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Abstract

Background: Research has shown that receiving a psychiatric diagnosis can have both positive and negative consequences for people. The way in which diagnoses are imparted is an under-researched area and may play an important role in reducing stigma and aiding recovery.

Aims: The aim of the present study was to get an in-depth understanding of service users' experience of receiving a diagnosis of bipolar disorder.

Methods: Nine service users recently diagnosed with bipolar disorder were interviewed using a semi-structured interview schedule designed to elicit information regarding the positive and negative aspects of receiving their diagnosis. All transcripts were analysed using Interpretative Phenomenological Analysis (IPA).

Findings: The findings can be described in terms of three master themes: 1. 'Perceived fit between diagnosis and lived experience', 2. 'Evaluating the utility of carrying the diagnostic label' and 3. 'The role of diagnosis in searching for solutions to one's difficulties'.

Conclusion: This study draws attention to the importance of evaluating the fit between diagnosis and personal experiences and to the relevance of perceived stigma. The findings also highlight the significance of the client-clinician relationship in establishing fit and instilling hope, which has implications for the acceptance of the diagnosis and engagement with services.

Declaration of interest: None.

Keywords: *Bipolar disorder, psychiatric diagnosis, service user perspective, qualitative research, IPA.*

1. Background

Mental health difficulties are usually categorised into diagnoses using either the Diagnostic and Statistical Manual of Mental Disorders or the International Statistical Classification of Diseases and Related Health Problems. Having a common diagnostic framework can be advantageous as it helps to promote consistency and objectivity in clinical practice, reduce treatment idiosyncrasies and increase diagnostic agreement between clinicians (Jablensky, 2012). However, a concern often raised is how mental health diagnoses have been used to label and control people whose behaviour is considered outside the norms of a given society or culture (Kutchins and Kirk, 1997; Sharkey, 1994). Kutchins and Kirk (1997) also highlight the difficulties in distinguishing non-pathological distress from disordered distress, especially where there is an overemphasis on focusing on symptoms and ignoring context.

Research has highlighted both positive and negative consequences of receiving a psychiatric diagnosis. Positively, diagnosis can help service users to get a better understanding of their experiences (Perkins et al., 2018) and facilitate engagement with services (Jutel, 2009). Furthermore, receiving a psychiatric diagnosis can, according to Brody and Waters (1980), be regarded as therapeutic in its own right. According to Hayne (2003), a diagnosis can provide a sense of validation and relief by ascribing an individual's symptoms to an independent disease entity and Pitt et al. (2009) found that receiving a diagnosis can reduce feelings of shame by externalising one's difficulties. With regard to the recovery process, having a psychiatric diagnosis can help by providing a focus for treatment (Hayne, 2003), while accepting a diagnosis can lead to better adjustment (Dinos et al., 2004).

In terms of negative aspects, diagnosis can in some instances result in people being denied access to services (Schulte and Holland, 2008). Studies have also found that diagnosis can have a stigmatising effect on the individual. Research suggests that diagnoses are often accompanied by both feelings of stigma and overt experiences of discrimination (Hayward and

Bright, 1997). As an example, Hayne (2003) describe how some participants struggled to see themselves represented by the diagnostic label, while Dinos et al. (2004) found that disclosing one's diagnosis often led to experiences of overt discrimination. In addition, studies have shown that stigma can have a negative effect on self-esteem (Lysaker et al., 2008), contribute to social isolation (Goffman, 1963), result in a reluctance to engage with mental health services (Holmes & River, 1998; Dinos et al., 2004) and lead to premature discontinuation of therapy (Camp et al 2002). As such, diagnosis may therefore negatively affect the recovery process, in particular for diagnoses with poor prognoses (O'Connor, 2018).

