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Trust, belief and transitions: people's experiences of multidisciplinary inpatient treatment for persistent physical symptoms. A qualitative study

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ABSTRACT

Purpose: People with Persistent Physical Symptoms experience physical symptoms that are not wholly explained by a medical disorder or disease. Multidisciplinary treatment is recommended for people with severe difficulties and is provided in a small number of specialist centres in the UK. Only brief descriptions of this treatment are available, and the experiences of people receiving this treatment as an inpatient have not been explored. This study aimed to explore how people with persistent physical symptoms experience inpatient treatment from a specialist multidisciplinary team, and to identify which factors facilitated their engagement in the rehabilitation.

Materials and Methods: 18 people who had received inpatient multidisciplinary treatment for persistent physical symptoms participated in semi-structured interviews. The transcripts were analysed using reflexive thematic analysis.

Results: Participants' experiences were influenced by whether they felt believed by the healthcare team, and whether they could place their own trust and belief in the staff team and the treatment approach. Their experiences involved a series of transitions; both in environment and understanding.

Conclusions: Improvements are possible for people receiving inpatient multidisciplinary treatment for severe PPS. Trusting relationships between patients and staff members take time to develop but play a major role in patients' experiences of treatment.

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> IMPLICATIONS FOR REHABILITATION

- People with persistent physical symptoms view the building of trusting relationships with rehabilitation professionals as a vital component of specialist treatment
- Patients value the interpersonal style of the professional as much as the content of the intervention delivered.
- Developing an alliance and a shared understanding of symptoms takes time, high levels of tailoring, and a skilled multidisciplinary team
- Patients found abrupt discharge difficult, and desire easier access to appropriate follow up

Introduction

People with Persistent Physical Symptoms (PPS) experience physical symptoms that are not wholly explained by a medical disorder or disease. Symptoms can include pain, fatigue and weakness. Persistent physical symptoms is the term preferred by people with personal experience, although "medically unexplained symptoms" may also be used [1]. In ICD-11, functional neurological disorders are classified as dissociative conditions ('dissociative neurological symptom disorder', ICD code 6B60) [2], but this may be problematic as it postulates a specific psychological mechanism which may not be relevant in all cases. Other recent definitions of PPS are not restricted to "medically unexplained" symptoms, recognising such symptoms can occur in the context of somatic diseases, as well as functional somatic disorders. Both purely biomedical or purely psychological models are now widely viewed as outdated and simplistic, and the causes are formulated as complex and multifactorial [3], involving an interplay of physical and psychological factors [4,5].

People with PPS account for 25% of all GP visits, and up to 50% of attendances in secondary care [6], where they are seen in most medical specialties. PPS encompasses a range of functional syndromes such as irritable bowel syndrome, functional neurological disorder, and fibromyalgia. Whilst PPS present across a spectrum of severity, 20% of people experience severe chronic symptoms [7], high levels of disability and poor quality of life. People with PPS can experience functional limitations of a similar severity to those with multiple sclerosis or rheumatoid arthritis [8].

Multidisciplinary treatment is recommended for those with the most severe difficulties [9]. This includes occupational therapy and physiotherapy provided alongside psychotherapy and medication. This treatment is currently provided in a small number of specialist centres in the UK, in outpatient and inpatient settings. Early studies indicate it may be of benefit [10–13], however, these studies provide only a brief description of the treatment provided. Some individual components (mainly psychotherapy) have been the subject of multiple trials [14–17] but how the other components (occupational therapy and physiotherapy) may be best provided

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to people with PPS remains relatively unexplored, alongside how the multiple components might best work together. This in contrast to other long-term conditions, such as stroke or chronic pain, where multidisciplinary treatment has been described and evaluated, and clinical guidelines are well-established [18–20].

Importantly, the experiences of patients receiving these services have not been explored. Several qualitative studies of people receiving treatment from one or two disciplines in the community have been conducted [21–23], but the opinions of people receiving intense intervention from multiple professions simultaneously have not been studied. It is not known whether the various therapy components are all experienced as relevant, whether they fit together coherently, and whether some components are experienced as more helpful than others. People with PPS frequently report feeling misunderstood, distrusted and abandoned by health care professionals [24,25], but it is not known if these experiences continue once receiving treatment within specialist multidisciplinary PPS services.

Despite the high prevalence of PPS, there are only a small number of centres in the UK that offer multidisciplinary inpatient treatment to people with PPS. These units therefore prioritise offering treatment to people who have severe symptoms and high levels of disability. These units offer biopsychosocial treatment to people with the most severe symptoms who have not been helped by outpatient approaches. There has been at least one qualitative study of inpatient staff's experiences working with people with PPS, conducted in Iceland [26]. This highlighted the importance of addressing the stigma towards people with PPS when providing treatment. However, to our knowledge there are no studies exploring how inpatient treatment is experienced by people with PPS. Exploring their perspectives will provide valuable understanding of important aspects such as how the different components might best be delivered together, and how interventions such as occupational therapy and physiotherapy might work alongside psychological interventions and medication.

This study, therefore, aimed to understand how people with PPS experience multidisciplinary inpatient treatment. The objectives were:

- To understand how people with PPS admitted to specialist inpatient MDT units experience the different components of multidisciplinary care, and view the overall coherence of their treatment
- To identify the barriers and enablers to their engagement with a rehabilitative team approach
- To explore how patients understand changes they made as part of treatment, and how they conceptualise their illness following treatment

Materials and methods

Study design and setting

A qualitative approach using semi-structured interviews was chosen as an approach well suited to exploring the experiences and perspectives of people receiving inpatient treatment for PPS.

