ABSTRACT
A newly developed specialist personality disorder service in the United Kingdom arranged a focus group with seven service users with a diagnosis of borderline personality disorder (BPD) to explore their experiences of the Care Programme Approach (CPA) while under the care of a community mental health team. A thematic analysis generated seven themes. Understanding Borderline Personality Disorder and Understanding Recovery were highlighted as difficulties service users face, with a lack of staff understanding. They also spoke about the struggle of having a voice in their CPA meetings and the lack of information they received in the CPA process. They discussed the deliberation between progression versus consistency and moving on from services. Service users discussed the challenges of accessing treatment and lack of follow up in the CPA process. Greater service user involvement in the process would help address the dissatisfaction and disempowerment in care planning experienced by individuals diagnosed with BPD. [Journal of Psychosocial Nursing and Mental Health Services, 51(10), 38-45.]
A Qualitative Study on the Use of the Care Programme Approach with Individuals with Borderline Personality Disorder

A Service User Perspective

The United Kingdom Department of Health’s innovative document Personality Disorder: No Longer a Diagnosis of Exclusion (National Institute of Mental Health in England [NIMHE], 2003) highlighted the neglectful treatment of individuals with a personality disorder in the National Health Service (NHS). Individuals with a diagnosis of personality disorder find it difficult to manage and label their emotions, often experiencing a great deal of distress. This can affect their relationships with friends and family, along with their ability to feel accepted and seen as productive members of society. A number of suggestions for the treatment and management of personality disorder were consequently proposed as a direct result of this paper. It was suggested that “specialist services” should be encouraged to most effectively treat and manage personality disorder. A further helpful feature was recognized as a service that “listens to feedback and has [a] strong voice from service users” (NIMHE, 2003, p. 22).

The Care Programme Approach (CPA) was developed as a standard of good practice when working with service users with complex mental health difficulties in the NHS. A CPA involves identifying a care coordinator who has responsibility to assess the needs of a service user, develop a plan based on needs identified in collaboration with the service user, share responsibility with the service user to put the plan into action, and review the plan periodically to ensure it is being adhered to and updated. It is an approach that advocates collaboration and an individualized care pathway for those with higher levels of care needs.

One such group identified as requiring a CPA level of care were individuals with a diagnosis of personality disorder. Individuals with this disorder have been marginalized from mental health services in the past, with staff attitudes historically referring to them as “not mentally ill” and “attention seeking” (Lewis & Appleby, 1988). Staff attitudes are gradually changing to a perspective of treatability, although staff continue to feel unskilled in working with this client group and would prefer them to be managed in a specialist service (James & Cowman, 2007). Guidance on the implementation of the CPA highlighted that “people with a personality disorder should be able to benefit from treatment and support, and this guidance applies to them just like anyone else” (Department of Health, 2008, p. 4). However, National Institute for Health and Clinical Excellence (NICE, 2009) guidelines on borderline personality disorder (BPD) identified that the CPA was generally not adhered to or was unhelpful for those with a diagnosis of BPD.

Due to the success of the pilot sites (Crawford et al., 2007), a specialist service was commissioned and developed in 2008 in a rural county in England to work specifically with individuals with a diagnosis of personality disorder. Specialist services are set up in the NHS (and privately) to provide dedicated services for specific client groups who have chronic or complex needs and require access to specialist care/treatment. Specialist services that serve people with mental health difficulties would adopt the CPA as a method of good practice. As part of service development, a series of focus groups was held with a selection of service users under the care coordination of the specialist personality disorder service to discuss their experience of mental health services. One of the focus groups was set up specifically to discuss the CPA process for service users with a diagnosis of BPD. Although the service is for individuals with any type of personality disorder, service users who attended the focus group all had a diagnosis of BPD. The purpose of this article is to report the findings of this focus group of service users to explore their experiences of the CPA while under the care of a community mental health team.

LITERATURE REVIEW

In an attempt to tap into the current knowledge of views and opinions of this client group, available qualitative research was sought. An online database was used, including both PsycINFO and MEDLINE. Terms used
included *borderline personality disorder*, personality disorder, care programme approach, treatment, National Health Service, qualitative, and lived experience. The reference lists of articles found were also scanned to seek additional studies. There were no time period limitations when the searches were conducted. Qualitative research into the experiences of individuals diagnosed with BPD indicates that care and treatment has continued to be unsatisfactory.