The way in which diagnoses are imparted may play an important role in the recovery process. Findings indicate that receiving a diagnosis can be experienced positively as a way of confirming and legitimising personal experiences (Hayne, 2003), by providing a sense of hope and possibility for change (Horn et al., 2007) and as a way of facilitating access to treatment, support and understanding (Pitt et al., 2009). Conversely, receiving a diagnosis can also be experienced negatively as a way of labelling personal experiences as illness (Hayne, 2003) and causing feelings of rejection or disempowerment (Horn et al., 2007). These findings suggest that there is a great deal of overlap between different disorders in terms of the experience of receiving a diagnosis. However, it is also evident that each diagnosis brings about its own set of challenges. As an example, Horn et al. (2007) reported that participants who received a diagnosis of BPD sometimes experience the diagnosis as a rejection from services, a theme not echoed in the studies by Hayne et al. (2003) or Pitt et al. (2009). With regards to bipolar disorder, research suggests that there may be particular challenges in relation to endorsing this diagnosis because of the shame associated with certain symptoms (Lam et al., 1999) and the challenges in maintaining a coherent sense of self due to changeable mood (Inder et al., 2010).

Consequently, this study focused specifically on *one* diagnosis, namely bipolar disorder. As this is an under-research area, a qualitative methodology was adopted. The aims were to investigate the subjective experience of receiving a psychiatric diagnosis, to compare the findings with studies on other diagnoses, to assist clinicians who are imparting diagnoses and ultimately to improve experiences for service users.

2. Method

2.1. Design

Nine semi-structured interviews were conducted and analysed using IPA (Smith & Osborn, 2003; Smith, 2007; Smith et al. 2009). IPA was chosen as it provides a flexible approach to research that puts the participants' subjective experience at the centre of the research process whilst allowing complex and novel information to emerge. A double hermeneutics methodology (Smith & Osborn 2003) was adopted that acknowledged the findings as the researcher's own interpretation of the participants' interpretation of their subjective experiences. The researcher's identified views around diagnoses were that they provide a useful framework for developing a shared understanding of psychological difficulties, but that they should be used sensitively and as a guide, rather than an absolute truth.

2.2. Procedure for Data Collection

2.2.1. Participant Recruitment

In keeping with IPA sampling requirements, a small purposive sample of nine service users with a recent diagnosis of bipolar disorder took part in this study. The recency by which the diagnosis was imparted was deemed important as this study focused specifically on the experience of receiving a diagnosis. All participants were aged 18 or above and recruited

through Community Mental Health Teams in London by members of their mental health team. Participants were given information about the study and gave informed consent prior to participation. The interviews lasted between 22 and 49 minutes and were recorded using a Dictaphone. From the interviews nine individual verbatim transcripts were produced, which formed the basis for the analysis.

2.2.2. Interview Schedule

A semi-structured interview schedule was developed based on relevant findings from the literature (Hayne et al., 2003; Horn et al., 2007; Pitt et al., 2009) and published guidelines on devising interview schedules (Smith & Osborn, 2003; Smith, 2007; Smith 2009; Charmaz, 2006). Questions were designed to be neutral, non-leading and without jargon. Initial questions were followed by prompts to encourage elaboration, while funnelling was used to further explore unexpected areas in more depth. An example of an interview question was: '*Can you tell me about your experience of receiving a diagnosis of bipolar disorder?*', followed by prompts such as: '*Were there any particular positive or negative aspects you could tell me about?*'. The schedule was used flexibly, in order to allow unanticipated areas to emerge and was refined re-iteratively by incorporating novel areas from initial interviews into subsequent interview schedules.

