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Autism and hypermobile Ehlers-Danlos syndrome (hEDS): A challenging combination

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ABSTRACT

Hypermobile Ehlers-Danlos syndrome (hEDS), a multi-systemic connective tissue disorder with extensive biopsychosocial impacts, occurs with greater than expected frequency in autistic people, yet the specific impacts on their daily lives and healthcare experiences are largely undocumented. In particular, there is limited information regarding ways in which each condition (autism, hEDS) might complicate or ameliorate the needs associated with the other one. We conducted semi-structured interviews with five women diagnosed with both autism and hEDS, which were analysed using Interpretative Phenomenological Analysis (IPA). While journeys to diagnosis were lengthy and distressing, obtaining diagnoses yielded the benefits of self-knowledge and self-compassion, improved self-management of their health, and better negotiation of practical and emotional support. Participants also noted that while autism facilitated some aspects of hEDS self-management, hEDS could exacerbate the medical challenges already disproportionately faced by autistic individuals. Overall, our preliminary findings suggest that the unique healthcare needs of this poorly understood and vulnerable subgroup may be unmet by current healthcare provision; moreover, potentially adaptive autistic strengths for illness management may not be commonly facilitated. To better accommodate these needs, communication training for healthcare professionals, adaptation of patient care environments and adoption of a holistic management approach are recommended.

The Ehlers-Danlos syndromes (EDS) are complex, multi-systemic conditions affecting collagen and associated connective tissues. Hypermobile Ehlers-Danlos syndrome (hEDS), and the related condition Hypermobility Spectrum Disorder (HSD), are characterised by symptomatic joint hypermobility and associated musculoskeletal and extra-articular manifestations. Individuals with HSD experience many of the same clinical features and associated impairments as those with hEDS, but do not fulfil the more stringent 2017 criteria

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required for a hEDS diagnosis (Malfait et al., 2017).[5]

Hypermobile EDS and HSD are the two most common symptomatic hypermobility conditions, occurring more frequently in autistic than non-autistic people (Glans et al., 2022; Ward et al., 2023). Diagnosed hEDS/HSD cases are also disproportionately female (Demmler et al., 2019). Research has focused on elucidating the biological mechanisms underpinning diagnostic co-occurrence (Baeza-Velasco et al., 2025), but lived experience of autistic people with hEDS has largely been neglected. Exploration of the latter is important as additive difficulties may arise for recipients of both diagnoses (Donaghy et al., 2023). For example, autonomy and executive function, vital for successful navigation of societal systems that both populations experience as challenging and in which they encounter stigmatisation (Donaghy et al., 2023; Quadt et al., 2021), may be compromised both by autism and the myriad, pervasive symptoms of hEDS. Autistic people note that medical systems especially fail to accommodate their neurodivergence, with interactions leading to feelings of invalidation and resulting in trauma responses, such as hypervigilance and hypersensitization (Doherty et al., 2022). As such, being forced into frequent medical engagement to manage their health may negatively impact overall wellbeing or eventually lead to medical non-adherence, as reported by autistic people with diabetes (Vinayagam et al., 2024).

Thus far, only one qualitative examination of the experiences of individuals with both diagnoses has been undertaken (Beckwith & Stephens-Lewis, 2025), which focused on participants' navigation and sense-making of the two identities following challenging diagnostic journeys. Interviews with four women revealed the relief, vindication, empowerment and community connection accrued through being formally diagnosed with hEDS and/or autism. Their narratives of masking and misdiagnoses resembled those of autistic women in previous literature (Gosling et al., 2023; Kentrou et al., 2024), and their dismissal by healthcare professionals echoes that described by other women querying diagnoses of both autism (Murphy et al., 2023) *and* hEDS (Halverson, Cao, et al., 2023).

When considering how life experiences might be shaped by both diagnoses in *interaction*, Beckwith and Stephens-Lewis (2025) focused predominantly on impacts to identity and self-concept. Their data suggested a complex interplay; diagnoses oscillated between being *core* or *subsidiary* to the participant's identity dependent on their current life circumstances (i.e., hEDS took precedence when they were experiencing new or heightened physical symptoms) and each diagnosis could changeably have positive or negative impacts on the participant's developing self-concept. To give further voice to this under-researched sub-group and assess the representativeness of Beckwith and Stephens-Lewis' findings, we qualitatively examined the lived experiences of people diagnosed with both autism and hEDS. In first asking our participants about their two diagnostic journeys and experiences within the wider medical system, we aimed to provide rich experiential accounts of navigating these structures when autistic (Casanova et al., 2020; van Schalkwyk & Dewinter, 2020); accounts made even more necessary by elevated occurrence of chronic health conditions in autistic people (Ward et al., 2023). We also aimed to extend Beckwith and Stephen-Lewis by posing questions that allowed reflection on the more tangible, non-identity-related impact that the two diagnoses, in *interaction*, might have on participants' day-to-day lives: specifically, how they perceived being autistic affected the experience and management of hEDS, and to similarly understand the effects of hEDS on living as an autistic person.

