Received: 26 October 2022 | Revised: 23 June 2023 | Accepted: 4 July 2023

DOI: 10.1111/jpm.12959

ORIGINAL ARTICLE

Perspectives of service users and carers with lived experience of a diagnosis of personality disorder: A qualitative study

Anna Balmer[1] | Laura Sambrook[1] | Hana Roks[1] | Peter Ashley-Mudie[1] | Jackie Tait[1] | Christopher Bu[2] | Jason C. McIntyre[1] | Amrith Shetty[2] | Rajan Nathan[2] | Pooja Saini[1]

[1]Faculty of Health, Liverpool John Moores University, Liverpool, UK

[2]Cheshire and Wirral Partnership NHS Foundation Trust, Chester, UK

Correspondence
Pooja Saini, Faculty of Health, Liverpool John Moores University, Liverpool, UK.
Email: p.saini@ljmu.ac.uk

Funding information
Liverpool John Moores University

Accessible Summary

What the paper adds to existing knowledge?

- Personality disorder is a serious mental health condition affecting up to 52% of psychiatric outpatients and 70% of inpatients and forensic patients. People with a diagnosis of personality disorder have higher morbidity and mortality than those without.
- Service users and carers reported a lack of training for staff in the management of individuals with a diagnosis of personality disorder, particularly with regard to self-harm and suicidal behaviours.
- Staff burnout creates barriers to compassionate person-centred care for individuals with a diagnosis of personality disorder as staff struggled to accommodate the nature of the presentation when under significant emotional, psychological and professional strain caused by understaffing and lack of support.

What are the implications for practice?

- This paper adds new knowledge by informing services of ways to improve care provision from the perspectives of both carers and service users.
- A more holistic and less medicalised approach to the treatment of problems associated with a diagnosis of a personality disorder should be adopted, and personality disorder training introduced for all healthcare practitioners, to improve patient outcomes.

Abstract

Introduction: There is limited understanding of the experience of people with complex mental health (CMH) needs, including those with a diagnosis of personality disorder (PD) and carers of those individuals. Little is known about carers of those in inpatient forensic settings, yet it has been identified that they may have additional needs when compared to general carers. Research highlights that community carer support services were perceived as inadequate and out-of-area placements were described as putting an added strain on ability to support loved ones. Understanding

PD within a population of people with CMH needs and how a diagnosis described as PD impacts on care and treatment experience is vital to providing high-quality care.

Aim: To evaluate the care experience of service users and carers with lived experience of a diagnosis of PD and out-of-area placements.

Method: Semi-structured interviews were conducted with six service users and four carers to explore the experiences and perspectives of people with a diagnosis of PD. Interviews were audio recorded and thematically analysed.

Results: Four interrelated themes were developed; Influence of a diagnosis of PD on Staff, Early and Appropriate Intervention, Recognition of the Individual and Training and Knowledge of people with a diagnosis of PD.

Discussion: Anti-stigma interventions for staff, research on care provision and structural changes to services including more evidence-based therapy for individuals with a diagnosis of PD may help reduce disparate treatment and improve prognosis for recovery.

Implications for Practice: This paper informs services of ways to improve care provision from the perspective of carers and service users. A more holistic and less medicalised approach to the treatment of problems associated with diagnoses of PD should be adopted, and PD training for all healthcare practitioners to improve patient outcomes.

KEYWORDS
complex, mental health, personality disorder, recovery, stigma

1 | INTRODUCTION

There is limited understanding of the experience of people with complex mental health (CMH) needs, including those with a diagnosis of personality disorder (PD) and carers of those individuals (Lawn & McMahon, 2015a). Little is known about carers of those in inpatient forensic settings (Chemerynska et al., 2020), yet it has been identified that they may have additional needs when compared to general carers. Research highlights that community carer support services were perceived as inadequate and out-of-area placements were described as putting an added strain on ability to support loved ones. A diagnosis of PD is a known strong predictor of negative treatment outcomes and comorbidity with other mental health disorders (Tyrer et al., 2015). A diagnosis of a PD can occur when long-term cultural deviations in cognition, emotion and behaviour that begin in adolescence or young adulthood disrupt daily activities or cause distress (Sheehan et al., 2016). While a diagnosis of a PD contributes to difficulties in treatment of other mental disorders and symptoms, it is often neglected as a target of treatment due to patients requesting relief from clinical symptoms rather than personality difficulties (Lamb et al., 2018; Tyrer et al., 2015). In response to a consensus statement on PD that described the neglect and exclusion of those given the diagnosis (Lamb et al., 2018), the Royal College of Psychiatrists' position statement on PD stressed the need for staff training, supervision and reflective practice (RCPsych, 2020). A diagnosis of a PD is a serious mental health condition affecting up to 52% of psychiatric outpatients and 70% of inpatients and forensic patients (Banerjee et al., 2009; Bowden-Jones et al., 2004; Keown et al., 2002; Singleton et al., 1998). Given the significant public health implications associated with the disorder—including extensive use of healthcare resources, high rates of suicide and reduced life expectancy—effective treatment is a priority (Chiesa et al., 2002; Fok et al., 2012; Lamb et al., 2018; Moran et al., 2016; Stone, 1993).

People with a diagnosis of PD have higher morbidity and mortality than those without; UK data suggests that life expectancy at birth is shorter by 19 years for women and 18 years for men than it is in the general population (Fok et al., 2012). Increased mortality can be explained partly by increased incidence of suicide and homicide in people with a diagnosis of PD (Hiroeh et al., 2001), experiencing adverse childhood events including trauma (Felitti et al., 1998), stigma (Ring & Lawn, 2019) and social isolation (Holt-Lunstad et al., 2010). Increased mortality from cardiovascular and respiratory diseases and lifestyle factors also contribute to the high morbidity and mortality in this population, with high prevalence of smoking, alcohol and drug misuse (Tyrer et al., 2015). Difficulties in interpersonal relationships, a hallmark of a diagnosis of a PD, has been found to deeply impact relationships with healthcare professionals, resulting in misunderstandings, miscommunication and poor-quality care (Ring & Lawn, 2019). A recent study reported that relational practice approaches have the potential to facilitate better community care for people with complex emotional needs, including people with a diagnosis of PD (Trevillion et al., 2022). Relational practice gives priority to interpersonal relationships, in both external and internal aspects. It is the foundation upon which effective interventions are made, and it forms the conditions for a healthy relational environment (Dale et al., 2020). Relational practice requires relationships based on reliability, consistency, curiosity, flexibility, and authenticity, an enabling and facilitating attitude and an understanding of the inner and outer lives of individuals in their social field.