The setting for the study was two inpatient treatment centres offering multidisciplinary treatment over periods of several months, with admission length dependent on individual needs. Both centres accepted referrals for people with severe PPS from across the UK, with one unit specialising in functional neurological disorder (FND) and the other treating people with all PPS presentations. Criteria for admission included severity of symptoms, high levels of disability, and lack of improvement following

engagement with outpatient services. People admitted to these units often have significant mobility issues, may be bedbound, and require assistance with personal care. A recent cohort study of the outcomes of specialist inpatient treatment of FND, conducted at one of the participating centres in this study, showed that 43 of 52 patients included in the study showed global improvement in their condition by the time of discharge. For example, at discharge 34 of the 52 patients were able to mobilise independently without walking aids, compared to only 19 at admission [27]. Exclusion criteria include severe acute mental health difficulties and ongoing active self-harm, as these will generally make engagement with the inpatient rehabilitation process very difficult, if not impossible.

Both treatment teams included psychiatrists, nurses, health support workers, occupational therapists, physiotherapists, and psychological therapists/psychologists as core members, and could access advice from pharmacists, dietitians, speech and language therapists and social workers when needed. One unit also employed rehabilitation support workers, who carry out specific rehabilitative activities with patients, prescribed by the occupational therapist and physiotherapist (such as exercises, mobility practice, cooking, and community-based tasks). Patients in both centres received individualised treatment plans addressing physical, psychological and social needs, with rehabilitation provided on a predominantly individual basis accompanied by therapeutic groups and activities. Treatment followed a biopsychosocial approach, and interventions included psychoeducation, grading and pacing of activities, cognitive behavioural therapy, eye movement desensitisation and reprocessing (EMDR) therapy, relaxation, sleep hygiene training, and graded exposure.

The study received ethical approval from Yorkshire & The Humber - Leeds East Research Ethics Committee (21/YH/0254).

Sampling and recruitment

Study participants were a consecutive sample of people who had experienced inpatient treatment from one of the two study sites. All participants had a diagnosis consistent with PPS and had been discharged no more than two years prior to recruitment (in April 2022). Whilst this meant some participants were asked to recall events from two years prior, the study's Patient and Public Involvement (PPI) group felt people would retain clear memories of their inpatient stay due to its duration and significance in their lives.

People discharged within the last six weeks were not approached, also on the advice of the PPI group, who felt these individuals needed to focus on settling into life at home. Other exclusion criteria were being admitted for assessment only (and therefore not receiving treatment) and where the clinical team felt an invitation may cause distress or harm.

Clinical teams identified potentially eligible participants who received a letter informing them of the study. This was followed by a telephone call from a clinical team member outlining the study and asking whether they consented to a call from a researcher. Those that agreed to contact from the researcher were sent an information sheet about the study. At least a week later they were contacted by either HL or HJ, who would be conducting the interviews. HL is a female senior cognitive behavioural therapist and occupational therapist at one of the participating sites. HJ is a female clinical specialist occupational therapist and works at the other participating site. Both have carried out interviews and subsequent data analysis in a previous qualitative study. Each interviewer only contacted and interviewed participants from the

site they do not work at, and therefore had no prior relationship to the participant. During this phone call, HL or HJ explained the study, answered any questions, and obtained informed consent. Participants were informed that all data would be anonymised and that their own clinical team would not see their interview transcript or be able to link data to individuals.

Data collection

Participants took part in semi-structured interviews with one researcher. Most interviews took place over Microsoft Teams, although a few participants chose telephone interviews instead. Most interviews lasted approximately one hour.

The interviews followed a topic guide drawing on the study aims, existing literature and PPI input, including pilot interviews with members of PPI group to ensure acceptability and coverage of key topics. Interview topics included details of each person's illness and symptoms, and their experiences of treatment whilst admitted to the unit, including the different intervention components and how they were experienced. Examples of questions from the topic guide are included in [Figure 1](#). The guide was updated iteratively during the data collection as new ideas were generated via concurrent data analysis. Interviews were audio-recorded, anonymised at the point of transcription, and transcribed verbatim.

Data analysis

The data were analysed using reflexive thematic analysis [28]. This enabled close attention to be paid to the researchers' roles as members of the PPS clinical teams, and for their potential influence on data collection and analysis to be considered. Braun and Clarke's [28] six stages of reflexive thematic analysis were followed. HL and HJ each familiarised themselves with the data from the interviews they conducted, generating initial codes by reading and re-reading transcripts. To protect participants' anonymity, they did not share transcripts with each other. Instead, they shared anonymised extracts and quotes where any potential identifying information had been removed. They met to discuss and refine initial codes, before applying them to the transcripts of the interviews they had conducted. Initial theme ideas were generated through mapping of codes and identifying the relationships between them. Subsequently they met with an experienced qualitative researcher (RK) on several occasions to explore and develop these initial themes. Themes were further developed through checking them against the coded data and through discussion with the wider research team (NM, PT and EG). Each theme was

then further refined through cycling between the themes and the data, and continued discussion between HL, HJ and RK.

Analysis was an iterative process, running alongside data collection, with familiarisation with the data and coding beginning during data collection. This enabled refinements to the topic guide for subsequent interviews to allow further focus on issues highlighted by earlier participants. For example, participants discussed issues around long waits for admission and discharge arrangements that had not been included in the original topic guide. Participants were offered the opportunity to have early themes shared with them for comment and reflection on how well they represented their experiences, with one participant taking up this offer. Transcripts were stored and analysed using NVivo version 12.

