

**Illuminating the Lived Experience of Chronically Ill Young
Women: A Narrative Study and Autoethnography into
Postural Orthostatic Tachycardia Syndrome and
Ehlers-Danlos Syndrome**

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*I declare that this thesis is a presentation of original work and I am the sole author.
This work has not previously been presented for an award at this, or any other,
University. All sources are acknowledged as References.*

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“Stories have to repair the damage that illness has done to the ill person’s sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations.”

*— Arthur W. Frank, **The Wounded Storyteller: Body, Illness, and Ethics***

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Abstract

This thesis examines the ways in which young chronically ill women narrate their chronic illness experience. Specifically, I sought to illuminate the lived experiences of women between the ages of 18 and 35 who had been diagnosed with Postural Orthostatic Tachycardia Syndrome (POTS) and/or Ehlers Danlos Syndrome (EDS). These chronic conditions are severely understudied and as such this research strove to address the gap in the literature and research surrounding these invisible illnesses. The research involved the use of in-depth, unstructured narrative interviews with twelve participants, who were encouraged to 'tell their story' of the ways in which being a chronically ill young woman has impacted their life. It was sought, in particular, to draw out topics such as when they first developed symptoms, how they negotiate their self identity in relation to their illness, and the process of obtaining a diagnosis and treatment. In order to illuminate the lived experiences of chronic illness, a narrative-based approach to data collection and analysis was taken, focusing in particular on collecting and analysing 'illness narratives' from participants (Kleinman, 1989). In summary, this study was able to gain a rich and detailed understanding of the lived experiences of chronic illness, drawing out emergent narrative themes of diagnostic journeys, gendered issues, stigma, invalidation, identity, and patient expertise from the data. This was aided by my narrative methodological approach as well as my own autoethnographic understandings of the topic which prompted me to undertake this research in the first place.

Abbreviations

ANS	Autonomic Nervous System
BPM	Beats Per Minute (used for measuring heart rate)
CFS	Chronic Fatigue Syndrome
EDS	Ehlers-Danlos Syndrome
hEDS	Ehlers-Danlos Syndrome (Hypermobile Type)
HSD	Hypermobility Spectrum Disorder
ICI	Invisible Chronic Illness
JHS	Joint Hypermobility Syndrome
ME	Myalgic Encephalomyelitis
POTS	Postural Orthostatic Tachycardia Syndrome

Terminology

Autonomic Nervous System	A division of the nervous system that controls automatic bodily functions such as heart rate, digestion, breathing, and temperature regulation.
Beighton Score	The 'gold standard' diagnostic test for hypermobility.
Dysautonomia	Dysfunction or disorder of the autonomic nervous system.
Hypermobility	Colloquially known as "double-jointedness"; joints which can stretch further than usual.
Subluxation	A partial dislocation of a joint, connective tissue, or organ. A common symptom of hEDS.
Tachycardia	An excessively rapid heart beat; a heart rate that exceeds 100 bpm (in an adult) when not engaging in exercise. Tachycardia can lead to fainting.
Tilt Table Test	The 'gold standard' diagnostic test for POTS.

Chapter I: Introduction

Understanding health, illness, disability, and medical interactions through a sociological framework is the basis of the sub-discipline of medical sociology, and the foundation upon which this research is based. Exploring the social factors that contribute to experiences of illness provides a broad scope of understanding to the ways in which patient's lives are impacted by the label of "ill" or "disabled". In this research, narratives of invisible chronic illness (ICIs) were explored; ICIs are described as "diseases that are characterised by chronicity and symptoms that are not externally manifested" (Donoghue and Siegel, 2002, p.4). In particular, the following research focuses on patient's experiences of obtaining a diagnosis for, and living with, Postural Orthostatic Tachycardia Syndrome (POTS) and Ehlers-Danlos Syndrome (EDS). POTS is characterised by an abnormal increase of heart rate upon standing, causing symptoms such as lightheadedness and palpitations (British Heart Foundation, 2023). EDS refers to a group of inheritable connective tissue disorders; The EDS type referred to most commonly throughout this thesis is hypermobile Ehlers-Danlos Syndrome (hEDS). This is the type of EDS most frequently related to POTS and is characterised by abnormal joint and tissue laxity and instability leading to issues such as subluxations and dislocations (ehlers-danlos.org, 2023). These chronic health conditions are often comorbid and are suspected to be causally linked to each other, as will be discussed in Section 2.1. Furthermore, these two conditions predominantly affect women and as such, questions of gender and the ways in which womanhood interacts with healthcare are central to this thesis. My research will focus on "illness narratives". Kleinman (1988, p.49) refers to an illness narrative as a "story the patient tells [...] to give coherence to the distinctive events and long-term course of suffering" which not only reflects the experience of an illness but also reflects the person's experience of social life as a whole. Kleinman, therefore, argues that it is vital for doctors to listen to the patient's illness narrative in order to fully understand their experience and "take heed of the lay person's story" (Nettleton, 2013, p.74).

Furthermore, I contend that sociological and psychological research into health and illness related issues has often been predominantly conducted by people who do not themselves have the illness or condition they are writing about. In my view this de-centres the lived experiences, feelings, and suggestions of patients that are essential to making significant and necessary changes to the way in which many health issues are studied, treated, diagnosed, and perceived by society as a whole which leads me on to the motivations for conducting this research.

1.1. Motivations for the Research and Autoethnography

When introducing this topic it is important to state my motivations for undertaking this project. I sought to explore and illuminate the experiences of being a chronically ill young woman with POTS and/or EDS for a variety of reasons. Autoethnography is defined by Ellis et al (2011) as the study of the self through analysis of lived experience. In the tradition of autoethnography, my own identity and lived experiences have contributed to the framing of the research aims I sought to explore, as well as influencing the lens through which I conducted my research.

Why POTS and EDS?

Firstly, before embarking on the main body of the thesis, it is contextually necessary to reflect upon my own situatedness to this research and to self-disclose my own 'illness narrative', as without my own lived experience of chronic illness I may not have even been aware that POTS and EDS existed and certainly would not have understood the magnitude of the lack of support, understanding, and knowledge regarding these conditions. As a child I was diagnosed with scoliosis and joint hypermobility syndrome, but after being monitored until puberty to make sure the curvature of my spine did not worsen considerably enough to necessitate surgical intervention, I was discharged from orthopaedic care. No link was ever

made or queried between the severe anxiety I suffered with throughout my childhood and any joint problems I had. During adolescence, anxiety, panic attacks, depression, fatigue, frequent vomiting, and feelings of dizziness and faintness worsened. These symptoms were attributed solely to the typical issues of a teenage girl: hormonal changes, anaemia, and anxiety. I was also referred to physiotherapy for joint pain, especially in my knees, that was labelled as 'growing pains'. Therefore, I did not consider myself 'chronically ill' for most of my life, but merely someone who was overly sensitive, and who had less stamina than others my age. However, despite being told on numerous occasions throughout the years that there was nothing 'really' wrong with me, I knew, on some level, that the way I felt wasn't normal, that my body and my experiences in that body were not 'normal'. I began to realise I was unsatisfied with not having answers about *why* I was often in pain, and *why* I was frequently sick or feeling faint and exhausted. After months of internet research I self-diagnosed my own case of POTS and subsequently realised that I have hEDS too (indeed, some medical professionals would consider my childhood diagnosis of JHS as the same condition as hEDS (Tinkle *et al.*, 2017)). The interconnectedness between these two conditions began to make my body, and my life as a whole 'make sense' (Frank, 2013). Once I had received my official diagnosis of POTS via a tilt table test I joined support groups online and was struck by how 'typical' my experience was. Negative experiences I had had with doctors, issues of misdiagnosis and misogyny, and mental health struggles after years of confusion and frustration, were not unique to me, but present as thematic narratives across the population of the groups, prompting me to think about utilising my own lived experiences and my 'insider status' (Merton, 1972) to conduct sociological research into these conditions.

Additionally, there is very little research and understanding about these chronic conditions in particular. A lack of awareness and knowledge regarding POTS and EDS can be observed in the general biomedical literature, let alone in sociological study. Not only have most people I have spoken to never heard of these conditions, but medical professionals have not either. During my own diagnostic process, it was striking to me to have to explain to my GP

what POTS was and why I thought I needed to be tested for it - I was not a medical student or doctor myself, but a lay person who had been desperately searching for answers about my own health for years. Yet I was in a position where suddenly I was the expert in the situation, explaining concepts such as tilt table tests to a doctor and trying to convince them that my standing heart rate was not normal. One may presume, then, that such a condition is extremely rare; however, the true or exact prevalence of POTS sufferers remains unknown (in part due to lack of physician knowledge and thus diagnosis). Vernino et al. (2021, p.3), however, claim their estimates based on experience from autonomic centres show that “it is clear that POTS is one of the most common forms of autonomic dysfunction.”

Indeed, it is noted that there are significant gaps and deficits in understandings of POTS, resulting in a paucity of information and evidence that could be used to inform treatment for patients, often leading to “suboptimal care for this patient population” (Vernino *et al.*, 2021, p.3) Furthermore, it is asserted that “the vast majority of physicians have minimal to no familiarity or training in the assessment and management of POTS” and that funding for research into this condition “remains very low relative to the size of the patient population and impact of the syndrome.” (*ibid.*) My own cardiologist Dr. Sanjay Gupta, states in his blog that although POTS was first recognised in medical journals 30 years ago, in 1993, many medical professionals are still unaware of the condition. He asserts that the process of attempting to obtain the correct diagnosis can be lengthy and frustrating due to patients often being “misdiagnosed with other conditions such as anxiety and depression [...] and chronic fatigue syndrome” (Gupta, 2018). In my own experience this was certainly true, and was echoed throughout the narratives that were gathered through interviews with the participants in this study, becoming a central theme to the story of a ‘typical’ POTS/EDS illness narrative. The associations between POTS and HSD/hEDS, as well as with various other comorbidities such as allergic and autoimmune disorders have been clearly described, showing that patients with these problems need to be treated in a holistic, broader clinical context (Vernino *et al.*, 2021). Additionally, with such a lack of awareness and knowledge

about these associations, patients are largely failing to be appropriately monitored or tested for co-morbidities, leading perhaps, I argue, to an even greater sense of confusion and frustration for patients who have unexplained symptoms from multiple, interacting conditions.

1.2. Aims and Objectives of the Study

Following on from my motivations for conducting sociological research into the lived experiences of young women with POTS and/or EDS, I will now reiterate and refine the aims and objectives of this study. In broad terms, the primary aim of this research is to highlight the ways in which young women make sense of and describe their lived experiences of chronic illness. The purpose of this study is, in particular, to address the significant gaps in literature and research that are present when exploring the conditions of POTS and EDS; as well as hoping to highlight the issues of a lack of awareness and understanding surrounding 'low-status' conditions (Album, 1991). Through interviewing young women between the ages of 18-35 who suffer with one or both of these conditions, and by using my own autoethnographic experiences, this research seeks to illuminate the issues that females, in particular, face when attempting to obtain diagnoses and treatment for ICIs. The objectives of the research are thus:

- To make sense of and reclaim the narrative of chronic illness from the patient's point of view.
- To explore patient-centred approaches to chronic illness diagnoses and treatments and advocate for changes to be made to the way in which young women with chronic conditions are perceived by healthcare professionals.
- To illuminate the lived experiences of invisible illness/disability.

1.3. Structure of the Thesis

This thesis will begin with a literature review exploring the range of studies and theories that have been posited around the topic of women's experiences of illness and sociological inquiry into illness narratives, as well as addressing the potential gaps that my research aims to illuminate. A chapter on the methodological aspect of this study will outline the ways in which I designed and carried out the research; this includes the methods of data collection and analysis, the participant recruitment process, and ethical considerations. Next, the analysis and discussion of findings will be split into three separate chapters relating to the three narrative themes that emerged from the interviews I conducted - these chapters are:

- Narrative 1: The Ghost Story - Invisible Illness
- Narrative 2: The Myth of the Hysterical Woman - Gendered Issues
- Narrative 3: The Diagnostic Odyssey - The Journey to Diagnosis

Due to the large volume of data and the way in which I sought to weave autoethnographic elements of analysis into the exploration of participant's illness narratives, splitting the findings into individual narrative-focused chapters seemed most fitting. Within these analysis chapters, content is split up into smaller thematic elements of the narrative types in order to explore these ideas in detail. Finally, a conclusion chapter will outline the findings and results of this study, reviewing the research aims, and reflecting upon the potential for future research and recommendations in relation to the findings.

Chapter II: Literature Review

This literature review aims to outline existing information regarding POTS and EDS in order to provide wider medical context for this study. It also intends to highlight existing sociological research in the area of chronic illness, gender, and illness narratives. Finally, the debate of the value of 'subjective' sociological methods such as autoethnography and narrative interviews will be considered.

2.1. POTS and EDS: What Do We Know?

When reviewing relevant literature to this topic, it is first important to provide a general biomedical definition of the conditions that this study focuses on and to briefly outline the ways in which they affect the body to provide a better understanding of the conditions being written about.

Biomedical Definitions

POTS is a form of dysautonomia - dysfunction of the autonomic nervous system - which is characterised primarily by an abnormal increase in heart rate upon adopting an upright position. Symptoms also always include dizziness, lightheadedness, and feeling faint upon standing (Stewart, 2004). A positive POTS diagnosis was first defined by Low et al. (1993) as a heart rate increase of more than 30 beats per minute and/or a heart rate that increases to over 120 bpm within the first ten minutes of standing from a supine position. Anderson et al. (2014) note that additional symptoms such as chronic fatigue and difficulty concentrating, as well as a high instance of symptoms of depression, elevated anxiety levels, and anxiety sensitivity are commonly presented by patients with POTS, leading to a poorer overall quality of life in both mental and physical ways.

Ehlers-Danlos Syndrome (EDS) (Hypermobility type) is a hereditary connective tissue disorder that is often identified as a clinical phenotype in patients with dysautonomia, with POTS being highlighted as the most prevalent “autonomic profile” for these patients (Tinkle et al, 2017 p.56). EDS can be characterised by a range of symptoms but complaints are largely musculoskeletal in nature, such as pain from joint hypermobility, scoliosis and kyphosis, regular subluxations and dislocations of joints and other soft tissue and skin issues. Many EDS patients experience “activity related pain” and go on to have chronic pain and fatigue issues as a result (Tinkle et al., 2017, p. 48).

Links between POTS & EDS

In explaining why I have chosen to focus on POTS and EDS in terms of my sample of participants, it is first necessary to acknowledge the strong link between the two conditions. Vernino et al. (2021, p.3) state that although there are “well-established clinical associations” between a diagnosis of Ehlers-Danlos Syndrome (hypermobile type) and Postural Orthostatic Tachycardia Syndrome, a precise prevalence of this co-morbidity is currently unknown due to a lack of biomedical research into these conditions.

To further explain the pathology of POTS, it is important to note that Urich and Hartung (2015) assert that POTS can generally be classified as either ‘primary’ or ‘secondary’. Secondary POTS usually presents after (and is therefore thought to be caused by) a viral illness or autoimmune condition such as COVID-19, Lyme disease, and Lupus. Primary POTS, on the other hand, is more likely to be idiopathic in nature, present for most of, if not all, of the patient's life and can be divided into ‘partial dysautonomia’ and ‘hyperadrenergic’ (Urich & Hartung, 2015, p.109). Grubb et al. (2006) described three types of partial dysautonomia: post-viral, developmental, and other. Although more research is needed, it appears as though Joint Hypermobility Syndrome (JHS), (which is often used interchangeably with Hypermobile Ehlers-Danlos Syndrome) can be a potential cause of POTS. This is due to joint hypermobility causing an “abnormal elasticity in the cardiovascular connective tissue” which in turn results in excess venous blood pooling which causes the body to compensate with tachycardia (Grubb et al., 2006).