2.3. Procedure for Data Analysis (IPA)

The data was analysed using IPA based on guidelines from Smith & Osborn (2003), Smith (2007) and Smith et al. (2009) and guidelines for ensuring quality in qualitative research (Morse at al., 2002). In accordance with IPA's commitment to ideography, each interview was subject to a detailed individual analysis before themes were examined across transcripts (Smith et al. 2009). This included listening to each recording and reading each transcript several times,

while making initial annotations in line with the concept of free text analysis (Smith et al., 2009). The transcripts were then re-read, noting emerging themes within each account by drawing on both the transcripts themselves and the initial annotations. This was followed by identifying clusters of related themes within each transcript. The next stage involved identifying patterns across transcripts and developing higher order themes, which were abstract enough to capture shared experiences among the participants, while at the same time remaining grounded in the ideography of the individual's experience. The narrative account provided in the findings is based on the table of master themes (Table 1) and supported by verbatim extracts from the transcripts. Finally, the trustworthiness and face validity of the findings were enhanced through comparative analysis carried out by an independent researcher and through feedback from participants, which broadly supported the findings as illustrated by the quote below.

“Yeah it does, it really does. You’ve hit the nail on the head. You’ve got the main three reactions to receiving the diagnosis.” (P2).

2.4. Ethical Considerations

Ethical approval was obtained by NRES Committee London-Surrey Borders on 09/11/11. Participants were assured that any information they provided would not be linked to them in any way and would only be used for the purpose stated in the participant information sheet. In addition, all major identifying details were removed and replaced with pseudonyms where appropriate. After the interview, each participant was offered access to psycho-education and/or sign-posting.

3. Findings

3.1. Sample

Demographic information is provided below in order to contextualise the qualitative findings. In summary, seven women and two men with a mean age 38.3 years (range 26 to 45 years) and a mean length of time since diagnosis of 17 weeks (range 1-47 weeks) took part in this study. Three participants had received a diagnosis of bipolar 1, five had received a bipolar 2 diagnosis and one participant had received a diagnosis of bipolar other (rapid cycling). Seven participants identified themselves as White British, one as Black British and one as African. Seven participants were in full-time employment and two were unemployed. Eight participants were on medication, two participants were receiving psychological therapy, while one was waiting to start therapy.

3.2. Qualitative Findings

The findings can be described in terms of three master themes (table 2): 1. 'Perceived fit between meaning of diagnosis and lived experience', 2. 'Evaluating the utility of carrying the diagnostic label' and 3. 'The role of diagnosis in searching for solutions for one's difficulties'.

(Table 1 about here)

Master Theme 1: Perceived fit between diagnosis and lived experience

This master theme described how well participants felt the diagnostic label fitted their subjective experiences. For some participants, this was a process that occurred gradually over time, while for others, receiving the diagnosis was a way of confirming what they already

suspected. A good fit was often experienced as ‘making sense’ or fitting with participants’ prior knowledge about the condition.

“What he was saying was exactly what I was experiencing and actually yeah, from that point of view it’s a huge relief.” (P3, 193).

Establishing a good fit also appeared to be influenced by the quality of the therapeutic relationship. Experiencing a good relationship with the diagnosing clinician was for some participants important in order to begin the process of accepting the diagnosis and engaging with services.

“...they spoke to me very much on a level and there was no kind of pussyfooting around the issue. It’s like, okay, this is probably what it is. And it was yes, I thought like it was a two-way process, like they were asking me genuine questions and I could...I mean we’re kind of working together towards finding a treatment and it’s...and a plan that was going to work...” (P2, 89).

“The psychiatrist was listening, he extended the appointment time even though he had someone else waiting cause he wanted to hear it. That’s how it felt. Much more concerned with what he was hearing from me, so yeah, just a complete different experience...just more questions and a sense of understanding and it was almost like a bedside manner, it was just how he was, it made it a completely different experience.” (P9, 55).

Apart from making the experience better for service users, the quotes illustrate how a positive therapeutic relationship facilitate a mutual understanding, cooperation and a sense of

being listened to, which are all-important pre-conditions for a fit between the diagnosis and personal experiences to occur.

A rejection of the diagnostic label appeared to be more likely to occur when descriptions of the symptoms did not fit with participants' personal experiences and symptoms. A poor fit seemed to occur particularly if participants associated having bipolar disorder with being dangerous or if they did not identify with the symptoms of mania as described by the diagnosing clinician.

