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“There’s no one-size-fits-all kind of solution”: An interpretative phenomenological analysis of the experiences of autistic individuals living with Ehlers-Danlos syndrome

Rhoslyn Beckwith [*,1], Danielle Stephens-Lewis [2]

University of Gloucestershire, Francis Close Hall, Swindon Road, Cheltenham, Gloucestershire, UK

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ABSTRACT

Objective: Approximately a third of individuals live with multiple health conditions and this number is rising. Research suggests that living with a chronic condition can profoundly impact upon one’s life and identity, however little attention has been paid to the experiences of those with multiple conditions. Ehlers-Danlos syndrome (EDS) is a rarely-diagnosed connective tissue disorder causing extensive debilitating symptoms and while these symptoms are primarily physical, EDS often co-occurs with autism. This study sought to gain insight into the experience of autistic individuals living with EDS and thus investigate how illness identity occurs with multiple conditions.

Design: Interpretative Phenomenological Analysis (IPA) was used.

Methods: Semi-structured interviews were conducted with four autistic women living with EDS.

Results: Analysis resulted in three superordinate themes, consisting of ‘Transformation,’ ‘Making sense,’ and ‘The negatives.’ While interrelated, these themes capture the ways in which the conditions have changed the participants’ lives, both positively and negatively. Furthermore, they capture how the participants make sense and create meaning in their new identities.

Conclusion: Individuals living with co-occurring conditions have multiple illness identities which affect their overall sense of self. Within this study, participants incorporated both conditions into their new identities, although the extent to which they rejected or accepted these conditions varied individually based on numerous biopsychosocial factors, which shifted continually, including healthcare professionals’ attitudes and awareness of conditions, stigma, finding community and symptom severity. Thus, illness identity is in a constant state of flux. These findings highlight the need for more individualised, supportive care for autistic individuals living with EDS.

What this study adds?

- This study offers insight into illness identity amongst an often-overlooked population, those with multiple conditions.
- This is the first study to examine how autistic individuals with EDS experience identity when living with these diagnoses.

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* Corresponding author.
E-mail addresses: rhoslynb@yahoo.co.uk (R. Beckwith), dstephenslewis@glos.ac.uk (D. Stephens-Lewis).

[1] https://orcid.org/0000-0002-4051-7608

[2] https://orcid.org/0000-0001-6694-9954

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- Illness identity is constantly in flux for those with multiple conditions and this is based on numerous biopsychosocial factors.
- More individualised and personalised support is needed for those living with autism and EDS.

1. Introduction

Ehlers-Danlos syndrome (EDS) refers to a group of heritable connective tissue disorders affecting the body's collagen (Malfait et al., 2021). Symptoms include joint hypermobility, dislocations, poor wound healing, skin elasticity, gastrointestinal symptoms, gynaecological issues, fatigue, pain and organ and blood vessel fragility (Brady et al., 2017; Ghali et al., 2019; Malfait et al., 2017). While 14 subtypes of the condition have been identified, currently genetic testing can only identify 13 (Malfait et al., 2020). The most common sub-type, hypermobile EDS (hEDS), accounting for 90 % of cases (Tinkle et al., 2017), remains only diagnosable through clinical examination (Malfait et al., 2017). Furthermore, while EDS is a rarely-diagnosed condition (Van Doren, 2023), recent studies suggest that the condition may affect up to 10 people in every 5000 (Demmler et al., 2019), with approximately 70 % of cases being females (Demmler et al., 2019). However, medical professionals' knowledge around EDS remains scarce, contributing to delays in diagnosis (Langhinrichsen-Rohling et al., 2021). Resultantly, diagnosis can take an average of 14 years, with over half of individuals receiving misdiagnoses (Demmler et al., 2019). Furthermore, EDS is associated with multiple comorbidities, including anxiety, eating disorders and depression (Bulbena et al., 2017). Autism is also reportedly common among the EDS population, although a link frequently missed due to the conditions being assessed by different specialists (Baeza-Velasco et al., 2018). Nevertheless, research suggests that individuals with EDS are 7.4 times more likely to be autistic than peers (Cederlöf et al., 2016). Such findings are particularly important given that living with both conditions has also been linked to heightened psychological distress (Rocchetti et al., 2021).