Fallon’s article in 2003 looked at experiences of mental health services for individuals with BPD, with four major themes emerging: living with BPD, the service response, relationships, and traveling through the system. The latter theme, “traveling through the system,” emerged from the data as the core theme, characterized by positive and negative movement through the NHS mental health system. This theme also emphasized the facilities required to assist positive movement in the system.

Another article on the experiences of diagnosis and service access for BPD identified three major themes: living with a label, living with self-destructive behavior described as manipulative, and living with limited access to care (Nehls, 1999). Service users reported the downfall of discriminatory attitudes due to the “PD” (personality disorder) label and helplessness at being told there was a lack of treatment available for people diagnosed with a personality disorder.

Horn, Johnstone, and Brooke (2007) identified five superordinate themes, which were (a) knowledge as power, (b) uncertainty about what the diagnosis meant, (c) diagnosis as rejection, (d) diagnosis is about not fitting, and (e) hope and the possibility of change.

Although limited, findings appeared to center on the notion of prejudice experiences and unsatisfactory care, despite new developments in the treatability of the diagnosis and the establishment of specialist services to provide appropriate care to these individuals.

**SPECIALIST PERSONALITY DISORDER SERVICE**

It was therefore inevitable that a new service that specialized in working with people diagnosed with a personality disorder, the Specialist Personality Disorder Service (SPDS), would seek high service user input in understanding the service users’ experiences so far to help direct the development and future of the service. A focus group was set up 1 year after the establishment of the SPDS. The focus group aimed to explore the experiences of service users with a diagnosis of BPD to facilitate the ongoing development of the SPDS. This report intends to contribute to the awareness of lived experiences of service users with a diagnosis of BPD by presenting the feedback obtained from the focus group. Findings here will hopefully encourage further qualitative and quantitative research into the unique experiences of these service users.

**METHOD**

**Design**

This article focuses on a service development project conducted in the United Kingdom in 2009, using a qualitative design based on a semi-structured focus group. Participants were purposefully selected due to their involvement with the SPDS and previous experience of being cared for under a community mental health team in the NHS. Data were analyzed following the process outlined in Braun and Clarke’s (2006) article on thematic analysis to generate key themes arising from the focus group.

**Participants**

Service users were recruited via their care coordinators from the SPDS, which holds a caseload of 65 service users. They were given a flier outlining the focus group date, time, and venue, and were invited to contact the team secretary if they wanted to attend. Seven service users attended the focus group, consisting of five women and two men, with an age range of 21 to 61.

**Procedure**

To ensure the focus group was well managed, the SPDS sought a former service user who had previous experience in facilitating focus groups. Using a former service user as the facilitator allowed the two assistant psychologists (authors of this article) to take an observer role in the group, hopefully encouraging a peer discussion rather than a formal interaction between professionals and service users.

To ensure a range of issues were covered, the authors met with the facilitators to discuss which topics the focus group should be based on. A great deal of time was spent on brainstorming and exploring themes for the focus group. The assistant psychologists and facilitator (former service user) were careful to consider important topics that could potentially generate a lot of discussion. A series of prompting questions were derived, although the discussion was flexible in covering other related issues:

- Do you feel you are listened to and considered during your CPA meetings?
- Was your care plan properly discussed with you?
- Do you feel your care plan was a collaborative effort?
- Do you feel you have benefited from a structured care plan?
- In your work with the SPDS, do you feel you would also benefit by maintaining contact with your Community Mental Health Team worker?
- Would you prefer to have all of your care (excluding medical) transferred to the SPDS?
- What does recovery mean to you and how do you feel the SPDS could help you with this?
- Have you felt in control of your care?
- If you could change anything about your care what would it be?
- Is there any other issue or concern that you would like to raise today?

Prior to the focus group starting, service users were asked to sign a consent form, enabling the team to audio-record the focus group discussions and
publish information collected. This project was not subject to an ethics process, as it was conducted as a service development project. The focus group lasted for 2 hours, and service users were reimbursed £15 for their contribution to the focus groups.

