



## The personality disorder patient pathway: Service user and clinical perspectives

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### ABSTRACT

**Aims** – There have been recent policy developments and research into care provision for service users with personality disorder. However, few studies have focused on service user and staff perspectives on how services could be improved.

**Methods** – A qualitative study was undertaken in the UK between 2016 and 2017. We conducted six focus groups with clinicians in mental health services with experience of working with people with personality disorder. Using an online survey, we asked current and past service users with personality disorder to describe their experiences of mental health services and make recommendations for improvements. A thematic analysis was conducted.

**Results** – Forty-five clinicians participated in the focus group and 131 service users contributed to the online survey. The main areas of concern identified by both staff and patients were the diagnosis of personality disorder, the absence of a coherent care pathway, access to psychological treatment and staff training.

**Conclusions** – The care pathway for individuals with personality disorder is unclear to clinicians and service users, and elements of the pathway are disjointed and not working as effectively as they could. Guidelines recommended by National Institute for Health and Care Excellence are not being followed. Specialist psychological interventions should be available to ensure consistent and stable care provision. © 2019 John Wiley & Sons, Ltd.

### Introduction

Personality disorder is defined as inflexible, embedded patterns of behaviour characterized by problems with thoughts, perceptions and feelings and difficulties in psychosocial functioning particularly with interpersonal relationships.<sup>1</sup> The classification of personality disorder in ICD-11<sup>2</sup> is moving away from diagnosing different types of personality disorder and is considering placing

emphasis on the severity of interpersonal relationship problems and ability to engage in social and professional roles in line with societal expectations.<sup>3</sup>

Coid *et al.*<sup>4</sup> estimated the prevalence of personality disorder in a community sample in Great Britain using a self-report online version of the Structured Clinical Interview for DSM-IV Axis II. In a sample of 626 participants, the researchers found a prevalence of 4.4% for any personality

disorder in people aged 16–74 years and 10.1% if ‘unspecified’ personality disorders were also included. For individual diagnoses, the rates were 0.6% for antisocial personality disorder and 0.7% for borderline personality disorder. A more recent study by Trull *et al.*<sup>5</sup> in the USA used data from the National Epidemiologic Survey on Alcohol and Related Conditions, a study assessing mental illness in a representative general population sample of over 40 000 people. They reported a prevalence of 9.1% for any personality disorder, a similar proportion to that of Great Britain. A Danish register study analysed over 250 000 adult patients’ admissions (inpatient and outpatient) in 1995, 2000 and 2006. A prevalence rate of 15.4% was recorded for primary and secondary diagnoses across the 3-year study period, which decreased to 10.3% for primary diagnosis only.<sup>6</sup>

In the UK, the National Institute for Health and Care Excellence (NICE)<sup>7,8</sup> provides quality standards on how people with personality disorder should be managed (Table 1) and guidance on evidence-based treatment that should be offered. Whilst evidence has found therapies to be effective, provision among mental health teams in England is inconsistent (17% of questionnaire respondents from mental health teams in England provided specialist personality disorder services whilst 28% provided nothing) and often difficult to access.<sup>9</sup> Improving access to services and delivering better outcomes for people with personality disorder were central to the policy document

‘Personality Disorder: No Longer a Diagnosis of Exclusion’,<sup>9</sup> which reiterated findings that those with personality disorder often faced a revolving door within services, and owing to insufficient training, resources and skills clinicians were reluctant to work with those with personality disorder. Since this publication, access to care and dedicated personality disorder services in England has significantly improved.<sup>10</sup> However, just under half of the National Health Service (NHS) mental health trusts and independent organizations stated that patients did not have equal access to dedicated personality disorder services owing to their area of residence.<sup>10</sup> Similarly, in 2003, the Scottish Executive published *Mind the Gaps*, which acknowledged that Scotland had basic services available for individuals with personality disorder; however, these services were often only in forensic settings, were short programmes and were unable to meet the individuals’ needs.<sup>11</sup> Northern Ireland also published a policy document ‘Personality disorder: a diagnosis for inclusion’ in a bid to improve services for people with personality disorder. The report concluded that service users and carers should have meaningful involvement in multi-agency working, which should occur across a multitude of settings.<sup>12</sup>

To date, there has been limited research exploring the provision of mental health service for people with personality disorder from both clinician and service user perspectives. This study aimed to obtain the views of both groups on the

Table 1: National Institute for Health and Care Excellence (NICE)<sup>7,8</sup> guidelines

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NICE recommendations state that people with borderline personality disorder and antisocial personality disorder should

