"..like am I really just one like to get a message out there that like most people with EDS like do just live normal lives and aren't like completely encapsulated with like living in a drug life and like having all of these like different interventions."
	Page 34, lines 4-5	".."there was no evidence, like everything they ever brought up with the social workers it was like a complete conjecture.."
	Page 33, lines 5-7	"..They were very specific never to mention like Munchausen's or FII, but like that's what they meant every week."
	Page 15, lines 4-5	"firstly, people didn't believe her, and also her medical notes were mixed in with somebody else's."
	Page 49, lines 3-5	"..I think that's why that medics have such a hard time understanding the condition is because of like the way it presents isn't always like the same.."
	Page 49, lines 7-9	"..I feel like as soon as collagen doesn't work properly, it is unpredictable and I think that's why, like the unpredictability for scientists and medics is just like not okay for their brain, I guess."
	Page 31, lines 3-5	"..some of them knew where we were going and some of them were happy about it, that they were like "Get out," I think some of them knew and weren't that happy about it."

Participant's understanding of EDS being considered as psychological	Page 33, lines 9-11 – page 34, line 1	"..I feel like in, um, in like a mum, dad situation, like the typical textbook, like it's like all of the dads like [inaudible 00:23:59] mum is a bit, you know, and actually, I'm a bit worried about my wife"
	Page 15, lines 4-7	"..she ends up on psychiatric unit because firstly, people didn't believe her, and also her medical notes were mixed in with somebody else's. So, she had, um, a girl from around like this area, her notes went in and she had like severe mental health problems so that kind of like integrated with Lauren.."
	Page 9, line 2	"..unfortunately, a lot of the medic kind of said it was psychological"
	Page 9, lines 2-5	"..if you don't know about the condition, like especially with mental health having seen the amount of respect these days and like you believe doctors, you'll think like, "Okay, I don't mind what she's got as long as it's getting treated.".."
	Page 39, lines 10-11 – page 40, line 1	"..I was like, what's actually happening here, like no one's actually given us answers. And then that's when they started like bringing up, um, the [redacted] Unit at [redacted] Hospital, and that's like when it kind of like spiralled into like a mental health thing."
	Page 72, lines 7-10 – page 73, line 1	"..there's a Psychologist at [redacted] who is supporting Lauren now not because of, um, (pause) not because of like mental health in terms of like, "Oh, you make it all up in your head," but she's there to talk about like, um, Post-Traumatic Stress Disorder cause that's the diagnosis now for being like put in that unit for so long."
	Page 41, lines 4-6	"..and I remember getting home, um, in my boyfriend's house and like just bursting into tears into his mum's arms and I was like, "This is just horrible, like I hate it."."
	Page 41, lines 6-10	"..it wouldn't matter to me if she had a mental health problem. Like that wouldn't be an issue, it wasn't like, "Oh, you know, she's got mental health issues, like I don't…" like I don't know what to say, like if that was true, that really was what was wrong with her, like that would made no difference like our family still would have supported her in the same way."
	Page 55, lines 2-3	"..she was the one that they were saying had anxiety and anorexia problem.."

		"..she's been in that mental health situation even though that didn't – that label didn't belong to her."
	Page 9, lines 7-11	"..but like we just believe the doctors like for the first like couple of weeks anyway, because you do like… And then like none of it started adding up, and even the mental healthcare she was receiving wasn't what I would want her to receive even if that was what we thought of her.."
Perceived lack of support for family	Page 66, lines 3-6 Page 66, lines 7-9	"..I would have loved to set up like a siblings' support group, uh, at EDS UK, but I think it's so hard because a lot of people think about like, oh, how are the younger siblings going to cope in terms of not getting the same attention? And I feel like that's as far as it goes.."
		"..there needs to be like even if like someone gets diagnosed when they're 80 and they've got like an 82-year-old like brother, like there needs to be support.."
	Page 66 line 10-page 67 line 1	"..siblings need to be recognised as a category of people who are affected by it"
	Page 85, line 8	"..she might die one day, like I'd love to be able to talk to somebody about that"
	Page 74, lines 7-10 – page 75, line 1	"..it's a shame but maybe, you know, that's not the NHS's job or the government's job to fund mum's time off, I don't know. Um, yeah, I feel like that obviously builds up a lot of the problems with that at the moment in terms of like the relationship for me and mum and my sister and these whole like people who have Lauren for a night while I go and see my friend.."
	Page 44, line 10 and page 45 lines 3-4	"..like my Nan and Granddad.." *and* "They… they like, they dedicated their lives to her whilst she was in the hospital."
	Page 41, lines 6-7 and lines 9-10	"..it wouldn't matter to me if she had a mental health problem." a*nd "..*that would made no difference like our family still would have supported her in the same way."
	Page 69, lines 4-6	"Like I want to help any way I can, like with school like it's such… like rewarding but it's also like you feel like it's your duty to be supportive in there.."
	Page 20, lines 7-9	