Stigmatising views of a diagnosis of a PD represent a significant problem within mental health care settings and among mental health professionals, such as a lack of knowledge, staff avoiding patients and negative attitudes held by psychiatric nurses towards patients with a diagnosis of a PD (Black et al., 2011; Deans & Meocevic, 2006; Lawn & McMahon, 2015a, 2015b). This lack of knowledge is often involuntary, and the result of a lack of training and education provided to staff. Cleary et al. (2002) found that 76% of mental health professionals surveyed reported wanting skills training workshops specifically in relation to a diagnosis of a PD, while 74% wanted regular education in-services to help deal with patients and 95% were willing to spend 1 h per month or more on further education or training with regards to their patients with a diagnosis of a PD. This is a clear oversight as education has shown to lead to a positive shift in mental health professionals' attitudes towards patients with a diagnosis of a PD (Warrender, 2016). Stigmatising attitudes and lack of knowledge directly impact patient access to, and experiences of, care (Lawn & McMahon, 2015a).

There is limited understanding of the experience of carers of people with a diagnosis of a PD (Lawn & McMahon, 2015a) and relatively little is known about carers of those in inpatient forensic settings (Chemerynska et al., 2020), yet it has been identified that they may have additional needs when compared to general carers. Carers reported significantly elevated levels of distress, negative caregiving experiences and expressed emotion, as well as maladaptive coping strategies, compared with general population adults or carers of people with other serious illnesses (Seigerman et al., 2020). Significant challenges and discrimination when attempting to engage with, and seek support from, health services has been reported by carers of people with a diagnosis of a PD (Lawn & McMahon, 2015a). Research highlights that community carer support services were perceived as inadequate and out-of-area placements were described as putting an added strain on ability to support loved ones (Chemerynska et al., 2020). Inconsistencies in the support available to carers in practice are reported despite government initiatives (Chemerynska et al., 2020; Meshkinyazd et al., 2020; NICE, 2009).

Evidence-based practice is imperative to mental health care and literature suggests that problems associated with a diagnosis of a PD can be successfully treated and managed, especially with therapies such as dialectical behavioural therapy (DBT; Ring & Lawn, 2019), Mentalization-based treatment (MBT; Bateman & Fonagy, 2004), Transference-Focused Psychotherapy (TFP; Clarkin et al., 2006), schema therapy and therapeutic communities (Stoffers et al., 2012). As the Consensus Statement notes (Lamb et al., 2018), there is no evidence for the superiority of one of these effective therapies over another for any particular individual; thus, a choice of therapies would be helpful with relational practice in the service to be a key component (Dale et al., 2020). However, bespoke services for patients with a diagnosis of a PD are not uniformly provided across all jurisdictions. This contributes to extensive waiting lists for evidence-based treatments, such as DBT, exacerbating the exclusion and stigma experienced by many patients (Lawn & McMahon, 2015a, 2015b).

Research suggests that service users have an experience of being cared for by people whom they believe do not have the knowledge and skills to be able to provide adequate care (Lamb et al., 2018; Trevillion et al., 2022). This is also supported by carers' experiences of inconsistent support for them (Chemerynska et al., 2020; Meshkinyazd et al., 2020; NICE, 2009). Understanding how a diagnosis of a PD impacts on service experience for individuals and their carers is vital to providing care for individuals due to high mortality, increased comorbidity, negative impact on suicidality and overall recovery. The present study aimed to evaluate the perspectives of service users and carers with lived experience of a diagnosis of PD and out-of-area placements, as well as their overall experiences of care.

2 | METHOD

2.1 | Design

A qualitative approach, using semi-structured interviews to explore the experiences and perspectives of service users with a diagnosis of a PD and carers of those with a diagnosis of a PD. We invited service users and carers to ensure we included the perspectives of both groups experiencing mental health services for people with a diagnosis of PD. This was important as treatment decisions made by services impacted both service users and carers.

2.2 | Participants

Six service users and four carers were interviewed about their experience of contact with relevant services and of the way treatment decisions were made. This work formed part of a larger study (Saini et al., 2022). For this paper, only those interviews where people had a diagnosis of a PD were included. Participants were excluded if they were under the age of 18 or were unable or unwilling to provide written informed consent.

2.3 | Materials

Service user and carer participant information sheets, consent forms and interview schedules were designed with the study stakeholder group, including public and patient advisors, clinicians, researchers, housing association staff and ward nurses.

2.4 | Procedure

Participants were given an information sheet and consent form to sign prior to participation in the study. Interviews were undertaken remotely due to ongoing COVID-19 restrictions. Interviews lasted between 15 and 79 min and were carried out between August 2021 and April 2022. Interview schedules were designed to facilitate discussions with participants about their experiences of contact with mental health services, as well as the care received. Prompts were included to guide the discussion if necessary, covering areas such as involvement in decision-making, autonomy, placements, psychological therapies, relationships with staff and experience of discharge. Interviews were recorded using a digital audio recorder and transcribed verbatim. Participants were given pseudonyms to anonymise interview data.

2.5 | Data analysis

Data were analysed following the principles of qualitative thematic analysis using NVivo software (Braun & Clarke, 2006), adopting a critical realist perspective and using the framework approach. Transcripts were checked against the audio files for accuracy by AB and HR, who conducted the interviews. The analysis of all transcripts was conducted and discussed by members of the research team, each with different disciplinary backgrounds including public and patient involvement (PS, TN, LS, AB, HR, JT and PAM) to establish procedural reliability and conceptual credibility (Leung, 2015). The iterative coding process enabled the continual revision of themes until the final classifications of major themes were agreed by the team. During meetings, frequent comparisons were made across codes and the interview data to develop, review and refine themes based on the complementarity, convergence and dissonance of ideas across data sources (Braun & Clarke, 2006; Farmer et al., 2006). All findings were reviewed within the research group and any disagreements were resolved by discussion. The data were then re-analysed in context of these themes, focussing specifically on mention of a diagnosis of a PD and its impact across these areas. The Critical Appraisal Skills Programme (CASP) tool was used for appraising the strengths and limitations of the qualitative research methodology used in this study (CASP, 2018).

2.6 | Ethical approval and conduct

Ethical approval was obtained from the NHS Health Research Authority and West Midlands-Coventry & Warwickshire Research Ethics Committee on 19 March 2021: (REC Ref: 21/WM/0020) Integrated Research Application System (IRAS) prior to study commencement. The study was undertaken in compliance with the research protocol. All participants were given a participant information sheet and completed a written consent form prior to taking part in the research. Personal data were documented on a password protected and encrypted computer.