COREQ guidelines were followed in the reporting of the study [29].

From the beginning of the process, the team were aware of their strong links with the two treatment units. The two interviewers carrying out the interviews and most of the analysis (HL and HJ) had worked clinically on the units (one at each unit), and therefore, as discussed earlier, did not interview, or view full transcripts from, participants from their own unit. They both kept reflexive diaries during the interviews and discussed how their thoughts and feelings may be influencing the analysis with RK. Early themes and illustrative data were shared and discussed with the wider team to provide further reflexive opportunities and to help ensure the themes were grounded in the data.

Patient and public involvement

Three people, who had lived experience of severe PPS and had received specialist inpatient treatment, were invited to advise on the project as lived experience experts. They advised on areas including ethical issues, recruitment methods, and the interview topic guide, and reviewed and gave feedback on the draft themes. They also took part in pilot interviews, providing feedback on necessary changes. Care was taken to ensure their involvement was meaningful and that they were well supported and remunerated when providing their expert input.

Results

In total, 26 people met the eligibility criteria for the study and 18 of those completed an interview with a researcher: 9 from each site. Of those 8 who did not take part, 5 declined participation (without giving a reason) and 3 were not able to be contacted or available to take part within the timeframe. Details of the 18 participants who took part are provided in [Table 1](#).

- What were you expecting from an admission to the unit?
- What was it like being on the unit?
- Can you tell me about the different parts of your treatment? (e.g., physiotherapy, occupational therapy)
- What was helpful about the treatment?
- What was unhelpful?
- Did the different parts of the treatment fit together? How? Did it make sense?
- Were your family or carers involved in treatment? What did they think about it?
- Tell me about your experience of being with other patients on the unit.
- Did you find the admission helped you at all? How, or in what way?
- *Why* do you think the treatment was helpful/unhelpful? (Has how you think about your illness changed?)
- Can you suggest any ways in which treatment could be improved?

Figure 1. Examples of questions from the topic guide.

Table 1. Participant demographic and clinical characteristics.

	<i>n</i>
<i>Gender:</i>	
Female	11
Male	7
<i>Age:</i>	
20-29	3
30-39	6
40-49	4
50+	5
<i>Reported diagnoses:^a</i>	
Functional Neurological Disorder	10
Myalgic encephalomyelitis/Chronic Fatigue Syndrome	7
Chronic pain or Fibromyalgia	3
Depression and/or anxiety	2
Other	2
<i>Length of admission:</i>	
4-5 months	6
6-7 months	6
8-9 months	3
10 months +	3

^aSome patients reported more than one diagnosis. "Other" refers to rarer diagnoses that could identify the participant and are therefore not specified.

One site specialised in FND treatment, and nearly all participants from that site had FND, alongside other diagnoses. The other site treated people with a wider range of PPS, including myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Admissions were lengthy at both sites; the median admission at one site was 6 months, and at the other was 7 months.

Two main themes were developed through the analysis: "Building trust and belief" and "Managing transitions." People described their experiences of treatment in terms of their relationships with those who provided it. Whether they had trust in the health professionals and their approach, and whether they felt their illness experience was believed by them, were vital components in how they perceived treatment. Lack of trust was a significant barrier to their engagement. The changes that people were able to make were seen as gradual changes, occurring in a very different environment from home, that needed continuing after discharge.

Building trust and belief

The participants described the importance of trust, both in terms of forming trusting relationships with staff and developing trust in the treatment approach. When the participants felt that their symptoms and illness were believed by staff on the treatment unit, they began to build trust in them (described in the first sub-theme, *Validating illness: "recognise that it's real"*). It was then strengthened further when staff worked carefully and collaboratively with them to develop a person-centred treatment plan (*Care and collaboration: "come to a plan together"*). When this trust developed, it then allowed patients to engage in the rehabilitative plan, which could involve carrying out activities that may feel risky to them. Whilst nearly all participants talked about the importance of positive relationships with staff, there were significant differences between participants as to the extent of the trust developed. This trust needed to be maintained or negotiated over time and was influenced by the extent to which the staff and patient shared an understanding of the rationale for the treatment approach, (*Shared understanding: "it does make sense"*). As well as the importance of feeling believed, some participants described developing belief in the possibility of recovery (*Hope-inspiring relationships: "you can have dreams"*).

Validating illness: "recognise that it's real"

Many participants talked about how their pathways into the specialist units were characterised by misunderstanding and disbelief from multiple health care professionals, meaning their illness had not felt validated. Often this had lasted for several years, with multiple experiences of being unable to find access to any specialist treatment or a clinician who understood their condition.

you're going through week after week after week after week, year after year before you go to the unit of everybody that you come in contact with having no idea what the hell is wrong with you. And even if they do know what's wrong with you, no idea how to fix it (Participant 05, FND)

Participants described feelings of vulnerability when coming into the units, influenced by these negative prior experiences of disbelief, and often by the high levels of assistance they required from staff to meet their basic needs. They shared that their early interactions with staff, when they often felt their symptoms were understood and believed for the first time, could help to counter these previous negative experiences. This could lead to trust beginning to develop with the team and a sense of relief when they no longer had to repeatedly set out and defend their symptoms and needs. Having their experiences believed and validated in this way enabled people to move beyond focusing on feeling heard, to actively engaging in the treatment being suggested and being able to feel some optimism about the treatment they could expect from staff.

