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ARTICLE

Exploring the complexities of illness identity and symptom management in seeking a diagnostic label of postural orthostatic tachycardia syndrome (POTS): An inductive approach

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Abstract

Objectives: Postural orthostatic tachycardia syndrome (POTS) is a debilitating and under-recognized condition of the autonomic nervous system. This study applied Leventhal's Common-Sense Model of Illness Representations to explore the journey to a diagnosis of POTS and to understand its relevance to poorly understood conditions which have common comorbidities.

Design: An inductive qualitative approach was used to explore the processes by which patients formulate explanations and management of symptoms within the search for a diagnostic label and to investigate illness identity in the context of existing diagnoses or multimorbidity.

Methods: Participants ($n = 29$) for this nested qualitative study were recruited from a larger longitudinal study of people who had been newly referred to a specialist POTS service. Semi-structured interviews were conducted via video call. Three researchers coded and analysed data using Reflexive Thematic Analysis and elements of Grounded Theory.

Results: The analysis resulted in three overarching themes: *'Seeking physiological coherence and validation'*, *'Individual persistence'*, and *'Navigating the cumulative burden'*. *'Accessibility and disparities of health care'* was noted as a contextual factor. Receiving a POTS diagnosis was regarded by participants as providing legitimacy and increased access to treatment. Overall, delays in the diagnostic journey and the lack of a clear diagnosis impacted negatively on patients through

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increased uncertainty and a lack of clear guidance on how to manage symptoms. Findings also suggested there were great complexities in assigning symptoms to labels in the context of multimorbidity.

Conclusions: Participants' stories highlighted the urgent need for better recognition of POTS so that the self-regulatory process can be initiated from the early stages of symptom detection.

KEYWORDS

diagnostic journey, illness representations, postural tachycardia syndrome, reflexive thematic analysis, self-management

Statement of contribution

What is already known on this subject?

- The common-sense model specifies that when people experience symptoms, they are motivated to find a label (diagnosis) to explain these symptoms.
- Illness identity (the label and symptoms people associate with this label) is a key driver in illness self-management and adjustment.
- Postural orthostatic tachycardia syndrome (POTS) is an under-recognized condition. Obtaining a diagnostic label is challenging, which may uniquely impact self-regulatory processes.

What does this study add?

- The POTS label was viewed as providing legitimacy, 'permission' to be ill, as well as guiding how to manage the condition.
- Journeys to diagnosis created a high emotional and physical burden and required significant persistence.
- Better recognition of POTS is imperative to reduce this burden and mobilize more helpful self-regulatory processes sooner.

INTRODUCTION

Leventhal's Common-Sense Model of Self-Regulation (CSM) is a widely used theoretical framework in health psychology for understanding individual differences in responding and adapting to illness self-management (Leventhal et al., 1980). The model outlines the processes by which patients become aware of symptoms (e.g., headache) and/or signs (e.g., rash) as potential health threats, and how the process of labelling these symptoms as signs of illness (creating an illness identity) forms the starting point for developing a personal, common-sense illness representation. The illness representation includes beliefs about the timeline (acute, chronic, cyclical), consequences, controllability, and cause of the illness and symptoms (Leventhal et al., 2016). The presence of a label, or diagnosis, is seen as imperative in driving the dynamic nature of ongoing symptom perception, interpretation, and self-management (Scott et al., 2013). For instance, once patients have received a label for an illness, they may interpret a range of signs and symptoms as part of that illness, including those that may relate to another illness, everyday

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somatic changes, stress, or side effects of medications (Main et al., 2003). This in turn might escalate attempts to manage the condition.

Since its inception, the CSM has been extensively applied to chronic/long-term conditions (LTCs), whereby numerous quantitative studies have shown the relationship between illness representations and behavioural and illness outcomes across LTCs (Broadbent et al., 2015). However, few have focused on the process of developing the illness representations described above and the factors that may influence this. In addition, the CSM as currently conceptualized largely focuses on a single illness. Many people with LTCs are also diagnosed with associated physical or mental health co-morbidities (Fund, 2015; Naylor et al., 2016), which may obfuscate the attribution of symptoms to various diagnostic or 'illness' labels. Moreover, the CSM was originally formulated through interviewing people with well-recognized medical conditions such as cancer or heart disease (Leventhal et al., 1980). The CSM may not fully explain the role of the illness label in the context of a condition that is not currently well understood, defined, or recognized, where patients often undergo a difficult journey to receive a diagnosis, and in turn how this may affect the process of developing illness representations and associated coping behaviours.

Postural orthostatic tachycardia syndrome (POTS) is one such novel condition. POTS is a relatively recently defined (Schondorf & Low, 1993), under-recognized, and debilitating LTC of the autonomic nervous system with many possible causes and symptoms. It is defined by a sustained orthostatic heart rate increment of at least 30 bpm accompanied by symptoms, without a drop in blood pressure (Sheldon et al., 2015). The prevalence of POTS is estimated between 0.2% and 1.0% in developed countries (Zadourian et al., 2018), although this may be on the rise due to its association with long COVID-19 (Gall et al., 2022). POTS mostly occurs in younger women and significantly impacts their quality of life, physical functioning, and mood (Knoop et al., 2022). Aside from the gold standard tilt table test or active stand test to confirm diagnosis by measuring the excessive orthostatic heart rate increase (Plash et al., 2012), there is little consensus regarding testing regimes. Symptoms of POTS can also vary widely (Raj et al., 2020) and be influenced by comorbidities, but orthostatic symptoms (such as dizziness, tachycardia, and exercise intolerance) are the most discriminatory group of symptoms experienced by patients with POTS. Multimorbidity is prevalent in people with POTS, with around 83% reporting at least one physical comorbidity (Shaw et al., 2019).