1. Methods

1.1. Participants

Recruitment commenced following approval by Bournemouth University Faculty of Science and Technology ethics panel in April 2023. Participants were recruited through advertisements posted to the Facebook and Twitter pages of 'Ehlers-Danlos Support UK', SEDS Connective (a community-led charity supporting individuals with symptomatic hypermobility, neurodivergence and related conditions), Dr Jessica Eccles (an academic psychiatrist internationally recognised for her research on neurodivergence and hypermobility) and the first author (SLC). The participant information sheet and agreement form were sent to the first five respondents. Purposive sampling, which involves targeting participants who meet specific inclusion criteria, was considered appropriate to gain initial insight into the topic (Palinkas et al., 2015). Eligibility criteria included age 18 + years, access to the internet for an online interview, and having diagnoses of both hEDS and autism, without learning/intellectual disability. Participants were five White British, cisgender, University-educated females aged 58 (P1), 24 (P2), 32 (P3), 34 (P4) and 28 (P5), who had obtained diagnoses privately. Four participants received their hEDS diagnosis before their autism diagnosis.

1.2. Procedure

The first author (SLC) conducted semi-structured interviews over Zoom (May –July 2023). The interview schedule (see Supplementary Materials) was informed by existing literature and consultation with experts by lived and professional experience. These comprised two autistic autism researchers with knowledge of preferred communication styles and socio-communicative differences in autistic individuals (e.g., interpreting language literally, requiring additional time to process information) who advised on question wording, and an expert academic clinician autism researcher who advised on use of person-first versus identity-first language. An autistic person participated in a pilot interview and gave feedback on question wording. The interview schedule was emailed to participants before the interviews to cater for possible autistic differences in processing speed and executive functioning. Rapport was

[5] Revised international diagnostic criteria for hypermobile Ehlers-Danlos syndrome (hEDS) and Hypermobility Spectrum Disorder (HSD) are scheduled for publication in December 2026 as part of a new global classification framework. These revisions may alter the diagnostic distinction between hEDS and HSD, combining them into one condition (The Ehlers-Danlos Society, 2025)

built with participants through prior email contact with the interviewer, and a brief initial discussion before asking demographic questions (e.g., age, gender identity). The semi-structured interview schedule probed the participants' two diagnostic journeys, their support structures, and day-to-day experiences of living with both diagnoses. Audio-recorded interviews (with cameras on) lasted approximately 70 min, after which participants were thanked and in line with standard guidance for research on sensitive topics, signposted to relevant support agencies (i.e., EDS UK, National Autistic Society), in case the interview caused distress.

2. Data analysis

Interviews were audio-recorded using Sonocent audio note-taker software (Sonocent, 2022), then transcribed using the dictation feature in Microsoft Word online (Microsoft 365). Automatically generated transcripts were reviewed against the original audio recordings, and any errors corrected, then recordings deleted and identifiable information redacted. Data was analysed using Interpretative Phenomenological Analysis (IPA), which provides in-depth exploration of idiopathic lived experience within small, homogenous samples (Clarke, 2010). IPA has been utilised in research on sensitive and complex topics (Arnold et al., 2023), including chronic illnesses other than hEDS (Collins et al., 2023; Hook et al., 2026; Sweeting & Arden-Close, 2022). IPA allows identification of intra- and inter-dataset patterns within participant reflections, from which participants' intended meanings can be derived (Smith et al., 2021).

The first author familiarised herself with each transcript and annotated these with initial interpretative codes capturing how each participant *perceived* the experiences they described, which were used to build initial cross-transcript themes. The meaning, completeness and representativeness of each theme was considered, refined, and agreed by the first author and last author, who also second-coded one transcript.

3. Reflexivity

The first author disclosed her autism and hEDS diagnoses to participants, consistent with previous qualitative research demonstrating that disclosure of shared lived experience may help reduce traditional power differentials between interviewer and interviewee, facilitate rapport and trust and encourage richer, more nuanced responses (Beckwith & Stephens-Lewis, 2025). The researcher's lived experience also supported an informed "insider perspective" (Berkovic et al., 2020) providing contextual understanding of participants' experiences, while facilitating empathy and sensitive questioning throughout the interview process. Reflexive engagement with this dual role as researcher and member of the participant community enabled ongoing consideration of how lived experience influenced data collection, interpretation, and theme development.

Frequent discussions with the last author, and invited input from other autistic people (detailed in the Procedure) mitigated the influence of the first author's positionality on interview construction i.e., ensuring that question wording was appropriately open to elicit personalised responses. The first author experienced a lengthy, distressing diagnostic journey and perceived multiple benefits from being diagnosed; they systematically journalled their response and relationship to the data to ensure their own experiences did not unduly bias interpretation of participant responses (see Supplementary Materials). One other author is autistic.

4. Results

We identified two main themes from the data (see Fig. 1).

5. Theme 1: "The diagnostic odyssey and its impacts"

Subtheme one details the lengthy, gruelling, and expensive journey to diagnoses (particularly of hEDS). In subtheme two, participants described how receiving diagnoses benefited self-knowledge and compassion, diagnostic management and the elicitation of practical and emotional support.

5.1. The personal and financial costs of seeking a diagnosis

All five participants sought diagnoses due to the long-standing, negative impact on their lives of feeling different – due to their "bendy bodies" and social difficulties – and not understanding the reason for these differences. Four participants first received their hEDS diagnosis; a process described as challenging and time-consuming (*"Five years of pain and it made me depressed"* [P3]), and often fraught with emotionally distressing medical invalidation:

> "I found out about EDS when I was 17… took it to my doctor. He said I wasn't skinny enough… he'd expect me to have blonde hair and blue eyes." (P5). Medical invalidation appeared enhanced under circumstances of diagnostic overshadowing, whereby the participant's physical symptoms were inappropriately attributed to a (given or suspected) preceding or concurrent, psychiatric 'diagnosis': "There was an implication that it was because I was a teenage woman… it was mostly anxiety… I felt very much dismissed by doctors" (P5).