2.7 | Reflexivity and rigour

To ensure quality and rigour, the approach of the study used the principles recommended by Yardley's (2000) framework that outlines sensitivity to research context, commitment and rigour, transparency and coherence, and impact and importance. The data collection process used open-ended and semi-structured questions, ensuring high-quality data by enabling participants to respond freely with the help of prompts as needed. Thematic analysis (Braun & Clarke, 2006), the data analysis process, incorporated several key principles to ensure the research was conducted rigorously (Lincoln & Guba, 1986). For example, the prolonged engagement with each transcript for multiple researchers allowed credible findings, as the familiarisation of the content reduced the likelihood of data being misinterpreted, with the use of quotes within the findings ensuring confirmability by having conclusions grounded in the data itself.

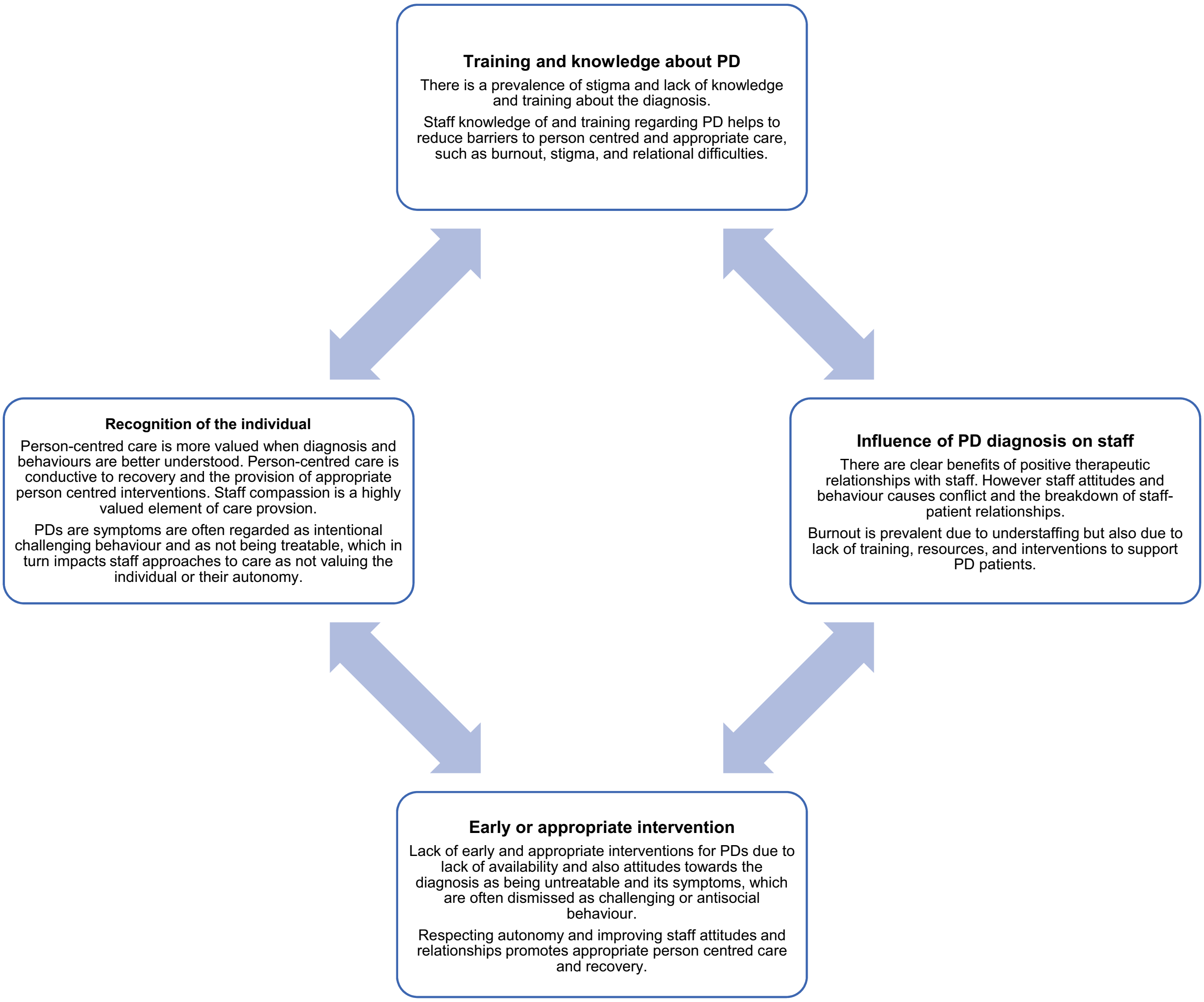
3 | FINDINGS

Four interrelated themes were developed to reflect the perceived context-specific facilitators and barriers of treating individuals with a diagnosis of a PD from the perspective of service users and carers (Figure 1). The first theme *Influence of a diagnosis of PD on Staff* related to the negative attitudes towards people which arise from the diagnosis, and how staff burnout further impacts and creates barriers to compassionate care. The second theme identified *was Early and Appropriate Intervention*. This highlighted the positive impact of timely, person-centred and appropriate intervention for recovery. It also highlighted delay in receiving this later, the impact of their presentation on clinical decision-making surrounding intervention, and the inaccessibility of interventions specifically tailored to their diagnosis. The third theme *Recognition of the Individual* encompassed the benefits of compassionate person-centred care and the need for greater attention within services to this principle. The final theme *Training and Knowledge of people with a diagnosis of a PD* related to stigma surrounding the diagnosis and the need to eradicate this, in addition to lack of knowledge and training to best care for and understand those with a diagnosis of a PD. Each theme is further discussed below.

3.1 | Theme 1: Influence of a diagnosis of PD on staff

3.1.1 | Attitudes towards patients

Among a range of reported staff attitudes, there was evidence of some negative attitudes towards people with a diagnosis of a PD within services, and this negatively impacted their treatment. It was clear that while many staffs were focussed on providing compassionate person-centred care, there was a clear struggle from others to accommodate challenging presentations and the demands of the role, leading to people sometimes feeling resented and alienated; '*In there [inpatient ward] were some fantastic staff, there were some amazing staff who she worked with, they were really supportive, and some absolutely useless ones*'.—Joe (Carer).



Training and knowledge about PD

There is a prevalence of stigma and lack of knowledge and training about the diagnosis.

Staff knowledge of and training regarding PD helps to reduce barriers to person centred and appropriate care, such as burnout, stigma, and relational difficulties.

Recognition of the individual

Person-centred care is more valued when diagnosis and behaviours are better understood. Person-centred care is conductive to recovery and the provision of appropriate person centred interventions. Staff compassion is a highly valued element of care provsion.

PDs are symptoms are often regarded as intentional challenging behaviour and as not being treatable, which in turn impacts staff approaches to care as not valuing the individual or their autonomy.

Influence of PD diagnosis on staff

There are clear benefits of positive therapeutic relationships with staff. However staff attitudes and behaviour causes conflict and the breakdown of staff-patient relationships.