The likely multifactorial pathophysiology of POTS is currently not fully understood (Vernino et al., 2021). Hypothesized mechanisms include autoimmune problems (Johansson et al., 2022), low blood volume, small-fibre neuropathy, and hyperadrenergic states (Fedorowski, 2019). There are no licensed treatments for POTS, but symptoms can be relieved to some degree by a combination of pharmacological, non-pharmacological, and self-management strategies (Kichloo et al., 2021). Importantly, receiving a correct diagnosis of POTS and treatment has been shown to lead to improvements in quality of life (Flack & Fulton, 2018). Despite this, not all medical practitioners are familiar with the condition and some remain sceptical of the legitimacy of the diagnosis. Diagnostic delays and misdiagnosis of POTS, often with anxiety disorders, are common (Knoop & Dunwoody, 2023; Shaw et al., 2019), in part due to the similarity between somatic symptoms of anxiety (such as tachypnoea, palpitations, dizziness) and physical POTS symptoms (Raj et al., 2018).

Given these complexities, the journey to diagnosis can be challenging for many patients with symptoms suggestive of POTS. Help-seeking and other coping mechanisms such as pacing and adapting daily activities, encapsulate the self-regulation required for patients with LTCs to manage and adjust to their condition (Deary, 2008). However, without a label, this process may become disrupted. People waiting for confirmation of a diagnosis of POTS therefore provide an exemplar opportunity to explore complex processes not clearly delineated in the CSM of illness representations.

The current study aimed to explore the processes by which patients form explanations of symptoms within the search for a clear label, and how they manage their ongoing symptoms when trying to navigate this journey to diagnosis. An additional objective was to investigate illness identity in the context of existing diagnoses or multimorbidity. This is the first study to document and evaluate patients' subjective experiences of the journey to a POTS diagnosis. To provide a more in-depth understanding of participants' experiences and explore the nuances and intricacies of this more freely, this study embraced

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an inductive, qualitative approach, rather than starting the analysis by deductively linking to these specific concepts.

METHODS

Research design overview

Participants in this nested qualitative study were recruited as part of a larger quantitative longitudinal single-centre study investigating correlates and predictors of POTS symptom burden. Ethical approval for the study was granted on 27/10/2021 by HRA and Health and Care Research Wales (HCRW) and London-Surrey Research Ethics Committee (Research Ethics Committee reference: 21/LO/0728).

Participants

Twenty nine participants were recruited from a list of patients who were due their first appointment with a national POTS clinic within 1 month. Eligibility of participants was determined by three criteria: if they (1) have a suspected diagnosis of POTS; (2) were older than 18 years of age; and (3) spoke English.

Recruitment

Patients on the specialist national health service (NHS) POTS clinic waiting list were sent a letter inviting them to take part in the wider longitudinal study, which participants accessed online. In the questionnaire, participants had the choice of opting into the nested qualitative element of the study. The first 20 participants were included on a first come first served basis. Purposive sampling was used to invite an additional nine participants to try and capture the experiences of a diverse range of individuals in regard to ethnicity, age, and gender. As sampling in this nested study was done from a larger database, participant numbering reflects the numbers of the participants in the larger database. Maintaining these numbers enabled us to relate back to participants' quantitative data such as diagnosis, demographic information, and symptom scores.

Data collection & identification

Participants were contacted to arrange an interview through video link at a time convenient to them. Interviews, conducted by IK, were semi-structured and included broad open questions and suggested prompts (Appendix 1). To minimize any participant distress due to the emotive topics discussed, participants were offered the option to take breaks, choose not to answer questions, or stop the interview at any time without any negative consequences. Signposting to further support services was included in the debrief.

Interviews, conducted between 14/11/2021 and 01/09/2022, were audio recorded and transcribed verbatim. Any references to names of doctors, hospitals, or locations were removed to protect the identity of individuals and hospitals. Transcripts were coded by three researchers (IK, SG, SF). Field notes were taken by IK. Line-by-line coding was carried out, with 10% of transcripts double-coded by researchers to calibrate coding and provide a communal codebook after the first 17 transcripts, which formed the codebook for the remaining transcripts. Codes were repeatedly discussed between the coders and wider research team (RMM and AJ), which led to the identification and refinement of the final themes.

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Data archiving statement

All collected data will be stored securely for 5 years at King's College London in line with the Caldicott principles, after which time they will be permanently destroyed.

Analysis and rationale for choice

A Relativist epistemology and Critical Realism ontology was adopted to embrace a concept of truth and reality while recognizing that this is always shaped by human experience (Clarke & Braun, 2021). Although we adopted a predominantly inductive approach, questions in the topic guide were influenced in part by the CSM in relation to illness identity development and beliefs about coping strategies. These dimensions of the CSM likely indirectly influenced framing and coding of the data as well as thematic clustering. The coding process was unstructured and attempted to capture the researchers' understanding of the data. Interviews were read repeatedly before being coded using NVivo (version 12.7). Data were analysed by working iteratively with the phases mapped out by Braun and Clarke for Reflexive Thematic Analysis (Clarke & Braun, 2021), supplemented with techniques from grounded theory (Corbin & Strauss, 2014; Glaser & Strauss, 2017; Table 1). This combination enabled structured analysis to achieve a richer interpretation of the data. Rather than focusing on a purely narrative approach, this theoretically flexible method allowed interpretation to be grounded in participant experiences, while conceptualizing central organizing concepts. Two coders focused on those with no previous diagnosis and a third coder on those who reported having a diagnosis. Themes and central concepts between these groups were compared and discussed with the wider research team. Key themes were agreed, and any contrasts between those who had received a preliminary diagnosis versus those who did not were reported within the theme. Illustrative anonymized participant quotations were used to validate themes. The analytical procedure was accomplished through a process of integrating and clustering together significant statements across transcripts to construct common themes. Table 1 details the summary of analytic processes completed by researchers and how specific grounded theory strategies were used.

Methodological integrity and reflexivity

This research was supervised by investigators experienced in qualitative methods (AJ & RMM) and an expert in POTS (NG) and utilized the diverse perspectives of multiple researchers. Several actions were undertaken to establish trustworthiness of analysis. To establish credibility, the study team had prolonged engagement with data during the familiarization phase, where researchers performed multiple readings of all transcripts. To establish confirmability, there was an audit trail during the data coding phase, where the codebook was consulted and updated after every new interview. Additionally, a team consensus was used to refine, define, and name themes. Finally, to aid transferability of findings, this study provided thick descriptions and the reasons behind the analytical choices made in this study. Researchers practised reflexivity in multiple ways (see Tables 1 and 2 for details).