Gendered Nature of the Conditions

It is important to state that the vast majority of patients diagnosed with POTS are young women (Stewart, 2004). Raj (2006) notes the female to male ratio of POTS to be 4:1, whilst Grubb (2008, p.2815) estimates “a roughly 5:1 female to male ratio exists”. Similarly, and unsurprisingly due to the co-morbid nature of the conditions, EDS patients have also been

identified as predominantly female young adults with Castori et al. (2010, p.2406) naming EDS as a syndrome with an “excess of affected females” despite the expectation that a genetic disorder would proportionally affect an equal number of females and males. Castori et al. (*ibid.*) cite that around 89% of EDS patients are female and around 11% male but note that despite this gender bias being well recognised and widely known within clinical practice “the mechanisms underlying this female preponderance have not been well studied.”

2.2 Gendered Conditions - Women as an ‘absent subject’

In light of these conditions being clearly gendered, and being a young woman myself, my research will therefore be focused on female POTS and EDS patients who are between the ages of 18 and 35 and the experiences that they have had in regards to interactions with medical professionals, their feelings surrounding diagnostic labels, and the ways in which they ‘make sense’ of their experiences of living with ICIs, and their illness narrative as a whole.

Towards a Feminism of Chronic Illness

Taking a feminist approach to this study, women as an ‘absent subject’ in research (especially disability research) is described by Dorothy Smith (1988) as the way in which research produces ‘alienated knowledge’. Morris (1992, p.158) identifies that “women have previously experienced research as alienation” too in the sense that they are alienated “from the product of research, from the research process, from other research subjects, and from one’s self” (*ibid.*) Furthermore, Morris (1992, p.159) argues that biomedical models of disability research in particular are modes of research that often fail to account for or make space for the absent subject. She goes on to state that such models can be viewed as analytical tools which are the product of theory and research which “treats us as objects”.

Smith (1988, p.107) notes that feminist research is characterised by a method which creates space for an absent subject and an absent experience “at the outset of inquiry”; a type of research that is “to be filled with the presence and spoken experience of actual women speaking of and in the actualities of their everyday worlds” (p.107). Additionally, Morris (1992) seeks to identify the ways in which knowledge can be produced in an ‘unalienated’ way through a feminist approach to disability research. She highlights the importance of the researcher ensuring to ground themselves as a “non-disabled person holding certain cultural assumptions about disability” wherein there is the context of “an unequal relationship between non-disabled people and disabled people” (Morris, 1992, p. 159).

Therefore, when researching disabled and chronically ill women, it is necessary to address these issues with a feminist approach so as to produce research that does not simply approach chronically ill women as ‘subjects’ of a sociological inquiry but as equal to the researcher. This disconnect between the people who are the subject of research and the people who are researching them is something that I aim to confront within my own research and as such I think it is invaluable for people to conduct research into their own lived experiences (in this case I am conducting research into my own disability, as well as that of others) that may otherwise be absent from the discourse.

Following on from this, Moss and Dyck (2003, p.9) propose a ‘radical body politics’, created through their research into women with chronic illnesses. For Moss and Dyck, this radical body politics is useful for analysing and illuminating issues surrounding power and identity within women’s experiences of chronic illness and disability. This is done by focusing on the “discursive and material aspects of the body” in order to see how women negotiate and mediate in different spaces (2003, p. 9). For example, by considering the ways in which chronically ill women must reconstruct an ‘ill identity’ and come to terms with the way in which their body is limited when moving through space, we can explore theories of bodies and illness, gender, power, and identity within society. However, Moss and Dyck (2003)

highlight that it is integral to retain the knowledge that when discussing these theories and analysing the experiences of chronically ill women we are speaking about real women's bodies and lives. In my research I aim to remain cognisant of these issues and to highlight the fact that whilst theoretical discourse, feminist analysis, and a 'radical body politics' can be useful tools for understanding these issues, the main focus must be on the real lived experiences of chronically ill women.

Furthering this idea of a radical body politics, and building upon a social constructionist approach, Lupton (2000) states that "a body that does not function normally or appear 'normal' [...] is both visually and conceptually out of place" (p.38). This raises an interesting point of contention and perhaps a gap in the literature that I hope to address regarding the lived experience of people who suffer from 'invisible' illnesses; how do people who are still 'conceptually out of place' but not 'visually' out of place navigate their identity within society? When you do have a non-normative body, but you do not appear externally as if you do, how then, do you negotiate the experience of being both non-normative and 'normal' at the same time? Whilst initially it may seem desirable to appear 'normative' and to be able to function in society without being automatically labelled as 'out of place' or 'abnormal' this in itself can cause complex and difficult issues for chronically ill young women in particular.

In part these difficulties can be related to the performative gender roles and the ways in which women's bodies are intrinsically tied to prewritten 'cultural scripts' that inform our gendered identities within society (Butler, 1990). These cultural scripts and the binary nature of having to 'perform' gender in socially acceptable ways relates to pervasive dualisms within Western societies and, in particular, how one side of the dualism tends to hold more value than the other - for example, "man over woman" and "health over illness" (Moss & Dyck, 2003, p.13). Recognising this helps to problematise the way that binaries traditionally have been used in relation to health, illness, and bodies. Furthermore, an 'either/or' perspective of

health and illness leaves no room for the idea that bodies can exist as “both abled and disabled, healthy and ill, normal and deviant.” (*ibid.*)

This is particularly relevant to chronic conditions and invisible illnesses and when considering labelling people as ‘healthy’ or ‘ill’, as often such illnesses fluctuate in severity and the impact they have on people’s bodies and lives. Regarding POTS and EDS specifically, from my own experience I am aware that it is possible to fluctuate between feeling ‘healthy’ and ‘ill’ or ‘able-bodied’ and ‘disabled’ within the course of just one day and as such it is important to remember this when discussing theories of chronic illness and disability. In my research I aim to evaluate and illuminate the implications of the ways in which these oftentimes uncategorisable states of the body exist within society and how chronically ill women then have to negotiate spaces within everyday life that expect them to fit into a binary.

Ideas of gender binarism, binary thinking in society regarding health and illness, and expectations of women can be linked to further literature detailing the binary rhetoric of ‘giving in to’ or ‘overcoming’ an illness or disability.

Linton (1998, p.18) explains that the idea of ‘overcoming’ disability or illness is not one that has been created inside the disability community. Instead it is a rhetoric produced within wider society that it is possible for an individual who simply works hard enough to ‘overcome’ and triumph over their condition. Linton’s (1998) research suggests that the internalisation of this social narrative leads to chronically ill and disabled people having to live with a similar kind of burden to the role that feminists have identified in the ‘super mom’ narrative. This describes the social expectation that women should be able to overcome and triumph over the challenges of motherhood without complaint, similar to how disabled and chronically ill people are expected to function within society.

Furthermore, when thinking about binaries, my research aims to address a potential gap in the literature relating to the ways in which POTS and EDS specifically are primarily fluctuating, invisible illnesses. I posit the question: when you are not temporarily ill *or* permanently disabled, where do you fit within a society that appears to currently be only set up to cater for the binaries of 'ill' or 'healthy' and 'able-bodied' or 'disabled'? I argue that especially for young women with 'invisible illnesses' (such as POTS and EDS) who look healthy and 'normal' due to the physical perception of their bodies not looking 'out of place', and their youth presupposing health is especially difficult to navigate as there is often no acknowledgement from the government, healthcare professionals, employers, and even friends or family that they exist as a chronically ill person and that their illness experience is valid and real.

Women's experience of healthcare

Following on from this, it may be argued that if you do not 'look' disabled or ill then it becomes much more difficult to access support, both informal and formal. However, a gendered aspect perhaps makes this lived experience of chronic invisible illness even more challenging for women in particular. Many women who suffer from invisible illnesses feel that they have to 'convince' people around them, including doctors, to believe them when they say they are ill. In fact, studies have shown that women are three times more likely than men to be given diagnoses of medically unexplained symptoms (MUS) (Schaefer et al., 2012). Risberg et al. (2009) observe that there is a possibility that is due to a gender bias from medical professionals, wherein similar or the same symptoms are viewed as 'unexplained' or 'medically explained' depending upon the gender of the patient. To add to these injustices that women with MUS are subject to, we can also consider the conceptual idea of "testimonial injustice" wherein ill people are often regarded as unreliable narrators in terms of cognition, emotions, and objectivity. In this sense, I argue that chronically ill young women face a dual injustice - they are invalidated and their narratives perhaps treated as less reliable by the very fact that they are ill and by the fact of their gender and age.

2.3. The Expert Patient

In light of the ways in which ill people have been historically excluded from speaking with legitimacy on the topic of their own illnesses (Fricker, 2007), the concept of the 'expert patient' is one that my research seeks to explore. The term was first introduced in 2000 by the UK's Department of Health, with an aim of encouraging "user led self-management" for NHS patients with chronic illness (Tattersall, 2002, p.227). Although this concept initially started as a policy decision for the NHS, the term 'expert patient' has since been useful to apply to sociological studies of chronic illness. Timmerman and Haas (2008, p.661), for example assert that an important part of the doctor-patient relationship to consider in sociological study is the tension between the value placed upon different modes of knowledge: experiential self-knowledge from the patient vs. the doctor's impersonal clinical knowledge.

2.4. Narrative interviews and Autoethnography

For Sarbin (1986), narrative research is based primarily upon the fundamental idea that people understand their lives and experiences through "storied forms", meaning that life events are connected by a 'plot' that has a beginning, a middle, and an end. Harwood & Eaves (2017) raise the question "Can one's own experiences be construed as good research material?". I believe, as a methodology, autoethnographic research has the unique ability to capture a complex reality, where the researcher can fully and deeply reflect on and seek to understand the meanings, thoughts, and emotions behind their own social experiences (in this case, experience of chronic illness). The observation of self and reflection on one's own experience is argued to provide "deep reflective, emergent, and generative insights," (Harwood & Eaves, 2017, p1) . Furthermore, it is noted by Liggins et al. (2013) that multiple perspectives of an individual's experiences can be reconciled by autoethnography - for example, if you are simultaneously a user of healthcare services and a scholar of them, can serve to help the researcher make sense of lived concepts in a complex and nuanced way. It can also be argued that autoethnography can be used as a tool to

provide diverse perspectives in health research and to capture voices and data that would otherwise be unheard, by giving voice to the experiences of patients (Rier, 2000). I unavoidably become part of the study; my *self* becomes part of the subject. As my own lived experiences influence the ways in which I may interpret participants narratives and upon which themes I was most drawn to when critically analysing the data. However, rather than seeing this situatedness as a limitation of the study, my objective is to focus on the value that can be placed in 'subjective' experiences and narratives. This debate will be further explored in the literature review chapter, wherein I will describe in more depth the pros and cons of the subjectivity associated with narrative inquiry. Furthermore, in Chapter III: Methodology, I will further discuss the reflexive process of incorporating autoethnography into this research.

Storied forms and Meaning Making

Josselson and Hammack (2021) highlight that the importance of narrative analysis lies in its capacity to show how "individuals position themselves in their worlds and make sense of themselves through stories" (Josselson & Hammack, 2021, p.5). However, it is important to note that although the meaning-making process can be something that is sought by people who are telling a narrative of their illness, these constructions of the self and understandings of lived experience are often 'negotiated settlements' that are fragile and temporary (Scambler, 2018). Furthermore, with chronic illness there is perhaps no perceived 'end' to the illness narrative. Unlike diseases such as cancer where there is a clear goal of undergoing treatment until the illness is in remission, the tumour is removed, or the 'battle' is over, with chronic conditions there is often no clear conclusion to the storied form of the illness experience.

In addition, it is important to recognise that the storied forms that illness narratives take are likely to be gendered. Hammack and Toolis (2019) highlight that all stories and narratives are the product of the culture or society in which they were created. In particular, stories that we tell about our own lives and narratives that we construct to make sense of our own identities

are always embedded within a particular culture and “emulate variations of pre-existing circulating narratives that are constrained by social expectations”. (2019, p.465)

Therefore, similarly to how Butler’s (1990; 1996) theories of performative gender are useful to keep in mind whilst conducting my research, it is also necessary to acknowledge that no storied forms can ever be completely independent from the social, cultural and gendered expectations that have influenced them and that no negotiated settlements for chronically ill young women will be uninfluenced by these factors.

Therefore, it is important to note that my research needs to be specifically situated within the framework of *chronic* illness narratives, as these differ substantially to illness narratives of acute disease or injury. When you have no way to remove the label of ‘ill’ from yourself, how do you cope with being implicitly ‘deviant’ and out of place in society? When there is no ‘beginning, middle, and end’ of the illness ‘plot’ (Sarbin, 1986) in our lives, how do we then construct a narrative that makes sense to us? How do we connect and make sense of our lives into storied forms if the experience of chronic illness does not have an envisioned end point? As such, I believe that the usual abnormality of ‘illness’ for most people in society becomes the normal state of being for chronically ill people. However, there is a conflict with this negotiated understanding of illness as the norm for people with chronic conditions as to other healthy, able-bodied people in society, our bodies and life experiences may be seen as ‘abnormal’. Kleinman (1988) suggests that by using the concepts of ‘illness’ and ‘disease’ somewhat interchangeably, biomedical practitioners are losing “something essential to the experience of chronic illness” (p.6). He goes on to discuss the problems with medical treatment and intervention that is decided upon and assessed “solely through the rhetoric of improvement in disease processes” (ibid.). For Kleinman, this becomes a source of conflict, internally and externally, for chronically ill patients who cannot be cured, and have to continue to co-exist with their illness, resulting in an identity that is disembodied from the self.

The Subjective as Valuable

When reviewing debates on the use of illness narratives, Thomas (2010) sheds light on the clash between poststructuralist and ‘traditional sociological’ methodologies in particular. She states that in general, post-structural methodologies place emphasis upon values such as reflexivity, empathy and ethical actions, whilst the traditional sociological methodologies such as surveys or semi-structured interviews are more commonly viewed as positivist and treating “illness narratives as social facts to be interpreted” (p.655). My research aims to take narrative analysis and autoethnography as a poststructural form wherein I can build reflexivity and empathy into rigorous and valuable, rich data.

Furthermore, Anderson and Bury (1998) observed that many broad medical and health related studies relating to long-term conditions and chronic illnesses often neglect (or exclude altogether) the subjective lived experiences of the patient in favour of placing emphasis on the traditionally more valuable and important empirical data of the objective observations of the biomedical profession. However there are a number of scholars who argue that ‘subjective’ data is not inherently less valuable than ‘objective’ data, despite the somewhat contentious nature of this view point.

Additionally, drawing upon theorists such as Mishler (1986) is useful for my aim of collecting interview data that highlights the value of the subjectivity of a participant’s narrative - Mishler’s (1986) work conveys the importance of aiming to resituate sociological research interviews to focusing more heavily on respondents’ or participants’ problems rather than the researcher’s problems (for example “technical issues of reliability and validity”). In particular, Mishler calls for us to shift the focus onto the way in which participants aim to “construct coherent and reasonable worlds of meaning to make sense of their experiences” (1986, p.118). This ‘meaning-making’ and construction of understanding one’s own lived experience is what my research will primarily focus on. I believe that the conventional approaches that a

lot of interdisciplinary research into health and illness is based upon is fundamentally dehumanising and disembodied from the real lived experiences of people who are chronically ill. Additionally, I aim to challenge the idea that subjectivity, stories, and qualitative, personal narrative data is less valuable in terms of sociological research than technical, quantitative, and 'objective' measures of social and medical interactions.