“So when they, when they actually diagnosed me I just thought there is no way, there is no way that I can have this you know because like I said I mean I was there first hand and he had destroyed the place we were living in you know... so... Yeah, because I have only seen bipolar, the manic side of bipolar in a really destructive way and I knew that I wasn't destructive.” (P4, 62).

In addition, when a sufficiently positive therapeutic relationship was not established, moving towards a mutual understanding was less likely to occur.

“I didn't gel with her and I didn't feel anything with her. She didn't encourage me, she didn't offer me anything. I would ask her a lot of questions, she would give me a lot of answers but it just didn't feel like we were getting anywhere, I just feel like, I didn't feel she was helping me, I felt even worse after seeing her or I wouldn't feel anything, you know. So I didn't feel that she helped.” (P7, 326).

Participants were also less likely to endorse the diagnostic label if they felt unable to open up to the clinician to develop a mutual understanding of their difficulties.

“It was more of a clinical environment. Dr. [Name of psychiatrist] was there. She is a... Dr. [Name of Psychiatrist] is a lovely lady, as you know, but she is a lovely person and [name of social worker] is a lovely guy, I know, but it was quite clinical and I didn't really get a chance to sort of open up in a way that I would have liked possibly.” (P5, 201).

The potential for establishing a good fit also appeared to be negatively influenced by contextual factors such as, short and infrequent sessions.

“...more time would help because at the end of the day, if you see me now for thirty minutes, the idea you would have of me would probably be different... because it is not enough.” (P1, 146).

“I have only seen him four, five times in the last seven years, so it's not been really an understanding if you see what I mean...” (P8, 383).

Master Theme 2: Evaluating the utility of carrying the diagnostic label

The second master theme concerned participants' perception of the utility of carrying the diagnostic label. It appeared to involve thinking about how useful having a diagnosis of bipolar disorder would be both in terms of an internal understanding of their difficulties but also in terms of the explanatory utility of the diagnosis when considering disclosure to friends, family and colleagues. Diagnosis was perceived both as legitimising, leading to a readiness to disclose to others as well as stigmatising, leading to a reluctance to disclose the diagnosis to others. With regard to positive aspects, participants spoke of how a diagnosis had helped them to develop a better understanding of their difficulties and to become more compassionate towards

themselves but also how the diagnosis had provided them with a helpful framework for explaining and legitimising certain symptoms or behaviours to others.

“Yeah, it could explain them. It wasn’t that I was just a grumpy person sort of thing...there was actually a chemical imbalance in my brain and you know that depression, mental illness is an illness and you can’t help it...” (P6, 340).

In terms of negative consequences, participants spoke about perceived stigma and fears of being judged or discriminated against at work as a result of disclosing their diagnosis.

“I mean obviously from my point of view I wouldn’t have liked for it to go down on my record if I had mental health issues stamped on my public record as a result of it.” (P3, 242).

Master Theme 3: The role of diagnosis in searching for solutions to one’s difficulties

The final master theme represented participants’ desire to find solutions following diagnosis. This process involved searching for medical and psychological treatments. Diagnosis was experienced both as empowering as well as disempowering. A sense of empowerment appeared to occur when diagnosis helped to name and accurately identify subjective difficulties and challenges while instilling hope and tangible solutions. This experience was characterised by a sense of agency and control over one’s difficulties.

“Yeah I can think about medication, I know I need to avoid people stressing me cause when they’re stressing me I get hyper.” (P1, 310).

For some participants, staying engaged with services was key part of feeling empowered and moving forward.

“...without that diagnosis you are nowhere ‘cause you are stuck, you are stuck without a diagnosis, you are not getting no help, no support and it can go on for years and years.” (P8, 464)

Other participants talked about feeling disempowered, as exemplified by feeling a lack of control over symptoms, worrying about becoming dependent on help and medication as well as worrying about the impact of medication and on losing certain aspects of their personality.