RESULTS

Participants

Twenty nine participants were interviewed. Although people were recruited on the basis of waiting for a diagnosis of POTS, during interview 11 people mentioned they had received a diagnosis in private health care ($n = 6$), some of whom had the private appointment with the consultant and clinical lead of our recruitment site (the NHS POTS clinic). Others had a tentative diagnosis from another hospital

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TABLE 1 Summary of analytic process.

Thematic analysis phase	Implementation	Supplementary techniques derived from grounded theory
1. Familiarization	• Researchers familiarized themselves with the transcripts through reading the transcripts multiple times and making notes for points of interest.	Researchers also listened to audio recordings where possible
2. Data coding	• The first 17 transcripts were used to create the initial codes and a coding manual. The coding manual was then used for the subsequent 12 transcripts and revisions were made to the manual iteratively when necessary. • All researchers reviewed the coding manual to agree on the codes and its usage on the subsequent transcripts.	Line-by-line open coding was used where codes were freely created and there was constant comparison between transcripts and researchers.
3. Generating initial themes	• As coding continued, codes that were related were grouped together as potential themes or subthemes. • Researchers came together to discuss possible combinations of codes and the themes present.	Researchers used constant comparison between transcripts, identified key concepts in data and kept written notes on ideas about themes.
4. Reviewing and developing themes	• Potential themes and sub-themes were reviewed to check if they were consistent with the extracts highlighted. • Researchers came together and checked to see if the themes captured relevant material from across the data set.	Researchers used constant comparison between transcripts, and searched for deviant case summaries to capture participants' unique illness experiences and symptom management methods.
5. Refining, defining and naming themes	• Themes were refined and explicitly defined to clarify and succinctly capture patterns in data relevant to research objectives. • Researchers confirmed the themes and their interrelations.	Researchers used constant comparison between transcripts and discussion between researchers to compare themes.
6. Writing up	• Researchers selected appropriate and compelling quotes to illustrate the themes and sub-themes. The final analysis and contextualization of findings were in relation to existing literature and research objectives.	Not applicable.

Note. Adapted from Hughes et al. (2020)'s approach to report the process used in the current study.

($n = 5$). The status of these diagnoses was often not clear. Some people mentioned they were awaiting the Tilt Table Test (TTT) to get this confirmed. Others felt it was indicated or confirmed, but they needed further assessment, or reporting and interpretation of test results, by the NHS specialist POTS clinic to guide treatment. As all participants were still awaiting their first NHS POTS diagnostic clinic appointment, further tests, results, and/or a treatment plan, and there appeared to be considerable lack of clarity with the preliminary 'diagnosed' group, we decided to include them in the data analysis and explore if the themes were any different for this group than those who had not received a preliminary diagnosis. Average self-reported Kessler psychological Distress (K10) scores indicated mild levels of distress (Merson et al., 2021). Average self-reported Orthostatic Grading Scale (OGS) scores of participants indicated severe orthostatic symptom burden (Frith & Newton, 2016). Eight participants (27.8%) reported their ability to work/study being impacted by POTS. Most participants (82.7%) reported having white ethnicity. The average age of participants was 37.3 (Table 3).

Themes

Analysis resulted in three superordinate themes: *Seeking physiological coherence and validation; Individual persistence; and Navigating the cumulative burden* (Figure 1, Table 4), while *Accessibility and disparities of health care* was

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TABLE 2 Summary of reflexive practices.

Researcher:	Practices carried out	Practice influence on analytical process
SG	1. Conducted observations in the POTS clinic of patients attending their first appointment	Helped SG to see patients' experiences in clinic and observed the communication and relationship between patients and HCPs. This influenced how SG perceived the importance of the POTS specialist clinic appointment to patients and observations contextualized the importance of the journey to diagnosis. Additionally, showed what symptom management may entail for patients.
SG, SF	2. Sitting in on interviews conducted by IK	Showed how emotional patients were during the interview and influenced how SG and SF perceived participants' interviews and narratives.
SG, SF, IK	3. Reflecting on own role and perspective	Noticed a lack of awareness of POTS to be relevant to the general population and health care professionals and also influenced how SG and SF wanted to describe patient experiences more accurately. IK maintained a reflexive diary which was audited by supervisors.
SG, SF	4. Explorative discussions with IK	Helped confirm and reflect on themes and their relevance to each other. Also confirmed initial patterns in codes to form themes. Deepened their understanding of POTS from both lived experience and research knowledge.
SG, SF, IK	5. Discussions with wider supervisory team (AJ, RMM and NG)	Helped to refine themes to be more specific and helped with the creation of theme names and definitions.

noted as an important contextual factor. The bidirectional relationships between the identified themes, and the emotional responses, representations and attitudes of participants, were described throughout each theme. This includes descriptions where there were contrasts between groups of participants who did and those who did not have a preliminary diagnosis at the time of interview, although very few differences appeared to be reported between those who reported a previous or tentative diagnosis and those with no diagnosis. A sense of unpredictability and uncertainty was salient in participants' experiences, and prevalent throughout all themes.

Seeking physiological coherence and validation

Participants described the difficulties associated with not knowing what was wrong with them, and how they needed to find answers and explanations for their symptoms. Participants talked about a range of precipitating events which they believed caused the onset or exacerbation of their POTS symptoms. These included viral (including COVID-19) or other infections, physical and emotional trauma, and vaccination. Some noticed a more gradual rather than acute onset, with many describing how they had experienced some POTS-like symptoms for a much longer period of time but just assumed these were normal. The narratives exhibited a strong desire to make sense of the symptoms and physiological sensations experienced.