Continual dismissals often meant participants needed to engage in extensive and exhausting self-advocacy to refocus investigations on their physical symptoms. These experiences sometimes led participants to adopt behaviours that they admitted contributed to diagnostic delays. Some became reticent during their appointments, due to hypervigilance to anticipated further invalidation: *"…I*

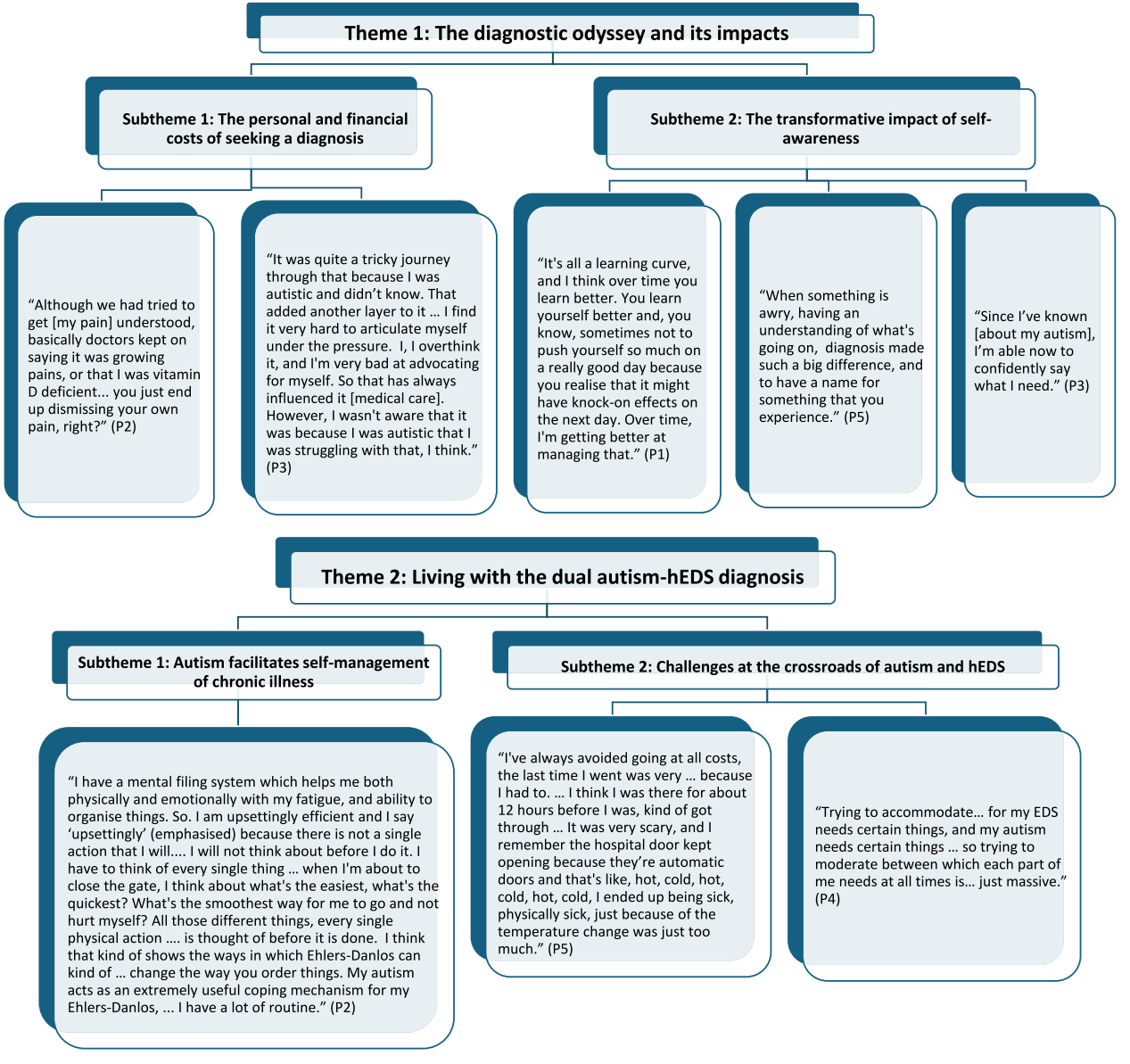

Fig. 1. IPA-derived themes, subthemes and illustrative quotes.

have huge anxiety speaking to doctors… I get nervous, I get upset because I've had so many bad experiences from such a young age… [most] doctors I've seen have been not only cold, and withdrawing, but dismissive, uninterested and, clearly … uncaring" [P2].

Others withdrew from the medical system completely to quell appointment-related anxieties, reduce the burden of self-advocacy, and avoid further traumatisation: *"There was a long time when I just disengaged from the whole thing… probably about four or five years… I didn't have the stamina to keep pushing."* (P5). All participants eventually felt forced to expedite the hEDS diagnostic process, pursuing an expensive private route: "*I have spent a lot of money on private healthcare because I couldn't get the help I needed on the NHS*[6]." *(P2).*

In contrast, receiving an autism diagnosis appeared relatively more organic: the diagnosis was suspected and sought due to insight accrued through their own work in autism assessment, in response to suggestions from partners (*"My husband kept saying 'you are' and I knew I was struggling with certain sensory things…"* (P1)), or because their children had received a diagnosis (*"Three out of four of my kids are autistic… I just went to my GP… then I had my assessment"* (P4)).