III People vs. Patients

Atkinson (1997) openly questioned the legitimacy of early illness narrative work conducted by various scholars including Kleinman (1988) and Frank (1997). His criticisms drew upon the way in which he perceived illness narrative work to have goals that are "therapeutic rather than analytic" (Atkinson, 1997, p.335), and the way in which he viewed Kleinman (1988) as being "at heart a storyteller rather than a story analyst" and Frank (1997) as "inspired more by ethical than methodological preoccupations" (Atkinson, 1997, p.338). Within my research I take issue with Atkinson's derisions of subjective "storytelling" - this thesis aims to illuminate the value and importance of allowing marginalised narratives to be heard, explored, and taken seriously. The distinction between 'patients' and 'ill people' is, Frank notes, a crucial point that Atkinson's standpoint excludes, and a point that my research aims to address. My participants in this study are not "medical subjects" or "patients" but simply young women who have experiences of chronic illness.

'Ethics as first' Sociology & Making the Ill Hearable

A further point that Frank (2013, p.355) makes, and one that is important to the aims of this thesis is that we should, especially in medical sociology, be aiming for an "ethics as first sociology" where methodological rigour is essential but where "to afford priority to the methodological is to risk becoming one of the specialists without spirit" (*ibid.*).

It can be argued that Frank's 'ethics as first sociology' approach provides an explanation for the exclusion of medical professionals' voices in sociological illness research. Biomedical voices and perspectives are not excluded because doctors do not have stories to tell that deserve attention but because Frank is specifically interested in how ill people narrate their own experiences. This, too, is the focus of my research and the reason why I am only interviewing people who are chronically ill and not their loved ones, carers, or medical professionals. Furthermore, it is argued along with Frank, that the presence of dominant medical voices in illness research have the potential to "relegate ill people to patienthood and render their stories into fragments of a larger medical story", thereby missing the individual lived experiences of patients in research (Frank, 2013, p.360) and failing to "[make] the ill hearable".

Chapter III: Research Methodology

In order to illuminate the lived experiences of chronic illness, I took a narrative-based approach to data collection, focusing in particular on collecting 'illness narratives' from participants (Kleinman, 1988). I recruited twelve participants who fitted my desired sample criteria, as later described. Ten of these opted to convey their narrative through one-to-one interviews, with the remaining two participants opting to provide written accounts instead.

Specifically, in this chapter I will outline the research design and philosophy that contributed to the way in which I collected and analysed my data before outlining the theoretical frameworks that have been the lens through which I have interpreted and collected the data, as well as the framing of the research question. Additionally, a motivation for my research was my own experience of being a young woman with POTS and EDS, a factor that has influenced my methodological approach, which will be explored reflexively in this and other

chapters. Therefore, it is necessary for me to briefly reflect upon my situatedness within the research in terms of my 'insider status' (Berger, 2015). Following this, the participant recruitment and ethical considerations of conducting this research in a practical sense will be explored. Lastly, I will discuss data analysis itself and the methodologies used to collate my data and conduct narrative analysis of the illness narratives I gathered.

3.1. Research Design & Philosophy

Due to the complex nature of health and illness within society, both qualitative and quantitative methods are useful for answering questions about this topic at a range of levels. Additionally, qualitative approaches are particularly applicable to studying concepts, behaviours, and attitudes. My study is focused on individual's lived experiences and their own understandings of their lives as chronically ill young women and as such in order to illuminate the complex and nuanced issues of this topic in detail, narrative interviews were the most appropriate form of qualitative research for me to address my research objectives.

It is important to note that narrative analysis requires the presupposition that the social experiences of people are cultivated into storied forms (Ochberg, 1994). As such, the role of the researcher when gathering narratives from participants is not to collect uniform, structured datasets from participants, but to compile their individual stories in as much detail as possible with as little interference as possible (Josselson & Hammack, 2021, p.9). Therefore when using this approach, I had to anticipate some variety in the length, content, and structure of narratives gathered. However, all narratives should share the commonality that they are rich, long-form, and detailed enough to allow for in-depth hermeneutic analysis. Additionally, narrative research and analysis was useful for my study in particular since its approach to data collection and interpretation centres on an 'idiographic' or person-centred, holistic methodology, rather than a variable-centred or 'nomothetic' one (Hammack & Toolis, 2019). As Josselson and Hammack (2021) assert, idiographic data analysis allows for

research to be “concerned with particularity and diversity in human experience” (p.9) which I believe applies appropriately to a research project focused on subjective lived experiences of a complex and diverse problem such as chronic illness and disability.

Due to the design of my study, I was able to speak at length and in depth with participants about their lived experiences through the use of narrative interviews. As such, the use of unstructured narrative interviews allowed me to ask the participants for their general illness ‘story’ or narrative of how they got their POTS and/or EDS diagnosis, which was the foundation of my study. Throughout the process of the interviews I felt that it was important to be actively listening in the discussion with the participants as much as possible so as to build rapport and trust whilst they were divulging personal stories to me. Therefore, I did not want to be constantly referring to a structured interview guide or a set of questions, or to be writing down notes whilst they were talking. Although I had general topics and broad questions in mind - such as “diagnosis”, “family”, “mental health” - these were used to prompt me if needed. This lack of a specific set of questions allowed me as the researcher, and the participants themselves, the freedom to explore any questions, ideas, or experiences that may unexpectedly arise in the course of our conversation. This was especially helpful because I wanted my data collection to be as organic and inductive as possible in order for narrative themes to emerge from the data, and to allow room for ideas and issues that I may not have considered.

This approach was effective in producing a large amount of data from participants, with no interview lasting less than an hour, and most taking around two hours to complete. Additionally, the two written narrative accounts were detailed and rich accounts of several pages in length. Due to the nature of the topic being studied and the way in which participants would be talking about experiences surrounding their own illness, I was conscious that some might have anxiety around speaking to a researcher or may find the prospect of a spoken interview too daunting or potentially fatiguing. Therefore, in order not to

exclude any participants, I gave the option of participants being able to write their illness narrative and responses to my general questions instead.

During the spoken interviews, the majority of the talking was done by participants, whilst I, as the researcher, predominantly took an active listening role. A majority of participants appeared to value my position as a fellow POTS and EDS patient and as such drew me into the conversation with them. For example, in some instances participants would ask their own questions back to me, e.g. “what about you?” after they had finished answering a query such as ‘do you take any medication?’ In part, this was due to a shared knowledge and community understanding of what it is like to be a young woman with an invisible disability/chronic illness. Additionally, many participants would add phrases such as “I’m sure you’ll have experienced the same thing,” or “as you’ll know” to their narrative accounts, which indicated to me that simply by disclosing that I had the same chronic illnesses as them had already built up a strong rapport and served to bridge the gap between participant and researcher between up by automatically giving up a commonality of experience.

Due to the length of time that many POTS/EDS patients have to wait to be diagnosed - according to the organisation Dysautonomia International (2013) the average diagnostic delay for a POTS patient is 5 years and 11 months - participants spoke at length about the diagnostic process since, for many of them, the process spanned multiple years of their life. Additionally, due to their nature as chronic illnesses, the symptoms, emotions, and experiences associated with them were experienced by participants throughout most of their lifecourse. This allowed them to revisit their past and childhood experiences and to make sense of these memories through the lens of their current diagnosis. As such, there were no specific time constraints on the interviews, although I gave an estimated indication on the participant information form that I anticipated each interview may last around an hour; I wanted participants to be able to speak freely, at-length, and to ‘go off on tangents’ about

whatever they felt was relevant to their own illness narratives (as I told them at the beginning of the interview).

3.2. Autoethnographic Reflexivity and Insider Status

Following on from exploring the research design decisions, it is particularly pertinent when discussing methodological issues to consider reflexivity for this study, due to the fact that as mentioned previously I, myself, am a chronically ill young woman who has had similar experiences to many of the participants I interviewed. Anthropologist, Ruth Behar (1993, p.13) describes reflexivity as needing “a keen understanding of what aspects of the self are the most important filters through which one perceives the world and, more particularly, the topic being studied.” For me personally, the aspects of my own self that are most strongly reflected in the way in which I perceive and experience moving through the social world are probably the characteristics in my thesis title itself; that is to say, age, gender, and disability. Reflexivity served to greatly help me to 1) conduct the interviews in a way that quickly built rapport and trust, and 2) to interpret and engage with the topics spoken about and analyse them in a way that a researcher without the lived experience of the topics may not have been able to do. I also highlighted this with my participants at the start of their interview as I stated that, “I want this to be more of a discussion or conversation between us rather than a formal interview”. Although it is not impossible for researchers who are ‘outsiders’ to the population they are studying to gain ‘insider knowledge’ and trust (Bucerius, 2013) it is arguably more difficult to gain authentic knowledge as an outsider. As Berger (2015, p.223) states, a researcher who is an ‘insider’ in their research has a “head start in knowing about the topic and understanding nuanced reactions of participants” due to the knowledge and experience that they will have surrounding the area of study, before the research has even formally begun.

3.3. Participant Recruitment and Sampling

Following on from the previously discussed issue of reflexivity as a researcher, I argue that studying one's own illness can be extremely useful when gaining the trust of participants, building rapport, and gaining access to groups. Due to my insider status in the POTS and EDS community, I was in a unique position as a researcher when recruiting participants and studying this topic. I was already a member of multiple online support groups relating to POTS and EDS and also already had an awareness of the main national charity for such conditions: POTS UK (<https://www.potsuk.org>).

At first, I planned for my own cardiologist to act as a gatekeeper (which he had agreed to), allowing me to advertise my request for research participants within his own private ie non-NHS patient pool, alongside recruitment through social media and online support groups. However, my recruitment via social media was much more successful than initially anticipated and this was no longer needed as I was able to draw my sample of participants solely from the response to the initial post in the POTS UK Facebook group and the subsequent sharing of the post.

My approach to recruitment was to directly contact POTS UK via their email address, expressing my interest in conducting research into chronically ill young women living in the UK. Due to POTS UK having a large reach of 17,000 followers on Facebook and the fact that they are a respected charity, I felt that they could be utilised in order to directly access my desired population of participants. I emailed info@potsuk.org with an expression of my interest into conducting research into POTS and related syndromes, and enquired if I would be able to work with them to reach a wider audience of participants. The Charity Secretary replied with an internal research ethics form from the organisation, and requested that this be completed and returned as it enabled POTS UK to stay consistent in their approach to researchers and to gather all the information about the research that they needed to make a decision on whether to support it. The Request for Support Application form (See Appendix

A) was completed and returned to the secretary, along with a copy of my University of York Ethics approval certificate (Appendix B), as well as the participant information sheet (Appendix C) and informed consent form (Appendix D) for my research. Following this process, POTS UK confirmed that they would be happy to support me with my research by posting a recruitment call or poster on their social media sites. I created a poster to be used online to advertise my research (Appendix E), requesting that people who fit the sample criteria email my university email address with an expression of interest. This poster was made available on the POTS UK Facebook group, Twitter, and Instagram accounts. Following this, many other organisations such as EDS Yorkshire saw the post initially on these pages and shared it across other social media platforms and groups which led to a wide range of participants coming forward.

Within the first hour of POTS UK sharing my recruitment poster I was very quickly overwhelmed with a huge response of hundreds of participants emailing me expressing their interest in taking part in this study. I think this is important to mention and of particular interest because in my assessment, it speaks to the deep need and desire of chronically ill young women feel to tell their story, to be listened to and to be heard. Many respondents told me that their interest in the study was also piqued by my disclosure on the recruitment poster that I have POTS and EDS myself. Furthermore, they mentioned how pleased they were to see that someone was studying POTS and EDS and a desire to raise awareness of such little-known conditions.

There were twelve participants in total in the final sample. I took into account the common recommendation that qualitative research should aim to prioritise “depth of case-oriented analysis” rather than quantity and generalisability when deciding upon a suitable sample size (Vasileiou et al., 2018, p.2). I aimed to select participants to span my entire age range of the definition of ‘young women’ which I quantified as age 18 to 35. But, due to the large volume of responses the recruitment process was mostly on a first-come-first-served basis and

centred upon those who responded to my follow-up email giving their availability for interviews. Therefore, the type of sampling used in my research was purposive in nature as participants needed to fit into my specific requirements of being a woman between the ages of 18 - 35 who was diagnosed (or in the process of being diagnosed) with POTS and/or EDS.

Researchers such as Clarke & Braun (2013) and Fugard & Potts (2014) have asserted that a sample size of twelve is the appropriate minimum when conducting qualitative research, as this number enables a researcher to reach satisfactory data saturation. Originally, when planning this study I had aimed for a sample size of 10 to 15, accounting for the potential that I may only be able to recruit ten participants. However, due to the unexpectedly large number of eligible people that volunteered to participate in my study I wanted to accommodate and interview as many participants as I could and was hoping to interview fifteen or more participants. During the course of the interviews, however, I realised that the emotional toll and fatiguing impact of conducting such long, personal interviews and listening to participants recount narratives that had many parallels with my own life story was more taxing than I had initially anticipated it to be. Therefore, I decided to cut off the recruitment of participants after I had ten spoken interviews and two written narratives as I felt that, especially with the length of the interviews and written accounts, I had more than enough data to produce a meaningful piece of research.

3.4. Data Collection

The option of in-person or Zoom interviews was provided to participants , but all of them ended up being conducted via video call rather than in person due to their preference. This was the most practical option, given that many of the participants lived in different parts of the country to me. Due to many people having become more familiar with Zoom, remote working solutions, and online meetings over the course of the COVID-19 pandemic, participants appeared comfortable with participating in video call interviews. Each interview

lasted between one and three hours. I did not start with a plan of how long the interviews would last but initially anticipated they would last around an hour, as stated in the participant information sheet. The average length of an interview was approximately two hours. Conducting the interviews on Zoom allowed me to capture the entirety of my conversation with each participant, not just via audio recording but by video too (with their consent) which provided extra data to provide context to the participant's illness narratives for analysis through non-verbal cues or gestures. I simply initiated conversation by explaining my own position as a researcher and my insider status as someone who is also a chronically ill young woman. I began by asking if they could tell me their illness story and the story of how they were diagnosed with POTS and/or EDS for both the spoken interviews and the written responses.

3.5. Ethical Considerations

I anticipated that the participants would be likely to suffer with some form of chronic fatigue given their POTS/EDS diagnosis or pending diagnosis and may find it challenging to talk on a one-to-one basis with me for the length required of a narrative interview. Therefore, as explained above, I put in place the measure of offering video calls via Zoom rather than requiring participants to meet in person. Thus, participants could engage with me from the comfort of their own home or place of their choice. I also aimed to be very flexible with my own schedule during the period of time when I was conducting the interviews so that I could let participants decide the date and time that would suit them best. Furthermore, I made clear in my participant information sheet that there was not a set length of time that I expected participants to talk to me for, and at the beginning of the interview with each participant via Zoom, I reiterated that they were free to have a break whenever they needed to, I also stressed that they did not have to tell me anything they were uncomfortable with and could end the interview at any time. Additionally, as described above, participants who were uncomfortable verbally telling me their illness narrative had the option of completing a written response instead. Participants were sent the participant information sheet (see

Appendix C) and the informed consent sheet (see Appendix D) via email and were asked to read through the documents. These forms made participants aware that all personal data would be anonymised and confidential. I reiterated in my correspondence with participants that if they had any additional questions or concerns about the research and the process of data collection, they were free to contact me with such queries at any time, although no participants felt the need to utilise this option prior to the interview.