> I just want to know what I'm dealing with, then me and my husband can deal with it… once I know what I'm dealing with I'm okay.[…] It's not knowing what's wrong that's causing the problem.
>
> (Participant 11)

This search for understanding and a diagnosis was often a long and at times frustrating process, with participants feeling like they were being sent around in circles between health care professionals who may not know about, or have expertise in the condition. This cyclical journey is illustrated in Figure 2.

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TABLE 3 Summary of demographics reported by participants.

Number of participants	29
Mean age	37.3 (*SD* = 13.9, range 18–63)
Sex	23 (79.3%) Female 3 (10.3%) Male 3 (10.3%) Non-binary/third gender
Mean OGS score (out of 20)	10
Mean K10 score (out of 50)	21.4
Co-morbidities	13 (45%) Hypermobility/Ehlers Danlos Syndrome (EDS) 9 (31%) Migraine 6 (21%) Irritable Bowel Syndrome (IBS) 6 (21%) Long Covid 5 (17%) Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) 5 (17%) Asthma 4 (14%) Mast Cell Activation Syndrome (MCAS) 4 (14%) Fibromyalgia 2 (7%) Autoimmune condition 2 (7%) Gastroparesis 1 (3%) Raynaud's Phenomenon 1 (3%) Other
Average number of co-morbidities per participant	2
Occupational status	10 Employed – Full time 2 Employed – Part time due to POTS 1 Employed – Part time by choice/other reasons 5 Unemployed – Because of POTS 2 Unemployed – Unrelated to POTS 1 Student / Training – Full time 1 Student / Training – Part time due to POTS 1 Student/Training – Part time by choice/other reasons 2 Homemaker 1 Retired 3 Other
Ethnicity	19 (65.5%) White British 3 (10.3%) White Irish 2 (6.9%) White Other 2 (6.9%) Asian or Asian British: Indian 1 (3.4%) Chinese 1 (3.4%) Mixed: White and Asian 1 (3.4%) Mixed: Other

Abbreviation: K10, Kessler Psychological Distress Score; OGS, Orthostatic Grading Scale.

> I was just going in circles with nothing being done, at all. And a doctor saying, Oh well, it's not my responsibility, it's this person, and we'd go to them. Say, Oh, it's not right – ping back and forward for, you know, like a decade and a half.
>
> (Participant 74)

Seeking a diagnosis was mostly in response to debilitating symptoms but was often accompanied by a need to understand the bigger picture and connect the dots. For example, this might include needing to understand the connection between their POTS-like symptoms and other common comorbidities such as hypermobile Ehlers Danlos Syndrome (EDS).

In addition to searching for a label for their symptoms to help them make sense of their symptoms and guide coping strategies, participants strived to have this validated by a health care professional. The importance of being heard and taken seriously, and for symptoms to be investigated, was palpable.

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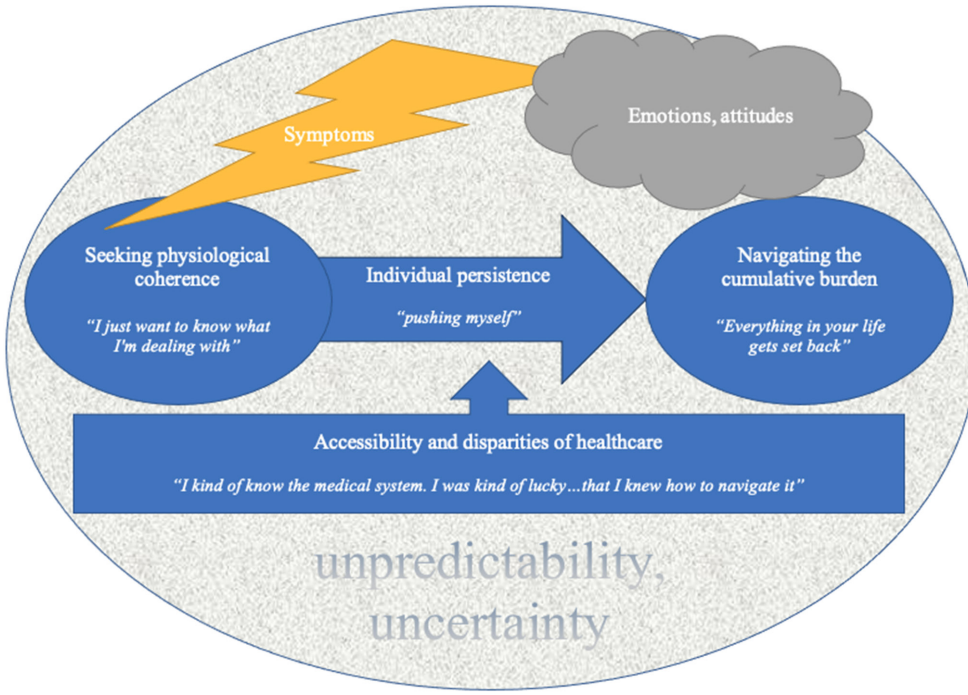

FIGURE 1 Illustration of identified themes.

> It's having somebody that will actually listen and validate what you are saying, yeah, I think that's it for me. The single biggest important thing is not being fobbed off and not being just given pills and go away.
>
> (Participant 1)

Participants felt that acquiring a diagnostic label for their symptoms would validate their experience, but also somewhat protect them from dismissive attitudes. Many had encountered disbelief from HCPs, family, colleagues, and friends, which sometimes led to self-doubt.

> So to get the diagnosis actually would – it would just change things for me.[Name] I cannot even – words cannot even explain how much that would – what that would do for me. Because then I would be like, right, this is what is going on. And then other people who were not believing, like whoever they are. Then it's there. I have not been neurotic or a hypochondriac. This is what's happening, Please. Now, can we move forward?
>
> (Participant 80)

> I think if I can get a diagnosis, it would just make me feel less bad, because I kind of feel like, I'm not lazy, but I have all these good intentions and then never the energy to kind of pull through.[…] There's a reason I do not have the energy to do this. I'd just feel a bit more accepted, I think.
>
> (Participant 3)

> It's horrible. You end up feeling, like it's all in your head. You know, when you keep going and they do not listen, and you begin to sort of feel that it's not right, you know,

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TABLE 4 Summary of themes, central concepts, and their influence on illness perceptions and self-regulation.