Participants who first received a hEDS diagnosis felt some traits (then unattributable to their autism) had further complicated diagnosis, particularly their autistic socio-communicative differences. Participant 2's account, however, indicates that being unable to attribute differences, difficulties and communicative impasses to their autism was not a singular barrier to a physical health diagnosis. Despite having received an autism diagnosis at 13 years, she still underwent a difficult and eventually privately mediated route to a hEDS diagnosis. Theme 2, relatedly, shows how characteristics identified as autism-related post-diagnosis continued to impact the participant's hEDS healthcare journey.

5.2. The transformative impact of self-awareness

The three sub-subthemes below document ways in which receiving diagnoses positively impacted our participants' lives.

Self-understanding and self-compassion. All participants found the medical hEDS diagnosis helpful: receipt of a tangible diagnostic label gave them permission to, and facilitated, research into the condition's biological underpinnings, and allowed them to escape clinician-driven, internalised self-doubt about the biomedical legitimacy of their symptoms.

Participant 3 reflected that diagnostic certainty and condition understanding were particularly valuable when autistic: *"If you're autistic, you're going to want to understand, because we've got quite a mechanical, logical brain."*.

All participants described undertaking a process of post-diagnosis *recalibration*. This entailed reframing past experiences, particularly pertaining to their autism, more compassionately. Participant 4 said *"It [autism diagnosis] makes you reflect backwards… and almost be kinder to your younger self",* while Participant 5 commented *"The biggest difference [with an autism diagnosis] is recalibrating my mind… trying to unlearn some of that stuff around how I talk to myself about it". Recalibration* relatedly involved developing a kinder, more tolerant approach to the future self: *"It makes you think about what you might need now, so you can put those adjustments in place." (P4).*

Facilitating self-management. For all participants, recognising, being compassionate towards, and developing a greater knowledge-based understanding of their diagnosis-related needs catalysed discernment and refinement of self-management strategies. Tying these components together in relation to their hEDS, Participant 3 reflected: *"I needed to understand the mechanics behind why my body was failing me… Once I knew, I was able to understand it and break it down clinically and then work out what adjustments I needed." (P3)*.

Self-management strategies pertaining to participant's hEDS typically comprised: (1) calculating required angles of limbs before making specific movements: *"every single physical action is thought of before it's done [so as to think of] the smoothest way for me to go and not hurt myself." (P3);* (2) activity pacing, to reduce expressions of pain and fatigue: *"I've been given some strategies around pacing… it's a relief to know there's something I can do, not just sit and wait for the pain to pass." (P5)*, although all five acknowledged struggling with pacing: "*I still can't get the hang of pacing – I want to do everything now,*" (P3), and (3) using disability aids, which enabled continuation of enjoyed activities in the presence of symptoms: *"When I finally accepted the walking stick, it meant I could go to events again… I had my life back in a way."* (P5). Two participants also emphasised the value to wellbeing of applying self-management approaches to diagnosed and/or suspected comorbidities (such as Mast Cell Activation Syndrome [MCAS]). Both had made dietary modifications, with one experiencing relief when these changes both improved her symptoms and helped her to identify and avoid allergy triggers, reducing subsequent hospital admissions: "*I kept a food diary for ages because of people saying it was MCAS. I'm allergic to eggs I have found out, so I cut them out.*" (P1).

To accommodate their autism-related needs, participants more sensitively considered their environment: *"For autism I would say particularly learning when I'm in an over-stimulated environment and taking myself out of that environment."* (P2).

All participants emphasised that self-management, particularly for hEDS, necessitated trial-and-error with self-identified strategies and gadgets (e.g., heat pads for pain). This process could be frustrating and disappointing when it: (1) provided little discernible positive impact or could have temporary adverse consequences: *"I've been given some strategies around pacing… but if I get it wrong, I crash and it wipes me out for days."* (P5); (2) necessitated involvement of healthcare providers, who were sometimes reluctant to prescribe requested medication or recommended inappropriate alternatives, e.g., participant 2's healthcare provider prescribed contraindicative hormonal medications that worsened rather than ameliorated symptoms; and/or (3) incurred significant, personal financial costs, as the resource fell outside the NHS' scope:

> "I get a lot of financial support from my dad, which has allowed me to get the actual… mobility things [an electric wheelchair] that I need …if I had applied through the NHS, I don't think I would have even got as much as walking stick…." (P2)

[6] NHS: National Health Service, the publicly funded health system in the UK.

Despite the trial-and-error process incurring multiple challenges and frustrations, participants suggested that it became easier to hone over time, and that the end product was worthwhile.

