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ORIGINAL PAPER

“It’s Us That Have to Deal with it Seven Days a Week”: Carers and Borderline Personality Disorder

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Abstract Carers provide unpaid support to family or friends with physical or mental health problems. This support may be within the domain of activities of daily living, such as personal care, or providing additional emotional support. While research has explored the carer experience within the National Health Service in the United Kingdom, it has not focused specifically on carers of individuals with a diagnosis of borderline personality disorder (BPD). Eight carers for those with a diagnosis of BPD were invited to take part in two focus groups. The first carers’ focus group, entitled ‘The role of Mental Health services,’ produced four super-ordinate themes. The second carers’ focus, entitled ‘Experiences in the Community,’ produced six super-ordinate themes. It seems carers of those with a diagnosis of BPD are continuing to be overlooked by mental health services, and subsequently require more support to ensure their own well-being.

Keywords Carer · Personality disorder · Thematic analysis · Qualitative research

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Introduction

Recent reports in the United Kingdom (UK) have exposed the neglectful treatment of individuals with a diagnosis of borderline personality disorder (BPD) (Crawford et al. 2007; NIMHE 2003; NICE 2009). BPD is characterised as experiencing great interpersonal difficulties and trouble managing emotions, making it difficult for individuals to sustain relationships. Subsequently, caring for individuals with BPD can be a very difficult and emotionally draining role to undertake. The Crawford et al. (2007) report highlighted the neglect of unpaid carers (family members or friends) of those with a diagnosis of BPD by mental health services. The report recognised the value of considering carers when managing their needs and the needs of the individual they are caring for.

The National Health Service (NHS) in the UK is based on the core principle that good healthcare is available free of charge to all residents in the UK. The NHS covers both physical and mental health, offering assessment and treatment by a range of professionals. Mental health Trusts within the NHS provide a range of mental health and social care services for individuals with a diagnosable mental health condition (known in the UK as service users).

Previous research exploring the experiences of carers of individuals with mental health problems is sparse, with few published articles reporting on their needs. Cleary et al. (2005) explored the information and resource needs of service users (any individual who uses mental health services) and carers. The study found that only one-third of carers were satisfied with their involvement in discharge planning, with a further 35 % of carers not being contacted or consulted regarding the discharge of the service user. This study highlights the neglect and dissatisfaction of carers, and the lack of communication between staff and carers.

Rees Jones et al. (2009) carried out a qualitative study on the service user and carer experience of mental health services, with particular regard to continuity of care. An interesting finding to emerge was the ‘invisibility and crisis’ theme. Carer participants felt mental health services were more likely to ignore service users ‘in crisis’ if they were aware that there was a carer available. Findings here warn against the potential for carer burn-out, as reduced involvement of staff in mental health services could increase the pressure on carers to provide more practical and emotional support.

A ‘crisis’ is a term often used to describe a time where individuals with BPD are more likely to experience chronic stressful events due to the nature of the diagnosis e.g. interpersonal difficulties. This combined with the person’s high emotional reactivity to such events makes it hard for people with BPD to manage the intensity of their emotions and return to a pre-crisis neutral emotional state (Linehan 1993). It is during crisis when individuals with BPD are more likely to engage in risky and parasuicidal behaviours, bringing them to the attention of mental health services. However, due to the stigma attached to the BPD label in mental health and emergency services (Rogers and Dunne 2011), service users are arguably more likely to rely on the support and assistance of carers when in crisis.

A series of focus groups held in Australia sought to explore the experiences of service users and carers engaging with mental health services (Goodwin and Happell 2007a, b). The reports highlighted the importance of nursing staff respecting carers and their needs, and the experience of negative attitudes from nursing staff towards carers. From the ‘communication’ theme it was evident that carers appreciated being involved when staff were discussing service user treatment plans, but still felt shut out by services despite playing an active role in the service users’ life. Carers also reported that developing relationships with nurses was important, as they valued a point of contact for advice and support.