Theme	Central concepts	Impact on representations and/or self-management
Seeking physiological coherence and validation	• Understanding symptoms and physiology • Seeking validation from an HCP	Uncertainty in the absence of a label, which might delay self-regulation. Participants seeking legitimization of their experiences and symptoms, waiting for validation before attempting self-management. Feelings of invalidation and discreditation from others because of absence of a diagnostic label.
Individual persistence	• Pushing for referrals and investigations • Pushing themselves	Persistence in the face of dismissive attitudes, fighting for care: striving for confirmation of existing illness beliefs. Continuing to progress on the diagnostic journey despite negative interactions with HCPs, maintaining activity and work despite new-found limitations.
Navigating the cumulative burden	• The accumulative effect of symptoms from multiple conditions, psychosocial impact, and burden of investigations & treatment • Coping with the impact of the condition	Needing to prioritize conflicting needs (between symptoms, conditions, mental and physical health), which could affect mental well-being and the ability to utilize adaptive coping behaviours due to limited energy resources. Complexities between different representations, for example which sensations are caused by what, and whether they are dangerous. Attempting self-regulation through pacing, adapting and acceptance. Management and avoidance of energy deficits, finding 'ways around' things.

> it's just, you are not imagining it, but, you know, it is all in your head and just to sort of shut up and go away. And that can be quite, it's just horrible. It's negative. It's depressing as well.
>
> (Participant 33)

There was a sense that receiving a diagnosis and validation would alleviate some of the uncertainty and negative responses, relieve internal dissonance about the cause of their symptoms, and provide participants with self-acceptance and ways to move forward. Others had less positive expectations about receiving a diagnosis. These participants were less sure that a diagnosis would lead to better understanding from others, with some recounting how receiving other comorbid diagnoses had not led to improvements.

> It's made no difference being diagnosed with Ehlers Danlos apart from the fact I know I've got Ehlers Danlos, no it's made no difference to me at all.[…] It means absolutely nothing having a diagnosis, a bit like having Long COVID, nobody understands.
>
> (Participant 4)

This highlighted that a diagnosis may not always translate to better care and management. The absence of a definitive diagnostic label at times contributed to ambiguity around the threat of symptoms. In particular, some participants were unsure which symptoms may be dangerous versus benign, for example with POTS-like cardiac symptoms such as tachycardia and chest pain, leaving participants uncertain how to cope. The emotive language and hyperboles often used by participants to express their symptom experience appeared to demonstrate a need to be heard, with the current situation being experienced as intolerable by some.

> I used to run my own business as a jewellery designer and maker as well as run, work full time as a project manager. I've gone from that to sitting on my ass, twiddling my thumbs and hoping my heart rate will go down, so I do not have a heart attack or a stroke.[…] I need this resolved, because of the impact it has on my life. It's bad. I've literally sat around for the last two years… at various stages wishing I would die.
>
> (Participant 22)

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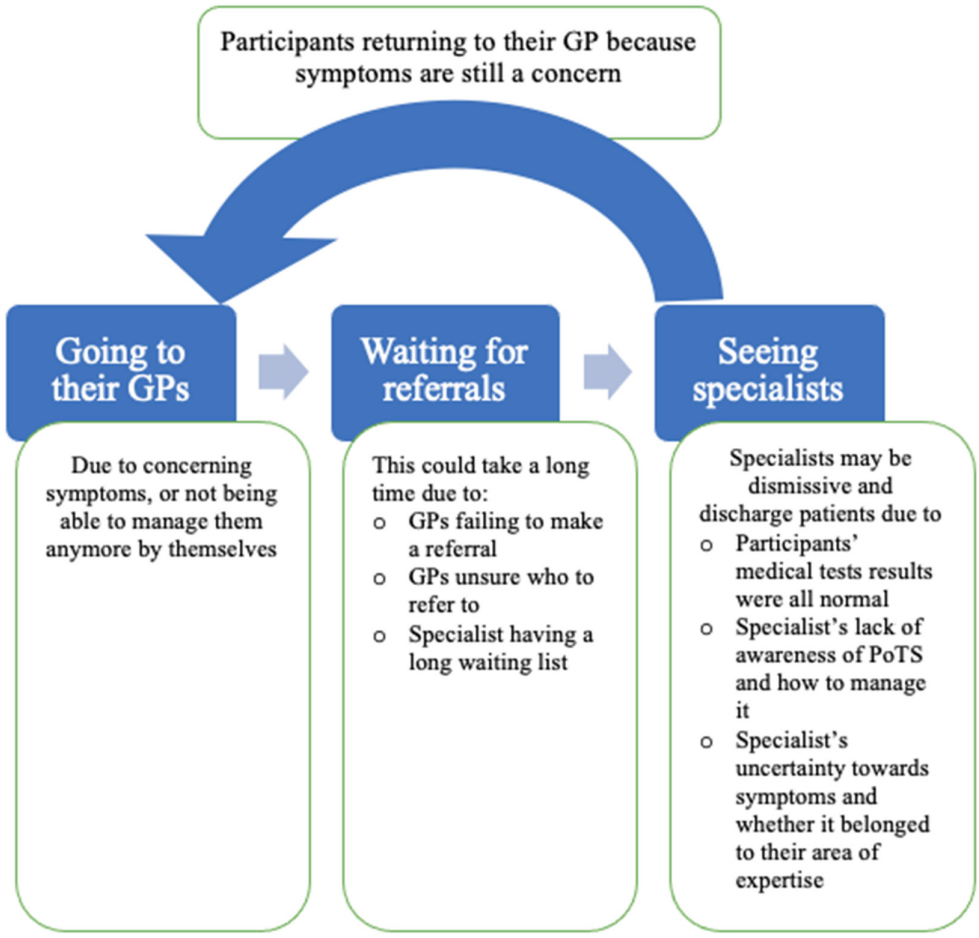

FIGURE 2 Circling between health care professionals and within the national health service (NHS).