Data Analysis
Once the focus group was finished, the audiorecording was carefully transcribed and qualitatively analyzed by the two assistant psychologists using a comprehensive thematic analysis. To ensure the thematic analysis was performed accurately, the Braun and Clarke (2006) article on thematic analysis was used to highlight the stages of the process.

Rigor
To ensure interrater reliability, a second data analyst blindly cross-checked the thematic analysis. The primary data analyst extracted two pages from the transcript that reflected a sufficient amount of themes. The second data analyst was required to select extracts from the two pages and place them in the table under the appropriate themes identified. A percentage agreement was then calculated at 82%, which increased to 95% after discussion between the two data analysts.

Ethical Considerations
Written information about the focus group was distributed to potential participants prior to taking part, with an option to ask questions prior to consenting. Participants were reassured that participation was voluntary, confidential, and that they could withdraw their data up until the point that qualitative data analysis was complete. As the focus group was completed as part of a service development project, no ethical approval was required.

RESULTS
The focus group discussion generated seven themes: Having a Voice, Progression versus Consistency, Moving On from Services, Understanding Personality Disorder, Understanding Recovery, Lack of Information, Follow Up, and Accessing Treatment.

Having a Voice
Service users often felt uninvolved during CPA meetings and care plan development and believed that collaboration between the care coordinator and the service user was vital. Service users reported that CPA meetings often consisted of being told what staff had decided rather than consulting with the service users about what they believe might help and coming to a joint decision. Related quotes included “Everybody’s made their decisions/choices without my input at all” and “They’re just basically just telling you what they’ve already decided.”

The importance of having an active role was further reiterated at the end of the focus group discussion, when service users were asked if they could change one thing about their care: “I’d like to explain what I believe is best for me…. And then we all come [to] an agreement” and “Just to be more involved in my own care…[and] have a say about what I feel is best for me really.”

Despite the service users being the best source of information about how they are feeling and what needs to change, they seem to be a massively underused resource and made to feel insignificant when decisions are being made about care.

Progression versus Consistency
One of the themes to emerge from the CPA focus group was the dialectic of progression versus consistency. Service users often spoke of wanting to move forward and make progress: “Every aspect of the care that I receive it seems that I’ve had to chase”; “Each month it would be just the same three points at the bottom of the care plan, exactly the same.”

They were unhappy with the repetitive CPA meetings during which nothing seemed to change, yet consistency (particularly staff consistency) was also something they craved. They acknowledged that moving forward also came with some negative consequences, namely service/staff changes: “Because I’ve had that same service for 2 years it felt quite—I felt vulnerable [leaving]”; “The last thing I’d want to do is be shoved off to another service…I’m frightened to death!”

The service users emphasized the point that rejection in relation to attachment and abandonment is a substantial part of their difficulties; therefore, changing services may be a positive change, but it needs to be done over a period of time to reduce the feeling of rejection.

Moving On from Services
Although there was often an issue with rejection surrounding the issue of progress, another significant theme to emerge was the idea of moving on to another service. This issue was particularly related to service users moving to the specialist service and how it was both a positive and potentially negative experience. The service users believed there was more involvement and choice after moving from a community mental health team to a specialist team: “The whole CPA was based on what I wanted… it was a completely different experience”; “That’s the first time that I’ve had an input into the care plan.”

Although they believed the specialist was a good service, some service users were wary of the new service as possibly being a stepping stone to moving on from services completely; therefore, they were understandably wary of having all their care transferred to the new team: “If it’s all left under one service and you’re discharged from that service, then you’re left high and dry.”

Linking back to the theme of progression versus consistency, service users were wary of the potential rejection when coming into a new service and the possibility of being abandoned by mental health services once the specialist service deemed it was appropriate to discharge them.
Understanding Personality Disorder

Another common issue among service users was the lack of understanding among staff of personality disorder. Despite well-documented characteristics of individuals with BPD experiencing fears of rejection/abandonment and emotional dysregulation, staff appeared to perpetuate these features by making rejecting comments while service users were present: “My psychiatrist told me, ‘As far as I’m concerned, I don’t want nothing to do with you anymore.’”