- not be excluded from services due to their diagnosis,
  - be provided with a choice of treatment and take ownership of their recovery,
  - be made aware that recovery is possible and attainable within the realms of a trusting, open staff–patient relationship,
  - be informed of the opportunity to involve carers and relatives in treatment,
  - have a transparent diagnosis process and the diagnosis itself explained,
  - be provided with additional support if sensitive issues have been discussed during the assessment process,
  - be informed about any changes in care and clinicians should ensure they consider the effect ending treatment may have on the individual and put necessary measures in place to ensure effective transitions, and
  - have access to mental health professionals who are trained to diagnose the condition, assess risk and need, and provide management and treatment and who have routine supervision and support.
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care and support provided and how access to services could be improved.

## Method

### *Study design*

The findings are from a UK-wide, mixed-methods study undertaken by the National Confidential Inquiry into Suicide and Safety in Mental Health, formally known as the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (NCISH<sup>13</sup>), which examined the care and services provided to people with personality disorder in the UK prior to their death by suicide or conviction for homicide. The data presented are the qualitative study findings from the larger study.<sup>13</sup>

### *Data collection*

Data were collected via an online survey between 1 April 2016 and 31 December 2016. One hundred thirty-one service users with personality disorder participated. Service users were recruited via the NCISH website, Facebook and Twitter. Charities such as Emergence Plus and patient user groups helped to promote the survey. Service users provided their diagnosis and gender. Regarding their care, service users were asked, 'What worked well or less well?' and 'How could services change or do things differently to improve care quality?' Responses were provided anonymously.

Six focus groups were conducted with services from each UK country between 2016 and 2017. Forty-five participants were recruited from NHS Trusts, ensuring representation from a number of occupations working across the personality disorder care pathway, including mental health nurses, team leaders, emergency department liaison practitioner, social workers, service user consultants and ward managers. Participants worked in a range of settings such as inpatient wards, community teams, crisis resolution and home treatment teams, and specialist personality disorder services.

Staff were asked for their perspectives on current service provision for people with personality disorder within their Trust/Health Board, for their views on service improvement and the challenges that might come from implementing change. The focus group discussions were digitally recorded and transcribed verbatim.

### *Qualitative analysis*

Thematic analysis was undertaken by the first, second and third authors in accordance with the principles described by Braun and Clarke.<sup>14</sup> The six phases of thematic analysis were used to explore the responses from the online survey and focus groups; familiarization of the data, generating initial codes, searching for themes, reviewing themes, defining/naming themes and interpretation. The findings were discussed among the research team to ensure the themes accurately represented the participants' views. Data were stored and managed using NVIVO 10. An iterative approach was taken to revising themes until saturation was reached.

### *Ethical approval*

The study received ethical approval from the National Research Ethics Service on 31 March 2016; Health Research Authority Confidentiality Advisory Group on 31 March 2016; Public Benefit and Privacy Panel for Health and Social Care on 6 July 2016; and Research Management and Governance approvals from individual NHS Trusts and Health Boards across the UK.

## Results

One hundred thirty-one current and former services users completed the online survey; 121 (92%) had emotionally unstable personality disorder (borderline type). Other diagnoses included antisocial, narcissistic, histrionic, mixed, paranoid, schizotypal, avoidant, anankastic and dependent personality disorder. Forty-five staff members across a range of mental health services in the

UK participated in the focus groups. Six key themes emerged from the data, which fall under two groups: firstly, individual-level factors ((1) being diagnosed with personality disorder, (2) receiving compassionate and consistent care, and (3) understanding recovery in personality disorder) and secondly, structural-level factors ((4) access to services, (5) access to effective therapies and (6) staff training and support; see Table 2).

### *Individual-level factors*

*Being diagnosed with personality disorder.* Staff and service users described positive and negative aspects related to receiving a diagnosis. A negative aspect of receiving a diagnosis of personality disorder was the perception by some staff and service users that the term was unhelpful and stigmatizing. The stigma associated with the diagnosis was evidenced by participants who explained that the diagnosis can change the way people with personality disorder are perceived and also effect the treatment available to them. Most notably, it impacted on care pathways. Staff said that the diagnosis could be used as a means of excluding people from a range of services.