Burnout is prevalent due to understaffing but also due to lack of training, resources, and interventions to support PD patients.

Early or appropriate intervention

Lack of early and appropriate interventions for PDs due to lack of availability and also attitudes towards the diagnosis as being untreatable and its symptoms, which are often dismissed as challenging or antisocial behaviour.

Respecting autonomy and improving staff attitudes and relationships promotes appropriate person centred care and recovery.

FIGURE 1 Four interrelated themes were developed to reflect the perceived context-specific facilitators and barriers of treating individuals diagnosed with a PD.

'So, when staff members made the extra effort to show an interest in you or to help you through something that you were struggling with, that was definitely really helpful. Just being validated in how you felt, but also offering another kind of outside perspective of where you were at, so that you could try and rationalise some of the things that you were thinking, whereas the unhelpful thing would be staff further alienating you on the ward or just making assumptions about you before they'd even tried to get to know you as a person'.—Lois (Service User).

There were several mentions of behaviour by staff, which was perceived as inappropriate and unkind by service users. This maltreatment was detrimental to recovery and seemed in many instances to be enduring and something which these individuals had to become accustomed to within their care. There were underlying themes of staff resentment and frustration towards these individuals and a lack of compassion and understanding of their presentation, which in turn exacerbated presenting issues;

'You sort of get used to the way they are with you, like you know that they're going to be a certain way… You get used to it, basically. Then, when they start being nice to you, you're quite shocked and you're like, "Oh, okay, is this sarcasm or something?"—Samantha (Service User).

'While I was at [hospital name], as well, I had some of the staff there being horrible to me and shouting at me and stuff. It went on, on one ward, for 18 months'.—Joseph (Service User).

3.1.2 | Staff burnout

Staff burnout and lack of staff working on some wards were discussed particularly with regards to the substantial impact this had on staff well-being and their ability to fulfil the demands of their role; this was commented on by both service users and carers. It seemed that staff burnout could create barriers to compassionate person-centred care for individuals with a diagnosis of a PD as staff struggled to accommodate the nature of the presentation when under the significant emotional, psychological and professional strain caused by understaffing and lack of support. The consequences of staff burnout were notable in terms of escalated risk and clinical decision-making, with individuals often not receiving the care they required for recovery;

'Someone is really, really going to hurt themselves. And they don't care. There are not enough staff to care'.—Samantha (Service User).

'Even in services the staff are so burned out and they don't have the time or the energy to show compassion or constructive feedback. Being able to really help someone who's struggling. I don't necessarily blame that on the staff if they are in that state of mind because I can understand what that feels like on a level'.—Joshua (Service User).

Service users discussed how their treatment was altered to provide relief for staff. For example, some people felt they were overmedicated or moved to different wards to provide staff with respite;

'They tended to just medicate people so that they had an easy shift, unfortunately'.—Lois (Service User).

'On one of the wards I used to joke they wanted a respite from me, so they'd send me down to the PICU whenever they couldn't be bothered dealing with my risks anymore. I laugh about it, but it's frustrating because I hated the PICU'.—Joshua (Service User).

Both carers and services users spoke compassionately for staff who seemed to be struggling due to burnout and were understanding when staff shortages affected visiting from carers. However, the unanimous answer for improving the situation was the need for more experienced staff to be available on the wards;

'I don't know. Any improvement? I'd say they need more staff because, literally, there are no staff, and it's not fair on us because we can't do anything. It's not fair on the staff because they're stressed out and getting burnt out'.—Samantha (Service User).

'There're quite a few who seem to be struggling, as everybody is, with staff'.—Joanne (Carer).

3.2 | Theme 2: Early and appropriate intervention

3.2.1 | Person-centred intervention and recovery

Experience of interventions within recovery varied. It seemed that those who received person-centred treatment for a diagnosis of a PD, such as DBT, benefited from it immensely and psychological input had a profound effect on recovery. Appropriate therapy and support were highly valued by service users;

'I definitely think that, if I had received the right help earlier on, that I would have avoided many admissions and as long as it [therapy] was in hospital, because obviously, when I went to [hospital name], I was there for nearly three years… it was at a specialist ward that did DBT therapy, and it was the DBT therapy that got me better'.—Lois (Service User).

'During that course [DBT], that was a breakthrough for me and like and after that, then I started moving forward. A couple of years after that, they started preparing me for discharge…I just picked everything apart and went through everything and then made sense of what happened to me, I made sense of my behaviour, I made sense of why I was feeling the way I was feeling'.—Joseph (Service User).

3.2.2 | Lack of early or appropriate interventions within services

There was also, however, in some feedback, evidence of inappropriate use of therapies and lack of stabilising input to allow for effective therapeutic intervention. There seemed to be a few therapeutic interventions tailored towards individuals with a diagnosis of a PD;

'They weren't actually teaching her any skills or coping, not that she felt able to use them'.—Claire (Carer).

'They're meant to be teaching you ways of coping and stuff like that, but I found that they never, ever taught me ways of coping. They just let me talk about my past, and they didn't know what to say to help me because I'd get so upset'.—Samantha (Service User).

'Even as an inpatient they look at your diagnosis and they're like, "He doesn't need medication." I was having very bad mood swings and fluctuations, but they assumed it was just EUPD [emotionally unstable personality disorder]. It turns out I desperately needed lithium. I've been on lithium for coming up to maybe two years now and I've never been so stable in my whole life'.—Joshua (Service User).

There seemed to be a lack of consistent care provision or time to form therapeutic relationships with staff, particularly for psychological therapy;

'Whenever you get a psychologist, they always end up leaving after so long and you're never able to finish any piece of work, which is really debilitating. Especially when you need it and you've got so many traumas—Joshua (Service User).

Interviewees also highlighted their need for mental health care from a young age and discussed how this need was often unmet; it seems that these individuals were seen as a 'lost cause' or dismissed due to the emotional nature of their presentation. They reported that had earlier intervention been provided this may have been helpful to their recovery;

'No one ever asked a question or questioned why I was behaving the way I was behaving, I was just treated as a young offender…I think, because I was with the Early Intervention team, they should've really been asking all the right questions and all that but that never happened so we never got to the bottom of my problem so I carried on offending'.—Joseph (Service User).

'I'd say it was hard to get help when you were younger because they just put it down to emotions and puberty and stuff like that'.—Megan (Service User).

Therapeutic intervention specifically tailored towards individuals with a diagnosis of a PD was largely unavailable or difficult to access, often requiring an out-of-area placement. Psychological intervention seemed inconsistent and lack of consistent access to therapy was detrimental to recovery;

All the while, they kept telling us she shouldn't be in hospital. Personality disorder, hospital is not the place for it. As much as they were *telling us that, and we were like, 'We get it but she is not safe to come home'.*—Joanne (Carer).