Service users also detected a lack of knowledge by psychiatrists in relation to personality disorder and believed specialist training on the BPD diagnosis should be required: “I would want the psychiatrists to be better educated on personality disorder”; “I haven’t come across a psychiatrist who specializes in personality disorders. So maybe…it would help.”

Although there were negative examples of receiving a diagnosis, some service users had encountered members of staff who were able to describe the diagnosis in a meaningful way: “Doctor [name] was really, really good…. He was quite able to explain this is a result of that and stuff”; “After all these diagnoses thrown at me, she sat there within 2 minutes and told me what was wrong with me.”

Understanding Recovery

In line with the implementation of the recovery model in the NHS Mental Health Trust where the new service was set up, service users were asked about their views of the recovery model, to identify whether an understanding of this model has been filtered down to service users. The main issue to emerge was understanding recovery; namely that the meaning of recovery was unclear. Service users felt that staff were not effectively communicating their definition of recovery in mental health: “Recovery hasn’t been explained properly to the clients…what [the Trust] mean by recovery”; “Nobody explained to me what they meant by recovery.”

Other service users were able to share their understanding of recovery and the recovery model and believed it was important to clarify that recovery needed to be personalized to suit each individual: “Don’t treat us like everybody’s the same, whereas everybody’s individual.”

It appears service users believe they are potentially missing out on useful services as staff are failing to signpost them to appropriate resources. A possibility is also that staff are unaware of services available, which is why this information is not being communicated to service users. Better promotion of services is necessary to ensure that both staff and service users are able to access information on relevant treatment/services.

When asked about any other issues they would like to talk about, service users specifically raised the lack of information regarding side effects of medication they were prescribed by psychiatrists. Service users believed they needed information regarding side effects before they began taking various medications so they could make an informed decision as to whether they wanted to be on the medication: “They wait until you’re on them and you start to feel better…and then they tell you the side effects”; “When you are put on medication, actually being told what the side effects are.”

Follow Up

Another theme to emerge from the CPA focus group was the issue of follow up by staff after a CPA meeting. A major issue under this theme was confidentiality; more specifically, being contacted via mail and fears of other people becoming aware of their involvement of mental health services: “If it went through someone else’s door and…they opened it, then they would know everything”; “The information on my last care plan was so personal to me…. I don’t want my daughter seeing it.”

On the other hand, other service users were concerned regarding the lack of follow-up information follow-
Some participants expressed a sense of abandonment when changing services, often exacerbating fears that their BPD label was a permanent condition. This was particularly emphasized in their interactions with mental health professionals, as the long-term use of medication may be associated with a lack of identity independent of it. One participant described feeling like a guinea pig, stating: “I’ve been on every antidepressant on the market, anti-psychotic...I’ve seen every one of them.”

Finally, other service users who received care plans reported receiving them following a CPA meeting that they had not been invited to, linking back to the first theme of “having a voice” and the exclusion of service users from their care planning: “You’re just getting letters, but no actual person really telling you why this changing or anything”; “All these care plans were going ahead, you know, every month without me actually even knowing.”

From this feedback, there appears to be a lack of either understanding of the CPA or the staff are choosing not to follow CPA procedures. Unfortunately, this perpetuates the problem mentioned earlier, that service users do not believe they have a voice or a say in their care.

**Accessing Treatment**

A final theme was accessing treatment, divided into discussions around the focus on medication and the lack of psychotherapies available. Service users discussed the emphasis mental health professionals tend to put on medication in their treatment plans: “[Doctor says] I could just put you on more medication”; “[I don’t want to] just to be plied with drugs. You know, medication.”

Although service users believed that the changes and developments on their care plan related to medication, they expressed a lack of expertise in prescribing for BPD and reported a trial-and-error culture in the treatment they had received: “I feel like a guinea pig, I feel like a lab rat”; “Every single antidepressant on the market, anti-psychotic...I’ve taken every one of them.”