Disappointingly, the studies investigating carers’ experiences and opinions were often written in conjunction with the experiences and opinions of service users. This reduced the much needed carer focus as research tended to explore carer needs with respect to the service user rather than in their own right. In addition, the reports were carried out with carers of those with mental health problems in general, without looking specifically at the carers of those with BPD. It seems that while those with a diagnosis of BPD have been neglected by mental health services historically, carers of those with a diagnosis of BPD are still being neglected and require some attention.

The Community Personality Disorder Service (CPDS) organised two focus groups for carers of service users with a diagnosis of BPD within the service. The first focus group aimed to explore carers’ experiences of the caring role, and the second focus group aimed to explore carers’ experiences of mental health and community services.

Method

The CPDS covers a rural county in England with a population of 2000 people with a diagnosable Personality Disorder, and is one of two specialist Personality Disorder services in the East of England. The CPDS was established to manage service users with a diagnosed Personality Disorder requiring more intensive input than generic community mental health care (known as Community Mental Health Teams in the UK) have the resources to provide. Community Mental Health Teams work with a spectrum of mental health diagnoses, and therefore lack the capacity to provide specialist intensive input for individuals diagnosed with BPD.

The CPDS set up two focus groups for carers of individuals under the care of the CPDS. The CPDS sought a facilitator with experience of caring for someone with BPD, to allow the CPDS to take a more passive role during the focus groups, hopefully reducing socially desirable responses from participants.

To ensure a range of issues would be covered, CPDS staff met with the carer facilitator to discuss appropriate topics and prompting questions to guide focus group discussions. Topics were grouped into two focus group themes: “The role of Mental Health services” and “Experiences in the Community”. Eight carers attended the first focus group, with five of the eight attending the second focus group. The group consisted of five males and three females (four partners, three parents and one sibling).

Prior to each focus group starting carers were asked to sign a consent form, enabling the CPDS to voice-record the focus group discussions and to publish information collected. Once both focus groups were over, the voice recordings were transcribed and then qualitatively analysed using thematic analysis (Braun and Clarke 2006). To ensure inter-rater reliability data analysts blindly cross-checked each others themes. A percentage agreement was then calculated, followed by the data analysts discussing each thematic analysis (to explore whether further agreement could be reached). The final percentage agreements were as follows: Focus group one: 81 % (originally) changed to 94 % (after discussion); Focus group two: 92 % (originally) changed to 100 % (after discussion).

Results

“The Carer’s Role Part 1: The Role of Mental Health Services” Themes

Carers’ Needs

One of the key super-ordinate themes to emerge from the first carers’ focus group was identified as carer’s needs. A core sub-theme considered the Personality Disorder diagnosis and how the majority of carers have had to research this diagnosis for themselves; “All I know about [borderline personality disorder] is reading a couple of books and what it says on the internet.”

Another very important aspect of Carers Needs concerns the official carers’ assessment. Unfortunately, carers expressed a lot of disappointing experiences with the carers’ assessment process: “I mean I’ve had a carer’s assessment which frankly was a waste of time because nothing came out of it at all.”

Discussions surrounding carers’ assessments logically led on to the topic of financial support. It seems a lot of carers are unsure of their entitlement to supportive funding and equally unclear over the financial assessment process: “It would be actually nice to know what if there was any financial help available because I certainly have never been told.”

A further sub-theme of Carers’ Needs considers how important it is for carers to look after themselves ‘as a person’ and not neglect themselves to the caring role: “I really feel it’s important for the service to recognise this, a lot of carers can become unwell themselves through being in this situation.”

Carers also felt that the stresses the caring role brings can be mediated by the option of respite. Certain carers expressed an interest in the option of respite, but were unclear over whether they would be granted it: “Yeah, that’s what I’m asking for in my carers assessment now that’s the kind of thing I want and I don’t know how that’s going to go.”