		"..mum is her like TPN provider, like mum is basically her TPN nurse at home, I guess for her. Um, and like I will help my mum out so she gets a break.."
	Page 25, lines 2-4	"..I got to meet like loads of lovely people and like find some support for like my family from learning from other people's stories as well."
	Page 74, lines 3-5	"..if you look at her in the street, you'll have no idea she has a disability, like mum doesn't get that same amount of support. Um, and I don't think that's right.."
	Page 73, lines 2-3	"SN: Good. And what about support for your family? J: They have nothing.."
	Page 73, lines 7-8	"..never have anyone like come over to stay or help or anything"
	Page 91, lines 3-4	"..I think that's like the biggest thing there. Um, not enough like respite care for people on artificial nutrition."
	Page 91, lines 1-3	"..that's what's missing is like people in a single parent family, like you just think, "Oh, the mum and dad will take it in turn each night," but like no, like it's mum every night. Like I think that's like the biggest thing there."
Comparisons	Page 61, lines 6-9	"And to get that diagnosis for me was like so long, and that was such like a drop in the ocean from what Lauren had experienced and then she's there like, I'm having to fight for a well-known condition, I'm to support on this, like what must Lauren feel like, like fighting for this, you know, the EDS."
	Page 87, line 1	"..bringing everyone together doesn't mean they're going to get on"
	Page 18, lines 2-3	"..compared to what it was like in the beginning and compared to what it's like now, it's very different."

	Page 87, lines 1-4	"..it's not necessarily a support with it because it must be hindrance because we're hearing how other people's lives are going with the same condition and you're like, "My life isn't going like that, well, what am I doing wrong?""
	Page 12, lines 10-11 – page 13, line 1	"..it's like, oh, like we're in a situation with the stuff and like (pause) there's no cure for this. Like at least with mental health, they're like structures of support whereas now, it's like, oh, it actually is true, yeah."
	Page 73, line 10 – page 74, lines 1-4	"..if she wants a break, like we have a friend who has a daughter with [redacted] and like with their disability… and like, she gets a lot of respite care funded and I feel like because Lauren is like, um, mentally and like verbally able and like if you look at her in the street, you'll have no idea she has a disability, like mum doesn't get that same amount of support. "
Participant's positive experiences of EDS	Page 73, line 1	"..I think [redacted] were like doing well for a change.."
	Page 102, lines 7-9	"..but like overall, like the way our story panned out, is like positive because like me and mum and Lauren have like such an amazing bond now because of it."
	Page 12, lines 3-7	"when she was diagnosed, a lot of people said like my mum as well when she got interviewed on like [redacted] and stuff they're like, "Oh, was it an absolute sense of relief, like we're you kind of overjoyed, was it a positive experience when she got diagnosed," and it's like it's only positive in the fact that you're like, this is her ticket out of this like psychiatric unit. It's not like, "Oh, I'm overjoyed that she's ill."
	Page 24, line 9 – page 25, lines 1-2	"So, I've… I've done stuff like running the EDS UK, like at races and stuff. Like I wouldn't have been able to like know that feeling of like being helpful without doing that."
	Page 25, lines 2-4	"..I got to meet like loads of lovely people and like find some support for like my family from learning from other people's stories as well. Um, so that's good."
	Page 67, lines 3-9	"..um, I had CBT for [redacted] when I was at uni because when Lauren got ill, that's when it kind of like came to surface and like things are getting like really bad with my own mental health. Um, that was a really good mix of CBT and also like counselling and she's in hospital at that time, so like that was like a good mixture, like she helps me. She wasn't meant to be helping with that, she's meant

		to be doing like CBT for [redacted], but it just turns to like both. So, like that was- that was great, like that really helped me."
	Page 37, line 5	"now it's better, our GP's really good."
	Page 11, lines 9-10 – page 12, line 1	"We took her and we went and then, he was like, um… yeah, and we just kind of made everything clear really."
	Page 71, lines 7-10 – page 72, lines 1-2	"..at [redacted] Hospital, there's a really amazing TPN nurse called [redacted] and she is… like she joined [redacted] the same week, I think, or the same time that Lauren was let out of the psychiatric unit and she went to [redacted] TPN training. Um, so that's when [redacted] joined the story and she's like, she can't believe like what happened before because she's like completely like on our side as it were and like so supportive.."
	Page 72, lines 3-7	"..the gastro ward, you know, all there, um, you see all the other like kids with TPN and all their pick lines and everything and like she fosters a really good relationship with all of them but as soon as Lauren walks in, she like gives her a hug and then like, like they build up such a good bond, I feel like Lauren's support was there."
	Page 101, line 10 – page 102, lines 1-4	"..one of the… her doctor at the [redacted] Hospital, um, we have to go and see him and we're like nervous, we was like oh what is he going to say, is it going to be psychological again, but he was like, "I think the best advice I can give you is, yeah, you've been through a horrible timeline but like what they did to you was wrong, but you can't live your life holding onto that."
	Page 20, lines 2-3	"..I think she would have always been amazing but like I think she's probably got extra layer of resilience now.."