I think we were expecting to have to explain like every single one of my needs and kind of fight for me to get what I needed. Whereas they were like, "Yes. Of course you'll need help with everything. No problem." Yes it was very different to other experiences I'd had previously (Participant 18, ME/CFS)

I feel like, okay she recognises that it's real. So then we can overcome it. Instead of having to be defensive constantly and having to defend everything (Participant 08, FND)

Reaching this level of trust often took time, and continued negotiation around the treatment approach. People valued being able to express differing ideas, including initial distrust in the team or approach, without their illness experience being disbelieved. This was vital if they were to follow a treatment approach that sometimes contradicted their pre-existing ideas regarding helpful or effective treatment:

As time went on, I started to trust them more. But initially, I didn't agree with anything they said, and I would tell them that. And I think, if I hadn't have been able to tell them that, then I just wouldn't have done anything, and maybe, I wouldn't have progressed as I'd liked to have progressed. (Participant 16, ME/CFS)

The power of validation and belief from staff was also displayed in contrasting, negative experiences. Even in these specialist units, some patients recounted experiencing of a lack of understanding or belief in their symptoms from some staff. The significance of this disbelief may be indicated through them remembering the words used to indicate this some time later:

One was, 'well, I don't know why you can't do that, you've only got FND (Participant 04, FND)

These displays of disbelief were particularly hurtful when they happened in a specialist setting, and against a prior backdrop of disbelief from staff encountered prior to specialist services being involved:

it felt like we were making it up and considering FND is a condition where you get told by a lot of doctors, it's all in your head, it's not real, you're doing it on purpose, going to somewhere specifically for the condition and them still making you feel like that didn't feel comfortable at all. If anything, it made us not want to be there. (Participant 02, FND)

Such attitudes were typically noted from particular staff members and were often contrasted with more helpful attitudes displayed by others within the same staff team. Many people particularly highlighted a lack of understanding from agency or temporary staff, who could be unfamiliar with the unit and with PPS. This could negatively impact care delivery if a temporary member of staff with insufficient understanding of PPS was providing care without understanding why that care needed providing in a particular way. Participants then felt they had to put extra energy into explaining their needs to these staff, to enable simple aspects of care to be delivered. Several people strongly recommended that further staff training in PPS was needed.

Care and collaboration: "come to a plan together"

Having trust in the staff and the treatment approach was an ongoing process and was strengthened when people felt treatment was tailored to meet their individual needs. Participants found it helpful when staff recognised the individual's own knowledge of their condition and enacted a collaborative approach to reaching a treatment plan which both parties agreed on.

[they said] "you probably know more about your own condition than I do so basically I'm going to use my judgement and we're going to sort of collaborate and we'll sort of come to a plan together about what we're going to do. (Participant 01, other condition)

This collaborative approach was also important in helping patients persevere with treatment plans. Attempting increases in activity levels required people to trust the staff team, as participants often had previous experiences of symptoms worsening after activity. Participants valued staff members who demonstrated how gradual increases in activity levels needed to be introduced, and who recognised the importance of a graded approach to the individual:

if it was going to go well, it needs to be graded and it needs to be done carefully.... The patience that's required of me was kind of reflected in her [staff member] (Participant 01, other condition)

This repetition of continuing to introduce new activities carefully and gradually each time was highly valued by patients, and allowed them to trust that the staff understood their condition and were aiming for lasting improvements. This process could take several months. Trust was often particularly placed in those staff who were leading the careful prescription of these activities, and so regularly demonstrating their understanding – the physiotherapists, psychotherapists or psychologists, and occupational therapists.

Participants focussed more upon this level of collaboration, and the interpersonal skills staff members used, rather than on the staff member's discipline or their part in the overall team approach. Participants often commented on how careful, kind, or encouraging a staff member was, rather than focussing on the treatment techniques they used. When they experienced this from multiple staff members, and when the staff members clearly communicated between themselves, this was experienced as a highly cohesive treatment approach.

I don't think of it as separate bits like doctors and nurses, you know, it's just a team. That's what it is ... it doesn't feel like you're getting bits of the physio, it doesn't feel like that, it feels like it's all one

treatment, that's how it feels, just that different people are delivering different parts of it (Participant 12, FND)

Whilst valuing shared decision-making and collaboration, several patients acknowledged the need to be encouraged to move between stages, and sometimes even "pushed." Achieving a careful balance between encouraging and recognising individuals' limits was important:

It was steady, but I think they were very good at just pushing a bit. Especially at the beginning, you don't have very much confidence in being able to push through. So, I think they were very good on pushing but also knowing when to not push (Participant 18, ME/CFS)

The value of attending to this balance was demonstrated by other patients who reported experiences where they felt this balance was lost. When this occurred, it could have a significant impact on both their relationships with staff and in how able they felt to engage in the treatment. Patients mostly expected to have influence over treatment planning, and many described discussions with staff about how treatment should proceed, and at what pace. On some occasions, there was prolonged disagreement, and these patients described experiencing a different "push" from staff – to engage in parts of treatment they found unhelpful.