Another sub-theme extracted from the analysis process concerns carers’ groups. It was brought to the attention of the group that there appeared to be no carers’ group specific to Personality Disorder across the county: “I really would love to see a carers group or some facility for carers of people with [Personality Disorder] in this area.”

Care Programme Approach (CPA)

Carers reported a mixture of feedback when they were asked if they were aware of or had seen a copy of their cared for’s care plan. Some carers stated that they were aware of aspects of the care plan, yet others had never been informed or consulted regarding it.

There was a certain amount of disappointment held in regard to the CPA meetings themselves. Carers reported attending these meetings and experiencing unprofessional staff members, along with a fairly ‘tick box’ attitude to the process itself: “I also feel that quite often CPA’s are merely tick boxes … they’re not really listening to carers’ views.”

Mental Health Services

Another fairly broad theme taken from the qualitative data, concerns the issue of mental health services and their involvement in carers’ lives more generally.

Some carers claimed to have had some helpful encounters with staff members, easing the high demands of life as a carer: “I’ve been maybe lucky because my daughter’s key supporter has been very willing to engage with me.”

However carers reported more widely that they felt there was a lack of understanding by staff, particularly with regard to caring for service users with a personality disorder: “There’s been a lot of stigma and a lot of unhelpful comments about ‘it’s just behaviour’ which has been very, very difficult both for her and for us”.

Another sub-theme concerns mental health telephone help-lines, with a variety of opinions reported. These ranged from “They are more than happy to talk to you whenever about any concern” to “Why did I just call you just so you can make me deal with it, [it] seems just pointless.” However agreement was reached with reference to the need for more effective advice, particularly concerning ways of managing high-risk situations.

The Mental Health Services’ sub-theme concerning the Community Personality Disorder Service (CPDS), again, fuelled a lot of conversation between carers. The feedback offered was very encouraging of the service, as carers reported being considered in the treatment and management of their cared for: “Anytime I’ve phoned up [they’ve] been very helpful.”

Another sub-theme which came to light concerned how carers wish to receive more communication from mental health services. Carers expressed that they would still like to be more informed in order to manage situations and potential conflicts more effectively: “I still think we need to be involved more than what we have … It’s us that have to deal with it 7 days a week.”

The issue of crisis accommodation was also touched on throughout the focus group. One carer in particular expressed their concerns here, emphasising the need for some form of crisis accommodation for service users with a personality disorder: “What is so important is when a person is really in crisis and the family just cannot help, there needs to be a crisis base.”

The Service User and Carer Relationship

The final super-ordinate theme identified was the service user and carer relationship.

A key aspect of this theme concerned how carers very much wanted to be able to understand how the service user feels, but found this very difficult: “I always try to understand why she is feeling this way and she just can’t tell me she can’t tell me what the problem is.”

A central sub-theme here concerns how painful and stressful carers reported their relationships can be at times. Carers reported the prospect of ‘walking away’ to be very prominent in situations of over-whelming pain: "After her breakdown I walked away I just had, I couldn't, I was too shocked and too damaged."

Carers expressed concerns over how they should be most appropriately managing those they care for, how to handle certain situations, and who to turn to for this advice: "I wanted someone to tell me how to deal with it. I don't know how to deal with someone with mental health problems."

Carers commented on this ability to be able to cope with and manage situations effectively, and the impact this may have on their relationships with service users. One carer in particular mentioned how her involvement with a carers' support group had helped her significantly. She claimed the group had: "[It has] definitely made a difference between myself and my daughter, how I deal with stuff."

"The Carer's Role Part 2: Experiences in the Community" Themes

Support

One of the themes to emerge from the carer's second focus group was the issue of support, and the varying forms of support for carers. One carer spoke of the availability of on-line support; "They have it- a carer's forum that you can join. That's an on-line support", and a carer of a Personality Disorder support group in another county. Unfortunately the consensus was that carers were not aware of any support available, but agreed it was something they would appreciate.