Participant's view of supporting SWEDS	Page 91, lines 3-4	"..not enough like respite care for people on artificial nutrition."
	Page 39, lines 1-5	"..I don't think I visited her in that time because she'd always been like a sickly child, like up and down [redacted] all the time with like different, you know, gastro and things like that. "Well, you know, it's just the same old…" I was quite like blasé about it because like she had had that medical input for a while."
	Page 23, lines 1-2	"..from her point of view, like why wouldn't I fight for her, you know?"
	Page 85, lines 9-10 – page 86, line 1	"..if ever I do her TPN, so like if I set up her like line and stuff like… I hate doing it because I'm like, I have to go to sleep not knowing if I've done this right, and if I'm asleep and like something goes wrong with her line, that's my fault."
	Page 86, lines 1-4	"..that's like another reason I don't really like doing her medical stuff, like it's just a responsibility I want because I don't want it to be like me that's like…during the night."
	Page 91, lines 4-10	"..artificial nutrition. It makes you feel like, peg fed and it's not like a case of, you know, if air goes into a peg, like it's not really… I mean it's not great, but like it's not going to kill you whereas if air goes into your heart, like you'll probably not going to make it, you know? Um, I feel like going to bed with that every night, like my mum like… my mum's fine with actually doing it for three years, but like putting—like doing that every night, and like thinking that like every night I do it is going to be the one that like kills her."
	Page 91, lines 10-11 – page 92, line 1	"..I feel like the perfect respite care like I feel a lot happier because I wouldn't have to do her TPN; like I don't like doing it, I don't like having that responsibility."
	Page 69, lines 2-4	"..that's a slippery slope with it being, oh, every Wednesday after uni I'll come over or… and I, I shouldn't feel like I don't want to do that but there's something in me tells me that like, you know, I don't want to be relied upon for that."

	Page 70, lines 10-11 – page 71, line 1	"..I feel like maybe siblings who show their support are then like relied upon. I feel like such kind of awful for saying that."
	Page 23, lines 10-11 – page 23, line 1	"..I didn't have the typical uni experience but I wouldn't… I wouldn't give that up because now I have her back, like it's obviously it wasn't like all me I'm not saying that, but like I know that I did the very best I could to set her free from there."
	Page 69, lines 5-7	"..also like you feel like it's your duty to be supportive in there, but at the same time like I, I completely agree with my dad and my boyfriend in like I need my own independence."
	Page 95, line 10- page 96, lines 1-6	"..I feel like, you know, have you ever seen that analogy where like you drop something in a pond and it like ripples out really fast, it's like thinking of like the impact they have, the ripples in that pond go, um, that it's not just like (pause) it's not just fishing out what you've dropped in the pond, like with like Lauren it's the thing that they dropped, like it's not just like the getting her back out it's like settling the water again like all around.."
Shared understanding between participant and SWEDS of their experiences	Page 69, lines 6-8	"..I completely agree with my dad and my boyfriend in like I need my own independence. And like Lauren's on the same page as me.."
	Page 88, lines 7-9	"..she's saying the other day, she was like, "I don't want to be in the same tutor group as this girl because, just because you've got EDS doesn't mean you're the same kind of person".
	Page 7, lines 7-9	"..it's hard to kind of, um, separate the two things because we don't really let like the EDS get in the way, it's not like trying to think of like specific EDS stuff and specific normal stuff like we kind of – it's just like one big life, you know?"
	Page 81, lines 9-10 – page 82, line 1	"..there's obviously like that awareness that like life is different for her. But I mean, like we don't – we don't read things like that from an everyday kind of basis."

	Page 51, lines 9-10 – page 52, line 1	“um, and we talked about like her…like talked about what she wants for her funeral and like, well that’s hard to hear because like… and she makes that joke all the time, she’s like, “Well, you know, I might be dead soon,”..”
Differing views between participant and others	Page 72, line 1	About TPN nurse: “..she’s like completely like on our side..”
	Page 14, lines 6-11	“..I feel like nurses can't like really err their opinion too much because they might get in trouble, but she kind of said to mum, she was like, “I don’t really think she should be here, like I think she looks like she’s got this condition instead.” So then that was like, “Okay, even the psychiatric unit at [redacted] telling us that it’s like it was…””
	Page 31, lines 3-5	“..Uh, I think maybe because some of them knew where we were going and some of them were happy about that, they were like, “Get out,” I think some of them knew and weren’t that happy about it.”
	Page 87, lines 6-8	“..there’s a lot of people within the community who don’t really have much else in their lives, so they’re all about their illness and the drugs they take like “what drugs have you got?” like, Lauren is nothing like that.”
	Page 33, lines 1-4	“..we even sat with Lauren and like try to help her eat Wotsits even though we knew it wouldn’t make a difference and I was saying to her, you know, like sit up straight, like let’s give it the best shot we can, like follow it and see what happened. Like just playing the game really, and also hoping that like it would work.”
	Page 78, lines 6-7	“..people will automatically think like, oh, it’s Lauren you’re anxious about..”
	Page 22, lines 3-6	“..my relationship with my boyfriend at uni was quite strained because, um, he’d be like, “Look, I know you love her but like you can’t keep fighting for her because it’s not really your job.” And at the time I was furious because everyone in my life kept telling me that”

	Page 18, lines 6-8	"…a lot of people in my life were like, you know, what are you doing, like I know you love her but like you've got to give yourself a break."
	Page 91, lines 1-2	..in a single parent family, like you just think, "Oh, the mum and dad will take it in turn each night," but like no, like it's mum every night."
	Page 72, lines 7-9	"..back then I was, "Oh, you know, why is everyone cross that I'm supporting mum, why is everyone thinking that I'm not living my life right by giving up things for my family?.."
	Page 32, lines 9-10	"..every Friday we got an hour and a half battle of like fighting against like opinions that we just didn't agree with."
The invisible becoming visible	Page 88, lines 5-6	"..Unless you saw her line, you'd have absolutely no idea"
	Page 8, lines 6-9	"Since she was younger, she would be like sick quite a lot, um, and like would ask to be carried all the time and I was just like, "Ugh." She just wants to be carried because, you know, she's little, but like now we understand her symptoms more because her joints were in pain like even when she's like five.."
	Page 73, line 10- page 74, lines 1-5	"..we have a friend who has a daughter with [redacted] and like with their disability… and like, she gets a lot of respite care funded and I feel like because Lauren is like, um, mentally and like verbally able and like if you look at her in the street, you'll have no idea she have a disability, like mum doesn't get that same amount of support. Um, and I don't think that's right.."