5.3. The importance of utilising a support network

Participants sought multiple types of social support to achieve various, sometimes overlapping goals. Following diagnosis, participants felt legitimised and empowered to join online EDS communities, where discussion drove and enriched self-education and self-management attempts, as members addressed "*things doctors don't tell you about.*" However, participants also perceived that catastrophising and scaremongering were present in some online health communities, exposure to which could negatively impact their wellbeing: "*sometimes there's really depressing posts on Facebook about people's lives ruined by the condition." (P2)* Self- and sometimes community-derived condition understanding furnished participants with the language required to effectively communicate their experiences and needs to close others. These conversations could engender greater sympathy for their challenges and thus elicit emotional support. Where lacking, such support was provided by pets, who four participants referred to as: "*emotional support/comfort on a bad day."* (P1). Conversations could additionally address more concrete concerns, allowing the participant to request specific practical help. Reflecting the latter, participant 4 said: *"My immediate support network is just my husband and my kids … honestly, I won't be able to do half of what I do without them."*

However, two participants reported negative consequences, sometimes resulting in attrition of connection, when their personal networks showed "lack of understanding" of their emotional or practical needs. They particularly highlighted this in relation to EDS-related pain, which they perceived their parents dismissed:

> "Unfortunately, because they haven't lived with a chronic condition in the way I have, my mum doesn't understand what rest means. my dad makes fun of me. When I was sat down trying to rest when they were up, my dad would make constant little jabs 'Oh, you're not doing anything' and it's infuriating." (P3)

6. Theme 2: Living with the dual autism-hEDS diagnosis

Participants felt some autistic characteristics, such as logical thinking and desire for structure, could facilitate self-management of hEDS. However, they also reflected that being autistic created additional psychological challenges that compromised their attempts to seek medical help for hEDS (through self-advocacy), or that hEDS necessitated means of managing symptoms which made their otherness visible (i.e., use of mobility aids).

6.1. Autism facilitates self-management of chronic illness

Participants felt that autistic hyperfocus facilitated accrual of condition-relevant knowledge and identification of self-management targets: *"I think it was beneficial being autistic because… I could immerse myself in it [managing my health] and really remember things that other people couldn't quite get a grasp on. So, it made it easier to know what adjustments I might need."* (P1).

Logical thinking and a preference for structure and routine also facilitated attempts to embed in their lives and systematically trial strategies they had identified.

6.2. Challenges at the crossroads of autism and hEDS

As suggested above, some participants attributed their superior ability to appropriately research, organise and implement hEDS-relevant self-management strategies to their autistic hyperfocus, logical thinking and propensity and preference to systemise. Conversely, however, reflecting the complexity of neurodivergence, four participants' accounts suggested that executive dysfunction, commonly associated with autism, sometimes reduced their available resources to fully realise plans in line with their strong autistic preference and desire for structure and systemisation: *"If I'm doing something and my husband asks me to do something… I'll usually walk off from what I'm doing to do it… and then forget what I was doing before. I don't deal with concurrent questions"* (P3). Failures to develop and execute perfect plans were experienced as psychologically distressing. More frequently, participants noted that hEDS symptoms (e.g., cognitive dysfunction, profound fatigue, extensive pain) and their fluctuating and unpredictable nature could more pervasively scupper strategy planning and implementation. Participants spoke of being forced into a difficult brokering arrangement whereby they attempted to maintain psychological and physical wellbeing through flexible, vacillating prioritisation of needs and preferences related to each diagnosis.

Participants also reflected feeling shame and embarrassment, especially pre-autism diagnosis, when their previously hidden hEDS disability became visible. Using disability aids (e.g., walking sticks, wheelchairs) meant accepting themselves as (publicly) 'disabled', which conflicted with lifelong attempts to mask their autism-related otherness: "*I remember the first time I had to use a walking stick… I felt like everyone was staring at me"* (P5). Sometimes participants then avoided using potentially beneficial devices: *"I didn't want to look like I was milking it… so I'd push myself to walk even when I shouldn't"* (P3).

Finally, participants reflected that autism made negotiation of public healthcare environments difficult. These environments represented uncertainty (when novel), were socially demanding: *"I get quite sick going to a new hospital if I don't know where the parking needs to be …. I get panicky and it's horrible because I've always hidden, because I was embarrassed…"* [P3], and were sensorily challenging: *"I didn't feel safe … there's certainly a sensory aspect to it as well [in non-private healthcare] people are loud."* [P2]. Combined, these

challenges sometimes led to medical non-adherence, even for acute, non-hEDS concerns.

7. Discussion

This study explored the daily experiences of autistic people with hEDS; a frequent diagnostic co-occurrence (Baeza-Velasco et al., 2025). Diagnostic journeys were lengthy, gruelling and expensive, particularly for hEDS, yet diagnosis increased self-compassion and facilitated self-management and self-advocacy attempts. While in some ways autism helped hEDS management, in others hEDS symptoms compounded difficulties associated with being autistic and vice versa.

The hEDS "diagnostic odysseys" our participants faced strongly resembled those described by others with hEDS (Halverson, Cao, et al., 2023) and different rare, poorly understood illnesses (Benito-Lozano et al., 2023). For all, diagnostic journeys were time-consuming, incurred significant financial costs, and followed extensive self-advocacy efforts to overcome medical minimisation and invalidation. Four participants received their hEDS diagnoses first; perhaps accordingly, their hEDS diagnoses appeared more momentous in their narratives. Greater space devoted to the hEDS diagnostic journey likely also reflects its hard-won nature, obtained after years of medical invalidation and traumatisation, with receipt helping our participants to self-legitimise and take ownership of the physical symptoms that had significantly shaped their lives.