The search for coherence and a diagnostic label was understandably more notable in the group of participants who had not received a diagnosis. For those participants who already had a diagnosis, uncertainty still prevailed, but sense-making and seeking coherence were somewhat less at the forefront of participants' experiences. The search for physiological coherence appeared to be a vital element of participants' journey towards adapting to living with their condition, by having an impact on symptom management and outcomes.

Individual persistence

In their search for coherence and striving for validation through receiving a diagnostic label, participants' narratives often displayed great individual persistence. They often described the need to push for appointments and referrals, do their own research, and self-advocate in the face of repeatedly encountering dismissive attitudes and a lack of awareness of the condition.

> He did not listen to me at all, at all.[…] when I said, I think it could be POTS and maybe you can do a tilt table, he got really angry with me. And said, 'Don't use that ridiculous

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> acronym or whatever that word is, with me, you don't and just kicked off about how POTS does not exist, basically[…] Like that [eventually being referred for a TTT after this was requested by a POTS specialist]. And I was just, like, why could you not have done this in April 2020? I might not have lost my job. I might not have lost my life.[…] it took you less than a week to organize that. Like, why could not you do that a year and a half ago?
>
> (Participant 18)

Many participants described similar difficult scenarios, while those who had more positive interactions with HCPs often referred to themselves as 'Lucky', suggesting that negative experiences were considered the norm rather than the exception. Participants often had a similarly persistent approach to managing their lives with POTS symptoms, where they often pushed through symptoms.

> I mean, I've continued to push myself and work full time. I mean, there are some people that aren't fortunate enough like me to work full time with these conditions. But I'm very much in the mindset that you know, if I do not do it, I will not do it. And, you know, life goes on, doesn't it? And you have to cope with what you have got.
>
> (Participant 4)

> It's just I really refuse to accept my situation and I want to be able to do the dancing that I love to do, which is really physical. It's not this stuff. And I want to be able to go for walks with my son, and I want to be able to go to the shops. I want to be able to do all those things and that's, it's like a stubborn, rebellious resistance.
>
> (Participant 18)

In contrast, others described the detrimental outcomes of pushing through.

> I was pushing myself to, like, my extremes completely, and so it would get to the point where I lost my hearing, and my vision would start to go, and I would start to have, I think they were called absence seizures, or something like that, where I'm still conscious, but I have no control over my body, and I would be fitting. And this was happening because of the physical strain that was being put on my body.
>
> (Participant 8)

This highlighted the difficulty in knowing how best to manage symptoms when the outcomes are uncertain. The fear of fainting or the onset of debilitating symptoms was tangible, where the appraisal of symptoms often led to a combination of avoidance and adaptation of activities.

> If there is somewhere, a long queue, I have to queue, I cannot do it. I usually try and avoid that, I avoid[…] going on a train where I cannot sit down. So, I fainted once in a full train with my daughter, and I do not want to do that again.[…] and it takes a while to kind of get around it, but I do not want that happening again, so I just try, if there is a space, I will sit down, and if there's no space, I even sit down on the floor.
>
> (Participant 9)

Participants wanted and needed to progress towards their symptoms being less impactful. The cyclical, dynamic process of identifying and understanding symptoms so that they could be managed better, appeared driven by the individual persistence of participants. For some younger participants, parents also played an instrumental role in persisting to advocate for their child.

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> My mother has gone kind of above and beyond[…] if it were not for her, I would not have any of the diagnoses I have now. Like none of the [diagnoses of] EDS, POTS. None of it. So I owe pretty much everything, medically, to her.
>
> (Participant 74)

Navigating the cumulative burden

Balancing the collective burden of unpredictable and fluctuating symptoms, with the uncertainty around diagnoses, their future, the associated psychosocial impact, and the burden of investigations and treatment, had an overwhelming, cumulative effect on participants. Some talked about giving up, losing hope and feeling left behind.

> Everything in your life gets set back.[…] everything just takes longer. It kills relationships with people. There is no aspect of your life that it does not f**k with…And there's so much you have to pass up, drop out of. And it never really ends.
>
> (Participant 74)

Living with comorbidities also affected the cumulative burden, sometimes making it difficult to distinguish between conditions and knowing how to manage these.

> I'm still finding my way with it all, what happens is, I think the POTS side is starting to become a bit more under control, but then obviously PoTS gets flared up by anything, so I've got hemiplegic migraines, so if I have one of them, then obviously that impacts my POTS and vice versa, so it's hard to know what's affecting what.
>
> (Participant 6)

The psychosocial impact of symptoms included feelings of anxiety and embarrassment.

> It just adds this added level of anxiety when you are out in a public space and you are like, okay, if I fall, I fall here or if I fall there, is there something nearby, and it's really embarrassing because I'm 29, and all my friends are quite young, so I'm just like that person who is like, god, could I just need to sit down quick with this – because I have the Ehlers-Danlos layers of pain and fatigue. And then I have the blood pressure POTS thing and it's just very hard to manage the two, basically.
>
> (Participant 120)

Participants employed various ways of coping with aspects of this cumulative burden, most notably their physical symptoms. Exercise, salt, water, medication, dietary manipulation, experimenting with alternative therapies, and strategies, such as wearing compression garments, bed tilting, and pacing, were common approaches. These were typically employed through trial and error, with high levels of self-monitoring, and often with mixed results. Participants often needed to prioritize coping strategies, where beneficial approaches for one symptom/condition or their mental well-being, had the potential to negatively impact another aspect of their health, requiring constant appraisal and monitoring. There did not appear to be one single coping strategy that was particularly effective for all participants, suggesting there is no one-size-fits-all approach to reduce the overall burden for patients.

Without a firm diagnosis or appropriate evidence-based guidance, some participants would rely on experimenting with sometimes less adaptive ways to manage and cope with their condition, such as trying to keep their heart rate down at all costs, smoking or not eating.