All data i.e. recordings and written responses was stored in a secure folder on my own personal computer which is password-protected and only used by myself. Although participants had already signed an informed consent document where they agreed for their interview to be recorded prior to the interview itself, I made sure to reiterate this at the beginning of the interview and explained once again why it was necessary to my research to do so, as well as reassuring participants of their right to withdraw from the interview at any time, and of their rights to anonymity and confidentiality. I waited for all participants to give verbal consent before I began the recording process. At the beginning of each interview I also disclosed my own insider status as a chronically ill young woman once again. I decided to do this because I felt it may help build trust and a willingness to engage in interviews with me if I made it clear that I was researching this topic in an empathetic, not an exploitative way. As stated previously, I wanted this research study to be more of a conversation and discussion between me and the participant, allowing for the researcher and the *researched* to become equals. As such, part of my methodology and analysis is supplemented by my own autoethnography of my lived experience as a chronically ill young woman, alongside the illness narratives of my participants. The procedures of handling the data by the methods outlined above were approved by the University of York Sociology Department Research Ethics Committee, (certificate attached in Appendix B) which follows the standard ethical procedures set out by the British Sociological Association. in addition to completing the aforementioned, internal ethical process for POTS UK.

3.6. Theoretical Framework

I sought to analyse the data collected from an interpretivist perspective with a post-structural feminist theoretical standpoint in order to embody and make sense of voices and perspectives that are often marginalised in society. Interpretivist sociologists have, since the 1960s and 70s, built upon ideas of symbolic interactionists such as Goffman (1961;1968) and Becker (1963) to form a micro sociological perspective that has been extremely influential in its lasting influence upon the domain of medical sociology (Thomas, 2010). Parsons' (1951) view of illness and disability being a form of deviance in society is shared by interpretivist sociologists. However their approach differs in that rather than attributing social deviance to inherent behaviours or attributes of people (such as being ill or disabled), they focus instead on the social processes by which labels of deviancy are applied by authorities in society, and seek to *interpret* the interactions and reactions of those who are subject to such forms of labelling (Thomas, 2010). For example, within my own research, it became clear that although myself and other chronically ill women may not consider ourselves inherently deviant for being ill, there were instances in our lives wherein it was felt we had been labelled as such by social actors such as doctors, nurses, friends, or family which in many cases led to internalised ableism, low self worth and self criticism.

Additionally, post-structural feminists have contributed greatly to the study of disability and illness. Preoccupied with critiquing the kyriarchy, post-structural feminist thought emphasises the ways in which people are othered and exiled due to the narrow constructs of what is considered 'normal' within society (Schüssler Fiorenza, 1992). The value of narrative interviews and autoethnography, specifically highlighting young women in this study, aligns with feminist theorist ideas of seeking to give an active voice to marginalised populations of which scholars are members themselves (Brooks and Hesse-Biber, 2007).

3.7. Data Analysis

I conducted a narrative analysis of the interviews to gain a thorough understanding of the similarities, differences and main themes in the lived experiences of POTS/EDS patients. Narrative analysis is especially useful to see how participants create an understanding of their own illnesses and how they make sense of their own illness narrative. I followed Susan Paulson's (2011) 'three stages of coding' as a general starting point to organising my data. Due to the large volume of content and the detailed narratives I had been provided with I felt it was necessary to retain the creativity and freedom of interpretation that is required for narrative analysis and elucidating emergent themes whilst still having something of a structure to refer to in order to identify themes and codes in a somewhat consistent manner. Paulson's (2011, pp.148-147) three stages of coding which were followed were:

- 1) open coding line by line
- 2) focused coding for sub-themes or smaller stories
- 3) identification of emergent narrative themes or larger stories

In practical terms, the data was analysed first by manually transcribing the interviews and then importing the datafiles into the qualitative coding software NVivo (Release version 1.7) This allowed me to code the interviews into narrative concepts. Transcribing the interviews involved listening to them multiple times which allowed me to familiarise myself with the data and in turn to be subconsciously thinking about potential narratives that were emerging from the dataset as I went through the interviews. It was also useful to refer back to the video files if I ever felt that any context was missing from a transcription and to be able to reassess a participant's illness narrative in full by reminding myself of the body language, facial expressions, or non-verbal gestures participants may have used, throughout the process of analysis.

Following the transcription of the ten participants' spoken interviews, I compiled these transcriptions with the two remaining participant's written illness narratives. I read through participant's responses and then re-read each interview multiple times, before progressing to coding the raw data by hand, noting emergent narrative themes that particularly struck me or had relevance to a particular sociological theory or concept. I then transitioned to digital coding due to the volume of data and assigned each participant as a 'case' in NVivo and saved their transcript documents in their individual files. Initial codes were condensed to five general themes and subthemes and then finally to three primary narratives that occurred most often throughout the data.

Chapter IV: Analysis and Discussion of Findings

The following chapters combine the findings and discussion from data analysis of the narrative interviews conducted with ten participants 'face to face' via video call, and two via written illness narratives they provided me with. Participants were all female, and between the ages of 18-35, as described in Chapter III referring to my desired sample. The table below shows the participants' diagnosis and the age they were when they obtained it and their age at the time of the interview. From the large amount of interest I received in terms of volunteers wanting to participate in the interviews I attempted to sample a wide range of ages within my criteria of 18-35 years old. This analysis chapter is split up into three narrative sections that serve as sub-chapters for ease of comprehension. The respective narrative sections consist of the findings from the data collected and the discussion of the data. As described in Section 3.7 initial common codes and then themes and sub-themes were identified from the data and over time these themes were solidified into the following three narratives that I observed as being the most commonplace and consistently spoken about by participants.

4.1. Participant Demographics

Pseudonym	Age at Time of Interview	Diagnosis	Age at Correct Diagnosis	Approx. Length of Symptom Onset to Correct Diagnosis	Type of Healthcare
Beatrice	25	POTS; EDS	23	7 years	NHS
Ellie	22	POTS	22	9 years	NHS
Helena	27	POTS; EDS	19	6.5 years	NHS
Heidi	19	Chronic Fatigue Syndrome; POTS; awaiting EDS diagnosis	16	2 years	Private
Jocie	30	POTS	29	11 years	American Healthcare System
Katie	23	POTS	18	2 months	Private
Laura	26	EDS; awaiting POTS diagnosis	24	16 years	NHS
Lucy	32	POTS; Hypermobility; Epilepsy	25	2.5 years	NHS
Megan	21	POTS; EDS	16	2 years	Private
Rebecca	25	POTS; EDS; Gallbladder Disease	14	2 years	NHS
Sasha	34	POTS; EDS; Fibromyalgia; Chronic Fatigue Syndrome	25	9 years	NHS

Sophie	31	POTS; Fibromyalgia; Chronic Fatigue Syndrome	29	15 years	NHS
Emi	25	POTS; EDS & Scoliosis	23	11 years+	NHS

Table 1. above shows an overview of relevant demographics of the participants and myself (Emi) due to the autoethnographic element in this study in order to provide context for the sample and to show that there is somewhat of an Weberian 'ideal type' associated with being a POTS/EDS patient wherein it is typical for many years to pass between symptom onset before obtaining an accurate diagnosis. And the age of diagnosis most commonly occurring in mid to late twenties. Gender as a factor is not shown in the chart due to all my participants being female as this was a prerequisite for people to put themselves forward for this research.

As my study focuses in particular on illness narratives centred around diagnosis (or lack of) and many patients mention their 'journey to diagnosis' or 'diagnosis story' I was interested to briefly quantify the average length of a diagnosis journey for young women with POTS and EDS in particular. I also decided to make a distinction between the diagnoses that were achieved through the NHS versus those that were gained through private healthcare as there appeared to be a marked difference in the length of time. Indeed, the mean average of time to wait for the correct diagnosis with the NHS was calculated to be approximately 8 years. Conversely, the mean average of time to wait for the correct diagnosis with private healthcare was 16 months. The shortest waiting time for a private healthcare diagnosis was 2 months, whilst the longest was 2 years; and the shortest waiting time for an NHS diagnosis was 2 years, whilst the longest was 15-16 years, highlighting a large disparity between NHS and private experiences of obtaining chronic illness diagnosis.

4.2. Narrative Templates

Frank's (1997) seminal work on illness narratives and storytelling argues that an emphasis must be placed upon the relevance of narrative templates to specific times, cultures, and situations. Therefore, when conducting my own narrative analysis, rather than using Frank's suggested templates of Restitution, Quest, and Chaos, I sought to categorise the illness narratives I had gathered into my own narrative themes, that were specific to POTS and EDS patients, and more broadly chronically ill young women. I named these narrative templates based upon archetypal literary story structures, and within them analysed specific key themes and subthemes that arose. The first narrative type identified was that of *The Ghost Story* - I define this as an illness narrative that focuses primarily on the invisible nature of the illness and the ways in which having a condition that cannot be seen by others can cause conflict and distress in an individual's life. The second narrative type was *The Myth of the Hysterical Woman* - referring to the historical stereotype of ill women being labelled as 'hysterical', and often seen as unreliable narrators to their own lives and experiences. Finally, the last narrative that emerged from the data was that of is defined as *The Diagnostic Odyssey*. It is somewhat similar to Frank's 'Quest narrative', referring to the 'journey' of seeking to obtain a diagnosis or a cure to an illness.

These narratives follow the main key themes of invisible illness, gender, and diagnosis and all participants drew upon these identified themes in their explanations of their lived experiences. Out of all these narratives, the main 'story' that participants appeared to focus on was that of the diagnostic journey. This is perhaps a key element of the lived experience of having POTS and/or EDS: the lack of research into these conditions leads to general practitioners having not heard of them, insufficient expertise and consultants available for diagnosis and treatment, and in general a prevalence of POTS and EDS symptoms being mistaken for other illnesses and misdiagnosed.

NARRATIVE A: THE GHOST STORY - Invisible Illness: *“I look normal. I look healthy. They just think I’m fine.”*

The Fear of Not Being Believed

The nature of chronic illnesses such as POTS and EDS as largely ‘invisible’ was a common narrative thread. To situate this narrative we can look to the definition by which Donoghue and Siegel (2002, p.2) describe invisible chronic illnesses (ICIs) as providing little to no external evidence of suffering - evidence that would usually elicit compassion. Instead, the invisible illness sufferer frequently has to contend with the opposite of compassion from outside observers. Many participants mentioned negative experiences with family, friends, and doctors due to the invisible nature of their illness. The perception of ‘looking fine’ or of appearing physically healthy and able-bodied and being perceived as a person having ‘nothing wrong’ with them was a source of worry for many:

*“I’ve had some terrible, terrible experiences with GPs. And I think it’s because the POTS, the EDS or the chronic illnesses that are invisible, they can’t see it. I look healthy. I look normal. They just think **I look fine**. So they’re like, “**well, there’s nothing wrong with you**”.” (Rebecca)*

*“Because it’s **invisible** [...] people like extended family, or even GPs who don’t see you in your worst moments, but they know you. They then kind of get surprised when*

you suddenly have all these labels and they're like "how come you've suddenly got this much going on with you?" (Laura)

Invisibility then adds an additional layer of difficulty to the lived experience of disability. As Asbring and Narvanen (2002) recognise in their study of women suffering with chronic fatigue syndrome and fibromyalgia, if a patient "perceives that others are challenging the reality of [their] illness" based on the patient's outward appearance, this threat to identity can often be felt to be "a heavier burden than the illness itself." (p. 152) Indeed, my participants were acutely aware that they 'look fine' which challenges the reality and authenticity of their illness.

*"Maybe like to a GP, they're seeing this supposedly healthy patient because **they look fine** and they're walking into the appointment or something. (Laura)*

*"I look perfectly well, I mean looking at me right now **I look fine** but even inside right now I'm in pain, I have pain right now. You know, even walking up [the] stairs just now I know my heart rate spiked, I could feel it, I went dizzy just walking up my stairs and I just wish people could realise that not all symptoms are visible. (Ellie)*

The repetition that they 'look fine' carries the implication that what the participants are actually saying is that they are not 'fine', despite the way they appear to others. What they "wish people could realise" (Ellie) is that being ill or having a disability does not always present in a way that is immediately visually obvious. The idea of looking ill appears to act as a kind of proof for the validity of the lived experience of chronic illness. Rebecca, for example, explained how doctors and employers alike had dismissed the idea of anything being "wrong" with her due to the fact that she looks "healthy" and "normal":

*"[...] And I feel like my managers **don't believe me**. It's that mistrust." (Rebecca)*

*“She just **didn’t believe me** with my medical conditions” (Rebecca)*

The way in which participants centred the idea of their disability not being visible in their illness narratives highlights that this perceived lack of belief that they are actually ill from outsiders reinforces the idea posited by Asbring and Narvanen (2002) that the reality of one’s illness being challenged can be felt by the sufferer as just as much, or more, of an issue than the illness itself. Additionally, along with the mental and emotional burden that the challenging of the validity of ICIs can have, there are practical effects too. Issues such as the use of mobility aids and disabled facilities were spoken of as a source of internal conflict for participants:

*You know with POTS, the longer you stand still, the longer you stand up, the worse everything gets. [...] When there’s a huge que for the Ladies [toilets] but the disabled toilet doesn’t have a que, I’ll go in the disabled toilet. And you get the “well, **there’s nothing wrong with you**, what’s wrong?” (Sasha)*

Here, Sasha highlights how appearing as though there is “nothing wrong” is translated into the real-world anxiety of potentially being accused of ‘faking’ a disability in public. Therefore, even without any direct lived experience of being accused of feigning an illness or disability in public, merely the *possibility* that this could happen prevents some chronic illness sufferers from utilising mobility aids. Other participants reinforced this idea of anxiety surrounding publically using facilities and aids made for disabled people whilst not outwardly appearing as disabled themselves:

*“I know so many people, myself included [that are] **scared** to use mobility aids in public because we’re ambulatory and don’t want people to think we’re **faking**.” (Heidi)*

*I'd be even **scared** to try to get like, a parking permit because I feel like if I put it in my car someone would be like "No, you can't park here, you look fine. You can walk". You know? **That fear of I look fine**, so I can't park in a disabled spot because I look fine, there's nothing wrong with me on the outside. It's all invisible. (Rebecca)*

The use of the word "scared" and "fear" by multiple participants when discussing their hesitations in using accessible spaces in public (that they are entitled to) highlights a tangible consequence of the way in which disability is currently perceived somewhat negatively in UK society. Further to this point, participants brought up the role of the media in reinforcing negative stereotypes about people with disabilities, contributing to the idea that people may be prone to faking or exaggerating their illness in order to gain benefits and attention.

It's [invisible disability] associated with benefits and people not working and stuff, and even I think it's on Little Britain, Matt Lucas plays a not very wealthy guy who's pretending to need a wheelchair and I think that does become a connotation. (Katie)

"The media perception of invisible disability, especially in the Mail and that, there's definitely been articles there, like always showing someone who's very overweight, that doesn't work, who's all on benefits, and they always take it as a lazy person and they angle it that way and they don't show the proper effects [of disability] and the impact it has." (Sophie)

The issue of being accused of "pretending to need a wheelchair" (Katie) was mentioned by multiple participants, who were concerned that people around them in public would have preconceived notions that they were using a wheelchair because they were paralysed and couldn't walk. Therefore, a sense of worry about "what other people could be thinking"

(Sophie) if they were to use a wheelchair as an ambulatory user, transferring in and out of the chair as needed, was prevalent in the illness narratives. This seems largely to be due to the idea that once again, invisible illnesses are not commonly acknowledged as 'real' disabilities. The lack of general awareness and understanding of ICIs from the media and the general public means that many people may actually simply be unaware that there are other reasons for needing to use mobility aids or disabled facilities that go beyond the visually obvious .