Individuals felt 'labelled', which led to feelings of distress particularly given the stigma associated with the diagnosis. An ex-service user, now working in collaboration with a specialist personality disorder service, emphasized the re-traumatizing effect of a personality disorder

diagnosis and stated that it can appear judgemental and deterministic in nature:

I was so traumatised, and that label was the worst thing anybody could have put on me... it condemned the fact that I could ever be normal again because somebody had actually said your personality is disordered, whereas someone had said to me you have an attachment disorder because you've been abused from when you were born all the way till you were 35, that would have made a lot of sense to me and I could have worked with that. (C6.3)

The diagnosis sometimes prevented patients with co-morbid diagnoses from getting the help they need. A member of staff commented on one service user not being able to obtain the support for their anxiety due to their co-morbid personality disorder diagnosis:

So an example of a person who came recently with anxiety, she was extremely anxious, and we've referred her onto CBT, but she was a patient who'd been with primary care but I think sometimes because she's a diagnosis of personality disorder, oh, go to the PD team, well, no, she needs to get the anxiety addressed first and that can be difficult, you know... (C4.4)

Staff indicated that diagnosing someone with personality disorder involved having a difficult and uncomfortable conversation. They commented that the service users were often unhappy with the diagnosis. Some staff indicated that service users were asked to decide whether a diagnosis of personality disorder was recorded in their health

Table 2: Main themes and subthemes arising from the data

Group	Themes
Individual-level factors	1. Being diagnosed with personality disorder 2. Receiving consistent and compassionate care 3. Understanding recovery in personality disorder
Structural-level factors	4. Access to services 5. Access to effective therapies 6. Staff training and support

record as it was thought the diagnosis could affect treatment pathway.

Positive aspects of the diagnosis related to the perception by staff that there needed to be some kind of 'diagnosis' or 'label' to enable discussions on treatment interventions. Additionally, some service users commented on how the process of being given the diagnosis and having the diagnosis explained was helpful:

For me, a massive breakthrough in improving how professionals treat me, was by having just three of them take the time to sit down and talk with me, to really look into my actions and get down to the bottom of them; establish why I would do the things that I'd do. Once I had this knowledge and understanding, I could defend my actions to those who judge them and made assumptions about them. And so, I was supported, respected and helped. (S52)

*Receiving compassionate and consistent care.* Service users perceived staff manner and behaviour to be critically important. Of particular importance were compassion, understanding and the ability to listen. Service users stressed the importance of having a trusting clinician–patient relationship and described instances where clinicians demonstrated these qualities:

The psychiatrist was outstanding—not only super-expert, but (more important to me) very human, warm, responsive, compassionate, non-judgemental. (S24)

Staff highlighted the importance of managing expectations to prevent service users becoming re-traumatized and let down when expectations were not met. Consistency of care in effective treatment was considered to lead to less dependency as service users felt supported and empowered to manage in crisis. However, it was commented that conflicting or contradictory approaches by professionals, particularly consultant psychiatrists, were not uncommon within teams:

So, somebody might court the attachment theory and say, well we're in it for the long haul with these

guys, you're offering something and it's [a] good intervention. Other people hold the boundary and say, no, discharge them, they have been offered [something], that will do. So, we have a variation in how our consultant psychiatrists would deal with that. (C7.1)

#### *Understanding recovery in personality disorder.*

Staff commented on the misconception among colleagues that people could not recover from personality disorder and/or what recovery 'looks like' in personality disorder, for example, what to use as a measure of success. It was perceived that the majority of services tended to focus on behavioural and service access indicators as a measure of success, for example, reduced readmission rates and reduced self-harm, whereas one clinician suggested that services should use a measure of success meaningful to each service user. They also acknowledged the cyclical nature of recovery, and therefore, one missed appointment does not indicate that a service user has failed.

#### *Structural-level factors*

*Access to services.* Both staff and services users described a fragmented care pathway for individuals with personality disorder. Whilst it was acknowledged that there are services that can be accessed in crisis, and some specialist services, the perception was that care provision in mainstream mental health services was lacking. Service users identified this gap in service provision and suggested that day centres would be helpful when they were on the verge of crisis. This would provide an alternative place of safety that does not involve presenting to accident and emergency (A&E):

I would like to see the introduction of crisis cafe's or drop-in centres... where ex-service users can call and/or walk into, to seek help and support when they feel they need it. (S124)

Service availability was considered to differ substantially according to where the service user lived. Both staff and service users acknowledged

long waiting times for psychological therapy. Service users reported having little to no support from when they were offered to when they received therapy. One service user said there were no intermediate services available at times of distress, only when in crisis or after a suicide attempt:

PD patients usually don't actually want to die but don't have somewhere safe to go to deal with overwhelming distress (if they're lucky enough to understand what is happening) and hence suicide becomes the only option as mental health services in many areas don't treat distress as a medical problem, only once a physical act of harm has taken place is it taken seriously. (S02)

Furthermore, service users indicated that the duration of therapy was too short and there were often no after-care arrangements.