I did go into the [therapy] meetings we had. I said, "Look, I don't want to- I don't feel they're particularly useful to me anymore," but they were like, "Oh, you're better off to keep doing it," and all of this, "Something might happen or unlock" ... It felt like you've got to have it done. You've got to do it sort of thing... it peed me off (Participant 06, FND)

These participants described frustration that the treating team were able to insist they engaged in certain tasks, which could lead to relationships with some staff breaking down. When this happened, patients identified still making some overall progress, but these unrepaired relationships with staff impacted on how useful they perceived the overall treatment to be. Other patients described disagreeing with the approach early on, but recognised the team did negotiate over how parts of the care was provided. When these carefully negotiated first steps led to improvement, they described being able to trust staff, and subsequently agreed to follow suggestions they had previously rejected. It seemed the balance of power in decision-making between team and patient could shift during treatment, in both directions, and how the staff team facilitated and responded to this was of importance

Shared understanding: "it does make sense"

Collaboration about a treatment plan usually required some level of agreement about the treatment rationale. This shared understanding could occur at different levels. Sometimes treatment could involve a gradual reduction of the assistance provided to the patient (for example, being asked to complete a task themselves, without adaptive equipment, or the reduction of supervision when experiencing symptoms). When patients disagreed with this, but were still encouraged to follow such a plan, they could experience staff as uncaring, or as ill-informed, advising something that felt risky.

A lot of the time, I felt their speed, their pace, was way too fast... I was terrified... I was convinced they were wrong (Participant 16, ME/CFS)

When this happened, previous trust that had been built up could be stripped away, and people would question not just whether staff believed them but whether staff cared about their wellbeing.

Those that considered themselves to have been treated with care and respect early in the admission did not necessarily require an in-depth understanding of the treatment themselves, instead feeling they had built enough trust in staff to be able to do what was suggested. When enough trust was there for patients to complete what the staff asked, this could then lead them to shared understandings developing as they began to see progress.

And we kind of trusted them that they would do the right thing even if we didn't fully understand what that would be (Participant 18, ME/CFS)

At the time, I didn't understand why we were doing the same thing over and over again. But then certain things would click... yes, most of it, yes, it does make sense" (Participant 04, FND).

Sometimes this shared understanding involved more than agreement over tasks to be done and involved a transition in the patient's understanding of PPS. This could be in relation to understanding how to better manage their symptoms. For others, it involved understanding what may have contributed to the development of their PPS, and how ongoing psychosocial factors may be influencing their physical symptoms.

I spoke about that and all the other things that I'd done, and I'd worked out why my brain decided to do what it did... And how I was working too much. I never gave myself any time to enjoy myself and I didn't deal with earlier... trauma (Participant 06, FND)

[They] spoke to me about all that and it really helped me a lot because I had quite a lot of set opinions about the illness and about my symptoms and stuff like that. So [they] really challenged that thinking and so that helped me a lot. (Participant 14, ME/CFS and FND)

If the patient felt this psychological work was necessary, and perceived it could be helpful, they were often able to engage in the difficult work this involved and see some benefit.

I was prepared to do it every week no matter how difficult it was for me. I was very committed. We went quite slowly because I would completely zone out, disassociate, either during, after and the following day or all of those. I find that gave me more insight into me and how to manage the FND, rather than about the FND. (Participant 09, FND)

Yet, for some, this focus on increasing understanding of psychological factors felt as if it went too far or was actively unhelpful.

So, I was clearly trying to get better and yet simultaneously they were looking for these like weird ways in which I might be sabotaging myself in one way or another. It just made no sense ... trying to push me like as far as they possibly could (Participant 01, other condition)

Mismatched understandings were present at the very start of treatment for some patients when they discovered there would be psychological aspects to the treatment approach. For those that had understood they were being admitted for a treatment focussed on physical factors, this came as a shock. Although most of these patients described going on to make significant progress overall, this impacted how they trusted the treatment in the first few weeks. They were unsure whether the unit would be suited to their individual needs, if the team may not be able to help them, or indeed, even cause them harm through unsuitable treatment.

It appeared it was not essential that patients agreed with staff over what caused their PPS, but that it was more important that they could agree on a pragmatic way forward with key staff members (particularly those involved in decision-making). When this happened, patients described a further strengthening in the relationships with these staff and went on to describe making

significant progress overall. They noted positive changes in terms of symptoms, activity levels and being able to re-engage with the world around them. Many of the most notable improvements were reported by the patients with ME/CFS, who described a gradual transition from often being bed-bound and unable to significantly communicate to being able to walk short distances and go outside with others. When combined with trusting relationships with staff, some referred to the overall process as being life-changing:

Just to echo again, just it really made the difference between living-being alive or not for me. And being understood, and listened to, and helped. And slowly and surely, being given- Time is such a massive thing (Participant 17, FND)

Hope-inspiring relationships: "you can have dreams"

Participants described differing experiences of hope before admission. Many described having a very broad goal (for those with FND it was often to improve their mobility) but no expectations or ideas about how this could be achieved or whether it would be possible for them to achieve it. This was perhaps unsurprising after their lengthy periods of illness and previous lack of effective treatment. Some participants then described positive and validating experiences within PPS services that led them to new feelings of hope, even at the beginning of treatment. When they began to recognise the staff's knowledge of PPS and were provided with an explanation of how the treatment could lead to progress, they began to experience increased hope.