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> So whenever I have a meal, I just get really, really sleepy, and I really, become really fatigued and sleepy, and I really hate that. So sometimes I might just starve myself to get work done, because I know that when I eat, I'll fall asleep.
>
> (Participant 47)

Participants described what care and treatment they would receive in an ideal scenario, which often included streamlined, coordinated care provisions. A tailored, multi-faceted, individual approach was considered helpful by participants to manage their changeable symptom burden.

> I just like to just try and deal with it and get on with it. So, I guess it would be a case of is there a medication, you know, magic tablet that will fix everything, which there won't be. Am I on the right medication already, you know, with all my other things. Something heightening a symptom that maybe should be adjusted. And you know, is there anything I can do for myself? You know, I don't know, exercises, or is there an alternative remedy to try and relieve things? And is it something that I maybe need to do all the time? Or is it that if I just feel a bit weird and a bit wonky that maybe I just do that then? It's that sort of a thing.
>
> (Participant 33)

However, having the diagnosis confirmed by a HCP before attempting self-management strategies was seen as important by some.

> I'd read about the self-management things and[…] I sort of did not want to try them because I still felt that I had to prove that I had PoTS.
>
> (Participant 21)

This demonstrated a need for a confirmed label and legitimacy of the condition before self-management would occur, and that without this, self-regulation could be stalled.

Accessibility and disparities of health care

We felt it was important to note accessibility to health care as a contextual factor that may impact coherence and coping. Access to private health care featured prominently, particularly among the group of participants who had a preliminary diagnosis at the time of their interview. Working as HCPs themselves also emerged from participants' accounts as being significant. Many attributed faster diagnoses, navigating care systems more effectively, and being taken more seriously, to their own medical knowledge.

> I can fight my corner kind of thing, and I come from a nursing background. So, you know, I kind of know the medical system. And I know I was kind of lucky in the way that I knew how to navigate it and get through it kind of privately and through, you know, navigating it then linking back into the NHS and stuff. But if you do not have that,[…] it would be impossible.
>
> (Participant 7)

Socio-economic and professional status, geographical location, sexual orientation and gender, and what one participant described as 'ableism' all appeared to be determinants for disparities in care, while power relations between doctors and patients were cited by some participants as sources of incongruence and mistrust.

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DISCUSSION

This study aimed to explore the journey to obtaining a diagnosis of POTS, a poorly recognized condition with common multimorbidity. Specifically, this search for a label was examined in the context of the relevant processes outlined in the CSM of developing an illness identity and how this may impact symptom management.

The requisite for a diagnostic label for participants' symptoms was clear, to validate their symptoms, provide physiological coherence, and provide agency through access to treatments and support. Perhaps the latter was further exemplified by the number of patients who despite having a diagnosis still pursued the initial assessment appointment with the NHS clinic. A diagnosis fostered self-acceptance, but also legitimacy towards others, although some raised concerns that the label itself may not necessarily prove helpful where the link to illness management was not clear. This is congruous with research in other chronic conditions such as Fibromyalgia, where despite the initial sense of relief and recognition of their symptoms as a condition when diagnosed, the benefits of a diagnostic label may be limited in the long run (Lacerda et al., 2019; Undeland & Malterud, 2007). Our study findings also encapsulated the potentially unhelpful behaviours that arise in the context of an undiagnosed condition, such as delaying self-management or not eating.

Due to the difficulties experienced during the diagnostic journey, which was in many cases not linear but cyclical and iterative, immense amounts of persistence were required. Participants appeared tenacious and emotive; however, this could be a reflection of the participant group who persisted on this arduous journey, which was fraught with complexity. 'Pushing through' was a contested approach among participants which had mixed outcomes; although it helped some progress or maintain activity, it at times caused conflict or deterioration, which ultimately added to participants' cumulative burden. Research of related LTCs suggests that focusing on maintaining activity is associated with better physical functioning but worse psychological adjustment, whereas accommodating the illness is associated with better psychological adjustment (Brooks et al., 2011) but increased disability. Greater focus on symptoms negatively impacts both physical and psychological functioning (Ransom et al., 2005; Ray et al., 1993), although this may differ in POTS populations.

The cumulative burden of striving to obtain a diagnostic label and coping with the condition(s) was considerable. Many employed a heuristic approach of trial and error, but also self-monitoring and pre-planning for all eventualities, to cope with their symptoms and reduce their impact. Strategies therefore appeared suggestive of symptom/problem-focused coping, more than emotion-focused coping (which is aimed at managing the emotions associated with the symptoms rather than the symptoms themselves; Carroll, 2020). There was however a sense that for some, the search for labels resulted in being trapped in a cycle rather than a self-regulatory process, due to a lack of progress or resolve.

Accessibility and disparities had the potential to impact the journey to diagnosis and receipt of care, with some attributing a smoother journey to diagnosis to their background as an HCP or access to private health care. This is an area worthy of further qualitative and quantitative enquiry.

In relation to the CSM, the framework specifies illness identity (the labelling of symptoms as part of a specific illness) as a starting point for developing an illness representation, which in turn mobilizes coping behaviours to reduce the health threat. Our results suggest that in addition to this, the label or POTS diagnosis provides important legitimacy for the illness and related disability for patients, even when there was more than one illness present, and despite interactions between conditions. In this context, it was felt it was important to distinguish which symptom might be attributable to which condition, and how this might influence the treatment approach depending on the condition. This was therefore congruent with the CSM, where a specific label will guide specific management approaches. The challenge for patients was that a strategy for one illness/symptom may be problematic for another one.

The CSM did have some limitations in the context of POTS. Our findings suggest that rather than processing an emotional response in parallel as proposed by the model, this likely interacts with other domains of the model, most notably POTS symptom stimuli, as autonomic homeostasis is heavily

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involved in both emotional regulation and POTS symptoms (Kanbara & Fukunaga, 2016; Owens et al., 2017; Owens et al., 2018). For example, participants described the interaction between their health conditions and the anxiety these symptoms could cause, with cross-overs of appraisal and coping responses occurring throughout rather than in a linear fashion. The relationship between symptom appraisal, emotions, and other domains appears more complex in a condition like POTS, which is made up of a constellation of sometimes seemingly unrelated symptoms, signs and associated conditions. Better recognition of POTS symptoms appears imperative to reduce the profound impact the journey to diagnosis and treatment delays can have on patients and may improve relationships between patients and those treating them.