3.3 | Theme 3: Recognition of the individual

3.3.1 | Staff compassion

For individuals with a diagnosis of a PD, there was a clear emphasis on the benefits of positive and supporting relationships with staff, particularly those who focussed on person-centred care. These supportive, caring and nonjudgemental relationships which valued the individual beyond their presentation and diagnosis were significant to recovery and their experience of mental health services. Staff input such as brief moments of pleasant conversation and acknowledgement seemed incremental and was highly important to their feeling of being treated with compassion, dignity and respect. Some participants reported how these positive relationships had saved their lives;

'Some of the staff members that have helped me over the years, if it wasn't for them, I wouldn't be here, but it's the ones that genuinely care and take time to talk to you, to get to know you, to help you with things that you're struggling with. You just don't ever forget those staff members because you knew that, if that staff member hadn't been there, then you wouldn't—I wouldn't—be here now'.—Lois (Service User).

'I think some staff can be decent with you, like really support you and just give you a friendly hug, just to say like, "It's okay, I'm here."'—Megan (Service User).

'Her psychologist, her social worker, her named nurse, have all been really, really, good and she's developed really good relationships with them to be able to, obviously, disclose what's going on and speak to them'.—Claire (Carer).

Simple yet positive interactions which valued individuality and common humanity contributed to building therapeutic relationships with staff; these subsequently facilitated engagement in treatment, therapeutic support and recovery.

3.3.2 | Person-centred care

Person-centred care was highly valued, allowing individuals to feel respected for their opinions and individual preferences. It allowed for better engagement in treatment and was reported to be an informed and compassionate collaborative decision that valued them as an individual, as opposed to an external and impersonal decision dictated to them;

I think person-centred is a very big thing and I think people don't value it enough. It helps that service users feel valued, and they think, 'They are listening to me. They are taking in my experiences and who I am. Not just treating me based on my diagnosis'. I think things like that are extremely effective and I think it massively helps someone to feel better about themselves. I think in mental health and the world in general, it's a very, very dark place.—Luke (Service User).

3.3.3 | Lack of person-centred care

Receiving care which disregarded individual needs was an upsetting and demeaning experience. It exacerbated pre-existing issues when individual experiences and needs were overlooked and, in some cases, resulted in negative patient outcomes;

'I did feel, on quite a few occasions, that they weren't really listening to anything I said and that they just disregarded anything I said. Then, if they were questioned on why they're not listening to me, they'd just say that I'm ill or something…I felt like they didn't listen to me about the side effects that I was experiencing, which was really hard'—Lois (Service User).

They then moved my ward, moved my hospital because I was a [district name] patient and not a [city name] patient. They know full well that I've got a lot of trauma around [hospital name], but they still did it anyway, and then that resulted in me doing a suicide attempt because they didn't listen to me and I didn't feel supported.—Megan (Service User).

3.4 | Theme 4: Staff training and knowledge of people with a diagnosis of a PD

***Stigma*.**

It was evident that staff could hold stigmatising views about a diagnosis of a PD, and that this impacted care provided. It was reported that the stigma created a less compassionate approach to care which devalued the individual and their recovery;

'I think I even see it because I've done PD training for staff, I've done it with several different psychologists. Even as a person training it, I can see the stigma there. We have staff saying they're all [PD patients] going to end up in the judicial system, which is quite concerning really because you think you can go to them to be treated'.—Luke (Service User).

'She kept passing comments and said, "I don't think you've got EUPD, I think you're autistic."' But not to [Service-user name], she just muttered it under her breath to [Service-user name].—Mark (Carer).

Both service users and carer reported how staff needed more training about stigma surrounding a diagnosis of a PD.

3.4.1 | Lack of knowledge and training about people with a diagnosis of PD

Interviews highlighted both a lack of and inaccurate knowledge surrounding a diagnosis of a PD; often regarding the diagnosis as being untreatable, which in turn impacts staff approaches to care and individual recovery;

When she was in [ward name], she came out of there with a diagnosis of emotionally unstable personality disorder. She came out with that, which is just horrible because nobody knows… We've since found out the professionals don't really know how to treat it and how to treat the person.—Joanne (Carer).

'I think there should be more therapies available for people with personality disorders because they seem to have a lack of insight. I think they just need training on it, really, especially for self-harm… they didn't understand self-harm, and every time I did self-harm, they would call the police. Then, I'd get more distressed because the police had been called. It would make me ten times worse. Then, I'd end up being arrested or something. It could have been prevented if they would have sat with me, helped redress it and then told me to go to A&E, but instead they phoned the police every single time'.—Megan (Service User).

Respondents noted that specialised training may improve management of suicide risk and self-harm; behaviours that are prevalent in individuals with a diagnosis of a PD. Decisions made to manage risk were described as rushed and chaotic and they lacked service user or carer input;

"I would say they need more training on self-harm and suicide attempts, like what to expect when you're looking after someone with mental health, instead of just throwing them in at the deep end and saying, "Deal with it."—Megan (Service User).

'When she ligatured one night, the kneejerk reaction was, "Right, we're going to move her." Again, about 10:30 at night, got a phone call, got a message of [Service-user name]. I rang the ward and they said, "She's ligatured, so we're moving her." They moved her to [Ward name] but, again, back over in [City name]. That was heart-breaking because there was a lot of really, really, seriously-ill patients over there that she found really, really, distressing and very, very, frightening.—Joanne (Carer).

The reoccurring theme of service users and carers not being informed or involved in decisions that sometimes impacted on an individual's care detrimentally was discussed across most interviews.

4 | DISCUSSION

The influence of an individual having a diagnosis of PD was highlighted by the negative attitudes staff displayed from both the service users and carers' perspective. Staff burnout further impacted and created barriers to compassionate care. Early and appropriate interventions were needed in a timely manner with person-centred care to aid recovery. Where delays occurred, this impacted on an individual's presentation and clinical decision-making surrounding the choice of treatment provided. The issue of inaccessibility of interventions specifically tailored to a person with a diagnosis of PD was repeatedly reported. The benefits of compassionate person-centred care and the need for greater attention within services to this principle were discussed. More bespoke training for people working with individuals with CMH needs is required to reduce stigma surrounding the diagnosis of PD and the need to eradicate this. Additionally, staff need further knowledge and training to best care for and understand those with a diagnosis of a PD.