Autism or autistic spectrum condition (ASC) is another complex condition (Csecs et al., 2022; Lord et al., 2020), characterised by differences in social communication, repetitive behaviours, particularly focussed interests and sensory issues (Rosen et al., 2021). Affecting approximately 1 in 100 people (Hodges et al., 2020), while public perception suggests that autism is more common amongst males than females, the gender ratio may be closer to three to one, than four to one, as previously reported (Loomes et al., 2017). Women and girls often miss being diagnosed, or are diagnosed later in life, because of the different presentation of female autism (Rynkiewicz et al., 2019). Furthermore, young autistic girls seem to be more aware of societal pressures and a sense that they must 'fit in', camouflaging or 'masking' their autistic traits to mimic their peers (Carpenter et al., 2019; Rynkiewicz et al., 2019). Importantly, this lack of diagnosis and support, as well as pressures associated with masking, can significantly impact the mental health of females (Rynkiewicz et al., 2019). Furthermore, despite advancements, stigma around the condition remains, with many considering autism an impairment (Botha et al., 2022). Nonetheless, there is increasing awareness around neurodivergence (Meulien & Baghdadli, 2024), with the term neurodivergence functioning as a shift from a deficit approach to highlighting neurological differences (Grinker, 2020). Subsequently, responding to such a movement, this article uses identity-first language (Bottema-Beutel et al., 2021).

Living with chronic conditions like EDS or autism has a profound effect on an individual's life, their ability to function, as well as on their sense of identity (Oris et al., 2018; Van Bulck et al., 2019). Since the 1980s researchers have been interested in how chronic conditions affect identity (Bury, 1982; Charmaz, 1983). Early theories refer to the way in which chronic conditions herald a "loss of self" (Charmaz, 1983, p. 168), highlighting how lives are narrowed and restricted by illnesses. Furthermore, chronic conditions create a "biographical disruption" for individuals (Bury, 1982, p. 167) in that one's world is changed because of one's condition and one's plans for the future have to be adjusted in light of one's new unwell role (Bury, 1982). More recently there has been a move towards considering how chronic conditions can also lead to positive consequences for individuals, using the concept of "biographical illumination" (Tan, 2018, p. 161). This term captures the transformative and enriching impact of chronic conditions, offering insight into identity and giving one's life new meaning, as well as potentially helping the individual find community (Tan, 2018). However, neither of these concepts captures the experience of those living with multiple conditions, which may be accepted or rejected in different ways. The nuances and fluctuating ways in which individuals can experience their identity in response to their environment, symptoms and contexts are also overlooked within these two concepts.

Studies have examined what it means to live with illness identity for single conditions, including cancer (Palmer-Wackerly et al., 2018), and chronic fatigue syndrome (Murray & Turner, 2023), but little attention has been paid to those with more than one condition. This is noteworthy given that around one third of the global population currently lives with multiple chronic conditions (NICE, 2023), with numbers increasing (Skou et al., 2022). Furthermore, even within the literature on single conditions, limited insight is provided around the nuanced navigation of illness identity, relying instead on quantitative approach focused on strategies for self-management (Thomas-Purcell et al., 2019). Thus, the voices of those living with multiple conditions are seldom heard.

Better understanding of illness identity for those with chronic co-occurring conditions is essential, particularly given that the different ways of experiencing illness identity can significantly impact upon illness severity and quality of life (Oris et al., 2018; Van Bulck et al., 2019), Subsequently, this study sought to examine the lived experience of autistic individuals with co-occurring EDS. Specifically, it aimed to provide insight into how individuals create meaning around their condition identities (Corrado & Ciardi, 2018; Reychler et al., 2021).

2. Method

Interpretative Phenomenological Analysis (IPA) (Smith et al., 2022) was employed in examining the experiences of four autistic women living with EDS. IPA was deemed appropriate in addressing the aims of this research, given its use in capturing the nuanced ways in which individuals make sense of their lived experiences (Cooper et al., 2022; MacLennan et al., 2022; O'Mullan et al., 2019).

2.1. Participants and recruitment

After receiving ethical clearance from the authors' UK university Ethics Research Panel (NSSS.PSYC.02042401), the first author recruited participants through the charity Ehlers Danlos Support UK in April 2024. The advert specified that participants must be over 18 with a diagnosis of both EDS and autism. While there was no requirement that the participants shared the same gender identity or the same type of EDS, the four participants all identified as female and were diagnosed with hypermobile type EDS (Smith et al., 2022). See Table 1 for demographic details of the participants.