Emotional responses from family and participant around experience	Page 41, lines 1-6	"..they have a nice balcony at [redacted] [inaudible 00:29:42]. And then mum was just like okay with it but on the train back, she's like, "This is like horrible" um, and I was like, "Oh, right okay," and like my positivity has had no effect. Um, and I remember getting home, um, in my boyfriend's house and like just bursting into tears into his mum's arms and I was like, "This is just horrible, like I hate it.."
	Page 29, lines 8-11	"..then mum called me and she was like angry in tears, she was like, "They're not letting us leave, they said we can't go anywhere today." Um, and then like I panicked, like when your heart like beats so quickly you think like is my opportunity gone, like they're never going to get her out of here.."
	Page 30, lines 5-8	"..that sticks out in my mind because like the absolute like panic like how my emotions turn into like physical, like my heart was beating like, I was like sweating, I was like, "Oh my God," like—yeah. So, I think like that amalgamation of like my actual like brain turning into like… Like I was so nervous, it was like difficult.."
	Page 39, lines 5-6	"..it like panicked me, I was like, I must get up there now you know.."
	Page 40, lines 6-10	"..I remember going to the [redacted] Unit with mum to go for a visit, that's [inaudible 00:29:22], and I remember going with like a really positive attitude. I think partly because I was naïve, but also because I was like if I was gonna breakdown, mum's going to breakdown, so like I'd go in here, into this scary unit and like pretend I'm okay with it.."
	Page 35, lines 1-4	"..I felt so bad but in the end I was just so tired of it that I just, I came home like—and I, like I could go like every couple of days like to work and stuff, but like I can't deal with that Friday afternoon anymore because it was just this plain rubbish every week.."
	Page 19, lines 6-7	"..I was happy because I got to see her all the time because I have to be there for her.."

	Page 36, lines 9-10 – page 37, lines 1-5	"..her paediatrician at [redacted] Hospital where Lauren still is under even like after all of this [inaudible 00:26:33], um, he goes to the meetings and like conferences [inaudible 00:26:41] now, um, and he's like, come back to [redacted] and be like, not like I'm sorry because obviously that shows that [inaudible 00:26:47]. It was like, "Oh, I went to this really interesting seminar the other day," and we're like, "Great, you could have gone like five years ago,"..."
	Page 101 line 10- page 102, lines 1-2	"..her doctor at the [redacted] Hospital, um, we have to go and see him and we're like nervous, we was like oh what is he going to say, is it going to be psychological again.."
	Page 39, lines 2-4	"..because she'd always been like a sickly child, like up and down [redacted] all the time with like different, you know, gastro and things like that. "Well, you know, it's just the same old…" I was quite like blasé about it.."
	Page 101, lines 5-6	"..I could sit here and like cry every day, probably if I thought about like what could actually happen to her.."
	Page 37, lines 5-7	"..now it's better, our GP's really good. Um, like now [inaudible 00:27:03] that's fine, but like at the time, like it literally felt like your life was like never going to get better.."
	Page 22, lines 3-6	"..my relationship with my boyfriend at uni was quite strained because, um, he'd be like, "Look, I know you love her but like you can't keep fighting for her because it's not really your job." And at the time I was furious because everyone in my life kept telling me that.."
Importance of knowledge	Page 58, lines 5-11	"..it has changed the way I relate to people in terms of like I want to… I want to make sure that many people as possible know about how some young children in education… and it's, oh, like I wanted to tell all the teachers, you know, like this isn't where… like know about it and retain this knowledge because like this is probably going to happen again. Like you'll… maybe not TPN but like an NG tube, NJ tube, you need to be aware of this type of thing because the more support there is for EDS and like the longer people with gastro issues lives are being prolonged because their condition there had been understood, like there's probably more and more of this."