You're suddenly in an environment where, okay, we know what the condition is, we know what the problem is, we know how to fix it... That alone is hugely encouraging. (Participant 05, FND)

These participants were provided with explanations of illness that not only validated their experience, but that allowed for the possibility of improvement, for example by including actively hopeful statements:

They were saying really early on, "You're going to do really well. You can have dreams. You can have plans for the future (Participant 18, ME/CFS)

This was immediately powerful for some, coming after many years of being unwell and of not hearing these messages from clinicians. For others, this new messaging could be confusing or take time to adapt to, and a belief that change was possible formed over time as trust in the process developed and they began to experience progress. When they began to make small improvements (such as increases in activity), they began to experience increased hope:

I thought well maybe I can do this, you know. I think they [staff] knew all along, but I didn't because I'd not seen this process before... they've seen the end from the beginning... they're so used to how it works there and they've seen all that, they've seen the struggle in between (Participant 14, ME/CFS and FND)

This hope and belief from staff led to the path towards improvement becoming clearer for some participants. This hope could come not just from staff, but also from spending time with other patients and seeing their progress. Whilst there were challenges to living on units with others with similar problems for weeks or months, it provided opportunities to meet others with shared experience of symptoms which further validated their existence. It also provided opportunities to meet and observe progress in people at different stages of their treatment, and a chance to see what progress was possible:

It was very inspiring to see people further along. And even if someone was maybe just a few weeks, a month ahead, it was quite interesting. I remember ... one of the [other patients] saying, "Oh, I went to the shop" ... And I remember thinking, I want to do that. So, at my next OT session, I said, "I want to start working towards going." (Participant 16, ME/CFS)

Managing transitions

People described that the transition in and out of the unit could be difficult. How they experienced these transitions impacted upon their experience of treatment, and (particularly regarding discharge) sometimes upon how they perceived its long-term helpfulness. These transitions were rapid, such as the sudden move from their home environment to the inpatient unit, which many described as challenging (*Adjusting to the ward: "understanding the place"*). Being discharged was then another difficult transition, particularly in terms of losing valued support and relationships, inadequate follow-up, and felt abrupt to many (*A sudden loss of support: "being dropped back home"*).

Adjusting to the ward: "understanding the place"

When being admitted to the inpatient units, people described needing to adjust to various factors, such as noise on the unit, the behaviour of other patients, and managing appointments with team members. Some described feeling unsure around what was expected of them and the routine of the unit, finding themselves struggling to understand how the unit operated. Some patients were still unable to leave their bed at this point, but some of those who were more mobile found their rooms a place to retreat to. People described significant uncertainty or sometimes anxiety in the early days of their admission, adding to their vulnerability, with several people reporting they would have valued greater explanations from staff about routines and expectations.

I struggled to kind of settle in... I didn't understand like who was who and just what the situation was really. I felt very like left in my room (Participant 11, ME/CFS)

When you come in, everybody's already in cliques, so you're going in and you're feeling very, very vulnerable, and you're like, I think I will just go back to my room.... you're scared (Participant 09, FND)

Adjusting to life on the unit was affected positively and negatively by other patients. For example, one unit provided treatment to people with acquired brain injury, as well as patients with PPS. Some participants found the behaviour of these other patients challenging, especially at first, describing difficulties adjusting to some people with brain injuries shouting out or wandering into others' bedrooms. Being with other patients with PPS could help ease the transition, through actions such as providing information about how the unit worked. For some, other patients provided more than information – they provided support that eased the transition further. This could be a positive transition -from feeling isolated at home to finding a sense of community.

I was struggling with being like assertive and just my confidence was not there, so I actually found out and understood things better by talking to other patients and making friends with them basically. That's kind of where I started to feel more comfortable with understanding the place and how it works... because I'd lost that interaction, so it was like massively and being able to relate to people who are struggling with similar things was really important (Participant 11, ME/CFS)

Those who formed strong relationships valued the social interactions when some were far from home, and sometimes after months or years of being isolated due to illness. These

relationships were about more than social contact; they had similar experiences and histories of misunderstood illness, and described it was helpful to be alongside others who were trying to make similar transitions and facing the same challenges of rehabilitation and Covid-19 restrictions. One person felt that such contact with other patients, particularly those further along in their treatment, could have eased the transition in the first few weeks:

I think what would have been helpful, I always thought, is to have seen some of the former patients... for me to see someone that says, "Yes. I was in your position and look at me now." Or even just to say, "You know what, it's so hard." (Participant 16, ME/CFS)

A sudden loss of support: "being dropped back home"

After slow and careful rehabilitation, amongst professionals they (mostly) trusted, many participants found being discharged home a difficult process, for which they did not feel they received enough support. Sometimes follow-up care did not happen as planned or did not meet their needs or expectations. Some people noted that, even with follow-up, the transition home was difficult, particularly after what was often a long inpatient stay.

When you get sent home at the end of the day it's very much a you're dropped back home. Bye. That's it even though they've like maybe put something in place for you when you get back home... it did sort of feel like it's being dropped at that point (Participant 02, FND)

This contrast from being around people, with frequent access to advice and support, to being at home with often limited access to professionals, could feel stark. Many participants wanted more advice and support with the transition out of inpatient care, echoing the requests for more support with the transition into an inpatient stay. This sudden loss of intensive, specialist support, treatment and understanding provided over several months, could feel difficult.

They just discharge you... no one spoke to me. No one called me. Nothing (Participant 08, FND)

[I needed] Positivity. Hope. Advice. Goal setting... you know, support. Like what was in the unit. And a modicum of that afterwards would have been nice (Participant 05, FND)

Participants missed the hope and understanding they had received on the unit, which they felt was not easy to find from other services after discharge. The lack of access to specialist services for follow-up, and difficulties accessing community resources, was exacerbated by the Covid-19 pandemic. Many commented on the impact this had on their treatment and discharge. Some admissions were interrupted at the beginning of the pandemic, and others caught Covid-19 during their admission and had to be transferred to a different ward.

With these multiple difficulties experienced upon discharge, it is unsurprising that many participants felt the discharge process needed to be improved. Whilst on the unit, there were often discussions around how coping strategies (e.g., methods for pacing activities) could be applied at home, and for some this helped the transition. When these strategies could be practised during home leave, this further aided the transition. It was not possible for all patients to have home leave, due to distance or Covid-19 restrictions, but those who took this leave valued the experience as part of their rehabilitation and transition towards home. However, at times, strategies for managing symptoms did not feel practical to patients and did not transfer well into their daily lives outside of hospital. Some felt unprepared for going home, both practically and sometimes emotionally.