2.2. Interviews

A semi-structured interview schedule was developed, with questions focussed on perceptions of autism and EDS, symptoms, impacts on the participants' wider lives and asking to what extent the two seemingly separate conditions influence the participants' sense of selves in different and similar ways.

The first author sent each interviewee the participant information sheet, a consent form, and a copy of the interview schedule before the interview, reflecting best practices increasingly employed to better support autistic populations (Norris et al., 2020). At the beginning of each interview informed oral consent was taken. The first author conducted the interviews using Microsoft Teams. All but one interview were recorded on Teams and the recorder function of the researcher's mobile phone. The final interview was recorded only with the phone's recording device at the participant's request.

While both authors identify as autistic and live with EDS, this was not initially revealed to participants. However, following feedback from the first interview that this information could have enabled the participant to feel more comfortable in sharing her experiences, the first author and interviewer disclosed her own experiences of being autistic and living with EDS before the three remaining interviews. Following a discussion between the first and second author, it was felt that providing this information could help to lessen the unequal power dynamic between interviewer and interviewee to a certain extent, as well as to ensure that the participants felt safe to share their experiences without judgement.

2.3. Analysis

Interviews were transcribed using Jefferson transcription conventions (Jefferson, 2004). The first author led the analysis, creating a pen portrait of each participant to retain a sense of what was notable in each interview. Subsequently, the seven stages of IPA as outlined by Smith et al. (2022) were performed. Stage one involved immersion within the first dataset, through the repeated reading of the transcript. In stage two the first author conducted detailed line-by-line textual analysis of the initial transcript, making exploratory notes about what was striking from the data (e.g. 'Feeling let down by services' or 'she was powerless and voiceless'). In stage three succinct experiential statements, relating to the participants' experiences of their conditions and diagnoses, were drawn from both the exploratory notes made in stage two and the transcript itself (e.g. 'the importance of specialists with awareness' and 'becoming an advocate due to her condition'). Connections between the experiential statements were then noted in stage four, creating clusters (referred to as Personal Experiential Themes of PETs) around particular themes. In stage five, the PETs were organised into a table and named with titles reflecting the overall meaning of the cluster (e.g. 'diagnosis as life-changing' and 'feeling at the mercy of her body').

At each stage, in line with IPA's reflexive approach, themes were moved, re-assessed, occasionally discarded and retitled. Stage six involved conducting steps one to five afresh for the next participant's transcripts. Stage seven involved gathering the PETs from the entire group and using these to create a set of Group Experiential Themes (GETs) (e.g. 'Transformation' and 'Making Sense'). These GETs allowed the researcher to identify the individual, shared and diverse experiences of the participants, capturing the nuance, commonalities and differences. Across this process, coding and themes were discussed with the second author to ensure credibility of the analysis.

2.4. Reflexivity

The lead author kept a reflective journal to reflect on how she was affected by the research and consider her own impact upon the data throughout the process, from the conception of the project, to creating the interview schedule, conducting the interviews and then engaging with the analysis. As both authors share the same diagnoses as the participants, they were aware that this could impact upon their reading of the data. By engaging in reflexivity, the first author was able to identify any areas of commonality she shared with the participants and potential for bias. This was then discussed with the second author to prevent colouring the data with the first author's

Table 1
Demographic information of participants.

Participant	Age	Subtype of EDS	Age at diagnosis of autism	Age at diagnosis of EDS
Rita	41	hEDS	37	35
Maryam	50	hEDS	43	34
Emmy	54	hEDS	[a]	52
Ada	57	hEDS	54	56

[a] Participant 3 Emmy – This participant self-identified as autistic but had chosen not to pursue a diagnosis.

experiences. The reflective journal also allowed the first author to remain continually conscious of the double hermeneutic (Smith et al., 2022) central to IPA, where the researcher makes sense of the participant's own sense making.

3. Results

Analysis resulted in three superordinate themes; 'Transformation' with two subthemes, 'Making sense' with three subthemes and 'The negatives' with two subthemes (See Table 2).

3.1. Theme one: transformation

This theme explores how the discovery and diagnosis of the participants' autism and EDS created a "biographical disruption" (Bury, 1982), changing their lives and offering a new sense of identity. The two sub-themes 'Diagnosis as life-changing' and 'Being unlike the others' demonstrate the shift in the participants' lives in the light of their diagnoses and symptoms, as well as how their self-perception has been changed by receiving these new labels. Life seems to have changed greatly due to their illness experiences and yet there remains a need to be considered as distinct and individual, not just typical of these conditions.