4.1 | What the study adds to the existing evidence

The value of treating individuals with a diagnosis of PD with compassion, dignity and respect was often lacking. The benefits that arise from a positive supportive relationship with staff were highlighted (Dale et al., 2020); however, barriers such as a lack of person-centred decision-making with regards to their care, staff burnout, lack of training and stigma often led to feelings of resentment and alienation in care. Similar findings of feelings of resentment and alienation have been reported (Bowers, 2005; James & Cowman, 2007; Rogers & Dunne, 2011). For example, Rogers & Dunne, 2011 found that a diagnosis of a PD triggered staff prejudice, which the staff openly expressed to service users. In further support of these experiences are studies investigating the attitudes of inpatient staff, which suggest that staff generally have both negative attitudes and expectations when working with a patient with a diagnosis of a PD (Bowers, 2005; James & Cowman, 2007).

The belief that individuals with a diagnosis of a PD are untreatable seemed to permeate care. However, it was clear that with the use of relational practice including person-centred care (Dale et al., 2020), some service users made significant progress and breakthroughs in their recovery, allowing far greater independence and well-being and successful discharge from inpatient services. There was a distinct lack of therapy largely due to service unavailability. This, in turn, led to out-of-area placements, which can be detrimental to individual well-being (Rambarran, 2013). The lack of appropriate interventions stemmed across people's timeline of illness and care. Indeed, all interviewees with a diagnosis of a PD had a background of trauma which in many instances had not received effective early intervention, as the focus seemed to be mainly on their challenging behaviour and emotions rather than underlying issues. More work is needed to understand whether early interventions for people with adverse childhood experiences could mitigate admissions to hospital and potentially reduce levels of criminality (Asmussen & Casebourne, 2020; Felitti et al., 1998).

Interviewees reported being treated solely on the basis of their diagnosis, which often removed autonomy and disregarded their individual needs and experience. This was detrimental to their mental health and recovery, whereas autonomy allowed for greater engagement with services and care plans. Person-centred care and its recognition of individual needs and experiences seemed to coincide with positive staff–patient relationships; all of which was highly valued by the patient and was enriching to their recovery (Trevillion et al., 2022). 'Having a voice' has been a key part of inpatient positive experiences such as the benefits of joint decision-making and listening to carers (Rogers and Dunne, 2011).

Burnout seemed to be related to understaffing and overstretched services and was reported to lead to less compassionate care and negative service user experiences. Both service users and carers reported that more training was needed for staff in providing better care for individuals with a diagnosis of PD; staffs were not only overstretched but were also often practicing without knowledge of the diagnosis. Previous research has reported similar findings (Cleary et al., 2002; Ring & Lawn, 2019; Warrender, 2016). Additionally, stigma and staff attitudes can create negative patient–staff interactions and failed care strategies added to preconceptions that individuals with a diagnosis of PD are untreatable, and their symptoms being viewed as manipulations or rejections of help. Stigma towards their diagnosis was highlighted throughout multiple levels of care and service user descriptions were reflective of beliefs that they were 'difficult and misbehaving' rather than unwell. Many reported that they felt less deserving of care and that their mental health needs were less valid or urgent than individuals with other psychiatric diagnoses. Similarly, Hayward et al. (2006) concluded that a diagnosis of a PD was associated with greater unmet needs among inpatients. Some issues regarding inpatient admissions reported feeling unworthy of a bed space due to staff attitudes (Fallon, 2003). Positively, Cleary et al. (2002) found the majority of staff wanted to seek further education in how to effectively treat and manage this client group.

Despite a prevalent misbelief among professionals that individuals with a diagnosis of PD did not respond to treatment, interviews in this study included feedback from service users who have responded positively to interventions that were tailored towards their diagnosis and individual history. Many cited a 'breakthrough' in their recovery having received appropriate psychological interventions that decreased distress and lowered risk; resulting in them living an exponentially more independent and fulfilling life; a key goal of mental healthcare services. This is in line with the principles of relational practice models (Dale et al., 2020). Out-of-area placements highlighted the barriers some people experienced when attempting to receive appropriate care. However, the quality of care and treatment was discussed more rather than the location of it (Chemerynska et al., 2020). For some, out-of-area placements were a catalyst for recovery; however, for others they were potentially detrimental due to strain on protective factors, such as family contact and visitation (Askey et al., 2009). However, for some people distance from a family within which there is a long history of trauma and attachment damage may have also been beneficial (Bonell et al., 2011). Carers reported being powerless and had a need to be valued and recognised by clinicians and suggested that a partnership approach between clinicians and carers is required. Similar findings have been reported (Wilkinson & McAndrew, 2008). More work is needed on effective out-of-area placements that have been positive in people's recovery. Lack of appropriate care can lead to decisions that negatively affected people's experiences and their long-term outcomes.

A strength of this research is the collection of in-depth data from individuals currently being supported by mental health services and carers of individuals with a diagnosis of a PD. The focus was on high complexity and accordingly, the sample was more naturalistic and the findings reflect 'real world' service provision and the experiences of users of these services. We have presented data on both service users and carers' perspectives of what is effective and beneficial within the current mental health provision. However, the findings should be interpreted in the context of some methodological limitations, as the results may not be representative of the rest of the United Kingdom (as data was only collected from North to West England, where the service is situated), although many of the issues we identified are likely to apply across other areas. Another limitation is the lack of diversity in terms of ethnic minority groups, as most participants were White British (9/10), with limited participation from those from ethnic minority communities. It is important to note, however, that our numbers are largely representative of the ethnic background of the local community, with only 3.19% of Cheshire West and Chester residents classified as being from ethnic minority groups (Cheshire and Merseyside Health and Care Partnership, 2021). Future research should aim to include more people from ethnic minority groups.

5 | CONCLUSION

There are multiple aspects of individual care which currently compound symptoms and compromise treatment for individuals with a diagnosis of PD as it can create additional barriers to care for people with CMH needs. Services, as they are currently configured, may not only have limited means but also limited efforts to provide comprehensive care for these individuals. For people caring for loved ones with a diagnosis of personality disorder, the service would benefit from utilising relational practice models when supporting both carers and service users in a more holistic non-medicalised way to improve health outcomes in the immediate and long-term. For individuals with a diagnosis of PD, quick and early access to good quality treatment and care is needed and an emphasis on relationships and continuity of care. Suicide and self-harm are prevalent in individuals with CMH needs *and* a diagnosis of PD, which highlights further risk factors. It is imperative for services to consider how individuals with a diagnosis of a PD are treated within the population of people with CMH needs. Anti-stigma interventions for staff, the involvement of carers, PD research and structural changes to services including more bespoke therapy for individuals with a diagnosis of a PD may help reduce disparate treatment and improve prognosis for recovery.