While receiving an autism diagnosis also appeared to have important, self-transformative properties, challenges incurred in its pursuit may have been overshadowed by those encountered in the hEDS journey, potentially explaining why our participants spoke less of these than other autistic samples (Gellini & Marczak, 2023; Kiehl et al., 2024). Indeed, prior research suggests that the relative nature of diagnostic journeys, where multiple apply, can considerably influence the way an individual experiences *each* journey and their adaptation to each diagnosis, respectively (Jeske et al., 2024). Implicated here also is the relative timing of each diagnosis; discrete journeys may be difficult to qualitatively probe when both diagnoses are received in close temporal proximity (i.e., in adulthood), as for four of our participants (and Beckwith & Stephen-Lewis' participants); this also complicates comparison with the experiences of our sole participant who received their autism diagnosis first *and* in early adolescence. Despite experiential diagnostic overshadowing and temporal proximity, however, several participants articulated how some of their autistic characteristics – particularly pre-autism diagnosis, when they comparatively struggled to identify, diagnostically attribute or manage these expressions – impacted their hEDS diagnostic journey. Specifically, these characteristics were perceived to complicate self-advocacy in medical settings (Shaw et al., 2024), while lacking a diagnosis for their physical symptoms deeply and distressingly compromised their strong, autistic drive for certainty and "mechanistic" understanding (Baron-Cohen, 2008).

Our participants perceived both diagnoses as positive and meaningful, affording greater self-insight and opportunities for self-compassion. As in other samples, receiving a medical diagnosis provided an explanation for the perceived bodily limitations and dysfunctions associated with hEDS (Bennett et al., 2021), just as an autism diagnosis provided explanation and feelings of vindication for previous, lifelong difficulties (Gellini & Marczak, 2023; Kiehl et al., 2024). The relief our autistic participants reported on receiving their hEDS diagnosis may have been more pronounced than that reported in non-autistic samples, due to the high levels of stress and autistic burnout they reportedly incurred during frequent medical investigation of their physical symptoms. Supporting this idea, in a recent quantitative study, individuals diagnosed with hEDS or Hypermobility Spectrum Disorder (HSD) self-reported poorer physical and mental health if they also had an autism diagnosis, or displayed a high degree of autistic traits, than their non-autistic counterparts (Crompton et al., 2026).

Beyond validation, our sample experienced their hEDS diagnosis as empowering (Beckwith & Stephens-Lewis, 2025; Wang et al., 2024); it enabled them to self-educate in illness management, with learnt strategies facilitating attempts to maintain quality of life in the presence of physical limitations (e.g., through activity pacing). An autism diagnosis, similarly, led participants, through increased understanding, to better management of associated challenges (Downs & Adams, 2025; Moseley et al., 2021). Like autistic people in other studies (Kiehl et al., 2024), this new understanding enhanced participants' ability to remove themselves from sensorily overwhelming situations, reducing risk of autistic burnout. Increasing self-compassion for past and future selves is a known corollary of receiving a long sought-after diagnosis, whether of a chronic illness like hEDS (Asbring, 2001; Barclay-Goddard et al., 2012) or an adult autism diagnosis (Gellini & Marczak, 2023; Kiehl et al., 2024). Finally, diagnosis-catalysed self-understanding allowed participants to better self-advocate for their autism- and hEDS-related needs, as in other hEDS (Wang et al., 2024) and autistic samples (Gellini & Marczak, 2023; Kiehl et al., 2024). Our participants conceptualised self-management as multi-faceted. While first engaging in self-education and strategy implementation, they also emphasised the need to flexibly engage in trial-and-error to find strategies to alleviate symptoms and improve quality of life, to bolster their understanding and protocol through involvement in online patient communities, and to use the knowledge they had accrued to communicate with and enlist the practical and emotional support of close support networks. These steps also appear in narratives of other individuals with chronic illnesses (Kingod et al., 2017; Roberts & Gaffiero, 2025). Similarly, like Beckwith and Stephen-Lewis's autistic hEDS sample, on diagnosis participants took ownership of self-management; a situation forced upon others with poorly understood chronic illnesses (McManimen et al., 2019; Melby & Nair, 2024).

Several observations from our participants, in conjunction with extant literature, may imply that being autistic uniquely impacts the experience of hEDS. First, while our participants, like other chronic illness groups (Brown, 2024; Roberts & Gaffiero, 2025), identified support from loved ones as vital for their wellbeing, autistic adults are statistically less likely to enjoy supportive friendships and relationships (Schiltz et al., 2024; Stewart et al., 2024). This makes it even more imperative to assess whether individuals with a dual diagnosis of autism and hEDS have access to the support they need. Second, we call for future research assessing the importance of online support for autistic people with hEDS. While online communities have come to crucially fulfil informational, social and emotional needs for many with poorly understood conditions (e.g., Kingod et al., 2017), internet-mediated communication is naturally