3.1.1. Diagnosis as life-changing

For Ada, the experience of diagnosis is described as "empower[-ing]" and gaining improved self- understanding has changed her life:

> Since I've had both diagnoses, it's really. It's actually really really helped me a lot. I feel really empowered. I feel like bags of cement have been taken off my shoulders. I feel like I don't need to apologise to the world anymore (Ada,p. 10)

Ada's use and repetition of "bags of cement" emotively captures how living with the uncertainty was a weight and burden she was forced to carry, but also by mentioning her "need to apologise," it reveals this was a burden to which shame was attached. In her descriptions, it is not simply the conditions themselves causing her profound suffering, but the lack of understanding as to why she felt this way. Gaining clarity around her experience changes her outlook and perspective on her symptoms, validating how she feels. Maryam, similarly, describes her diagnosis as a "relief." Her realisation of her neurodivergent identity particularly allows her to challenge her own negative self-image, demonstrating the negative impacts of living with undiagnosed conditions.

> I really thought I just couldn't be an adult; I couldn't be a grown up. Why could I not cope with things that other people could? (Maryam, pp. 14–15)

Rita's transformation is more physically and visually obvious, revealing how deeply intertwined physical and psychological symptoms can be for conditions like EDS and autism. She shares how her "mental health has been so much better since my autism diagnosis," explaining that she has not self-harmed in four years. Even externally, her physical abilities have improved:

> from 2018 being house bound to 20 kilometre really hilly walk two years later. So yeah, the diagnosis made a lot of difference (Rita, p. 15)

For these participants, gaining the diagnoses confirms and validates their own feelings, as well as their experiences of symptoms. Receiving these diagnostic labels is shown to be life changing for the participants, because it means they are no longer trapped in a position of suffering. Instead, the participants' suffering has been legitimised, allowing them to live their lives with greater self-understanding and the understanding of friends and family. By gaining the diagnoses, they have essentially been given the language to communicate and justify how they are feeling.

3.1.2. Being unlike the others

While the participants share the same conditions, their narratives reveal their need to differentiate themselves from others with the same diagnoses. Many of the participants shared experiences rejecting the limits of their conditions. Emmy describes how she can run upstairs, but "if you were to look at my MRI scans of my feet and my knees and my hips […], you wouldn't think that I'd be able to do that." There is a sense of needing to be seen to be pushing beyond one's limitations and not surrendering.

Ada also insists on the distinction between the Aspergers Syndrome she believes she has and "classical autism", which she sees in family members, characterised by domineering behaviour, "hav[ing] to be right about everything" and caring little about other

Table 2
Summary of superordinate and subthemes.

Superordinate theme	Subordinate themes
1. Transformation	1.1. Diagnosis as life-changing
	1.2. Being unlike the others
2. Making sense	2.1. Appearances deceive
	2.2. Doing the doctors' job
	2.3. Community and responsibility
3. The negatives	3.1. Paying the price
	3.2. Sense of separateness from one's body

people’s feelings. While intent on challenging the stigma around autism by being a positive example of neurodivergence, her description of family members, as having a “very narcissistic kind of […] autism” seems to reflect stereotypical descriptions of autism. Given that she later states “my whole life has been, like based around empathy,” it is clear she sees herself very differently. She states that although doctors “don’t diagnose Asperger’s anymore […] it’s very clear that’s what I have.” For her, Asperger’s is associated with being “academically bright”, rather than primarily “practical,” as well as being “more empathetic and sensitive” than most neurotypicals. It is important to Ada that she is not misunderstood and viewed in the same light as her family members, again suggesting a need not be reduced to the stereotype in the public consciousness.

Rita is also clear in articulating her differences. She shares from the outset that she discovered her neurodivergence “through the autism lectures on [my] masters,” rather than through personal struggles. She also associates the improvements of her symptoms with her “going away and doing a lot of research and knowing how to help myself get a lot better”. This distinction allows Rita to position herself with agency, having control of her own health. She may share similar symptoms, but her academic expertise allows her to establish herself in the role of expert rather than simply sufferer.

The continued stigma around these conditions is highlighted in the participants’ need to transgress the limitations. Furthermore, participant accounts highlight a need to identify as atypical of their conditions, a potential coping strategy preserving an individualised self-image in the wake of the new, perhaps limiting, identity placed upon them.