People spoke of the repercussions of being on medication over a long period of time, which resulted in both physical health problems as well as a lack of identity independent of them as a person on medication: “I was a perfectly, physically healthy person before [medication].... [Now] I’m physically unhealthy and mentally unwell as well”; “I’ve been on every medication for 20 years now, so I don’t know what it’s like not to be on medication.”

The long-term use of medication is likely to induce a fear of coming off medication, due to service users’ uncertainty of how they may feel or behave without it.

In contrast to the frequent offer of medication as a treatment option, there seemed to be a lack of different psychotherapies offered, or those available were subject to a long waiting list: “I’ve had to wait years to get psychology, and it’s been apparent for a long time that’s what I needed”; “If you need something like some sort of therapy, there [shouldn’t be] a 2-year waiting list.”

It appears there are insufficient therapies available to service users, with the main focus for those within the specialist service receiving DBT as the treatment recommended by NICE (2009). Service users raised concerns that if they were not engaging in DBT, they were unsure of what else was available to them: “I feel like I’ve done DBT, it worked at the time, but it don’t work anymore so what’s next?”; “I reckon there needs to be more options other than DBT.”

**DISCUSSION**

This service development project aimed to explore the experiences of those diagnosed with BPD who were under the care of a community mental health team, using a CPA. Although there has been some published research into the services received by this client group, the current project aimed to explore service users’ experiences of local services. Despite guidelines providing comprehensive information (NICE, 2009) on working with this client group, some of the concerns raised in previous research remain an issue.

A recurring theme across studies completed with this client group is the lack of understanding by staff regarding the BPD diagnosis and the options available for those who have received this diagnosis. This was particularly emphasized in their interactions with participants, often exacerbating fears of abandonment when sending participants to another service. Partici-
Participants reported that staff, particularly psychiatrists, did not appear to understand the diagnosis. Nehls (1999) made the distinction between a “diagnosis” and a “label,” reinforcing the idea that once this diagnosis was given, service users with BPD are often rejected by services with the notion that they cannot be helped. Despite receiving a diagnosis, it was frequently completed without explanation (Horn et al., 2007), leaving service users to research their diagnosis. This linked to the theme of accessing treatment, which exemplified the confusing journey for an individual with a diagnosis of BPD. There was little understanding on what was available to individuals with this diagnosis, with staff often resorting to medication as waiting lists for psychotherapy approaches limited their access to this treatment. Similarly, participants in Nehls’ (1999) study referred to their limited access to care, specifically that service providers did not appear to have the skills and knowledge on how to effectively treat and manage their diagnosis of BPD. Likewise, Fallon’s (2003) study also highlighted the service emphasis on the medical model, using medication as a primary treatment option. It appears from the staff’s approach to BPD that their limited understanding of BPD raises their own anxiety, which leads them to respond to service users in a detached way, reinforcing the service users’ belief that they are at fault when it may be an illustration of poor staff training and knowledge (Cleary, Siegfried, & Walter, 2002).

Participants also reported on the need to be independent when looking for treatment options available, as this did not appear to be accessible through staff. Nehls (1999) also identified the staff emphasis on treating the behaviors, such as self-harm, rather than attempting to explore the cause of the behaviors through the use of psychotherapeutic approaches. This was also identified as a limitation of the specialist service, in contrast to the work of Crawford et al. (2007), in which the specialist service was disapproved for only offering DBT as a treatment option, despite a range of treatments now available to those with BPD. The notion of “helping yourself” was interwoven through both studies, with participants requiring a level of independence in researching their diagnosis and its treatment. This raises the question of whether a medical model is easier to adopt with this client group as it enables a quick and practical solution, despite going against NICE guidelines. It is well documented that there is little evidence to suggest BPD is treatable through medication, with the exception of short-term use (see NICE, 2009, for a review), yet it continues to remain a central feature of their treatment (Rogers & Acton, 2012).