amenable to neurodivergent people as it affords lesser potential for social anxiety, is more accommodating of sensory sensitivities (Hassrick et al., 2021), and has been identified as an invaluable way to connect with autistic peers (Watts et al., 2024). That said, as autistic people often experience marginalisation and ableism in allistic spaces (environments designed by, and for, a non-autistic majority) both online and offline (Koteyko et al., 2025), the extent to which participants are included, and their needs met in chronic illness communities is unclear, as is the extent to which autistic people with chronic illness are proportionally represented within these spaces. Further, participants also perceived that some members of online spaces engaged in catastrophising and scare-mongering. Such behaviours have been perceived to exist in other online health communities (e.g., Tan et al., 2021) and may contribute towards the 'distressing content' Halverson et al. (2024) noted hEDS patients were at risk of encountering in online support groups and social media platforms. Additionally, we contend that exposure to excessively negative narratives may contribute to feelings of anxiety and uncertainty, already commonplace in autistic individuals (Nimmo-Smith et al., 2020). Third, possibly relatedly, our participants highlighted the importance of pets. While the value of animal companions is well-recognised for those with chronic illness (Brooks et al., 2016) and autism (Atherton et al., 2023), as interactions with animals are less socially demanding and less likely to trigger social anxiety than those with humans, companion animal support might be particularly valuable for autistic people living with chronic illness. Fourth, our participants, like Beckwith and Stephens-Lewis's (2025), showed a high capacity for independent research, experimentation and self-management which might not be possible for all autistic people, even those without learning difficulties.

Indeed, this last point particularly reflects our participants' consideration of the challenges and strengths existing at the "cross-roads" of autism and hEDS. Our participants spoke of ways being autistic might ameliorate or aggravate daily life with a chronic illness (and vice versa), while Beckwith and Stephens-Lewis (2025) predominantly highlighted how having the two diagnoses could complicate conception and development of identity and self-concept. On one hand, participants suggested that some autistic features helped with managing specific hEDS symptoms. Participants recognised that the "mechanical" autistic drive to "systemize" (Baron-Cohen, 2008) their health afforded them a logical approach to symptom management. Moreover, logical thinking could facilitate development of activity-pacing plans, shown to be effective for preserving functionality by mitigating expressions of fatigue and pain in those with chronic illnesses (Abonie et al., 2020). While participants mentioned instances where executive function difficulties compromised coping and illness management, these were less apparent than in experiential accounts of other autistic people living with chronic illness (Kalingel-Levi et al., 2022; Vinayagam et al., 2024). For example, autistic adults with diabetes reported prioritising avoiding autistic burnout over diabetes self-management, with executive dysfunction further impeding organisation of and adherence to treatment protocols (Vinayagam et al., 2024). Only one of our participants implicated these reasons as negatively impacting their "diagnostic odyssey." There are several possible reasons for this difference. First, our participants are not representative of the wider autistic population – all were highly educated, therefore possibly less constrained by cognitive difficulties that could impede independent research and trial-and-error self-management attempts. Second, our participants greater financial and social resources (all received diagnoses privately and had significant sources of social support) may have mitigated the impacts of their conditions.

On the other hand, participants reported various ways in which hEDS symptoms negatively impacted their autism-related needs, resulting in psychological distress. First, participants suggested that fatigue, pain and brain fog impeded engagement in even the deep interests that they held dear, engagement with which is considered vital for autistic people's wellbeing (Long, 2024). Indeed, while Crompton et al. (2026) found that EDS/HSD restricted ability to participate in everyday activities for all their participants, this more greatly compromised the mental wellbeing of their autistic than non-autistic participants. Second, illness fluctuations could prevent attempts to pre-plan and disrupt already-made plans, necessitating that participants engaged in a difficult balancing act to manage physical symptoms (e.g., energy limitations) alongside autistic preferences. The extent to which our participants' activity pacing-related frustrations went beyond those commonly expressed among chronic illness communities is unclear (Andrews et al., 2015; Pemberton & Cox, 2014), but neurodivergent features such as impulsivity and compromised emotion regulation may compound challenges associated with pacing. Third, physical limitations often necessitated use of mobility aids, which contravened masking attempts. The consistent implementation of masking behaviours is stressful and can incur long-term health consequences (Evans et al., 2024; Scheeren et al., 2025). Moreover, where healthcare professionals are often guided by outward presentation, masking behaviours can mean that clinicians overlook the extent of someone's difficulty (Dalmo, 2026). Nevertheless, since autistic people often employ these behaviours to hide 'otherness' and avoid stigma, ostracism, victimisation and discrimination (Evans et al., 2024), including from healthcare professionals (Grant et al., 2024), forced unmasking in psychologically and socially unsafe environments (e.g., when they are using mobility aids) might have adverse emotional consequences (Khudiakova et al., 2025). This contrasts with self-directed masking, which occurs at a pace and in a manner of the individual's choosing. Social acceptance and appropriate support are required to enable autistic people to thrive without the need to mask. Fourth, our data suggest individuals with both diagnoses may be more likely to avoid the frequent medical appointments needed to manage hEDS-related physical symptoms, potentially leading to severe adverse consequences.

Medical invalidation was common to both our and Beckwith and Stephen-Lewis's (2025) participants and was implicated in several participants' non-adherence decisions. Invalidation in healthcare has been reported by prior hEDS samples (Halverson, Cao, et al., 2023; Halverson, Penwell, et al., 2023; Halverson et al., 2021) and by autistic people, particularly women, whether these appointments related to their autism or other medical needs (Grant et al., 2025; Grove et al., 2023). Indeed, for poorly understood and stigmatised conditions, invalidating attitudes may be entrenched in the medical system, where they invoke a range of harms to patients, from depression and suicidality to healthcare avoidance and diagnostic delays (Bontempo et al., 2025). Autistic people with chronic illnesses may be particularly vulnerable to invalidation by healthcare professionals, given cross-neurotype mismatches in communication style, informational needs and expectations of the consultation (Nicolaidis et al., 2015; Shaw et al., 2024). Moreover, some