Implications for practice and future research

This study has theoretical, clinical, and empirical implications. Primarily, it needs to be recognized that in the context of conditions like POTS, participants' journeys to finding a diagnostic label are often complex. They do not fit neatly into the boxes of the CSM or indeed health care systems which often work in silos. The CSM may benefit from refinement to reflect the complexities of poorly understood multimorbid conditions. Although the model captures the dynamic concept of illness identity seen in our interviews, where people search for labels to explain their symptoms, it is a more complex process where multi-morbidity or lack of clarity in the label exists. The importance of the label here is not only explanatory but driven by the need for legitimacy of the symptom experience and associated disability.

The CSM also suggests that illness identity is the starting point for developing the illness representations, but some patients had already formulated other beliefs about the lack of controllability and chronicity of the symptoms even without the label. Indeed, it may be the lack of a label that enhances these more negative beliefs.

Furthermore, the interviews illustrate the distressing emotions generated from the symptom experiences as well as the frustrations of the diagnostic journey. Rather than the emotional representation occurring in parallel to cognitive representations as suggested by the CSM, they appear as interactive responses to these factors. There did not appear to be a separate coping response for emotions; the focus was more on managing the symptoms. This interaction is perhaps better represented by models such as the five-part cognitive behavioural model (Padesky, 2020; Padesky & Mooney, 1990), which broadly addresses the interplay between thoughts, behaviours, and mood but also encompasses physical reactions and situational factors. This model proposes to be helpful for collaboratively devising treatment plans with patients with a combination of difficulties.

From a clinical perspective, diagnostic journeys for people with suspected POTS are very lengthy, and it is difficult to develop specific management strategies without a diagnosis. An earlier diagnosis could be beneficial, but it is important to understand the delays and reluctance to treat patients with these conditions from a health care professional's point of view. Future research questions and assumptions to be addressed empirically are to understand how important a diagnosis is for moving forward, or whether strategies to manage distressing and often disabling symptoms can be provided before a diagnosis. This could be achieved through longitudinal quantitative assessment using illness perception measures, in-depth qualitative interviews, or randomized controlled trials of tailored interventions in those awaiting a diagnosis. A better understanding of the barriers and challenges of caring for this patient group is equally important, and this could be accomplished through interviews or focus groups with HCPs caring for this population.

STRENGTHS AND LIMITATIONS

Strengths of this study include its rigorous methodology, sizeable participant sample, and novelty. In terms of limitations, not all interviewed participants under investigation for POTS may have ultimately

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received a firm diagnosis of POTS. Furthermore, despite purposive sampling, the sample in the current study comprised of mostly white females. Past literature has identified that this demographic may be representative of the wider POTS population (Waterman et al., 2021). However, it is unclear whether this is simply a result of the demographics of patients who are able to access care and therefore research. Finally, the primary researcher (IK) has prior knowledge and lived experience of POTS, and while it is never possible to fully limit personal influence upon interpretations (Hughes et al., 2020), measures were taken to counterbalance any potential bias (Tables 1 and 2).

CONCLUSION

Receiving a POTS diagnosis was not regarded as the final endpoint of participants' journeys, but as a starting point on the road to relief and making sense of the phenomenon that has had such a substantial impact on participants' lives. In this light, it is understandable that it was generally seen as a positive by participants, providing hope, protection and ultimately the potential for improvement and accessing support. This is highly aligned with the theoretical basis of the CSM. However, limitations of the CSM as applied to the journey to diagnosis of POTS included the unidimensional nature of the representations, as emotional responses are likely highly intertwined and interactive with other domains such as symptom stimuli or psychological input, rather than compartmentalized and parallel. Our findings suggest there can be great complexities in assigning symptoms to labels in the context of multimorbidity, but that nevertheless, a label is important. Participants' stories highlight the urgent need for better recognition of the condition and improved coordinated multidisciplinary care provisions from the early stages of POTS symptom detection, so that the self-regulatory process can be initiated sooner and the associated impact hereby reduced.

AUTHOR CONTRIBUTIONS

Iris Knoop: Conceptualization; formal analysis; methodology; investigation; visualization; writing – original draft. **Stephanie Gu:** Formal analysis; investigation; visualization; writing – original draft. **Shamim Fareghzadeh:** Formal analysis; investigation; writing – original draft. **Annie S. K. Jones:** Conceptualization; methodology; supervision; writing – review and editing. **Nicholas Gall:** Supervision; validation; writing – review and editing. **Rona Moss-Morris:** Conceptualization; methodology; supervision; writing – review and editing.

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CONFLICT OF INTEREST STATEMENT

None declared.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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APPENDIX 1

Interview question schedule.

Section 1: Journey to diagnosis	
Tell me about your experience of the journey to diagnosis for PoTS	*Probes* • How long did it take to get diagnosed? • Who did you see to get diagnosed? • What other specialists have you previously seen for your PoTS symptoms (before your PoTS diagnosis)? • What other diagnoses have you have received (prior to being diagnosed with PoTS)? • Do you feel they were accurate? *If they describe being misdiagnosed*: • How many times? • What with? • What effects has this had, for example on you or the treatment you have received? *If no*, • What do you feel you owe your timely diagnosis to?
Section 2: Self-management strategies	
What are your experiences of managing your PoTS symptoms using non-pharmacological strategies?	• Can you give me an example of what you do to manage your symptoms on a typical day? • What are the most helpful strategies for you? • What are the least helpful strategies? • What made you decide to try it? • How effective are these strategies? (prompt: across symptoms or for specific symptoms) • What do you feel could be done to improve your self-management strategies? • What do you think should be offered • What have you been offered • What advice would give to someone else with pots to improve their self-management of symptoms?

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