6 | RELEVANCE STATEMENT

There is limited understanding of the experience of people with complex mental health needs, including those with a diagnosis of personality disorder, and carers of those individuals. There is little known about carers of those in inpatient forensic settings, yet it has been identified that they may have additional needs when compared to general carers. Research highlights that community carer support services were perceived as inadequate and out-of-area placements were described as putting an added strain on ability to support loved ones. Following in-depth interviews within a large mental health service provision, we found that hospital policies or procedures implemented to support staff, service users and carers address some of the issues raised for people with a diagnosis of personality disorder. For people caring for loved ones with a diagnosis of personality disorder, the service would benefit from utilising relational practice models when supporting both carers and service users in a more holistic non-medicalised way to improve health outcomes in the immediate and long-term.

ACKNOWLEDGEMENTS

The authors would like to thank Dr Rebecca Cummings and Dr Phil Elliott for their time and effort in support of the development of this study protocol. The authors would also like to thank the following stakeholders involved in meetings for the development of the study design and tools: Darren Birks (Wirral CCG), Robert Oxley (Wirral Local Authority), Lisa Newman (Wirral Local Authority—Housing), Angela Davies (Deputy Head of Service at CWP), Gagandeep Singh (Consultant Medic at CWP), Sean Boyle (Acute Care Director at CWP), Susie Williams (Team Manager), Bridget Hollingsworth (Wirral Local Authority), Sarah Batty (Rethink UK), Peter Ashley-Mudie (Public Advisor) and Dr Jackie Tait (Public Advisor).

FUNDING INFORMATION

The study was commissioned by Wirral Clinical Commissioning Group and routed through Cheshire and Wirral Partnership NHS Foundation Trust (CWP) to Liverpool John Moores University.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

Ethical approval was obtained from the NHS Health Research Authority and West Midlands—Coventry and Warwickshire Research Ethics Committee: [REC Ref: 21/WM/0020] Integrated Research Application System (IRAS) on 19 March 2021. The study was undertaken in compliance with the research protocol (Saini et al, 2022).

ORCID

Laura Sambrook https://orcid.org/0000-0002-4798-9536
Jason C. McIntyre https://orcid.org/0000-0002-5601-524X
Rajan Nathan https://orcid.org/0000-0003-2780-6170
Pooja Saini https://orcid.org/0000-0002-4981-7914

REFERENCES

Askey, R., Holmshaw, J., Gamble, C., & Gray, R. (2009). What do carers of people with psychosis need from mental health services? Exploring the views of carers, service users and professionals. *Journal of Family Therapy*, *31*(3), 310–331.

Asmussen, K., & Casebourne, J. (2020). *ACEs framework is 'no quick fix' for identifying and supporting children at risk from the effects of abuse and neglect*. Early Prevention Foundation: EIF Press Release. https://www.eif.org.uk/press-release/aces-framework-is-no-quick-fix-for-identifying-and-supporting-children-at-risk-from-the-effects-of-abuse-and-neglect

Banerjee, P. J. M., Gibbon, S., & Huband, N. (2009). Assessment of personality disorder. *Advances in Psychiatric Treatment*, *15*, 389–397.

Bateman, A., & Fonagy, P. (2004). *Psychotherapy for borderline personality disorder: Mentalisation based treatment*. Oxford University Press.

Black, D. W., Pfohl, B., Blum, N., McCormick, B., Allen, J., North, C. S., … Zimmerman, M. (2011). Attitudes toward borderline personality disorder: A survey of 706 mental health clinicians. *CNS Spectrums*, *16*(3), 67–74.

Bonell, S., Ali, A., Hall, I., Chinn, D., & Patkas, I. (2011). People with intellectual disabilities in out-of-area specialist hospitals: What do families think? *Journal of Applied Research in Intellectual Disabilities*, *24*(5), 389–397.

Bowden-Jones, O., Iqbal, M. Z., Tyrer, P., Seivewright, N., Cooper, S., & Judd, A. (2004). Prevalence of personality disorder in alcohol and drug services and associated comorbidity. *Addiction*, *99*, 1306–1314.

Bowers, L. (2005). *Dangerous and severe personality disorder: Reactions and role of the psychiatric team*. Routledge.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.

CASP. (2018). *Critical appraisal skills Programme (CASP)*. CASP. www.casp-uk.net/ (accessed 1 Aug 2022).

Chemerynska, N., Arsuffi, L., & Holdsworth, E. (2020). Ascertaining the needs of Carers of forensic psychiatric inpatients through their experience of navigating mental health services: Guidance for service. *Journal of Forensic Psychology Research and Practice*, *21*(3), 230–248.

Cheshire and Merseyside Health and Care Partnership (2021). Ethnicity Profiles in Cheshire and Merseyside. https://static1.squarespace.com/static/57d2317e579fb3d5c112ad5a/t/646b8e99ef30617fa5a24d17/1684770468624/Ethnicity+profiles+in+Cheshire+and+merseyside.pdf (accessed on 12 July 2022).

Chiesa, M., Fonagy, P., Holmes, J., Drahorad, C., & Harrison-Hall, A. (2002). Health service use costs by personality disorder following specialist and non-specialist treatment: A comparative study. *Journal of Personality Disorders*, *16*, 160–173.

Clarkin, J. F., Yoemans, F., & Kernberg, O. F. (2006). *Psychotherapy for borderline personality disorder: Focusing on object relations*. Wiley.

Cleary, M., Siegfried, N., & Walter, G. (2002). Experience, knowledge and attitudes of mental health staff regarding clients with a borderline PD. *International Journal of Mental Health Nursing*, *11*(3), 186–191.

Dale, O., Haigh, R., Blazdell, J., & Sethi, F. (2020). Social psychiatry, relational practice and learning from COVID-19. *Mental Health Review Journal*, *25*(4), 297–300.

Deans, C., & Meocevic, E. (2006). Attitudes of registered psychiatric nurses towards patients diagnosed with borderline personality disorder. *Contemporary Nurse*, *21*(1), 43–49.

Fallon, P. (2003). Travelling through the system: The lived experience of people with borderline personality disorder in contact with psychiatric services. *Journal of Psychiatric and Mental Health Nursing*, *10*(4), 393–401.

Farmer, T., Robinson, K., Elliott, S. J., & Eyles, J. (2006). Developing and implementing a triangulation protocol for qualitative health research. *Qualitative Health Research*, *16*(3), 377–394. https://doi.org/10.1177/1049732305285708

Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., Koss, M. P., & Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The adverse childhood experiences (ACE) study. *American Journal of Preventive Medicine*, *14*(4), 245–258.

Fok, M. L., Hayes, R. D., Chang, C., Stewart, R., Callard, F. J., & Moran, P. (2012). Life expectancy at birth and all-cause mortality among people with personality disorder. *Journal of Psychosomatic Research*, *73*, 104–107.

Hayward, M., Slade, M., & Moran, P. A. (2006). Personality disorders and unmet needs among psychiatric inpatients. *Psychiatric Services*, *57*(4), 538–543.