Another issue around needing support was the need to have someone to turn to for advice; "It would be helpful to have, like, a carer worker or something, because I struggle with what the line between what is support and what enablement is."

Life Changing

Another theme to emerge from the focus group was that being a carer is life changing; carers spoke of the significant impact that becoming a carer had on their life style: "I don't think you're the same person in many ways that you were before".

One of the impacts was on the carers occupation- carers spoke of the caring role being a full-time role, and unlike professionals they had to manage the problems twenty-four/seven; "I don't think they realise we've gotta put up with situations for a whole week, say, before they get seen again". The full-time aspect of the caring role meant it limited their time available for work or leisure; "My leisure time is spent at home looking after [service user]."

Another recurring issue was the differential impact on lifestyle depending on whether the cared-for was a partner or a parent. When the cared-for was a partner there appeared to be an element of choice in the role taken on; "I've chosen that person and that's what comes with the baggage if you like." When the person being cared for was the carers' child they often felt like they went above and beyond the parent role; "I'm doing a lot more than a mum would do probably for another nineteen year old, that's how I look at it."

Finance

Finance was another theme to emerge from the focus group; carers spoke of the financial strain of not being able to work due to the caring role; "We've got less money coming in as I don't work… Even little things like visiting hospital."

Carers also reported the financial hindrance associated with BPD, with carers reporting the debts incurred by the person they care for; "She rung up a lot of debts before [we'd] got together … [We've] sorted it out. But I've had to do that all kind of for her".

Accessing Information

Linked in with financial difficulties was the theme of accessing information; carers felt that mental health services did not provide carers with enough information on services available for carers. Furthermore most of the carers had not had, or been made unaware of, the carer's assessment; "I dunno, I've never really- not had (a carers assessment) so I can't say if it would work or not."

Professionals' Awareness of Carers

A key theme to emerge was the professionals' awareness of carers: "I find the system also has no idea what a carer is." Staff seem to be ignorant to the stressful role of the carer; "There just doesn't seem to be the thinking of well, how is it affecting the carer? And the support for them."

Carers also felt they were overlooked and un-involved by mental health professionals, despite the high levels of involvement they had in the service user's life. Carers spoke of being ignored by staff; "you're kind of snubbed [by professionals] in a way. That really hurts, 'cause you're at home cleaning, washing, cooking."

Understanding Personality Disorder

Understanding personality disorder was another major theme to emerge from the focus group, with carers experiencing a lack of understanding by family and friends, as well as the wider public.

It seemed carers particularly struggled when family and friends did not understand Personality Disorder; "So often family can't understand so even if you're close to your own family, it's very difficult."

Another sub-theme was the understanding of the wider public, and how Personality Disorder and mental health in general is presented to the public in the media, e.g. soap operas; "They did some on [borderline personality disorder] and that's the first time I'd ever seen that diagnosis on the media. Some of it was good, but some of it was very scary."

Discussion

Carers highlighted the difficulties associated with treating and managing Personality Disorders further by reiterating the naïve attitudes mental health professionals and GP's still hold regarding the diagnosis. Past research findings in Australia have also brought to light the unhelpful and damaging impact these negative staff attitudes can have on carers (Goodwin and Happell 2007a). Efforts need to be invested in educating and training staff on how to not only treat service users with Personality Disorders respectfully, but also on how to involve and value their carers.

This idea needs to extend particularly to the matter of service user crisis management. The general group consensus was that carers were not receiving enough support with their responsibilities until a crisis had occurred with the service user. There was even the feeling that, as a carer, if one appeared to be coping 'too well' then support and services would withdraw even more. These findings were not uncommon to those found in past literature considering mental health problems more generally. Previous research reinforces this notion of professional involvement reducing due to an over-reliance on the carer (Rees Jones et al. 2009), increasing the likelihood of burn-out and once again neglecting the well-being of the carer.