3.2. *Theme two: making sense*

This theme captures the way in which the participants have adjusted and reassessed their lives in light of their diagnoses. The three subthemes of ‘Appearances deceive,’ ‘Doing the doctors’ job’ and ‘Community and Responsibility’ demonstrate the heavy responsibility attached to their new identity, as well as the further challenges to be navigated which extend beyond symptom management.

3.2.1. *Appearances deceive*

Discrepancies between the way the participants appear to others and how they feel emerges across participants. The invisibility of conditions such as autism and EDS is a particular obstacle, making participants’ struggles harder to articulate and more likely to be disbelieved. For Rita the lack of understanding around female autism led to her being diagnosed with Emotionally Unstable Personality Disorder (EUPD). Rita feels the diagnosis of EUPD meant she was denied treatment or investigations for her physical symptoms, explaining that "the doctors were absolutely dead certain that that [EUPD] was the only thing wrong and […] saying there is nothing physically wrong and my symptoms weren’t believed."

Rita’s treatment under the mental health team for EUPD “traumatis[ed] [her] more,” as her neurodivergence, as well as the physical condition of EDS, were never considered. The doctors’ continued dismissal of her physical pain eroded her confidence, leaving her powerless in the hands of doctors focussing solely on visible symptoms such as self-harm, rather than considering the motivating factors behind these behaviours. Emmy similarly experiences her physical symptoms being “dismissed,” explaining how she felt medical staff suggested “You’re either lying or you’re mad […] or you’re stupid.” Emmy’s experiences are thus disbelieved and minimised, meaning she is also disempowered by medical professionals.

Masking also affects the visibility of these participants’ conditions. Emmy shares that she “always felt that like [she’s] been acting” and that it has diminished her sense of who she is as a person, leading to her feeling “like I blew with the wind, and I had no drive and that I was dangerously passive.” Describing herself as “dangerously passive” reveals how much of a cost this behaviour can have. Masking may begin as a helpful and often unconscious coping strategy to manage the neurotypical world, but for the participants, it may become maladaptive, resulting in self-critique and loss of a sense of authenticity. Maryam’s mandatory socialisation in childhood similarly camouflaged her autism:

> My parents are quite religious born-again Christians, so I was socialised within that atmosphere from a very young age […] lots of kids around, creche on a Sunday morning, Sunday school, youth groups, summer camps. So I was very, very socialised, which is the other reason why it was probably never picked up (Maryam, p. 3)

This does not seem to have helped Maryam, who describes retreating after such events and “stick[ing] my head in the [books].” Whether it is an external pressure or an internal wish to fit in, to cope with the neurotypical world, even before receiving their diagnoses, these participants reveal the difficulties in trying to conform and mimic a seemingly more societally acceptable identity.

3.2.2. *Doing the doctors’ job*

The powerlessness of being a patient is evident across the interviews. Maryam, seems to have reached a point where she is able to do her own research and approach her GP on an equal footing, saying “Right. Here’s the paper. Here’s the evidence. Please can I have?”. Rita’s academic background also allows her to take ownership of her own care. She explains that it is not treatment that has helped her thrive, but the fact, “I’ve done a lot of research into how to help myself get a lot better.” In the absence of sufficient medical help from professionals, these women feel obligated to take on the doctor’s role and this is often an empowering experience.

3.2.3. *Community and responsibility*

This subtheme captures participants’ sense of community with others living with the same diagnoses. Thus, the participants’ experiences demonstrate that a collective group identity, as well as a new personal identity, is imparted by the diagnostic labels. This new group identity is at least partially accepted by the participants. Emmy often references her symptoms and ties herself to the collective, with remarks such as “I’ve no idea where to start, and that’s. that’s an autism thing” and “again, that’s quite a common thing I think with EDS.” For Maryam, she finds a community of individuals with both EDS and autism in her workplace, “we ended up with a little kind of gang of three of us that work for the [company] that we’re all bendy, basically.” Their diagnoses and symptoms convey a sense of kinship and connection, despite the often-isolating nature of chronic conditions, which as revealed by Rita, can lead to a life where “I couldn’t really leave the house.”