	Page 11, lines 3-7	"..So, she was taken into a psychiatric unit in [redacted], um, we knew before she went in there that she had EDS but we didn't have a choice in her going there. Um, so we—one of our friends sent pictures of Lauren to [redacted] and he then phoned my mum and we were like, oh, this must be like a hoax call, like why would [redacted] just randomly call her?.."
	Page 59, lines 2-4	"..I just want like awareness for like, um, artificial nutrition, I think it's something like that we're really able to do.."
	Page 57, line 9	"..I'm like no, like she's always have this issue, like I want you to be aware of it.."
	Page 57, line 10	"..Um, I really enjoy educating people about EDS.."
	Page 93, lines 7-9 - page 95, line 1	"..SN: Okay. And is there anything that you wish you would have known? J: Um, (pause) oh, that's hard. Knowing about what or like anything? SN: Um, about the condition. J: About the condition. It's-… SN: Or about having a sibling with this condition. J: Um, that like EDS can mean that you're on artificial nutrition, that I feel like a lot of it in the media is to do with like, um, I'm going to be a wheelchair user and like, like more… more joint stuff. But actually, like Lauren is like reliant on something that is like killing her liver, you know? Like that kind of thing is like madness for me to like understand. Like, I just like, cause I forget about, like I try to forget about it, I don't want to think about it all the time. But like, yeah, I feel like if you are prepared and you knew what TPN was, it would be like less of a shock when you learn like, oh god, like a line is something that gets pulled out and like could get air in it, like… you know, all the dangers of being like fed through a central line.."
	Page 46, lines 4-7	"..these conditions for me, at the back of my mind, mean that like I have to think about things differently with my sister, like you can't just jet set to New York for the weekend, like there's a lot of thinking to be done before that.."

	Page 54, lines 2-5 Page 35, lines 6-8 Page 33, line 8 Page 34, lines 1-3	"..unfortunately, a lot of the medic kind of said it was psychological. And if you don't know about the condition, like especially with mental health having seen the amount of respect these days and like you believe doctors, you'll think like, "Okay, I don't mind what she's got as long as it's getting treated.." "..And it's always, like especially in the beginning when we didn't have a diagnosis, you always just waited for them to like get the social workers involved and like, you know, all that kind of stuff.." "..we weren't like a typical textbook Munchausen's EDS situation.." "..I think just like people need to be like more aware of like artificial nutrition but I just think the like probably like the impact it has on like every part of your life..."
Participant's balance between their needs and others'	Page 83, lines 8-10- page 84, line 1 Page 44, lines 1-3 Page 73, lines 8-10 Page 44, lines 1-4 Page 55, lines 4-7	"..the thing that I was kind of struggling with at the moment is like how much I help my mum with stuff like… Um, I mean I couldn't help her that much that's why I'm struggling at the moment so I'm like, I'm worried—like, it's like a duty versus like selfishness.." "..I don't help mum as much as I could because I want to… I would like my own life, like that's something I—like it's been difficult to come to terms with that." "..Um, I don't feel like I could really help mum. Like I feel so bad that I don't feel like I could be in a position to like help at the time with my own like reasons." "..I don't help mum as much as I could because I want to… I would like my own life, like that's something I—like it's been difficult to come to terms with that. I feel guilty for saying it but like, I don't want it to be a situation where like every Wednesday I'm looking after Lauren, like I want some like freedom."

	Page 70, lines 7-10 – page 71, lines 1-3 Page 69, lines 10-11 – page 70, line 1 Page 75, lines 4-9 Page 40, lines 6-10 – page 41, lines 1-6 Page 92, lines 6-10 – page 93, lines 1-3	"..Like I want to help any way I can, like with school like it's such… like rewarding but it's also like you feel like it's your duty to be supportive in there, but at the same time like I, I completely agree with my dad and my boyfriend in like I need my own independence.." "..I don't want to get into a routine of helping and then feel guilty for leaving, because I shouldn't feel that guilt for leaving, like that's not a situation I want to get into because that affects my mental health, the guilt of going. Like you should just feel like, "Oh, you know, I'm going now, like I'll see you guys in a couple of weekend's time," and that'll stay with me like it shouldn't be like, "Oh god, can I leave this area, like if Mum wants to go to bingo on a Wednesday?".." "..I feel like maybe siblings who show their support are then like relied upon. I feel like such kind of awful for saying that.." "..SN: Thank you. And since she's had this condition, has it changed how you think about yourself? J: Um, (pause) I like… (pause) I am proud of myself for what I did at the time. Like, I literally got a degree at the same time that this was happening. So yeah, like in a weird way, like what happened kind of have boosted my own self-confidence because like I did uni, kept my boyfriend.." "..I remember going to the [redacted] Unit with mum to go for a visit, that's [inaudible 00:29:22], and I remember going with like a really positive attitude. I think partly because I was naïve, but also because I was like if I was gonna breakdown, mum's going to breakdown, so like I'd go in here, into this scary unit and like pretend I'm okay with it. And I was like, "Oh, look mum, like she might be enjoying this, here look they have this nice, they have a nice balcony at [redacted] [inaudible 00:29:42]. And then mum was just like okay with it but on the train back, she's like, "This is like horrible" um, and I was like, "Oh, right okay," and like my positivity has had no effect. Um, and I remember getting home, um, in my boyfriend's house and like just bursting into tears into his mum's arms and I was like, "This is just horrible, like I hate it.".."