I do try and use the methods given to adjust but not always possible to make it work. One thing that I did notice is just like what you're told to do strategy-wise isn't always practical in real life (Participant 02, FND)

Maybe prepare people for what it's going to be like when you go home, what that wrench is going to feel like (Participant 13, ME/CFS)

Whilst several people described feeling unprepared and supported, there was variation in how much support participants received at home. Having benefitted from the social contact on the ward, some chose to maintain contact with other patients they had met on the unit and continued to give and receive support from each other two years later. Some participants received follow-up appointments from members of the inpatient teams, via telephone or video call; familiar contact which they felt eased the transition home. They valued the continuity of receiving input from someone with whom they had already built a relationship, as well as the practical advice or continued therapy.

I just stayed on with a therapist there when I went home until I could get a new therapist and she also like stayed with me and we had a joint discussion with the other therapist... I felt very supported in that sense (Participant 11, ME/CFS)

This passing on of the shared understanding to the next therapist was highly valued, and possibly provided an opportunity to build a trusting relationship with them in turn, to replace the support they were losing. It contrasts with other experiences where participants experienced the failure of follow-up as being let down by a team they had trusted to meet their needs.

Discussion

This qualitative study found that people's experiences of inpatient treatment for PPS substantially depended upon their relationships with the health care professionals delivering treatment. It was important that people felt believed by the healthcare team, and could place their trust and belief in the staff team and the treatment approach.

Trust has been defined in the therapeutic context as a belief that "our good will be taken care of" [30] (p190) or as an attitude in which one relies with confidence on someone [31], and as a willingness to engage oneself in a relationship with an acceptance that vulnerability may arise [32]. Building trust has been characterised as a process that includes various stages during which trust can be established and as an ongoing dynamic process [33]. Trust is also viewed as a relational phenomenon and to be the foundation of any therapeutic relationship [34]. In the context of this study, trust was developed through staff believing and taking seriously people's symptoms, providing a supportive and caring environment and working collaboratively with people to reach a shared understanding of their symptoms and a suitable way forward. This then led to hope for recovery.

The process of building relationships necessary to engage in a multidisciplinary rehabilitative approach has been explored in rehabilitation settings for other patient groups [35,36] but not in the field of rehabilitation for PPS. Existing research has focussed upon the concept of alliance; the quality of partnership and collaboration [37]. Within psychotherapy, the positive relation between therapeutic alliance and outcome is well-established [37]. "Common factors" such as alliance, empathy and goal consensus are correlated with positive outcomes and considered by some to be as or even more important than the specific ingredients of the individual psychotherapy treatment provided [38]. The results of this study demonstrate the importance of relational aspects of care for people with PPS.

One of the study objectives was to understand how patients experienced different components of the multidisciplinary treatment. When asked about the components of treatment, many participants talked about the relationships they built with staff, describing *how* particular members of staff worked, rather than *what* they did. We found that the interpersonal style of the staff member (particularly levels of collaboration) was more important than their profession or role, and the developing of a strong alliance was key to a positive outcome. Whilst current evidence about alliance is mainly in relation to psychotherapy, therapeutic alliance may also be correlated with positive outcomes in physical rehabilitation settings [39]. A strong therapeutic alliance is also associated with improved outcomes in people with chronic pain [40]. Whilst some studies have examined alliance in multidisciplinary settings [35,41], there is a lack of research examining how patients form and maintain the multiple concurrent relationships that are required in rehabilitative settings. Further study of how relationships with multiple staff can impact upon outcomes of treatment for people with PPS is needed to provide more clarity.

It is possible that forming these multiple relationships may be especially challenging for people with PPS, who have high levels of mental health co-morbidity [42] and may require time to form trusting relationships [43]. This may be compounded by multiple previous negative experiences with health care professionals and suggests that a focus on building therapeutic relationships should be a priority, not just at the beginning but throughout treatment.

There are several potential challenges for people with PPS who wish to engage in inpatient multidisciplinary treatment, and for the teams providing it. In the context of possible difficult prior relationships with health professionals, people with PPS need to build relationships with staff they will see daily and who will be suggesting new ways of managing their symptoms. Engaging with the team in a biopsychosocial approach, particularly the psychological aspects of treatment, may be challenging as some people with PPS may reject attempts at psychosocial attribution [44]. Several patients described feeling pushed into these parts of treatment and found them unhelpful. This emphasises the dynamic nature of trust which can be established but also damaged by a failure to appropriately attune to the person's concerns. The lengthy admissions on PPS units present an opportunity for treatment to be staged and paced according to an individual's illness beliefs so they feel understood and not undermined, but this requires a deft sensitivity and patience from the experienced staff who work on the units.

For those who felt disbelieved, it was especially painful to have these experiences on a specialist unit. PPS conditions are known to be complex, and the underlying mechanisms and interplay between biological, psychological, and social factors still present many questions [45]. It is perhaps unsurprising that some staff lacked understanding. However, our participants noticed not just a lack of understanding but sometimes unhelpful or negative attitudes. Klinke et al. [26] describe how specialist staff in this field have recognised their own need to move from "stigmatization towards competent care" (p1243). Our results mirrors this from a patient perspective; the people receiving care are very aware of negative attitudes from staff and echo the call for educating all staff on these units about PPS. These services may need to consider how this can be done in their teams, whilst also addressing how care can be better provided by temporary staff.