Findings also demonstrated that carers were generally not aware of available support and services for themselves, and had received disappointingly insufficient information on the Personality Disorder diagnosis. This is similar to those presented from an Australian carers' focus group, which reported carers often felt they had not received comprehensive enough information regarding the care of service users (Goodwin and Happell 2007b). Another key theme to emerge from the focus groups involved professionals' awareness of carers, in terms of the disregarding of the significance of the carer role for this client group. This lack of understanding regarding carers of service users with a Personality Disorder was highlighted in the innovative Crawford report (Crawford et al. 2007) and is reflected further in the lack of research available.

Carers next identified the requirement for a better system of communication between these services and carers of those with a Personality Disorder. The significance here was placed on carers not feeling informed with regard to the progress service users were making with their treatment. This concept is supported by earlier research, which recognised carers are often not consulted or considered with the service user's care plan—particularly concerning the discharge process from inpatient units (Cleary et al. 2005). Research conducted in Australia reinforces the importance of this involvement, as it revealed carers very much appreciated feeling involved and consulted with when staff discussed treatment plans (Goodwin and Happell 2007a).

Limitations

The carer focus groups were an extremely innovative and powerful event to be a part of. It was clear that carers were extremely passionate about their caring roles made all the more evident in vented frustrations involving the lack of communication and support they have traditionally received from mental health services. This common notion of carers being disregarded appeared to bring the focus groups closer together in terms of validating and identifying with each others' experiences. The unanticipated contributions offered by the focus group facilitator (carer representative) were even more encouraging, as this highlighted the powerful and emotive subject nature of the topics that were being discussed.

Despite the importance of the carer's well-being being central to the organisation of these focus groups, it was however noticed that carers would often revert back to talking about service user needs significantly more than those of their own. Though the service user was clearly a key reason why carers attended the focus groups, active effort would be required at times in order to get participants talking more about themselves as people and the needs of their own.

A disadvantage in the organisational approach of the focus groups involved the inclusion of participating carers. It was recognised that carers particularly from the east and outskirts of the county were fairly under-represented, due to transport difficulties. Another possible contribution to the relatively limited participant turnout can be rooted back to carer responsibilities and the inability for carers to find the time to attend.

Although there were a limited number of participants involved in the study, due to the qualitative nature of the research the emphasis was to focus on the phenomenological experience of the carers rather than the generalisability of the findings. The reduced sample size is typical of qualitative research and offers rich contextual data that is often lost in quantitative studies.

Upon reflecting on the focus groups further, it would be necessary to comment on the impact of the CPDS in organising these groups particularly in terms of potential biases. An active decision was therefore taken to exclude CPDS staff members from facilitating the groups, while also encouraging each focus group to share experiences across a variety of mental health services (i.e. not just the CPDS).

When it came to qualitatively analysing each focus group transcript, potential biases were also anticipated. This was particularly as the assistant psychologists (analysts and authors) of the CPDS may have perhaps been more biased in their empathy towards the ill treatment of service users and carers, who identify with BPD, by mental health services. This was tackled by utilising inter-rater reliability ratings (see "Method") and seeking expert advice on qualitative analysis.

Conclusions

The powerful opinions and suggestions that were offered at each focus group will not only inform effective practices within the CPDS, but will help raise awareness of the carer experience with this client group more generally across mental health services. These recommendations can also stretch and influence further afield, aiding other Personality Disorder specialist services when considering how to ensure the mental well-being of the often silent carer. Qualitative research is frequently employed as a methodology for innovative research areas, providing rich data to generate quantitative research questions. Future research would benefit from expanding upon these findings to explore whether they are a common experience of other carers of individuals with BPD.

It remains clear that there is a lack of specific research with this select group of carers. Further research would not only raise awareness, but also encourage action among traditionally neglectful mental health services.

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