	Page 105, lines 2-9	"..I feel like it's okay to change your opinion as well. Like also back then I was, "Oh, you know, why is everyone cross that I'm supporting mum, why is everyone thinking that I'm not living my life right by giving up things for my family? Whereas now I look at it with like a more balance view, and I feel like you shouldn't have to feel guilty about that. Like, like I shouldn't feel guilty about like not being there every single night and like that's fine, like you can live your own life, like learn what your balance is in terms of like just having a balance with like shopping and like being there for them."
	Page 43, line 11 – page 44, lines 1-4	"[SN:] .. And how is it—lastly, how is it been to talk to me about this? J: Like, one of the most positive experiences of like for a long time, like I actually feel like (pause) like I feel like I'd like piece my mind together by like putting it all out there. Um, and like it's really helped me particularly with like the guilt that I feel about not helping as much, like it taught me a few today kind of like justifying my reasons for that even though I still feel a bit guilty, like just like talking about it is really helpful. So, thank you."
	Page 81, lines 3-7	"..it's really hard for mum, but only like as I got older like selfishly, rightly or wrongly, I don't know, but I don't help mum as much as I could because I want to… I would like my own life, like that's something I—like it's been difficult to come to terms with that. I feel guilty for saying it but like, I don't want it to be a situation where like every Wednesday I'm looking after Lauren, like I want some like freedom.."
	Page 9, lines 7-9	"..I genuinely just live by the rule like just live every day. Like have a normal like life, don't try and like super exceed like expectations were like lived by other people's expectations because like that's just not—that's just like not a feasible way to live and I think you'll just constantly feel disappointed. Like if I didn't take Lauren to Florida Disney every summer I'd be like, "Oh, I failed.".."
	Page 22, lines 9-10 – page 23, line 1	"..in the beginning, I feel really guilty but like we just believe the doctors like for the first like couple of weeks anyway, because you do.."
	Page 60, lines 1-3	"..like looking back, if I'd have been here now thinking, "Oh, I didn't do everything I could have done," I think I would felt like, like guilt.."

		"..now, I don't think that has an impact like I'll see her when I can, like after work or after uni or whatever, but like now it's like now a lot more settled, I can have a lot more balanced life."
Participant's experience of support for self (mixed)	Page 63, lines 3-5 Page 68, lines 3-4 Page 25, lines 5-7 Page 65, lines 7-10 Page 105, lines 2-9 Page 67, lines 9-10 – page 68, line 1	"..my boyfriend, definitely like it caused some problems because I was like, it doesn't matter what you do, I'm never going to be able to forgive you for not supporting me during that time.." "Like, EDS UK have been like really, really helpful and I enjoyed working for them but obviously there's no like section of that like for me," "..like I didn't really get the support from the people in my life that like should have been there really. Um, like that thing about my boyfriend, um, and my dad as well.." "..Um, support for me? (Laughs), nothing. Like, (laughs) I think this is the most helpful thing I've ever done. Like talking this through right now, like I'm going to take this with me like (pause) for ages, like today has been so helpful for me, like [inaudible 00:50:22] it or like thinking about how it affects me." ".. And how is it—lastly, how is it been to talk to me about this? J: Like, one of the most positive experiences of like for a long time, like I actually feel like (pause) like I feel like I'd like piece my mind together by like putting it all out there. Um, and like it's really helped me particularly with like the guilt that I feel about not helping as much, like it taught me a few today kind of like justifying my reasons for that even though I still feel a bit guilty, like just like talking about it is really helpful. So, thank you." "..I feel like I wouldn't even know where to go, like what- what am I looking for, for support, you know what I mean?"

	Page 68, lines 3-5	"..EDS UK have been like really, really helpful and I enjoyed working for them but obviously there's no like section of that like for me. Um, (pause) yeah, I don't even know where to begin. Like it would be nice to like have a group going.."
The impact of participant's role with SWEDS changing over time	Page 33, lines 7-9	"..I think the lucky thing about our situation is that we weren't like a typical textbook Munchausen's EDS situation because I was so involved at that point.."
	Page 22, lines 5-7	"..if I'd have rested and like not thought about it for like a moment, like that's like letting my guard down about it, that's like…like letting them win, like I just wouldn't do that."
	Page 75, lines 7-9	"So yeah, like in a weird way, like what happened kind of have boosted my own self-confidence because like I did uni, kept my boyfriend, I mean, in life at the moment.."
	Page 18, lines 9-10 – page 19, lines 1-5	"..a lot of my energy went into saving her, or trying to anyway. So, I feel like that kind of—I'm happy about it because it brought us closer together, but I'm not happy about it because it kind of like added this extra dimension to a sibling relationship that I don't think really should be there. Like more of like a caregiver relationship, which kind of… I don't know, yeah, like… uh, I wasn't giving her care because we didn't have her at home, but kind of like fighting for her adds like extra pressure."
	Page 50, lines 9-10 – page 51, lines 1-2	"..I think like I couldn't say this to her, but she talks about it all the time, but I know that she's not probably going to live as long as I would like. So, you know, it's about… I don't think about that all the time but like, probably subconsciously that's why I like going to see her all the time or like do fun stuff.."
	Page 39, lines 7-10	"..that's when I really like started getting like invested in saving her because like, that's like six months and nothing had been done and she was like have her NG tube, NG tube like all of that and I was like, what's actually happening here, like no one's actually given us answers.."
	Page 18, lines 3-6	