“They see you in a wheelchair and you get out and walk a few steps they expect you to be paralysed, they expect you to not be able to get out. And then when you do get out to transfer into a chair or to do a couple of steps to sit somewhere, you kind of get stared at. And they don't believe it, you get a lot of that and it makes me kind of self-conscious.” (Sophie)

Here, Sophie describes feeling self-conscious due to the stares and looks of strangers in public when she is seen getting out of her wheelchair - looks that are perceived by the participant to be because “they don't believe it”. This is supported by Donoghue and Siegel's (2002, p.2) assertion that in addition to often having to navigate and manage painful, disabling symptoms, “the patient of invisible illness suffers, often deeply, from the negative reactions of others.” Furthermore, they go on to describe the impact that these reactions can have on patients, with such attitudes leading to feelings of loneliness, self-doubt, and confusion.

Stigma - Putting On a Mask

Following on from the reluctance to overtly identify as disabled when suffering from an invisible illness, it is evident that due to this anxiety of using the word disabled, participants often felt that they had to actively mask the way they were feeling when in social situations,

reinforcing the invisibility of our conditions. In addition to the internalised ableism described above, stigma from outside forces in society contributed to participants feeling as though they had to “pretend to be fine” or “put on a mask”.

Goffman (1963) describes stigma as a particular aspect of one’s social life and identity that affects and complicates interactions on a micro level. Clair (2018) notes that those who are stigmatised may be wary to interact and engage with people who do not share their stigma and that those without a certain stigma might react to stigmatised individuals by attempting to ignore, disparage, or overcompensate (p.1). Following on from the reluctance to overtly identify as disabled when suffering from an invisible illness, it is evident that due to this anxiety of using the word disabled, participants often felt that they had to actively mask the way they were feeling when in social situations, reinforcing the invisibility of our conditions:

In terms of identities, people who belong to social groups that have a social stigma attached (such as disabled people), may subconsciously begin to “perform” their identities and interactions with others (Kanuha, 1999, p.27). In his work on stigma (1963) Goffman describes the notion of passing as “the management of undisclosed discrediting information about the self”. (p.43). This management of identity and information about oneself was spoken about during interviews by multiple participants. For example, Sophie told of the ways in which she feels as though her symptoms are often dismissed or not acknowledged due to the fact that in public she is often “wearing a face”, which speaks to a level of performance in everyday life.

*“You get the thing of kind of ‘well, I’m tired too today’ or they look at you and say ‘Oh, you look better today’, and you’re like ‘I’m not,’ but **you’re wearing this face**. It’s one of my pet peeves when someone goes to me ‘Oh, you look better today!’ and it’s normally extended family, it really does my head in, it’s frustrating because you’re trying to get across to them that it’s chronic. (Sophie)*

This quote highlights the way in which in relation to invisible illnesses in particular, the issue of stigma is a complex one due to the fact that people with ICIs can be argued to have a choice about whether or not they 'come out' as chronically ill, which again speaks to Goffman's (1963) concept of 'passing'. On the one hand, lacking visible symptoms of illness or disability may be seen as a positive aspect of a condition such as POTS or EDS due to the way in which the decision to disclose or discuss your illness is not dictated by your outward appearance and thus you do not face the immediate stigma of being perceived as having a non-normative body. However, it can also be a negative aspect of having an invisible illness, as as Sophie mentioned, without a visibly stigmatised identity, it is "frustrating" and difficult to "get across" to friends and family that your illness is chronic and a permanent part of your identity.

*My mum and that understands a bit more how I'm actually feeling but it's that frustration of no actually, **I'm just wearing a mask out**, I'm not showing how bloody tired I am and how I'm not feeling great, I'm just covering that up and getting on with stuff because you have to." (Sophie)*

Here Sophie describes the frustration of outsiders judging how well or ill she is feeling simply by looking at her physical appearance, using phrases such as "wearing a mask" and "wearing a face" to describe the way she tries to hide how she is really feeling. Other participants spoke of "putting a facade on" (Sasha) and pretending to "act normal" (Katie). Once again, the unseen nature of POTS and EDS, is highlighted as a significant issue in 'trying to get across' to people that they have a chronic condition that affects them all the time - an invisible ghostly presence that follows us wherever we go, regardless of whether those symptoms can be seen by outsiders or not.

Yeah, we have an invisible illness,[...] and you wouldn't know we're dealing with it.

Because we are very good at ploughing through it and we are very good at putting this facade on to the people that we need to put the facade on to. (Sasha)

Indeed, in particular relation to POTS, in a recent study highlighting the stigma surrounding invisible illness and disability in people with congenital heart disease, health researcher Beth Greenaway describes how young patients often find it especially difficult to navigate stigma as they often “do not fit the normal mould of someone living with a significant disability” (2022, p.1). By this, Greenaway reinforces the narratives participants gave wherein she explains that patients with heart conditions often display “few visible signs of their illness” and “look otherwise ‘healthy’. Therefore making it difficult for others to comprehend, relate to, or be sympathetic to their daily struggles (*ibid.*).

This issue is also further exacerbated with a condition such as POTS where patients are treated by cardiology services but do not technically have a structural heart impairment. Therefore, POTS patients do not have the label of a ‘serious’ diagnosis such as heart failure and thus may not be taken as seriously by doctors, family, and employers. However, patients with POTS are widely reported, on average, to have a similar quality of life and symptoms to patients who suffer from congenital heart disease. Furthermore, POTS patients have also been shown to suffer with a similar degree of functional impairment to that which is seen in sufferers of chronic obstructive pulmonary disease and congestive heart failure (McDonald et al, 2014, p.1), leaving them with a severe impact on their quality of life, but without an acknowledgment or validation of this severity from doctors, family, and employers.

The Label of Disabled & Internalised Ableism

In particular relation to the fear of not being believed due to the largely invisible nature of POTS and EDS, participants described a cognitive dissonance in using the label of

'disabled'. By legal definition - "a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities" (Equality Act 2010, 2010) - POTS and EDS are recognised as disabilities. However, despite this, there were concerns brought up in the interviews as to whether participants feel they can actually call themselves disabled and in turn appearing to convey some internalised stigma and ableism towards their *own selves* during interviews. Internalised ableism is described as how, in order to "emulate the norm, the disabled individual is required to embrace, indeed to assume, an 'identity' other than one's own." (Campbell, 2009, p.26).

Helena, in particular, described struggling with uncertainty surrounding the term in relation to her own identity given that she still works and studies. In this way, there is a sense that those with chronic illnesses don't quite fit into any specific category or community - we are not disabled 'enough' to truly identify as disabled but we are also not 'normal' enough to fit in as completely able-bodied - I argue that we wander the liminal space between 'normal' and 'disabled', invisible to all.

"I still really struggle with the term disabled, I'm still uncertain of whether I can even say I'm disabled because I still work and study. Yet I'm considered a disabled student and my university considers any long-term health condition that could affect your studies as a disability. So I'm still getting my head around that. (Helena)"

Having to 'get your head around' the idea that invisible chronic illnesses are disabilities perhaps speaks to the stereotypes of disability that have been present in societal and media representations for decades - of disabled people being *visibly* disabled or unwell in some way that can be quantified by outside viewers, leading some people to feel more comfortable with identifying as having a chronic illness rather than a disability. Furthermore, in this narrative, Helena displayed awareness of the negative connotations surrounding the label of

disabled, describing the way in which she feels using 'disabled' as an identifier may open her up to further judgement and criticism from outsiders.

Disabled seems almost like a bad word. If I say I'm disabled, it unleashes a huge avalanche of assumptions and preconceptions and opens me up for further judgement. People expect you to behave a certain way I guess. So at the moment, I steer clear of that word and generally say I have chronic illnesses." (Helena)

Here Helena describes her concerns that if she calls herself disabled it will open her up for "further judgement", a fear that is supported by Donoghue and Siegels (2002, p.2) research showing that the invisible illness patient "often endures suspicion and withdrawal from others." Therefore, due to this potential for judgement, assumptions, suspicion, and withdrawal when identifying oneself as disabled or chronically ill, participants spoke of a narrative of 'pretending' to be okay. As Campbell (2009, p.24) states, "the desire to emulate the Other (the norm) establishes and maintains a wide gap between those who are loathed and that which is desired." In this case, for chronically ill young women, the 'other' is indeed the norm - the healthy, normative body is the strange and foreign concept to us that we desire to emulate, and the gap between 'normal' and 'abnormal' experiences of being a young woman are maintained, with the notion of 'disabled' becoming the thing that is loathed.

Following on from this, in her illness narrative Sasha asserts the things she *can* do - aligning herself with the Other, placing the emphasis on her similarities with the norm rather than her differences:

"I'm not disabled, I can go out, I can walk, I can swim, I can play with my nieces, I can walk my dog, I can do whatever I want to do. I'm not disabled." (Sasha)

The repetition of “I’m not disabled” in Sasha’s narrative is arguably a clear instance of internalised ableism, wherein the invisible chronic illnesses described at the beginning of this chapter are not only frequently not recognised as legitimate disabilities by outsiders and society at large but also by those of us inside the community. It is important to acknowledge however that, as Marks (1999) explains, “internalised oppression is not the cause of our mistreatment; it is the result of our mistreatment.” (p.25) As such, I certainly resonate with the ways in which participants spoke of the term ‘disabled’. When conducting the interviews I noticed that when participants such as Helena described the way in which, for example, they were uncertain of whether they could say they were disabled when they still work and study, I found myself thinking “of course you can!”. However, upon further reflection, the irony of my thinking shows my own cognitive dissonance to the label wherein I feel uncomfortable identifying as disabled or adopting that term as part of my identity but want to advocate for others who have the exact same diagnosis, symptoms, and experiences as myself.

Rebecca faced a similar issue at her place of work wherein as part of an impact network for disabled staff she decided to implement the phrase “long-term medical conditions” into the title of the network due to her own difficulties in using the word disabled as an identifier:

“ I just made sure that like long term medical conditions are in that title, because it's hard to use the word disabled, sometimes, to define myself. Because like, I don't look disabled. I have accepted that term, because I feel like I need to, because I feel like it helps me to get the support that I need.” (Rebecca)

However, Rebecca states that she has learnt to “accept” the term of disabled because having that label can help her access the support she needs. Once again, however, she describes herself as having difficulty with this due since she doesn’t “look disabled”. In conversation with Rebecca during her interview, I spoke about similar feelings I had encountered in my own chronic illness journey, noting that identifying as disabled made me

feel like a “liar”, despite being aware that “by all definitions we are disabled”, showing the complexity and duality of our own impressions of our self and how our illness interacts with our identities - something we struggle to make sense of:

“What you said about the label of ‘disabled’ - like, I’ve struggled with that as well because I feel like well, yeah, I don’t look disabled and I don’t like calling myself disabled because it just feels – I dunno, I just feel like a liar or something. So I think it’s really helpful that you’ve put that title of ‘long term conditions’ in the role because I definitely feel more comfortable saying “I’ve got a long term condition” than “I’m disabled”. But then that could speak to, kind of, an internalised ableism maybe. Because by all definitions we are disabled.” (Emi)

As Marks (1999) contends, “we harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives (p.25).

Similarly to Rebecca’s concession that sometimes she does “need” to accept the term of ‘disabled’ in order to receive the support she needs, Katie also described, in her narrative, that although she rarely refers to herself as disabled, when she does on days when “it gets really bad” it can be “a tiny bit empowering”:

I don’t call myself disabled very often, I don’t tell people I’m disabled but I think when it gets really bad, when there’s bad days and stuff, I feel like I’m telling myself and my family too [...] my mum’s always seemed to not want to accept that I’m like, disabled, and in some ways I’ve found it [the label of disabled] a tiny bit empowering (Katie)

By this Katie shows that perhaps for some sufferers the label of disabled is more flexible, wherein there can be contested feelings about when and where one identifies themselves as having a disability. For Katie the label is reserved for “bad days”. She describes feeling as though by accepting the label on those days when her symptoms are particularly bad she is “telling [herself] and [her] family too” that she *does* live with a disabling condition, therefore providing some validation for her struggling on some days, thus providing her with some ‘empowerment’.

NARRATIVE B: THE MYTH OF THE HYSTERICAL WOMAN - Gendered Issues:

“You’re just a fussy woman.”

Following on from the issue of invisible illness it is now necessary to situate the narratives that participants gave in terms of gender. As discussed in previous chapters, due to the highly gendered nature of POTS and EDS, my sample of participants were all females. During interviews, many participants brought up experiences of sexism, both overt and implied, that they had encountered during interactions with medical professionals. The

prevalence of participants being initially diagnosed with anxiety, or their symptoms being attributed to a gendered cause such as menstrual periods and associated issues such as anaemia was striking. All participants, including myself, had been told by doctors that their symptoms were due to these things, sometimes for years before obtaining an accurate diagnosis. This chapter draws comparisons between the treatment of women with POTS and EDS by medical professionals today and the way in which, historically, ‘hysteria’ was given as a label to ill women, psychologising physical symptoms in female bodies.

Tension in the doctor-patient relationship

Along with the factor of gender being significant in participant’s narratives, participants frequently mentioned their age as a factor in their difficulty getting a diagnosis or having interactions with medical professionals. For example, Helena stated how the doctor did not want to diagnose her with hEDS, not because she did not have the symptoms, but because she was “only 19”, and due to the fact that she had been diagnosed with other comorbid conditions such as POTS recently:

*“I got the impression that my doctor didn’t want to diagnose me with hEDS **because of my age**. I believe **he even mentioned that I was only 19** and I got the impression he didn’t want to diagnose me [...I thought it was ridiculous at the time because I either have the condition or don’t. If I do, a diagnosis is helpful.” (Helena)*

Additionally, Heidi described not being able to access certain treatments, which she attributes as due to being because she is “young and a girl” being an “excuse” for doctors not to give certain treatments.

“I have struggled with pushing for certain treatments, I often get the ‘you’re so young we only give this to old people’ excuse. (Heidi)

Age was also mentioned in other participant's narratives in relation to social life. Katie described feeling as though she is missing out on the 'best part' of her life by not having the same amount of energy that most people do in their younger years:

"Your social life is seriously affected because you've got no energy to do anything or when you do go anywhere, you end up in pain and miserable. (Katie)

Furthermore, Katie describes the process of looking back on her school experiences and making sense of them now that she knows she has a chronic illness.

"Looking back on it, I always struggled so much to wake up for school and I think everyone's like "oh, teenagers" (dismissive tone) but looking back on it I'm like no, I think I was actually quite ill. (Katie)

"All through school I'd always need to drink loads of water. I'd feel quite ill and stuff and I'd need to go to the toilet a lot but I think it kind of got brushed off as me being a bit naughty [...] like I was trying to skive, like I was just being a bit difficult." (Katie)

Again in this narrative, the issue of age comes up, with 'teenagers' being assumed to be lazy or tired or "difficult". Here Katie implies that it was her age at the time of her symptoms that prevented people such as parents and teachers from being overly concerned with her fatigue. She further goes on to explain that in addition to the general preconceptions in a school environment, in a working environment she has faced stigma as a young person wherein people have assumed she is hung over due to her fatigue.

“I think people look at you and think you’re fine and the connotation with being young and stuff [...] I think that’s the hard thing with being young and chronically ill, I think a lot of your behaviour gets pushed to you’re like a young person who’s a bit lazy, hasn’t figured their stuff out yet” (Katie).