autistic people may find that instinctual masking behaviour incurs disbelief from professionals (Dalmo, 2026; Moseley et al., 2025). Medical invalidation may be particularly severe for autistic people when set against a backdrop of frequent and pervasive interpersonal trauma (Jones et al., 2022), and antagonistic healthcare encounters have been linked by autistic adults to both healthcare avoidance (Brady et al., 2024; Doherty et al., 2022) and experiences of suicidality (Moseley et al., 2025). Autistic people whose chronic illnesses necessarily require medical and psychological aid (Turner & Kelly, 2000) may be especially vulnerable to deleterious consequences of healthcare avoidance. Another challenge in the interaction of autism and hEDS, in both our study and Beckwith and Stephens-Lewis (2025), was that participants' health needs frequently forced them into medical environments made inaccessible by sensory overload (e.g. bright lights), unpredictability (e.g. waiting times), and unwanted social proximity (e.g. crowded waiting rooms) (Hedlund et al., 2025; Radev et al., 2024). To better accommodate neurodivergent populations, we echo calls for better communication training for healthcare professionals, to reduce invalidation (of those with and without physical health diagnoses), understand masking behaviours (Dalmo, 2026), adapt patient-care environments (Doherty et al., 2023), and adopt a holistic management approach when catering for complex patient needs (Halverson et al., 2021).

8. Limitations and future directions

Our sampling method may have reduced the transferability of findings (all participants were cisgender women, educated to degree level and received both diagnoses privately). This gender disparity is characteristic of hEDS (Demmler et al., 2019), but not the autistic population as a whole (Rødgaard et al., 2022), particularly those with learning disabilities, who were unrepresented. Importantly, it is unknown whether hEDS is equally prevalent in autistic people with and without learning disabilities, though co-occurrence may be especially likely in autistic people with ADHD (Kindgren et al., 2021). While we inferred from the data ways that being autistic and having hEDS might multiply or alleviate challenges associated with either alone, not all participants explicitly reflected on this issue. Direct questioning on this topic might have gleaned further insights.

Our recruitment strategy might also have incurred limitations to representativeness: all participants were targeted through social media and patient support groups. In research on other chronic illness populations, those recruited from patient support groups disproportionately comprised both those who had comparatively negative medical encounters (Lian & Nettleton, 2015) and those less severely affected by their illness (Jerant et al., 2005). Indeed, individuals with more compromised functionality may have struggled to engage in lengthy interviews. Second, recruiting only those with formal dual diagnoses conflicted with diagnostic trends, whereby autistic people (particularly women) with EDS are often subject to missed or mis-diagnoses (Halverson, Cao, et al., 2023; Kentrou et al., 2024). As our sample were necessarily at the end of their diagnostic journeys, our data may also obfuscate whether the perceived complementary aspects of autistic traits for activity management, and frustrations associated with fluctuating symptoms and inabilities to mask, differ according to illness duration and time since diagnosis. Third, we note that in December 2026 new EDS and HSD diagnostic criteria will be released, in which they are expected to be merged as one condition.

In closing, we reflect that mental illness is well documented in autistic people (Lai, 2023), meaning that many clinicians are *aware* of mental health challenges in autistic patients, despite lacking confidence and knowledge to respond appropriately (Maddox et al., 2020; Procyshyn et al., 2025). Autistic people's poor physical health has been overlooked regarding documentation and awareness by professionals (Warner et al., 2019), but we now know that many autistic people live with complex, interrelated physical illnesses (Liu et al., 2023; Ward et al., 2023), and moreover, that physical illnesses are highly intertwined with their mental health (Charlton et al., 2023; Torenvliet et al., 2025). Beyond our participants, other accounts from autistic adults suggest that siloed healthcare systems, including the UK's, often fail to recognise and appropriately support the interrelatedness of physical and mental wellbeing in autistic people (Brady et al., 2024; Clark, 2025). We highlight the need for further research exploring the physical health needs of autistic adults in relation to their mental health, and the urgency of translating such knowledge into improved training for clinical professionals and more accessible and holistic healthcare.

9. Conclusion

The co-occurrence of hEDS and autism has the potential to facilitate management of hEDS, through recognising and actively supporting autism-related strengths. At the same time, autistic people with hEDS experience negative psychological consequences. To support individuals with both diagnoses, clinicians should develop a better understanding of their physical and psychological needs, through enhanced education, and further consider the appropriateness of medical environments. To add weight to this agenda, we encourage future exploration of this target group's lived experiences employing wider, more representative sampling.

CRediT authorship contribution statement

S.L. Clark: Conceptualization, Formal analysis, Investigation, Methodology, Project administration, Validation, Visualization, Writing – original draft, Writing – review & editing. **E. Portch:** Conceptualization, Writing – review & editing. **R.L. Moseley:** Conceptualization, Visualization, Writing – review & editing. **E. Arden-Close:** Conceptualization, Formal analysis, Methodology, Project administration, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

Ethical considerations

The study was approved by the Ethics Panel of the Faculty of Science and Technology, Bournemouth University (ID: 46980) on 13th

April 2023.

Consent to participate

All participants gave written informed consent to participate.

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Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Co-author has a Patient Expert role on EDS International Consortium (Psychiatric and Psychological Aspects Working Group): Sarah Clark. The other authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.reia.2026.202989.

Data Availability

Data is available from the corresponding author on reasonable request.

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