	Page 76, lines 2-5	"..Like in the beginning, when she was in the hospital for all that time, like I feel like our relationship was (pause) opening up that extra dimension of me not just being a sibling, like I was like fighting for her as well.."
	Page 9, lines 5-7	"..when I look back and I kind of think like even though like I had all these things that's happened, like I overcame it and I know that like now I've been that strong, like I know I'm in a position to like be there for her again.."
	Page 38, lines 8-10 – page 39, lines 1-5	"..Like if you had Anorexia or Bulimia, like that wouldn't have affected our relationship at all, like I still wanted to be there in the same sort of capacity as before.."
	Page 50, lines 6-8	"..SN: Yeah. And what was it like for you to see her go through with this diagnosis? J: Um, (pause) in the beginning, because she was in [redacted] and I was in [redacted] at uni, I kind of like kept away from it for a bit because like for five weeks she'd been in hospital with this tonsil infection, um, and I don't think I visited her in that time because she'd always been like a sickly child, like up and down [redacted] all the time with like different, you know, gastro and things like that. "Well, you know, it's just the same old…" I was quite like blasé about it because like she had had that medical input for a while.."
	Page 104, lines 4-6	"..Um, but like I feel like because she's been so poorly, like I… you know, not just on Facebook but there's more pictures of her, there's more like… like I do put more energy into building a relationship with her.."
	Page 20, lines 8-10 – page 21, lines 1-4	"..I just wish like, uh, everyone could see like what she is and how amazing she is, like I just wish like everyone could like know Lauren, yeah.."
		"..I will help my mum out so she gets a break but also, like I don't want it to become like, "Oh, I'll do it Wednesday, Thursday, Friday," because then that moves me back into the other category. Like I want to be like… like we're best friends now she's older, you know, like we were watching Friends together, like we're going out like… Yeah, like I want it to stay like that because I want to carry on like the positive things that we built on when she was poorly and have like a normal sibling relationship, I guess."

	Page 52, lines 9-10 – page 53, lines 1-2	"..the role I have is just like aimed to just be like normal siblings even though I'd say we're a lot closer than other siblings might be, partly because of what's happened but also because it's always been like me, my mum and my sister.."
	Page 54, lines 1-3	"..Like a particular role, like I think just like… like we were so close and we say like we're each other's best friend. Um, well I would say we're just like best friends.."
	Page 54, lines 7-10 – page 55, line 1	"..SN: Yeah. Thank you. And what does this mean for you that, you know, that you are best friends and that you just want to be able to spend time with each other? What does that mean for you? J: Um, it's like the best thing ever because she literally gets me better than like anyone else.."
Participant and family's management of EDS	Page 94, lines 5-8	"..Lauren is like reliant on something that is like killing her liver, you know? Like that kind of thing is like madness for me to like understand. Like, I just like, cause I forget about, like I try to forget about it, I don't want to think about it all the time.."
	Page 68, line 9	"..obviously my mum, like she wants more freedom and that is fair enough.."
	Page 69, lines 9-11	"..mum's like, "Oh, I don't go out very often," and I'm like… and I feel bad about that but also like, I feel like maybe siblings who show their support are then like relied upon.."
	Page 50, lines 9-10 – page 51, lines 1-2	"..I know that she's not probably going to live as long as I would like. So, you know, it's about… I don't think about that all the time but like, probably subconsciously that's why I like going to see her all the time or like do fun stuff.."
	Page 101, lines 8-9	"..everyone has to kind of make it a positive. Like you can't live like thinking about like all the bad stuff that's happened.."

	Page 45, lines 6-7	"..everyone would like buy her stuff as if it would make her better, like me included.."
	Page 64, lines 5-9	"..I was speaking to Paul and I said like (pause) like, you know, when we're—when Lauren dies, which is probably unless I get hit by a bus, that I'm going to go to Lauren's funeral, like that's—that's going to be a thing like, and I said like I need to be ready for that as much as you need to be ready for that, and I need you to be there for me.."
	Page 81, lines 3-8	"..I genuinely just live by the rule like just live every day. Like have a normal like life, don't try and like super exceed like expectations were like lived by other people's expectations because like that's just not—that's just like not a feasible way to live and I think you'll just constantly feel disappointed. Like if I didn't take Lauren to Florida Disney every summer I'd be like, "Oh, I failed." Like, you know, like you just felt like finding that enjoyment in like every aspect of that.."
Participant's negative experiences of EDS	Page 66, line 7	"Like I was a grown-up, like I was 20, and it's still like it wasn't great, you know?"
	Page 41, lines 2-4	"..mum was just like okay with it but on the train back, she's like, "This is like horrible" um, and I was like, "Oh, right okay," and like my positivity has had no effect."
	Page 25, lines 4-7	"..the negative experiences that stand out, I definitely like how at the time, like I didn't really get the support from the people in my life that like should have been there really."
	Page 85, lines 9-10 – page 86, line 1	"..if ever I do her TPN, so like if I set up her like line and stuff like… I hate doing it because I'm like, I have to go to sleep not knowing if I've done this right, and if I'm asleep and like something goes wrong with her line, that's my fault."
	Page 25, lines 4-7	"..the negative experiences that stand out, I definitely like how at the time, like I didn't really get the support from the people in my life that like should have been there really."
	Page 27, lines 4-7	"..J: What—so the negative—that was the negative part I'd say. SN: (Laughs) That's right, (overlapping conversation).