This positively regarded sense of community also seems to instil a sense of responsibility towards others within the group. The primary reason given by the participants for taking part in this research was to help others like them in the future, “I just think it helps awareness and helps people” (Maryam). This advocacy work also seems to create an “us versus them” dynamic, where those living with the conditions position themselves as the opponents of insufficient and uncaring medical authorities, often by identifying symptoms of EDS and autism in others and supporting them to get diagnoses. Many of the participants describe needing to raise awareness about conditions such as EDS, with Ada stating “I’m just angry about the fact the NHS won’t diagnose [EDS] because I just think it’s disgusting.” Maryam also describes how she “diagnosed someone from [another country…] in a bar” based on symptoms she recognised in herself. The use of the medical term “diagnose” reinforces the sense of authority conferred on her by her struggles; she has gained a sense of being an expert by experience.

The participants are also insistent on changing the negative perceptions around their conditions. Almost every participant challenges the narratives around autistic individuals lacking empathy, with Emmy arguing “I think I have more empathy than the average. And I think maybe other autistic people do as well.” The participants are also insistent that that they do not want to be seen as victims and refuse “to stagnate” as Maryam describes the notion of surrendering to one’s conditions and stopping progressing in life. Rita is very insistent that her conditions have not diminished her, but “given [her] a sense of purpose” allowing her to “lead a pretty full-on life.” Her life has been expanded by her experiences and again this challenges the preconceptions of conditions causing chronic pain and fatigue.

3.3. Theme three: the negatives

While the participants predominately seek to show a positive image of life with EDS and autism, this third theme captures the glimpses of the struggles and challenges associated with these conditions. These participants may be advocates determined to raise awareness about their conditions, but their testimonies also reveal how beneath their positivity, the legacy of unexplained symptoms, poor treatment and misunderstanding remains present. This theme explores what these conditions can take from the sufferers and the difficulties in inhabiting a body that can feel as if it is no longer one’s own.

3.3.1. Paying the price

This subtheme reflects both the material and psychological cost of living with EDS and autism. Given the difficulties in being diagnosed through the NHS, particularly with EDS, many of those with the condition are forced to pay large amounts for diagnoses. Rita has been forced into debt to gain self-understanding. She shares “I probably wouldn’t still be alive if I hadn’t spent the money I did” acknowledging that the cost of her life was this debt. Gaining an awareness of the cause of one’s symptoms is depicted as truly life or death in this case.

Living with symptoms is also portrayed as exacting a high price for many of the participants. While Ada comes across as a positive advocate of living with EDS and autism, raising awareness about the two conditions professionally, her descriptions of autism indicate her feelings may be more nuanced. Ada refers to autism on several occasions as a “mental health condition and a psychosocial disability.” While she states that she does not see “mental health as a negative issue,” Ada acknowledges that many dislike autism being considered a mental health condition, but “for me it is. It is within WHO’s definition. And for me that’s fine.” Thus, there is an implication that autism affects her adversely and she considers it to be disabling. Her descriptions of incontinence as a “bloody nightmare” further reveal that while she may argue “with my autism I wouldn’t want to change it,” there are elements of her conditions that have taken a toll.

Emmy is the most open of the participants in revealing the psychological cost of living with EDS and autism. She states, “I’m very keen not to define myself” by her conditions, although later in the interview she also reveals, “it’s hard not to feel defined by it.” It seems to be a difficult balancing act for Emmy between maintaining a separate identity and being consumed by the conditions. Before receiving her diagnosis and taking a career break, Emmy, like Rita, describes how life was “absolutely killing me.” For Emmy, the conditions robbed her of so much, because “managing EDS is a full-time job in itself.” Emmy states that “it’s impacted on my career so badly” and caused an estrangement from her family, which she refers to as “indescribably awful.” Emmy also mentions becoming “very, very isolated” due to her conditions and refers to symptoms of depression, including struggles “getting out of bed” and having “appalling self-esteem.” For Emmy, her autism and EDS also contributed to her inability to develop healthily during childhood:

> I think that identity, self-confidence, being able to be humorous and spontaneous, I think all of these things are so important in life and I think autism and EDS have massively impacted on that (Emmy, p. 32).

For Emmy, these conditions are directly linked to her “lacking a sense of self.” There is a sense that she has been forced to come to terms with the life she will not have because of her conditions. Her functioning has been impaired, even as she seeks to maintain a sense of independent identity away from the conditions.