Contested Illness and Low-Status Conditions

Following on from the tension present in doctor-patient relationships due to reasons such as age, we can also look at the nature of chronic illnesses causing tension themselves. Album (1991, p.232) states that conditions that are difficult to diagnose and treat, and those often include a variety of symptoms such as POTS and EDS, are not “delimited to a specific organ and able to be diagnosed in an objective way”. Thus, these contested illnesses then become shrouded in mystery and stigma for doctors who then regard such illnesses as low-priority or ‘low-status’. In regards to this concept, Sophie, in particular, attributed the dismissal of her symptoms by doctors to them not being ‘interested’ by chronic illness - and by extension, not being interested in helping her. She spoke of the way in which she felt that having a condition that was not curable contributed to her opinion that doctors have “got no interest in it or looking after you”.

“It’s kind of like they just wanna fob you off and they’ve got no interest in it or looking after you they just kinda wanna – it’s not interesting, it’s not something we can cure, it’s not interesting, we don’t wanna do anything with it, it kind of gives you that opinion.” (Sophie)

Here, Sophie situates her experience with doctors as giving her the impression that her chronic conditions were “not interesting”. This is a narrative that is, in part, backed up by literature surrounding the embodiment of patients in medical settings. Indeed, Bologh (1981)

describes the way in which a doctor's interests may be at a crossroads with the patients. Bologh describes that an 'interesting case' may hold more challenge and be more rewarding than a common chronic illness." (1981, p.203.) Indeed, Sophie specifically mentions doctors saying "it's not something we can cure " as being a reason, in her opinion, that they are not as 'interested' in her. This could be because without the capacity to effectively cure or 'heal' the patient (as is usually the case with acute illnesses), the physician must rescind some power in the patient-doctor relationship and would "cease being curers" (*ibid.*). Therefore the 'reward' of successfully diagnosing, treating, and then curing an acute illness may be more appealing to medical professionals too.

Other participants such as Lucy and Sasha spoke of feeling invalidated and dismissed in medical settings:

"It was generally dismissed and explained away by me 'standing up too quick', so for a long time, I thought everyone felt that way and dismissed it myself." (Lucy)

*"I'd **probably have no friends** because they'd get fed up with me moaning all of the time." (Sasha)*

This was spoken about in participant's illness narratives, wherein they discussed their insecurities regarding the potential of suffering from negative reactions from friends if they complained about their illness or from employers if they did not perform at the same standard as others around them:

"I'd then spend the day fast asleep because I was so exhausted from trying to keep up with everyone else." (Heidi)

“You’re expected to work to the same standard as everyone else around you and it’s exhausting.” (Lucy)

Lucy describes in particular the way in which being expected to work to the same standard as everyone else is “exhausting”, whilst Heidi speaks of “trying to keep up with everyone else”. Arguably these ideas can be seen as a way in which ableism within society manifests. According to some disability theorists, such as Campbell (2019), ableism can often present as an unattainable and unachievable expectation of perfection in our everyday and working lives. It is noted that the idea of being able to overcome disability or illness in order to reach the expected perfection is deeply ingrained into our thinking about bodies, leading ableism to not simply be relegated to the realm of overtly negative comments and actions towards disabled people but to be ingrained into everyday life. Furthermore, Lucy’s admission of feeling as though she is expected to work to the “same standard” as everyone else, perhaps speaks to the harmful - and indeed ableist - ideas of health and sickness that underpin capitalist society.

This ties in with the idea that Donoghue and Siegel (2002, p.2) described wherein a bleeding wound or a broken arm in a cast will elicit sympathy and compassion from social networks, but an invisible illness will not. Arguably, you will elicit sympathy for a visual illness or injury but unless a condition is physically obvious to people you will automatically be assumed to have a normative, healthy body and thus will be held to the same expectations and standards as everyone else. This is something that I myself experienced in a workplace setting wherein after a few months of quietly struggling with physical tasks in my job, causing myself to be in pain and feel ill, I decided that I needed to disclose my invisible disability to my employer. However, despite the disclosure, because nothing *physical* about me had changed there was never any discussion around what reasonable adjustments I may need or acknowledgement that I may not always be able to work to the same standard of other people my age (early twenties at the time). Whether this was correctly or incorrectly

perceived to be the case, in my experience in my previous job I felt as though there was a difficulty in comprehension, understanding, and compassion from my employer due to the way I came across as a healthy young adult. I truly do not think that had I been in a wheelchair or had some sign of visible disability, that an employer would have felt comfortable ignoring the disability in question and not offering any reasonable adjustments.

Anxiety as the Modern Hysteria - The Psychologising and Gendering of Symptoms

Helena drew distinctions between her experience with a male doctors vs. a female doctor. Whilst this may be a case of individual doctors having differing opinions in terms of patient care, it is notable that Helena feels that mentioning their gender specifically is important to her narrative. This raises the question of if women are more comfortable in medical settings around other women. Helena describes the male doctor as “haphazard”, “inaccurate” and “dismissive” and goes on to state that in particular, the reassurance she was given by the female doctor that her illness was not “mild” was “validating” for her, highlighting the importance of rapport building, reassurance and communication from doctors to their patients:

“He [the doctor] became dismissive of the idea and told me that if I did have the condition, it was only mild because most people with hEDS are usually in wheelchairs! When I spoke with a female doctor who was covering the male doctor one time, I mentioned to her that he had said I was mild and she said, ‘it’s not mild if you’re having symptoms!’ I found that to be quite validating.” (Helena)

Other participants spoke about specifically feeling stigma from doctors in regards to being a woman complaining of chronic symptoms. Laura for example describes the two times when

she was conversing with a male consultant as feeling as though the consultant thought she was “just a fussy woman”:

“There’s definitely a gender aspect for women, like those two times it was like ‘oh, you’re just a fussy woman’.” (Laura)

Although this is not something that the consultant directly said to Laura, the fact that she perceives this as the doctor’s attitude towards her shows a breakdown of the doctor-patient relationship. Laura relates this gendered narrative to her previous experience with a male GP who, via a phone call, stated that he did not believe POTS to be a legitimate illness or diagnosis.

“The doctor on the phone, maybe it made a little difference that he was also a man so, he said, which I thought was really outrageous, he said, “um oh pots is one these things that’s you know, recently invented and he was like it seems very popular for all these young women to get diagnosed with it and basically all women have pots these days and it’s just one of these new–” something like, he definitely said it’s an invention, he said the word invented, 100% and he said something like “all these doctors or consultants just sit around a table and they just decide that this condition existed because women have periods and it just makes them tired or a bit dizzy.”
(Laura)

This narrative particularly highlights that the doctor was referring to POTS as something “all women” have, citing it as a new invention that exists “because women have periods” which make them “tired or dizzy”. Although, once again, we must be mindful that this is Laura’s recollection of the narrative, and things that the doctor said cannot be verified, the way in which Laura has made sense of and recalled this interaction as gender bias and feeling

dismissed *because* she is a young woman are key themes in her experience of speaking with medical professionals.

The creation of anxiety and depression in patients - the trauma of being told you are imagining things: “I started to believe it was all in my head.”

Ironically, the labelling of physical symptoms as psychological appears to have contributed to the *actual* development of mental health issues such as anxiety and depression in many participants. This, of course, then makes an accurate diagnosis of POTS even more difficult as symptoms of panic attacks such as tachycardia and chest pains may be mixed up with POTS symptoms and feelings of fatigue may be amplified or attributed solely to depression.

Ellie describes starting to believe that her symptoms were “all in [her] head”, stating that she kept trying to “rationalise” her symptoms and convince herself that they were not an issue, such as telling herself that the dizziness could be “just natural” and that her tachycardia and fatigue could be because she doesn’t have much “stamina”:

“I started to believe it was all in my head, as daft as that sounds, I was like ‘no, maybe my heart rate isn’t going this high, maybe it’s because I just don’t have as much stamina, maybe it’s because I’m just not doing enough and it’s because I’m not walking as much as I should be and maybe the dizziness is just natural, it’s just a head-rush on standing up’. I kept trying to like, rationalise it in my head.” (Ellie)

This willingness to dismiss and invalidate one’s own symptoms appears to be a characteristic of patients with POTS/EDS who have not yet had an official diagnosis. Again, perhaps because of an impulse to protect oneself from the potential disappointment and trauma of your symptoms still not being able to be explained, it is easier to convince yourself that your symptoms are “all in your head” due to the fear that medical professionals may tell

you that they are. In this sense, Ellie's narrative greatly parallels my own wherein in the months prior to diagnosis (whilst I was waiting for my tilt table test) I frequently found myself trying to "rationalise" my symptoms and convince myself that I might just be exaggerating normal bodily experiences. Looking back on this time I believe now that this was partly a way to subconsciously prepare myself for the possibility of not obtaining a diagnosis or for the consultant to tell me that there is nothing wrong with me or that my symptoms were 'just anxiety' as had happened many times before in my life, and as had happened to many of the participants.

In parallel to this idea, Katie describes an instance where she had a severe migraine and was told the pain she was experiencing was due to anxiety and panic. She was told this by her GP after she had been diagnosed with POTS and when relaying her narrative to me she described feeling as though the doctors dismissal of her pain may have been due to the doctor reading her notes and dismissing her as a hypochondriac once they saw that she was diagnosed with a chronic illness:

"I literally had like a panic attack 'cause I was in so much pain and the doctor had basically been like 'you're imagining it'." (Katie)

Katie stated that she "literally felt like [she] was going insane" when told that she could be simply "imagining" the intense physical pain she was in:

"I literally felt like I was going insane 'cause I was like well, can I...is it possible that I actually am imagining this pain that's more than I've ever felt before?" (Katie)

Although now a highly overused and misused word in popular culture, this experience described by Katie is medical "gaslighting". Gaslighting is a social psychological term that is used to describe manipulation that "causes the victim to doubt their perception of reality"

(Shane et al. 2022, p. 178) and in Katie's case to doubt her perception of the reality of her physical pain. Further to this point, Shane et al. (2022) argue that gaslighting is often used to "contest official narratives" and in this sense, medical professionals are contesting patients' own 'official' narratives and lived experiences by attempting to convince them that they are not physically ill. In support of this point, Laura described her own experiences of contacting medical professionals as "emotional trauma":

Because I've gone my whole life without a diagnosis, I've worked out that I need to pace myself with contacting medical professionals in terms of the admin and the emotional trauma of just simply trying to get medical help. It's so hard. (Laura)

Laura noted that she has noticed, as a part of the POTS and EDS communities, a large prevalence of people with these illnesses who also suffer with poor mental health, perhaps due to the experiences of medical gaslighting that many have to contend with:

"I don't always know if mental health conditions have to go hand in hand with EDS and POTS or is it actually just because it's so misunderstood and misdiagnosed that that means that like people then get such a warped sense of who they are and feeling self doubt all the time, and feeling like you're lazy and putting yourself down."
(Laura)

Furthermore, almost all participants highlighted the difficulty of not having a diagnosis and of the anxiety and depression that often developed due to not understanding why you feel different to everyone else around you, and then the additional anxiety caused by doctors dismissal of symptoms and psychologising of physical issues:

“It’s awful [not knowing what’s wrong with you] and it does then cause anxiety and then the doctors blame the anxiety and it’s round and round in circles.” (Ellie)

*“Yeah, through all my childhood and teenage years I’ve just had this voice in my head like ‘why is everyone else coping so much better? What is wrong with me?’”
(Emi)*

Additionally, Helena describes that she “naively went along” with the idea that her symptoms were due to anxiety:

“I had no idea that it wasn’t normal to be breathless and to have a high heart rate/palpitations all the time!. (Helena)

In addition to psychological causes such as anxiety being blamed for symptoms of POTS (e.g. fainting, high heart rate) in patients, specifically gendered issues such as irregular menstrual periods and anaemia were also spoken about. In fact, Jocie talks about how the explanation of her symptoms being related to her period “made sense” to her, as she had initially posited the idea that her fainting could be due to blood loss:

“I had been on my period at the time [I first fainted] and so when I had an appointment with my doctor, I asked her ‘do you think that my period is why I passed out, like a blood loss kind of thing?’ So she thought that it was because of my period that I passed out so she put me on birth control so that I could have more regulated periods. And that made sense to me.” (Jocie)

Menstrual periods, in particular, are a reason commonly cited by doctors when female-presenting patients complain of issues with fatigue and fainting. This immediately

puts women with illnesses such as POTS at a disadvantage compared to men, as if a male-presenting patient complained of fainting or dizziness, the issue of periods would not be considered as a possibility for the symptoms, thus perhaps accelerating the process to an accurate diagnosis.

NARRATIVE C: THE DIAGNOSTIC ODYSSEY - “Being ill without a diagnosis was the worst thing.”

The final narrative identified in this research was that of a diagnostic journey or ‘odyssey’ having to be undertaken by sufferers of POTS and EDS. Long before beginning this study I was initially struck by how long and difficult my own process of diagnosis had been, and surprised by the amount of people in online support groups I encountered who had had exactly the same experience as me. One may expect a story wherein a child or teenager experiences debilitating symptoms of illness for not just years but decades, without explanation, empathy, or support from medical professionals to be an unfortunate rare experience. However, within the POTS and EDS community of ‘zebras’, misdiagnosis,

invalidation, lack of support, and dismissal of symptoms is an all too common narrative thread that appears. Additionally, among my participants, it was notable that when people *did* have a shorter diagnostic period or struggled less with obtaining answers regarding their symptoms, they were diagnosed by private health professionals rather than the NHS.

Stuck in a Limbo

Helena describes the time between researching her symptoms and self-diagnosing her EDS and getting an official diagnosis from a medical professional as being 'stuck in a limbo'. This is a phrase that resonates with me and my experience of waiting for a diagnosis. Even though I had self-diagnosed as having POTS through extensive research, poor man's tilt table tests at home, and in an unquantifiable way, as Helena describes simply deep down "feeling strongly" that I did have this condition, I still questioned myself often in the lead up to having my tilt table test at the hospital. As Helena describes, she (and I, too) invalidated herself and her experiences by reminding herself that other people who have EDS have it more severely: can it really be that bad if I'm not bedridden or in a wheelchair? Do I really have a disability? Do I really deserve a diagnosis? I believe that this compulsion to play down your symptoms and 'invalidate' your own experiences is a subconscious response to the aspersions of doubt that people cast upon invisible illnesses, therefore prompting sufferers to pre-empt this lack of belief or acknowledgement of the seriousness of their condition. If we are the first to say "it's not that bad" then it is arguably easier to cope with the prospect of other people telling you that.

"Through all that time, I was stuck in limbo feeling strongly that I had EDS but I was always questioning myself about it and reminding myself that the condition is so bad that everyone who has it are in wheelchairs, so I kept invalidating myself and my prior experiences." (Helena)

Indeed, as Sophie states, acknowledgement is a key feature of what invisible illness sufferers want. Multiple participants referred to their quest for a diagnosis as a “fight” or something that they had been “fighting for for years” (Ellie)

“I shouldn’t have to have that fight. It gets so tiring having to have to fight all the time for acknowledgement for any of your conditions.” (Sophie)

“I was actually really happy that I’d got a diagnosis. I know a lot of people when they get a diagnosis are like ‘oh my god this is is awful’ but for somebody that’s been fighting for ten years I was just so happy that I felt like finally somebody’s listened to me, there /is/ something wrong and I can finally help myself.” (Ellie)

For some participants, other diagnoses that they received before being diagnosed with POTS and/or EDS were significant turning points in their illness narratives wherein they realised that although some of their symptoms may fit into their understanding of their “chronic illness life”, “something else was up too.” (Heidi)

“They said once that I had Chronic Fatigue Syndrome. And then they said that that was overlapping with the POTS. So one doctor said I had Chronic Fatigue Syndrome and POTS and then the ones that say “no you’ve just got POTS, and then you’re quite fatigued as part of the POTS. So it’s like, I don’t know if I have Chronic Fatigue Syndrome as well as POTS or whether that chronic fatigue is just part of the POTS if that makes sense.” (Rebecca)

“I know when the rheumatologist diagnosed me with EDS and fibromyalgia at the same time I was like, “Can you diagnose both of them? Like in the same person at the same time.” She was like, “yes, you’ve definitely got both” and I was like, “okay,

then if you say so and you're a rheumatologist, then I've got both." But to me, I think that I have fibromyalgia symptoms because I have EDS and that's causing the symptoms. That means I reach a diagnosis of fibromyalgia, if that makes sense."