		J: Like my relationship with my dad and boyfriend, like people around that were just like weren't as supportive as they could have been…"
	Page 101, lines 3-9	"..the condition itself is more like have a negative impact in my life than a positive one. But like, I think it's what you make of it. Like, yeah, I could sit here and like cry every day, probably if I thought about like what could actually happen to her. But then like, you know, like you can't live like that. Like I can't probably live like that, like that would be no kind of life for me, let alone anyone else in our family, so, like… like everyone has to kind of make it a positive. "
	Page 86, lines 8-10 – page 87, lines 1-4	"..with EDS, but I think the worst thing you can do is group them all together. That's what I've seen at the EDS support group and I just don't—like that's kind of one of the reasons that I stopped doing it because that became too stressful because… we're bringing everyone together doesn't mean they're going to get on, like it's not necessarily a support with it because it must be hindrance because we're hearing how other people's lives are going with the same condition and you're like, "My life isn't going like that, well, what am I doing wrong?".."
	Page 73, lines 6-7	"..mum was like, "Great! Like, I get a night off. Like, perfect!""
	Page 21, lines 7-10 – page 22, line 1	"..Yeah, so, I feel like when she's at hospital, the caring aspect was like this little teeny girl is being neglected, like she had her artificial nutrition taken away for a month so she got really poorly. Um, because they said, oh, you know, we're taking it away kind of thing so you just eat if you got hungry kind of thing. I think that was like a really, really terrible time.."
	Page 32, lines 3-4	"..So, she was taken into a psychiatric unit in [redacted], um, we knew before she went in there that she had EDS but we didn't have a choice in her going there.."
	Page 45, lines 9-10 – page 46, line 1	"..like seeing mum, like her sister, like my mum, so like stressed. Um, it wasn't a good time but I feel like now it's still pretty awful because like she's reliant on this thing that might kill her.."
	Page 9, line 3	

		"..it's hard to distinguish EDS and like normal life.."
	Page 50, lines 9-10	"..I know that she's not probably going to live as long as I would like.."
	Page 64, lines 6-8	"..when Lauren dies, which is probably unless I get hit by a bus, that I'm going to go to Lauren's funeral, like that's—that's going to be a thing like.."
	Page 12, lines 3-11 – page 13, line 1	"..when she was diagnosed, a lot of people said like my mum as well when she got interviewed on like [redacted] and stuff they're like, "Oh, was it an absolute sense of relief, like we're you kind of overjoyed, was it a positive experience when she got diagnosed," and it's like it's only positive in the fact that you're like, this is her ticket out of this like psychiatric unit. It's not like, "Oh, I'm overjoyed that she's ill." Like I think a lot of people like mixed up that question whenever—like journalists, whenever they asked mum about it and she's like, well no, like it was horrible because it's like, oh, like we're in a situation with the stuff and like (pause) there's no cure for this. Like at least with mental health, there are like structures of support whereas now, it's like, oh, it actually is true, yeah."
	Page 66, lines 4-10 – page 67, line 1	"..I think it's so hard because a lot of people think about like, oh, how are the younger siblings going to cope in terms of not getting the same attention? And I feel like that's as far as it goes, like knowing things about the impact on like… Like I was a grown-up, like I was 20, and it's still like it wasn't great, you know? Like, there needs to be like even if like someone gets diagnosed when they're 80 and they've got like an 82-year-old like brother, like there needs to be support, uh, there as well, like it needs to be like, like siblings need to be recognised as a category of people who are affected by it.."
	Page 43, lines 8-9	"..it's had an impact on my mum as well, like she has no life really.."
	Page 39, lines 2-4	"..she'd always been like a sickly child, like up and down [redacted] all the time with like different, you know, gastro and things like that. "Well, you know, it's just the same old…"
	Page 79, line 6	

		"..I might lose my best friend.."
	Page 42, line 1	
	Page 32, lines 5-7	"..when Lauren was poorly.."
		"..most people would go home on Friday and that's when they have meeting but obviously, we were still stuck there at the weekend.."
	Page 35, lines 1-6	
		"..I felt so bad but in the end I was just so tired of it that I just, I came home like—and I, like I could go like every couple of days like to work and stuff, but like I can't deal with that Friday afternoon anymore because it was just this plain rubbish every week. So, like that is like… because it was so, um, all the time like it was so every week, you know, this constant grind of these meetings, like that sticks to my mind a lot.."
	Page 37, lines 6-7	
		"..at the time, like it literally felt like your life was like never going to get better.."
	Page 82, lines 8-9	
		"..her being in hospital was like the worst time.."
	Page 15, lines 4-7	
		"..firstly, people didn't believe her, and also her medical notes were mixed in with somebody else's. So, she had, um, a girl from around like this area, her notes went in and she had like severe mental health problems so that kind of like integrated in with Lauren.."

Appendix L: Sample Analysis: Felicity

[redacted]

Appendix M: Instructions for Authors from Journal of Disability and Rehabilitation

Please continue to the next page

Disability and Rehabilitation

For editing support, including translation and language polishing, explore our Editing

This title utilises format-free submission. Authors may submit their paper in any scholarly format or layout. References can be in any style or format, so long as a consistent scholarly citation format is applied. For more detail see the format-free submission section below.

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Disability and Rehabilitation

- Systematic reviews, meta-analyses - PRISMA

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s); figures; figure captions (as a list).

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Disability and Rehabilitation

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Checklist: what to include

01/08/2024, 01:23 Submit to Disability and Rehabilitation

Disability and Rehabilitation

a manuscript should include their full name and affiliation on the cover page of the author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

2. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on writing your abstract.
3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. 5-8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
5. A feature of this journal is a boxed insert on **Implications for Rehabilitation**. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document. Below are examples:

Example 1: Leprosy

- Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.