3.3.2. Sense of separateness from one’s body

This subtheme around the feeling of separateness from one’s body captures the sense that for those with chronic conditions, their bodies almost become strangers to themselves and in the worst circumstances, they become enemies. For the participants, their bodies are no longer reliable and trustworthy, and this does cause a shift from automatically taking one's body for granted, to a position of frustration and distrust. Ada's description of her sarcoidosis, another condition which emerged at a similar time to her autism and EDS, captures how her body has changed, stating that it occurs when the immune system is:

> overactive and basically it forms lumps in different parts of your body. It thinks that you're being invaded like you've been – you know you've cut your skin and it thinks you've like bacteria and stuff in there. So it forms a lump to protect (Ada, p. 4)

For Ada, her sarcoidosis has turned her body into a battleground, where her condition confuses normal bodily functions with threats. Ada's use of language such as "invaded" and the sarcoidosis's need to "protect" her suggests that living with these conditions has transformed her body into a site of warfare, rather than a comfortable home.

Emmy, similarly, describes feeling overwhelmed on many fronts by her conditions, detailing the way in which EDS affects multiple regions of her body, referring to:

> having loads and loads and loads of problems. So not just to do with the hypermobile joints, not just early arthritis in loads of my joints but also all the other problems that are sometimes associated. So gastric problems, […] Skin problems, lots of other problems (Emmy, p. 3)

For Emmy, her body has become the site of many diverse and difficult symptoms, which feel overwhelming due to their number and their widespread nature. Emmy's language, for instance by describing her "arthritis" as "early arthritis" also gives the sense that her body is almost unfairly rendered unfit for purpose at a young age. Her conditions are depicted as a cruel wave of symptoms she is forced to endure.

For Ada, the menopause is the catalyst for her body to become unmanageable and her life to stop abruptly. While she had managed her autism and EDS beforehand, albeit without a diagnosis, menopause "made me lose my coping mechanisms" and this was the point when she lost her ability to cope. She describes how disabling menopause was for her:

> I just couldn't function at all during the menopause – just at one point I was waking up every half an hour and crying for half a day, and my allergies had increased and my coordination. I've got so much worse (Ada, p. 3).

Similarly to Emmy, Ada's words here indicate how all-encompassing and overwhelming her experience of her conditions was during this period. Ada struggles both emotionally given her mention of frequent "crying" spells and physically with her issues with "allergies" and "coordination." Again, both her body and mind are affected, showing the pervasive and seemingly inescapable impact of these conditions.

4. Discussion

This study demonstrates how individuals can develop nuanced perspectives on their sense of self, moving fluidly between different identities while living with co-occurring EDS and autism. These identities range from feeling validated and empowered by their diagnoses, to feeling the need to take on the doctor's role, finding community amongst those similarly affected and feeling a sense of responsibility to this community, feeling their bodies have become battlegrounds and that living with these conditions can be like having a full-time job, as well as the sense that there is both a material and psychological cost associated with these conditions. Unlike earlier research which has shifted between demonstrating how chronic illness can negatively impact (Bury, 1982; Charmaz, 1983) or positively illuminate an individual's sense of self (Tan, 2018), this study sheds light on how illness identity is not fixed or clear-cut but remains a delicate balancing act for individuals to navigate in their daily lives. This study's participants reveal how living with multiple conditions can be reinvigorating and life-changing and simultaneously diminishing and isolating.

This research challenges theories that individuals integrate their illnesses into their identities, either adaptively by accepting or feeling enhanced by their experiences, or maladaptively by feeling engulfed or rejecting their condition (Oris et al., 2016). The participants in this study demonstrate that these concepts are much more fluid, with less distinct boundaries than previous research suggests (Shneider et al., 2024; Van Bulck et al., 2019). The participants' experiences also demonstrate how there is no one way of identifying with these conditions and while the participants express largely positive views about their experiences of having EDS and autism, their words also reveal the burden of living with these conditions. While autism is often associated with rigidity and black-and-white thinking (Petrolini et al., 2023; Stark et al., 2021), this study suggests that for these individuals, illness identity exists in a grey area, neither black nor white, wholly negative or positive and they are neither defined solely by their autism or their EDS, but rather exist on a constantly shifting spectrum.