*Access to effective therapies.* There was agreement from service users and staff that psychological therapies should be made more widely available and offered as a first line of treatment. Participants stated that psychotherapy and dialectical behaviour therapy, when received, were considered to be most effective and beneficial. However, these therapies were not readily available to all service users:

I was only referred to DBT once I got bad enough to be admitted to a secure psychiatric ward. This was after five or six serious suicide attempts, a lot of self-harm and daily dissociation. Before that, I was not offered any psychological help—just antidepressants. (S101)

*Staff training and support.* Service users perceived a lack of understanding of the personality disorder diagnosis among staff (predominantly borderline personality disorder). They felt that further knowledge and training would improve clinicians' attitudes towards personality disorder:

It really requires a large scale attitude change. More education and training for existing staff around the causes and symptoms of PDs, alongside how to treat people in their care with respect and dignity. (S98)

Clinical staff noted that training is provided but that it is basic, not easily accessible, not given to all and may not match the individual learners' needs. Those who had previously undertaken training commented on the positive effect of involving those with lived experiences:

We've got a service user who is there who talks about her lived experience of the treatment provision, and of course they're always very interested in that because they connect with her and it's not there's another professional saying come and do this, or go and do this, there's a service user saying I have done this, it was like this for me and it helped me in this way, or I struggled with it in this way. It can be really helpful for them. (C4.2)

Alongside the gap in training for staff, the requirement for staff support was commonly referred to within the staff focus groups and was also acknowledged by service users. Support was defined as supervision, peer support, organizational support of services and also multi-agency working so staff can support each other in ways of working and collaborative decision making.

## Discussion

Service users and clinicians consistently highlighted the same aspects of service provision that were not working effectively and also identified similar ways in which services could be improved. Six themes emerged from the data and were categorized into individual-level and structural-level factors. The key areas of concern were the diagnosis of personality disorder, staff training and understanding of personality disorder, and the absence of a coherent care pathway.

### *Diagnosis determines care pathway: Stigma and exclusion from services*

The aetiology of borderline personality disorder is complex and multifaceted. Factors considered to be causally related to its development include biological, psychological and social factors.<sup>15</sup> Although sexual abuse is frequently reported among

patients with borderline personality disorder, it is neither required for a diagnosis nor necessary for the development of borderline personality disorder.<sup>16</sup>

The diagnostic label 'personality disorder' is controversial, stigmatizing and not liked by service users.<sup>17</sup> However, reaching consensus on an alternative term has proved difficult. Our findings support previous research that has shown the stigma attached to the diagnosis can lead to patients being excluded from services.<sup>18–22</sup> Whilst this study was conducted in the UK, this issue is common elsewhere.<sup>23,24</sup> Consequently, some authors have argued that it would be in service users' best interest if they were not given a diagnosis at all.<sup>15</sup>

Psychologists advocate the use of case formulation as an alternative or as an adjunct to the diagnostic process.<sup>25</sup> This approach considers the service users' history in the context of psychological theory to propose an explanation for the development and maintenance of service users' difficulties.<sup>25</sup>

From a service perspective, there is concern that the diagnosis can be used as criteria for exclusion. Our findings have shown that having a diagnosis of personality disorder can affect the care pathway, as previously reported.<sup>9</sup> Despite specific guidelines and detailed quality statements produced by NICE regarding the care and treatment of patients with antisocial and borderline personality disorder,<sup>7,8</sup> we found that people with personality disorder are still being excluded from services.

#### *Training and support framework needed*

The findings presented reveal gaps in the knowledge and understanding of personality disorder and its treatment among some mental health professionals. Service users and staff stated that training should be given to everyone who works with service users across agencies to improve care and understanding, which may also reduce stigma. Training needs to be provided to everyone as part of their continuing professional development. Staff commented that current training is basic, not

readily accessible and does not match the learners' needs. These training gaps apply not only in the UK but also across international boundaries.<sup>26</sup>

The Knowledge and Understanding Framework<sup>27</sup> was developed for training staff who have contact with service users with personality disorder. Whilst some staff who participated in the focus groups commented on the benefits of undertaking this training, others commented that the content was basic with little access to in-depth training such as the undergraduate and master's degree programmes in personality disorder. There is some evidence that training makes a difference. Well-trained staff have been found to be more empathic.<sup>20,28</sup> A recommendation of the NCISH report<sup>13</sup> was that service users should be involved in training and that work with patients is currently an under-used resource within staff training, advocacy and peer support. Service user involvement has previously been found helpful in improving the trainees' attitude, empathy and communication skills.<sup>29</sup> Staff and service users also stressed that ongoing clinical supervision is essential. This confirms findings from previous research internationally.<sup>30–32</sup>