Patients having their symptoms believed was an important starting point for building a trusting relationship with staff, and when combined with care, respect and collaboration, allowed patients to engage in a treatment that felt risky at times. This

aligns with the concept of trust as “an optimistic acceptance of a vulnerable situation in which the truster believes the trustee will care for the truster’s interests” (p615) [46]. Trust was required if the patient were to accept and engage in an approach that made them feel vulnerable to worsening of symptoms. When improvements were then evident, this trust could develop into a confidence that progress would continue – a judgement made on experience of the treatment rather than the initial optimism.

Believing that significant recovery was a realistic goal required the patient and therapist to develop a shared explanation for treatment. Greco has called these explanations a form of treatment for PPS [47], which encourage the patient to re-imagine themselves, and act as “a lure to the possible” (p20). One participant described the staff providing them with a “roadmap” for their treatment. Patients usually had a broad goal for admission but were unsure how these goals might be achieved. With the pathway towards their goals made clearer by working with the team, they experienced increased hope. This echoes Snyder’s Hope Theory, that hope is “the perceived capability to derive pathways to desired goals” (p1) [48]

17 of the 18 participants described making improvements as a result of admission. As all participants were people with severe and chronic symptoms, who had not been helped by multiple attempts by previous services, this is a striking result. Even when there were difficulties in the relationships with staff, and disagreements about treatment, these participants still identified they made positive changes. However, those who did disagree with aspects of treatment felt that more improvement would have been possible if their care was improved. People with severe PPS are identified as a challenging group to treat, and this study suggests that improvements are possible, consistent with recent published findings in this area [27].

Transitioning from this environment (with multiple relationships) to home (often many miles away) was difficult for many. Frequent dissatisfaction with follow-up arrangements indicates this may need further consideration. Rimmer [49] describes this period after inpatient rehabilitation as “a critical window of opportunity... to capitalise on a person’s readiness to continue his or her recovery.” Transitions from inpatient settings to home have been identified as difficult for people with other long-term conditions (such as traumatic brain injury [50]). There are additional difficulties in arranging local follow-up from a national service. Finding appropriate services to agree to provide follow-up for people with PPS can be difficult in practice, reflecting the lack of structured multidisciplinary pathways for PPS [51]. Other options may need additional thought, not only to ensure recovery can be built upon further after discharge, but to actively prevent the loss of progress made. One of the units occasionally offered follow-up from ward staff *via* an online platform and this was well-received by those who received it. Continued online rehabilitation after an admission has also been used successfully with people with multiple sclerosis [52]. These results make a strong case for expansion of existing services to allow for greater follow-up after discharge and a smoother transition from the inpatient environment to life outside hospital.

One patient suggested the use of online peer support after discharge, to help with the transition. Several people had maintained contact with other patients after discharge and found this helpful. People with PPS report feeling isolated and lonely [25] and the transition from a busy ward to home may therefore have heightened these feelings for some of the participants. Continued contact with peers may have helped counter these feelings for some. Patients receiving structured peer support after inpatient rehabilitation for spinal cord injury had increased self-efficacy and

reduced unplanned hospital admissions at six months [53]. Considering such wider ideas may be another way of aiding the transition home.

Both units provide treatment over a lengthy period based on individual treatment needs, which involved an admission of between 4 and 8 months for most participants. Such admissions are costly, and resource intensive. However, this can be seen in the context of wider costs of PPS, which account for 10% of total NHS expenditure [54]. For people with severe PPS (and often co-morbid mental health difficulties) to build relationships with multiple professionals after a history of feeling disbelieved, and to make many significant transitions, often takes significant time.

Strengths and limitations of the study

This is, to our knowledge, the first qualitative study to explore people’s experiences of receiving inpatient care for PPS in the UK. A key strength is that it included participants from two different treatment centres, and included diverse participants in terms of gender, age and types and severity of symptoms.

Limitations include that only people who stayed for treatment after assessment were included. Additionally, it is possible that those who declined to take part had negative experiences at these units that we did not capture. For some participants, two years had passed since their treatment, and whilst they recalled many events clearly, it is possible that they may not have been able to remember other aspects in detail. Both researchers who conducted the interviews and participated in the analysis were clinicians who worked on the units under study. Each researcher recruited and interviewed participants who were not from their own unit. However, participants may have been aware that clinicians they knew were on the research team. Whilst they were assured that their transcripts would only be seen by their interviewer, this may have impacted what they disclosed in the interview. It is also possible that, as clinicians working in the participating sites, the researchers may have held an inherent positive bias towards the data. This was mitigated however by a reflexive awareness of this possibility by both interviewers and the supervision of an experienced qualitative researcher (RK) who had no investment in the treatment units or any specific treatment approach for PPS.

As acknowledged by participants, the Covid-19 pandemic impacted upon patients’ treatment, and some did not receive treatment that was fully representative of what they would have received before or after this time.

Conclusion

Treatment on PPS inpatient units was usually experienced differently to prior treatment experiences. Many people described how a trusting relationship with staff and other patients helped them make significant positive changes. Key factors in building this trust included feeling their symptoms were believed by staff, treatment being delivered in a caring and collaborative way, and developing a shared understanding of treatment. When this occurred, people described significant improvements in their illness, and developed hope that further improvement was possible. Several people described experiences on the unit that hampered the building of this trust. The transitions into and out of the unit were often challenging. Discharge could be experienced as feeling abandoned, as an abrupt ending, and highlighted the lack of services able to provide appropriate follow-up.

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