This nuanced perspective on illness identity supports the argument (Tan, 2018) that living with a chronic condition does not simply equate to loss and diminishment (Charmaz, 1983). Just as Tan's (2018) autistic participants felt validated by their diagnoses, conveying how beneficial it felt to finally understand the reasons behind their differences, this study's participants gained a stronger sense of self-concept and self-acceptance through realising their diagnoses. Nevertheless, findings also demonstrate how traditional negative attitudes about these conditions remain prevalent. Despite the enrichment Ada feels from discovering she is autistic, she also describes the condition as a "mental health condition and a psychosocial disability" under "the WHO's definition." The WHO (2022) defines mental health conditions as disorders which affect an individual's emotions, behaviours or cognition, often leading to distress and difficulties in functioning, while psychosocial disabilities refer to conditions which have a long-term adverse effect on one's ability to engage with daily life, emerging because of a mental health condition (Weld-Blundell et al., 2021). Thus, for Ada, being autistic is also associated with loss of functioning. This reflects the idea that chronic conditions can derail one's sense of who they are as a person, representing a break in the traditionally linear narratives of their lives (Bury, 1982; Fang et al., 2024; Van Bulck et al., 2019).

This research thus also adds weight to Potter's (2023) claims that those living with multiple conditions do not have one singular and distinct illness identity, but rather multiple illness identities, which collaboratively affect the participants' overall sense of self. Concurrently, this study also extends Potter's (2023) analysis, by offering a more complicated and intertwined picture of illness identity with multiple conditions. Unlike Potter's participants (2023), this study's participants do not express a sense of attachment to one condition, and a sense of disconnection from their co-occurring condition. Most of the participants in this study had seemingly incorporated both conditions into their new sense of self, although the extent to which they rejected and accepted these conditions and the limitations caused by certain symptoms varied for each participant based on numerous biopsychosocial factors, which shifted throughout their daily lives. Illness identity seems to be continually in flux for these participants.

These findings highlight the need for more individualised, supportive care for those living with autism and EDS. It is evident that there is no one way of experiencing these co-occurring conditions and participants report that the lack of appropriate support aggravates their negative perceptions of their conditions. For many participants it is not the conditions themselves that cause the most suffering, but social factors, including the participants' lengthy battles for self-understanding and diagnosis, their mistreatment, particularly by medical professionals, and the stigma they experience because of their conditions. As research indicates that feeling engulfed by one's illness leads to negative health outcomes (Shneider et al., 2024), this study suggests a need for more widespread understanding about the conditions amongst medical professionals and more tailored and psychologically-informed support for those living with co-occurring autism and EDS, to enable them to incorporate their conditions into their identity in more positive ways. This study also suggests a need for further research into the biopsychosocial factors which cause individuals to shift along a continuum of illness identity and whether these may be common to all individuals living with conditions which are difficult to diagnose. Future research could also explore whether living with two or more conditions that do not commonly co-occur, could lead to a different experience of illness identity. More qualitative research into co-occurring conditions and illness identity, focussing on lived experience, is evidently needed.

While this study offers extensive and nuanced insight into an area previously neglected, limitations must also be considered. As an IPA, this study provides in-depth insight into the nuances of illness identity when living with autism and EDS, but further research adopting more generalisable designs may be useful to draw out wider conclusions. Participants were also recruited through a single gatekeeper, the EDS Support UK charity (Negrin et al., 2022). Thus, those engaging with the charity tended to be individuals who felt a sense of connection to and interest in EDS. As such, the perspectives of those more averse to accepting their EDS diagnosis, were perhaps less present amongst this audience. The fact that the authors share the same diagnoses as the participants could also have potentially affected their reading of the data. Whilst every effort was taken to alleviate this risk, through extensive reflexivity and continual discussions between the authors, their own experiences may have subconsciously impacted upon their interpretations. Self-selection bias (Robinson, 2014) may also play a role in this study, as those volunteering to participate in such research tend to be individuals who feel more comfortable and confident articulating their experiences, rather than those who may have more complicated feelings around their conditions.

5. Conclusions

This is the first study to examine how those living with autism and Ehlers-Danlos syndrome integrate their conditions into their sense of identity. The views of the participants differ in many ways, each shaped by their backgrounds and the different challenges navigated to reach diagnosis, but they simultaneously demonstrate how complicated and changeable the subject of illness identity can be when living with multiple conditions. This qualitative approach also demonstrates the need to consider biopsychosocial factors when supporting those living with EDS and autism and how the medical approach can leave many feeling sidelined or unheard within medical services.

CRediT authorship contribution statement

Beckwith Rhoslyn Francesca: Writing – original draft, Investigation, Formal analysis, Conceptualization. **Danielle Stephens-Lewis:** Writing – review & editing, Supervision.

Declaration of Competing Interest

No potential conflicts of interest have been reported by the authors.

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Data availability

Data will be made available on request.

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