(Rebecca)

Here Rebecca expresses doubt at her diagnosis of fibromyalgia but defers to the rheumatologist simply due to their position of medical authority, "okay, then if you say so" but still sounds doubtful about the accuracy and validity of the diagnosis, asserting that she thinks it is more likely that it is her EDS causing fibromyalgia-like symptoms. This is of particular concern as *ehlers-danlos.org* (2022) states that the physiotherapy exercises and treatment protocols commonly given to fibromyalgia patients could cause harm if not specifically adapted for a hypermobile individual.

Other participants, such as Jocie, spoke of receiving numerous incorrect diagnoses, being given multiple labels and reasons to explain her symptoms over the years but conceding that the doctor "must" be correct:

" [The doctor said] when you're in a hot shower because you're too hot and that's why you keep feeling dizzy and that's why you keep passing out. And I was like 'yeah but it doesn't just happen in the shower, it's like randomly at other times, it just always happens in the shower'. [...] Like it's not just the shower when it happens, it's happens in this situation and this situation, like I just get dizzy a lot and he was like 'no, it's the shower thing' and I was like '...okay, well what do I know?' And went home and thought, that must be reason that I have issues." (Jocie)

Whilst multiple participants spoke about feeling "fobbed off" by doctors when attempting to obtain a diagnosis. Feeling dismissed was a significant theme throughout the interviews,

with the dismissal of medical professionals often resulting in patients dismissing their symptoms and experiences themselves.

Diagnosis as a Positive

However, leading on from this theme, in opposition to the negative feelings largely associated with the label of 'disabled', as discussed previously, the label of having an official diagnosis was seen by participants as a positive. Out of all 12 participants, none described their final accurate diagnosis of POTS and/or EDS as a negative event.

“I find for me personally, having a diagnosis isn't like, it's a label but it's a useful label that I can actually do something with and get treatment for.” (Laura)

“The GP talked about how it's bad to label yourself and how it can be a burden and I was like “actually I find labels quite helpful because I can use them.” (Laura)

Further to this point, Laura spoke of the way in which a diagnosis to her feels like an answer to questions and symptoms she has had her whole life.

“But for me I've found that the more labels I get, the better I feel because I've had these symptoms my whole life. My whole life I've had these questions about POTS, EDS, Autism, gastro things, essentially that whole list. I've had so many questions and now I'm starting to get answers.” (Laura)

The conclusion to which most participant's illness narratives built tended to be that of the point of diagnosis. All respondents reported diagnosis as ultimately being a positive event for them, despite the conflicting feelings this may produce. The most commonly reported emotion when being accurately diagnosed was that of relief.

*“I remember when I got the POTS diagnosis I felt this **huge sense of relief**. Me and Mum were at the hospital and we were just so happy to finally have an answer. To have an answer for all of these seemingly unrelated symptoms - we were just so happy. [...] It was just this huge sense of relief, it was positive. You know, there’s not a cure but there is management of symptoms out there and it was just such a relief.”*
(Rebecca)

*“It was **such a relief** to get an actual diagnosis explaining at least a part of what was up.”* (Heidi)

Additionally, participants reported their eventual diagnosis causing things to ‘make sense’.

It made sense [getting the POTS diagnosis] and I think it was kind of nice to be like ‘oh, wait a second, I wasn’t just like difficult at school’. (Katie)

As Katie mentioned here, she experienced an implied sense of relief that she wasn’t just ‘difficult’. Laura reports a similar feeling, using the same terminology of having felt and told like she might have been ‘just being difficult’ and also that she often feels like she is just ‘lazy’. In terms of my own diagnosis of POTS I feel a similar sense of an official diagnosis being something that “really helps” with self-worth and mental health issues that as Laura describes were “ingrained” into us. When a diagnosis is given and a label acquired the tormenting question of: “what is wrong with me? Why do I find everything so much harder than everyone else?” is finally answered accurately. For me, and for Laura too, prior to a diagnosis that question was often answered by a self-critical voice in our heads that replied “you’re lazy. You’re weaker than everyone else. You’re not trying hard enough,” and unsurprisingly, this inner voice seems to frequently grow into clinical depression and anxiety for chronic illness sufferers.

“And like, with my POTS, even though I don’t have medicine for it yet, now that I know what it is, you know like my parents understand [...] whereas before people would be like ‘you’re just being difficult’. And it feels better for myself as well because I often have this feeling of like I’m lazy? And it really helps with that. (Laura)

In contrast to the anguish caused by a lack of a medical diagnosis experienced in patients with POTS and EDS diagnosis for other illnesses may be seen in a different light. For example, when studying illness narratives of men who had prostate cancer it was found that the diagnosis of prostate cancer in particular caused many men to search for what it meant to them to be a man, when faced with the prospect of failing bodily functions, with the news of a diagnosis symbolising a part of their identity being taken away from them (Schultze et al., 2020). However, in my research, it can be seen that for young chronically ill women the story around being given a diagnosis - and what that symbolises for them - is often framed in a positive light.

“I was actually really happy that I’d got a diagnosis and I know a lot of people when they get diagnosed with something are like “oh my god, this is awful” but for somebody that had been fighting for ten years I was just so happy that I felt like finally somebody’s listened to me, there is something wrong, and I can now help myself.” (Ellie)

Rather than something being taken away from them or a part of their identity being lost, for chronically ill people who have struggled to be believed and heard regarding their symptoms, a diagnosis can feel as though you are gaining something back in your life, and a part of your identity is finally being validated. Whilst more sudden, acute illness and disease diagnoses may represent a part of your body changing and failing as Schultze et al. (2020)

described, for chronically ill people it can be an *acknowledgement* of the fact that your body is failing in some aspect that is desired.

“I was ill anyway, I couldn’t control that and that was not my fault, that was not within my control and diagnosis is a positive thing [...] Being ill without a diagnosis is really hard when you have no idea what’s going on. Being ill without a diagnosis when you know what it is is really hard because people don’t believe you. Diagnosis is important.” (Rebecca)

As Sophie mentioned, *“Once you get the diagnosis, you’re kind of looking back and going ‘oh, okay that completely answers that’ or ‘that explains why I always felt like that’”* showing the way in which a diagnosis can reconstruct and make sense of past experiences, thus positively affecting one’s identity and sense of self, rather than detracting from it. Additionally, for POTS and EDS patients, a diagnosis does not seem to be personified and attributed blame for symptoms in the same way that cancer diagnoses are often described. Perhaps because of the length of time that people with POTS and EDS have been ill before being diagnosed they do not see the label of POTS or EDS itself as a negative that is intrinsically tied to the symptoms of illness they experience, but instead as a positive end goal that will help them to make sense of their life and body. As Rebecca previously stated she *“was ill anyway”* and a diagnosis was not going to be the cause of her symptoms, but rather an answer and *“a positive thing”*.

However, even once obtaining a diagnosis, many participants spoke of still having issues of self-worth, and feeling like a burden in their everyday lives. For example, negative descriptors such as *“faulty”* and *“broken”* were used by Helena when talking about herself, perhaps making diagnosis a double-edged sword:

*“I feel that it affects your self-worth too. **You feel like you’re faulty/broken goods and you don’t want to burden someone with what you’re dealing with.***

Especially with social media, going to the gym and living a physically active lifestyle seems to be attractive, so who would be interested in dating someone who spends most of her time at home!” (Helena)

Helena spoke of social media and comparisons she made between herself and her life and the lives of others she saw on social media as an additional source of anxiety and lack of self-worth, highlighting the ways in which she placed an internal pressure upon herself by believing that unless she was acting as though she had a normative body (e.g. living a physically active lifestyle, not spending “most of her time at home”) she would not be of “interest” to anyone romantically. A similar issue was mentioned by Megan too wherein she discussed social media as a point of comparison between her and other people’s lives:

*[...] And then when you compare yourself to people you see on social media and the lives that they’re living, again, it does make you feel like **you’re a burden and you’re not doing what you should be doing.** (Megan)*

Comparison to able-bodied people creates a sense of anxiety that, as Megan states, “you’re not doing what you should be doing.” Furthermore, multiple participants spoke of not wanting to “burden” family, friends, or partners, using the word as a negative self-descriptor. Megan said she felt like she was “this massive burden”. Her framing of the narrative in this way personifies herself as the problem, rather than attributing the negative description to the illness she has. It is also notable that she talks of the way in which she feels her family has to “sacrifice” parts of their life due to her illness:

*My family, for example, are very very supportive but so much of our holidays and general life were focused around what I was able to do. **I’ve then felt like I am this***

massive burden, because I've not only lost all my friends, been treated badly in relationships, but now my family, the people that had stuck around are now having to sacrifice parts of their life just to make life easy for me. It does make you feel very small. (Megan)

In her narrative she speaks of this idea in terms of her support system having to do this “just to make life easy” for her. The use of the word “just” downplays the importance of her own health and comfort, portraying a sense of guilt that she feels surrounding her illness. Furthermore, I would argue that family looking after or trying to accommodate someone’s chronic illness is not something that will make their life “easy” but rather tolerable and manageable. To sum up, this wording arguably highlights an issue of a lack of self worth regarding one's own quality of life, and anxiety surrounding others perceptions of POTS and EDS that undoubtedly, over time, leads to poor mental and emotional health.

Narrative of the Expert Patient: “*The problem is I am teaching my doctors what my medical problems are.*”

Finally, many participants indicated a sense of feeling as though they had to teach doctors about their own illness. As discussed previously, the idea of an ‘expert patient’ is a term used by the NHS to refer to ‘self-management’ of a patient's own chronic illness Tattersall, 2002, p.227 In the case of POTS and EDS, these are relatively rare conditions that have little research conducted into them as a whole (Raj et al., 2021) Therefore many doctors have not heard of POTS and/or EDS and as such, during interviews it was highlights that it was important for patients to “advocate” for themselves:

“It's so hard to advocate for yourself to get the treatment and support you deserve.”

(Helena)

“I’d researched POTS a lot more and you know, again, prepared that whole court case of how to navigate it if they’re gonna be dismissive.” (Laura)

In this sense, I propose a sociological application of the NHS term ‘expert patient’ to mean, more broadly, the process by which some chronically ill patients, not only ‘self-manage’ their own condition in terms of treatment, but accurately self-diagnose too. Self-diagnosis is a point of contention for many healthcare professionals. For example, it was found that less than 5% of healthcare providers ‘find internet self-diagnosis helpful’. Certainly, there appears to be a sense of invalidation linked to having used the internet to research your own symptoms and self-diagnose. During my own tilt table test for example, the consultant cardiologist asked me why I felt that I had POTS. When I described my symptoms and said that I had researched the condition extensively online and that all the symptoms fit me exactly, he could barely conceal a roll of his eyes. I recall him stating that “we mustn’t jump to conclusions” and that anxiety could cause breathlessness and a racing heart beat, as though, at 22 years old, I had never been told that before. Although the process of the TTT was not enjoyable, I did - as participants also described - feel a sense of validation, relief, and even vindication when the heart rate monitor showed clear tachycardia and hypertensive crisis simply from being raised upright. As stated, for other POTS patients too, a diagnosis was not just a sense of relief but also a sense of validation and vindication:

“When I finally got the EDS diagnosis it was a huge relief, it was like I have known this for years, I have known this and known this and known this and I’ve told everyone this and it’s finally finally validated and I was right. For all these years I was right.” (Rebecca)

Ellie described a similar sense of thinking “*for all these years I was right*” after receiving her diagnosis, making a point to distinguish between the significance in the difference of ‘wanting’ and ‘needing’ a diagnosis:

“[When I got the diagnosis] I truthfully felt like just going to the GPs and pushing the letter in their face and saying “I told you!”. Truthfully, that’s how I felt. I was so happy just to get that diagnosis because I knew then I was going to get some help. That was all I wanted. I mean, I didn’t want the diagnosis, nobody wants a diagnosis of anything, but I needed that diagnosis to be able to move forward and I knew I did.”

(Ellie)

Indeed, it is an important distinction to make between being pleased or happy or relieved to have an answer to years of unknown symptoms, and being pleased or happy to have an illness. In conclusion, overall in the illness narratives collected, and in my own experience, an official diagnosis for POTS and EDS and being able to put a name to the symptoms i experienced was, ultimately, immensely helpful, showing that diagnosis can help to combat the sense of distress caused by medically unexplained symptoms by providing a sense of legitimacy to the patients suffering instead.

Chapter V: Conclusion

In this final chapter I will summarise the findings of my study, the implications for future research, and briefly discuss the potential limitations and improvements that could be made to this research. To review, the key findings of this research were collated and formulated into three main narratives that I identified during the transcription and analysis stage. These narratives ran across the datasets and were comprised of common thematic occurrences in the storytelling of participants' interviews. The first narrative theme of *Invisible Illness* was identified due to the way in which many participants highlighted the specific issue of 'not looking disabled' or ill in the eyes of family, friends, and society as a whole. Many participants spoke of the distress and conflict that living with an invisible chronic illness that is often seen as a 'low-status condition' caused them. Not visibly looking 'ill' and also due to assumptions of health being tied in with being a young woman appears to often result in a lack of empathy, compassion, and support for sufferers of POTS and EDS. Participants worried about coming across as 'hypochondriacs' - and in some cases, participants told

stories of how medical professionals had outright labelled them as such. This narrative led on to another common theme that emerged during interviews and subsequent analysis: the psychologising and gendering of symptoms.

The Myth of the Hysterical Woman was named as such due to the striking parallels between the ways in which women have historically had physical symptoms such as fatigue and pain dismissed as 'hysteria', and the ongoing lived experiences of modern women today who are misdiagnosed with anxiety or told they are imagining their symptoms. With illnesses such as POTS and EDS this appears to be a particular issue due to how heavily gendered these conditions are. For the young chronically ill women in this study, negative experiences with healthcare providers (predominantly general practitioners) were experienced by all participants. Accurate diagnoses, treatment, and care was only achieved by 1) the women taking on the role of 'expert patient' to research their own symptoms, self-diagnose and self-advocate for the correct diagnostic tests to be performed and/or 2) when a referral to a consultant with knowledge, experience and a specialised interest in POTS and/or EDS was made. Of course, it is unachievable to expect all GPs to have knowledge of every illness - especially conditions such as POTS and EDS where research and awareness is severely lacking. However, the experiences that participants spoke of in their illness narratives, and my own lived experience, perhaps portray a larger issue in the attitudes of healthcare providers (and arguably the NHS and biomedical system as a whole) towards young women with invisible illnesses.