Interestingly, participants in Fallon’s (2003) study identified service improvement over time, noting the implementation of the collaborative CPA as pivotal in this change. The current project, however, generated two main themes centered on the use of the CPA: having a voice and follow up. Participants were unanimous in their experience of having limited involvement in their care planning, despite feeling as though a collaborative approach was key to their care and a central aspect of the CPA. There was also a general experience of receiving information after a CPA that they had not been involved in or informed of, illustrating the lack of person-centered care. Furthermore, some individuals were unaware of what a care plan was, despite being under the CPA for a number of years. This illustrates a clear violation of the CPA good practice guidelines, which identify the importance of service user involvement in their care planning and ensures that care is reviewed regularly to encourage progress. If service users are not involved in their CPA, it limits the staff’s ability to monitor and maintain progress and increases the likelihood that service users with BPD will remain stuck in a pattern of repeated crises and use of crisis management.

A core theme identified in Fallon’s (2003) work was “travelling through the system,” which identified the journey through mental health services for individuals with BPD. Participants who were in the CPA identified progress and “moving on.” Service users in the current project, however, described the dialectic experience of progression versus consistency; there were high levels of frustration when they did not feel as though they were making progress, although if they felt they were “moving on” under the CPA pathway, there were high levels of anxiety and rejection related to the BPD-associated difficulties with abandonment in attachment relationships. The service users also commented on the promotion of the recovery model and the ambivalence associated with this; there was conflict between the long-standing difficulties associated with the BPD diagnosis and the idea of “recovering.” Service users believed this did not accurately represent a journey that was marked by progress and relapse (Fallon, 2003) over a substantial period of time.

As participants were recently moved to the specialist personality disorder service and it was identified as a discussion area, this inevitably emerged as a theme, particularly related to the previous theme of progression versus consistency. Moving to the specialist service raised the same anxieties of abandonment by services if moving onto a specialist service. They acknowledged the comfort of staying within a well-known team, despite their reported praise of the new service for adopting the CPA correctly and promoting high levels of service user involvement in care, which was a novel approach to most participants. Service users with BPD evidently require high levels of support when moving between or moving on from services so as to not activate abandonment schemas or feelings of rejection.
LIMITATIONS

Although it was a highly valuable experience for staff to be involved in the focus group discussions, it was acknowledged that it could potentially produce biases in the information given by service users. To ensure the impact of staff presence was as minimal as possible, the SPDS took a passive role in the focus groups and gave the lead role of facilitator to individuals independent of the SPDS.

Common to qualitative research, analysts were cautious of the subjective nature of the thematic analysis, particularly after being involved with the focus groups as co-facilitators. To ensure the thematic analysis was as objective as possible, interrater percentage agreement was used to assess reliability of themes.

RECOMMENDATIONS

The main recommendation to arise from the CPA focus group was ensuring service user involvement and collaboration. Service users repeatedly identified that staff made decisions about their care without consulting with the service user, which is inconsistent with the new personalization agenda adopted within the NHS. A key recommendation remains for staff to discuss their treatment/care plans with the service user and to take the user’s opinion into account. Another important recommendation is ensuring the service user is given some follow-up information after a CPA meeting. Finally, the process of changing services is inevitably a stressful time for any individual but particularly so for individuals who may have difficulties with abandonment or building new relationships. A key recommendation would be for a long-term handover period between services, with both services working collaboratively with the service user, until the service user has developed a strong therapeutic relationship with the new team/worker.

CONCLUSION

The available research on the experiences of individuals with BPD has failed to address their experiences of the CPA process, despite its implementation many years ago and its vital role in the care planning of individuals within community mental health teams. By exploring these experiences, recommendations can be accumulated and addressed, providing better facilities for service users. From the focus groups it has been concluded that a primary issue is staff attitudes and understanding toward individuals with the BPD diagnosis. Unfortunately, there is no rapid solution to improving staff attitudes, with changes likely to occur over time with improved knowledge of the disorder and its treatment (Cleary et al., 2002). Furthermore, adherence to the CPA process could improve staff-service user relationships in addition to facilitating person-centered care and promoting service user involvement in their care. A collaborative relationship between staff and service users could develop stronger connections between staff and a client group, which has had a historically tenuous relationship.

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The authors have disclosed no potential conflicts of interest, financial or otherwise. The authors thank the service users who took part in this study and Timothy Acton and Clare Cardy for supervising the study.

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Received: November 10, 2012
Accepted: May 10, 2013
Posted: July 12, 2013
doi:10.3928/02793695-20130628-03