Hiroeh, U., Appleby, L., Mortensen, P. B., & Dunn, G. (2001). Death by homicide, suicide, and other unnatural causes in people with mental illness: A population-based study. *The Lancet*, *358*(9299), 2110–2112.

Holt-Lunstad, J., Smith, T. B., & Layton, J. B. (2010). Social relationships and mortality risk: A meta-analytic review. *PLoS Medicine*, *7*(7), e1000316.

James, P. D., & Cowman, S. (2007). Psychiatric nurses' knowledge, experience and attitudes towards clients with borderline personality disorder. *Journal of Psychiatric and Mental Health Nursing*, *14*(7), 670–678.

Keown, P., Holloway, F., & Kuipers, E. (2002). The prevalence of personality disorders, psychotic disorders and affective disorders amongst the patients seen by a community mental health team in London. *Social Psychiatry and Psychiatric Epidemiology*, *37*(5), 225–229.

Lamb, N., Sibbald, S., & Stirzaker, A. (2018). A. Shining lights in dark corners of people's lives: Reaching consensus for people with complex mental health difficulties who are given a diagnosis of personality disorder. *Criminal Behaviour and Mental Health*, *28*(1), 1–4.

Lawn, S., & McMahon, J. (2015a). Experiences of family carers of people diagnosed with borderline personality disorder. *Journal of Psychiatric and Mental Health Nursing*, *22*(4), 234–243.

Lawn, S., & McMahon, J. (2015b). Experiences of care by Australians with a diagnosis of borderline personality disorder. *Journal of Psychiatric and Mental Health Nursing*, *22*(7), 510–521.

Leung, L. (2015). Validity, reliability, and generalizability in qualitative research. *Journal of Family Medicine and Primary Care*, *4*(3), 324–327. https://doi.org/10.4103/2249-4863.161306

Lincoln, Y. S., & Guba, E. E. (1986). Research, evaluation, and policy analysis: Heuristics for disciplined inquiry. *Review of Policy Research*, *5*(3), 546–565.

Meshkinyazd, A., Heydari, A., & Fayyazi Bordbar, M. (2020). Lived experiences of caregivers of patients with borderline personality disorder: A phenomenological study. *International Journal of Community Based Nursing & Midwifery*, *8*(2), 177–188.

Moran, P. R., Romaniuk, H., Coffey, C., Chanen, A., Degenhardt, L., Borschmann, R., & Patton, G. C. (2016). The influence of personality disorders on the future mental health and social adjustment of young adults: A population-based longitudinal cohort study. *Lancet Psychiatry*, *3*, 636–645.

NICE Guidance [CG78]. (2009). Borderline Personality Disorder: Recognition and Management. https://www.nice.org.uk/guidance/cg78/resources/borderline-personality-disorder-recognition-and-management-pdf-975635141317

Rambarran, D. D. (2013). Relocating from out-of-area treatments: Service users' perspective. *Journal of Psychiatric and Mental Health Nursing*, *20*(8), 696–704.

Ring, D., & Lawn, S. (2019). Stigma perpetuation at the interface of mental health care: A review to compare patient and clinician perspectives of stigma and borderline personality disorders. *Journal of Mental Health*, 1–21. https://doi.org/10.1080/09638237.2019.1581337

Rogers, B., & Dunne, E. (2011). 'They told me I had this personality disorders … all of a sudden I was wasting their time': PD and the inpatient experience. *Journal of Mental Health*, *20*(3), 226–233.

Royal College of Psychiatrists. (2020). Services for People Diagnosable with personality disorder (position statement PS01/2020). RCPsych.

Saini, P., Martin, A., McIntyre, J., Balmer, A., Burton, S., Roks, H., Sambrook, L., Shetty, A., & Nathan, R. (2022). COMplex mental health PAThways (COMPAT) study: A mixed methods study to inform an evidence-based service delivery model for people with complex needs: Study protocol. *PLoS One*, *17*(3), 1–14.

Seigerman, M. R., Betts, J. K., Hulbert, C., McKechnie, B., Rayner, V. K., Jovev, M., Cotton, S. M., McCutcheon, L., McNab, C., Burke, E., & Chanen, A. M. (2020). A study comparing the experiences of family and friends of young people with borderline personality disorder features with family and friends of young people with other serious illnesses and general population adults. *Borderline Personality Disorder and Emotion Dysregulation*, *7*, 17.

Sheehan, L., Nieweglowski, K., & Corrigan, P. (2016). The stigma of personality disorders. *Current Psychiatry Reports*, *18*(1), 1–7.

Singleton, N., Meltzer, H., & Gatward, R. (1998). *Psychiatric morbidity among prisoners in England and Wales*. Department of Health.

Stoffers, J. M., Völlm, B. A., Rücker, G., Timmer, A., Huband, N., & Lieb, K. (2012). Psychological therapies for people with borderline personality disorder. *Cochrane Database of Systematic Reviews*, *2012*(8), CD005652.

Stone, M. H. (1993). Long-term outcome in personality disorders. *The British Journal of Psychiatry*, *162*, 299–313.

Trevillion, K., Stuart, R., Ocloo, J., Broeckelmann, E., Jeffreys, S., Jeynes, T., Allen, D., Russell, J., Billings, J., Crawford, M. J., Dale, O., Haigh, R., Moran, P., McNicholas, S., Nicholls, V., Foye, U., Simpson, A., Lloyd-Evans, B., Johnson, S., & Oram, S. (2022). Service user perspectives of community mental health services for people with complex emotional needs: A co-produced qualitative interview study. *BMC Psychiatry*, *22*(1), 55.

Tyrer, P., Reed, G. M., & Crawford, M. J. (2015). Classification, assessment, prevalence, and effect of personality disorders. *Lancet*, *385*(9969), 717–726.

Warrender, D. (2016). Staff nurse perceptions of the impact of mentalization-based therapy skills training when working with borderline personality disorders in acute mental health: A qualitative study. *Journal of Psychiatric and Mental Health Nursing*, *22*(8), 623–633.

Wilkinson, C., & McAndrew, S. (2008). 'I'm not an outsider, I'm his mother!' A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings. *International Journal of Mental Health Nursing*, *17*(6), 392–401. https://doi.org/10.1111/j.1447-0349.2008.00574.x.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, *15*(2), 215–228.

How to cite this article: Balmer, A., Sambrook, L., Roks, H., Ashley-Mudie, P., Tait, J., Bu, C., McIntyre, J. C., Shetty, A., Nathan, R., & Saini, P. (2023). Perspectives of service users and carers with lived experience of a diagnosis of personality disorder: A qualitative study. *Journal of Psychiatric and Mental Health Nursing*, *00*, 1–11. https://doi.org/10.1111/jpm.12959