Finally, the narrative of *The Diagnostic Odyssey* was formed after collating a prominent strand of storytelling throughout the participant's illness narrative: the 'journey' - often many years long - of attempting to obtain an accurate diagnosis. Diagnosis was viewed as particularly important, if not the most important factor, to POTS/EDS patients when describing their lived experiences of chronic illness. Diagnosis, in almost every narrative, appeared to be the 'end goal' or conclusion to the story being told. For an acute illness or

injury, or certainly for something commonly life-threatening such as cancer, it is perhaps more likely to be *treatment* or *cure* that is perceived as the most important puzzle piece during the discovery of an illness. The issue of being 'cured' was something that was not present in illness narratives of POTS and EDS as they are incurable chronic conditions. However, this, interestingly, was not mentioned as a negative by participants, such was the relief of a diagnosis and 'knowing what was wrong' with them. The length of time that a typical POTS/EDS patient suffers from symptoms before being diagnosed may contribute to this feeling of a diagnosis being the end goal too, as many participants then felt as though they could then manage their condition on their own. This is an integral issue that I hope to be able to bring more awareness to in the future, as treating chronically ill young women with respect, care, and compassion and - most importantly - believing them when they say that they are ill, is an intervention that could easily be applied to the healthcare system and significantly improve the quality of life for patients.

In conclusion, the overall findings of my study show a significant impact on the mental and emotional health, self-worth, and general quality of life for young chronically ill women. POTS and EDS appear to be unique to other chronic illnesses in some ways. They are, as stated previously, severely underfunded and understudied, leading to a huge deficit of knowledge and awareness regarding their symptoms and treatments, not just from society as a whole, but most worryingly from medical professionals themselves. This lack of awareness consequently leads to a lack of clinical infrastructure to be able to conduct research and medical trials (Raj et al., 2021). Thus we become stuck in a situation wherein there is no true way to know exactly how many people are suffering from POTS and EDS - are they really as rare as one may think? Or are there hundreds, if not thousands of undiagnosed young women who are suffering the confusion, frustration, and anxiety or not knowing what is wrong with them? In future studies, it would be useful to be able to interview a larger number of POTS/EDS patients, to draw out further potential narratives that were

missed by the smaller scope of this research and to build upon the narrative themes already identified in this thesis.

Finally, reflecting on my own lived experience as a chronically ill young woman I find it shocking to realise the extent to which my physical symptoms were psychologised and invalidated over the years. For many years I believed that the doctors must be right and that there was 'nothing wrong with me' apart from anxiety issues and some minor anaemia. I was told by multiple different healthcare professionals, from GPs to consultant psychiatrists that if I could focus hard enough on my breathing patterns and think more positively then I could calm my heart rate down. I was told, and consequently internalised the belief, that I felt psychically ill because I was not mentally and emotionally strong enough to manage my own stress and to calm myself down adequately. I vividly remember a psychiatrist telling my parents (whilst I was in the room) that I was "a tough nut to crack" due to my insistence that breathing exercises and positive thinking was doing nothing to help my sickness, chest pains, and fast heart rate. My hope is that further research and awareness can be brought to the conditions of POTS and EDS and to other invisible illnesses. Further implications for research include illuminating the stories of patients for medical professionals, so that a more empathetic, effective means of care can be given to young chronically ill women in the future with illness narratives being used to inform a more holistic and compassion-centred approach to healthcare.

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APPENDICES

Appendix A - POTS UK Request for Support Ethics Approval



Request for support - application form

Thank you for contacting PoTS UK for support with promoting project/survey/research.

Please complete and send to jo@potsuk.org

Name:	Emi Frane
Job Title:	Postgraduate Research Student
Organisation:	University of York
Address:	Department of Sociology Law and Management Building Heslington East Campus University of York York YO10 5GY UK
Office Tel:	N/A
Mobile:	07518870044
Email:	emi.frane@york.ac.uk

Please clearly detail the aims and objectives of your project/research/survey

Request for support June 2015 v1



The main aim of my research project (undertaken for completion of a Masters by Research (MRes) in Sociology at the University of York) is to illuminate the lived experiences of young women with chronic illness by gathering qualitative data from participants in the form of 'illness narrative' testimonies.

In particular I am focusing my research on the experiences of POTS and EDS as they are illnesses I have personal experience of and are conditions that are very poorly understood and under-researched as a whole. I aim to combat the idea of young chronically ill women being regarded as unreliable narrators in terms of cognition, emotions, and objectivity.

How would you like PoTS UK to help you?	I would be grateful if POTS UK could help me recruit participants for my research project by circulating my participant information sheet via their website/ mailing list/facebook group etc.	
How did you determine the need for this project/research/survey?	There is a lack of biomedical research into POTS and EDS, let alone a lack of sociological research and as someone who has a diagnosis of these invisible illnesses I am acutely aware of how misunderstood, stigmatised, and often ignored these conditions are. From my own experience in support groups and talking to other people with POTS and EDS I've realised how shockingly common it is for almost all of us to have had difficult experiences with getting a diagnosis and with feeling listened to by medical professionals. I want to examine this trend and shed light upon the issue of young women with invisible illnesses commonly being dismissed for years before acquiring a diagnosis.	
If research, do you have ethical approval?	Yes / No / Not needed	
Name of ethics committee	University of York Department of Sociology Ethics Committee	

Request for support June 2015 v1

What is your research methodology?	Collection of 'illness narratives' from participants through the use of informal interviews.	
Will data be collected as part of this project/research/survey?	Yes / No If yes, please give details The data I will be collecting is that of people's medical history and diagnosis (as told in their own words) as this is necessary for conducting my research and collecting an 'illness narrative' from the participant.	
If yes, how will the data be collected?	I will collect data from participants by asking them about their experience of living POTS. Informal narrative interviews will consist of open-ended questions that will serve as general prompts for a discussion about the lived experiences of chronic illness between me and the participant. My goal is to have collected an 'illness narrative' from the participant by the end of the discussion. The length of the interview will be flexible and determined largely by the participant. I will offer the option of participants providing a written account if they would prefer this to an interview. Spoken interviews will be conducted online via Zoom, or if possible/preferred could be conducted in person in a suitable, private space such as a bookable room at The University of York library. Auto-ethnography will be used in conjunction with narrative interviews in order to also convey my own illness narrative and gather data from it.	

Request for support June 2015 v1



Is data anonymised?	Yes / no / pseudonymised The narrative interview/written accounts will take place solely between the participant and me (the researcher) in a private setting (either via video call or in person if plausible in a bookable private room at the University of York). The conversation will be recorded with consent and transcribed by myself. Once transcribed the audio will be deleted. The information participants provide will only be viewed by me (the researcher) and my thesis supervisor (Professor Ellen Annandale). The participants' personal identity, information, and any place names or names of people will be anonymised in my thesis to ensure confidentiality for extracts used in the thesis. The interview data will be kept on a password protected computer and the audio files will only be accessible to me via a password protected computer.	
If a survey, how will you be inviting people to participate?	N/A	
How will the data be analysed?	I will conduct a narrative analysis/inquiry of the illness narratives that I collect from participants whilst also relating the data to my own auto-ethnography in order to gain a full, deep, and thorough understanding of the similarities and differences in the lived experiences of POTS/EDS patients. Narrative analysis will be useful to see how participant's create an understanding of their own illnesses and how they make sense of their own 'illness narrative'. I will also analyse the data collected from an interpretivist/ social constructionist perspective and feminist theoretical standpoint in order to embody and make sense of voices and perspectives that are often marginalised in society.	
How will the results be promoted/published?	Results will be written up in my final masters thesis project (25,000 words). This will be completed by December 2022. In the future I hope to be able to work with my academic supervisor to perhaps produce an executive summary or article based on my results that may be presented to academic publications, presentations etc.	

Request for support June 2015 v1



What are the proposed start and finish dates?	April 2022 - Interviews with participants (Project as a whole started September 2021 and will be complete December 2022)	
Are you looking for financial support from PoTS UK?	Yes/No. If yes, what sum of money are you asking PoTS UK to donate to your project? What will it be used for? -please provide detail of proposed costs. If yes, have you applied for any other grants or funding Have any applications been successful? Please provide details *Please note you may be required to refund any money received if you do not complete your project.	

Date application form submitted	12/03/22
Project outline/ survey questions /research proposal attached	Yes / No / NA

Request for support June 2015 v1



Any other supporting documentation attached	Yes / No / NA
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To be completed by PoTS UK

PROCESSORS

Name of person receiving	
Role within PoTS UK	
Date received	
Ref number	
Proceed to full review?	YES / NO (give reason if no)
For review by	PoTS UK Trustee/ Medic/other
Lead reviewer if applicable	
Date sent for review	

Request for support June 2015 v1



REVIEWERS

Name	
Role	
Of benefit to PoTS Community?	YES / NO
Comments	
Consistent with the aims of PoTS UK?	YES / NO
Comments	
If research is this credible	YES / NO / NA
Comments	
If survey is this fit for purpose	YES / NO / NA
Comments	
If project is this fit for purpose	YES / NO / NA
Comments	
If seeking financial support is this viable for PoTS UK?	YES / NO / NA
Other Comments/Outcome	

Request for support June 2015 v1



Approved	YES / NO
Date Approved	

Request for support June 2015 v1

Appendix B - University of York Ethics Approval Certificate

2021/22



This certifies that

Emily Alice Frane

has obtained approved research methodology for
their thesis following the ethics approval process
in the 2021/22 academic year



Dr. Peter Gardner
Ethics Committee Chair

Appendix C - Participant Information Sheet

Participant Information Sheet: *Illuminating the Lived Experiences of Chronically Ill Young Women*

I would like to invite you to take part in a research study. This Participant Information Sheet explains why this research is being conducted and what it would involve for you should you choose to participate.

Please read all the following information carefully and consider if this study is suitable for you and if you would like to take part. If you have any questions, concerns, or require additional information or clarification please do not hesitate to contact me at emi.frane@york.ac.uk

Who am I and what is this research project about?

My name is Emi Frane and I am a postgraduate research student at the University of York. I am carrying out a research project that will constitute my Masters by Research in Sociology. My project aims to illuminate *The Lived Experiences of Chronically Ill Young Women*, specifically by collating the experiences, opinions, and stories of female Postural Orthostatic Tachycardia Syndrome (POTs) and/or Ehlers-Danlos Syndrome (EDS) patients aged between 18 and 35.

Why do I want to do this research?

I myself am a young woman with POTs and EDS, and as such I am aware that they are rare chronic conditions that disproportionately affect young females and that we significantly lack research, awareness, and understanding within the biomedical and social science research and wider society.

I am particularly interested in the way that these conditions seem often to present as "invisible disabilities" and what this means for young women's experience of having a chronic condition that is not necessarily physically visible or widely recognised, I am also interested in how this may impact mental health.

Aims of the research:

- To make sense of and explore young women's experience of chronic illness in their own words.
- To feed back study results to health care practitioners to support the development of patient-centered care.
- To foreground the voices, experiences, and stories of people in the POTs/EDS community which are often unheard.

What will taking part involve?

Taking part in this research is completely voluntary. If you do decide to participate I will be gathering information from you in your choice of either in an informal interview or by you writing answers to my questions. My aim is to collect rich, detailed accounts of young women's experiences, such as interactions with healthcare professionals and the impact of POTs and/or EDS on everyday life.

Requirements to take part:

- You must be either i) diagnosed with POTs and/or EDS or ii) strongly suspect you have POTs and waiting for a tilt table test referral and diagnosis.
- You must be female.
- You must be aged between 18 and 35 years old.

You will be able to choose whether you would prefer to:

- a) Write responses to the questions I send you via email or a simple word document format. This would take an amount of time determined by you, the participant, depending on how much you feel comfortable writing. You could also complete these questions over a number of weeks if needed.

OR

- b) Respond to the questions by speaking to me in an informal interview via video call (or in person in a private bookable study space at The University of York if feasible). The interview time would largely be determined by you, the participant, but I anticipate that on average the interview would be approximately an hour.

Because I also have POTs and EDS I aim for the research to be more of a collaborative discussion between us about our experiences of living with POTs/EDS rather than a formal interview.

I will have a list of open-ended questions to ask you that can direct the conversation, but any topic that you wish to discuss regarding your lived experience of chronic illness can be explored.

What are the benefits of taking part?

My aim is to highlight the voices of patients in research as I believe we can know as much or more about our condition than the 'experts', and that believe our knowledge and experiences are just as valuable as that of doctors. In the future I hope for my research to potentially be able to make a contribution to the way in which the treatment and care of young women with chronic conditions and invisible illnesses is approached. I would like to bring a more patient-centred, holistic, and sociological approach to solving some of the

issues young chronically ill women currently face by feeding back some of the results of this study to practitioners. Your participation will be invaluable to my research and I want to give you the opportunity for your voice to be heard.

IF YOU ARE ELIGIBLE AND WOULD BE INTERESTED IN TAKING PART IN MY RESEARCH PLEASE SIMPLY CONTACT ME WITH AN EXPRESSION OF INTEREST AT:
emi.frane@york.ac.uk

Thank you so much for your time!

Appendix D - Informed Consent Form

INFORMED CONSENT

Please tick the boxes to confirm your understanding:

- I am between the ages of 18 and 35
- I understand that my participation in this research is entirely voluntary
- I understand that I am free to withdraw from this research at any time
- I understand that my participation will be anonymous and confidential
- This research has been explained to me and I've had the opportunity to ask questions or for more information if needed

For written responses: The initial information I provide will only be viewed by Emi Frane (the research student) and my MA thesis supervisor (Professor Ellen Annandale). If any extracts from my response are used or quoted in the final in the thesis and potentially in academic publications and presentations my personal identity, information, and any place names or names of people will be anonymised in my writing to ensure confidentiality. The written response I give will only be accessible to Emi via a password protected computer.

For spoken responses/interviews: The conversation/unstructured interview that I participate in will take place between me and Emi Frane (the research student) in a private setting (either via video call or in person if plausible). The conversation will be recorded via Zoom and transcribed, and once transcribed the audio will be deleted. The initial information I provide will only be viewed by Emi and the thesis supervisor (Professor Ellen Annandale). If any extracts from my interview are used or quoted in the final research and potentially in academic publications or presentations my personal identity, information, and any place names or names of people will be anonymised in my writing to ensure confidentiality. The audio file will only be accessible to Emi via a password protected computer.

I consent to take part in this research
 (participant signature/name)

Date

MASTERS RESEARCH: PARTICIPANTS NEEDED

**ARE YOU A WOMAN AGED 18 - 35
WHO HAS (OR IS WAITING FOR A
DIAGNOSIS OF) POTS AND/OR EDS?**

I WOULD GREATLY APPRECIATE BEING ABLE TO
CONDUCT AN INFORMAL INTERVIEW/DISCUSSION
WITH YOU ABOUT YOUR EXPERIENCES OF
CHRONIC ILLNESS (CAN BE ONLINE, IN PERSON OR
WRITTEN E.G. VIA EMAILS IF YOU DO NOT WISH TO
SPEAK TO ME DIRECTLY)



I AM A RESEARCH MASTERS STUDENT AT THE UNIVERSITY OF YORK AND I
HAVE POTS AND EDS MYSELF. I AM LOOKING FOR OTHER YOUNG WOMEN
TO INFORMALLY INTERVIEW ABOUT THEIR EXPERIENCES OF CHRONIC
ILLNESS. MY HOPE IS THAT THIS RESEARCH WILL RAISE AWARENESS OF
THESE CONDITIONS AND GIVE A VOICE TO THOSE OF US SUFFERING
FROM THEM.

If you are eligible and interested please
contact: Emi Frane

emi.frane@york.ac.uk

If you would like more information or have
any questions please do not hesitate to
contact me! Thank you so much for
reading.

**MASTERS RESEARCH
PROJECT:
"ILLUMINATING THE
LIVED EXPERIENCES OF
CHRONICALLY ILL
YOUNG WOMEN"**

UNIVERSITY *of* York