#### *A service model that works*

The main structural concern raised by staff and service users was the lack of a coherent care pathway for people with personality disorder. Staff and service users were both in agreement on what an ideal service model would look like. Firstly, people with personality disorder need to be recognized as requiring help and support. Secondly, service users should have structured contact with a particular service. Thirdly, services need to formulate a clear multi-agency care plan so that all services (such as police, social services and A&E) know what to do if the person presents in a crisis. Finally, service users should have access to appropriate and timely psychological interventions, as recommended in the NICE guidance.

Service users proposed having services such as day centres that could be accessed when in distress, which would reduce the need for presentations to

emergency services. These services could provide preventative interventions where people could receive support prior to reaching crisis point.<sup>33</sup> Researchers have found this type of a preventative approach to be cost-effective. For example, Bateman and Fonagy<sup>34</sup> found that the proactive approach of providing psychoanalytical oriented partial hospitalization to people with borderline personality disorder was cheaper than general psychiatric care on the basis of the reduction in inpatient care and treatment in A&E following partial hospitalization. The NICE guidelines recommend that inpatient admission should be avoided where possible, although our wider study suggests it is still commonly used.<sup>13</sup>

Our findings suggested that there are services that people with personality disorder can access in crisis and there are good specialist personality disorder provisions. However, there are no consistent services available for people who are not in crisis but are awaiting specialist services. It was suggested that community mental health teams should provide regular, frequent appointments with a care coordinators in association with specialist day centres with access to supportive therapy. Previous research has indicated that such regular and supportive input is necessary and helpful when treating individuals with borderline personality disorder.<sup>35</sup>

The NICE guidelines for the treatment and management of borderline personality disorder recommend evidence-based effective psychological therapies such as dialectical behaviour therapy.<sup>36</sup> Support for families and careers through structured programmes and psychoeducation has proved to be helpful.<sup>36,37</sup> However, service users and staff described long waiting lists for therapy and specialist services, with staff noting that this is likely due to the lack of resources available. Service users may become disengaged from services whilst waiting for specialist input, they can be left with no support whilst waiting and, sometimes by the time therapy became available, they had reached a point where they were considered 'too ill to treat', which started the cycle of referral again. A 'holding service' providing support in community mental health teams,

as described above, could help to break this cycle and also reduce the number of crisis referrals.<sup>38</sup> These recommendations for a proposed service model would apply internationally.

### *Limitations*

Although we sought the views of a range of multidisciplinary staff across the UK, our findings are not representative of all patients with personality disorders. Similarly, as this was a qualitative study, the findings presented are subjective and therefore not representative of the views of all services or service users with personality disorder nationally.

The study focused primarily on individuals with borderline personality disorder, and the findings may therefore not be generalizable to other types of personality disorder. Furthermore, although we spoke to staff from services across the UK, our findings may not reflect service provision across all NHS Trusts or Health Boards within the UK. The online survey relied on active participation by individuals who chose to respond; therefore, it is possible that it is not a representative sample due to selection bias. Additionally, given the use of an online survey rather than focus groups and interviews with service users, we were not able to follow up on responses and ask for clarification, which could have provided further insight. However, we found that both service users and clinicians expressed similar views and made similar suggestions for service improvement.

As this study was conducted in the UK, we recognize the structural problems with the configuration of mental health service in the NHS may not be the same internationally. However, the individual clinical challenges in managing and understanding service users with this diagnosis are common elsewhere.

### **Conclusions**

The care pathway for people with a diagnosis or a suspected diagnosis of personality disorder is unclear and needs to be defined; the pathway should

be accessible to all and consistent across services and NHS Trusts. Services should be investing in recovery-focused intensive therapeutic interventions, promoting hope for service users and staff alike. Service users should be given a choice of NICE-recommended psychological therapies, which can be easily accessed through one service with a multi-agency care plan (developed with the service user and all agencies involved) so all agencies know what their care looks like and can be better placed to help that individual particularly in times of crisis. There should be an accessible and needs-matched training programme, involving service users in the delivery of the training, for all staff, to empower them to provide effective treatment compassionately and with a positive attitude. Our findings from this qualitative study and the wider analysis presented in NCISH report<sup>13</sup> suggest that to further the work of Dale et al, an nationwide audit of the quality of care for people with personality disorder should be undertaken.

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