“...at the moment I just feel like a guinea pig to be honest, this is how I feel and to start a new medication you know eh, I don’t know what the effect this new drug is gonna have on me, I really don’t know.” (P8, 293)

“...he (clinician) had said something about my husband being a carer... He is not my carer. Why would you say that he is my carer? You know because in my head, a carer is somebody who pushes a wheelchair around you know and it really angered me that he was calling my husband a carer.” (P4, 229).

4. Discussion

The findings from this study describe how participants report their experiences of receiving a psychiatric diagnosis as both positive and negative, supporting previous studies (Pitt, 2009; Horn, 2007; Haynes, 2003). In addition, novel findings are also presented, which can be used to further inform clinical practice in this area.

The first master theme ('fit') relates to how well (and how poorly) participants felt the diagnosis fitted with their own experiences of their difficulties, echoing previous research on personality disorders (Horn et al, 2007). The importance of establishing fit appeared to be particularly salient for this client group, perhaps due to the average time from onset to a diagnosis of bipolar disorder being more than ten years (Berk et al. 2007). A new finding from this study is the importance of establishing fit prior to starting the process of accepting the diagnosis. In addition, this study highlights the central role of the therapeutic relationship to begin the process of establishing fit. In particular, participants emphasised the need to develop a mutual understanding of the presenting difficulties. This is consistent with findings by Rose (2001) that suggest that when the process of deciding a diagnosis was considered as one of negotiation, the person was more satisfied with their overall care.

The second master theme ('utility') was concerned with participants' perception of the usefulness of having a diagnosis of bipolar disorder. Consistent with other studies (Hayne 2003; Pitt 2009), participants spoke about positive (or legitimising) aspects, where diagnosis was seen as a helpful explanatory framework that could lead to a better understanding of oneself. They also spoke about stigmatising aspects, specifically about perceived stigma and fears of being judged or discriminated against as a result of disclosing their diagnosis. Finally, participants spoke of self-stigma, specifically in relation to how receiving a diagnosis had caused them to adopt a negative view of themselves as weak, dangerous or 'crazy'.

One of the main differences between the findings from this study and previous studies on other diagnoses (Pitt, 2009; Hayne 2003; and Horn, 2007) was that participants in this study rarely reported actual experiences of stigma. This may be a result of how bipolar disorder is viewed in society. Many participants spoke about the positive influences of the media, especially of celebrities being open about having the disorder and of the perceived glorification of the manic side of bipolar in certain areas of society. Another explanation for the low levels

of actual stigma reported in this study, could also be a consequence of participants only having had the diagnosis for a relatively short time, and in some cases not having disclosed it to many people and therefore not having been exposed to many situations in which stigma might occur.

The third master theme ('solutions') emerged as a consequence of participants searching for solutions to their difficulties, which was experienced as either empowering or disempowering. A good fit led to a sense of agency, control and hope about improvement, motivating participants to stay engaged with services. Conversely, feeling disempowered was associated with fears of losing control or becoming dependent on medication and mental health services. Many participants highlighted the importance of collaboration and being given clear information as key factors in order to gain a sense of control and agency.

4.1 Clinical Implications

Having a good client-clinician relationship emerged as an important factor in beginning the process of establishing a potential fit between the diagnosis and personal experiences, which in turn, according to Hawke et al (2013), can increase the likelihood of continuing engagement with services. Participants who did not feel that the diagnosis provided them with an accurate or acceptable explanation for their difficulties often commented on sessions being too short or too infrequent to enable them to establish a trusting relationship where they felt able to open up about their experiences. Thus, having sufficient time to establish a good therapeutic relationship is crucial. The findings also suggest that addressing stigma is important. Helpful practices could include using externalisation and normalisation to reduce blame and guilt while instilling a sense of hope that the diagnosis could be a positive aid to recovery. Finally, it is also important that information is provided as clearly and unambiguously as possible, to reduce any misconceptions people may have about the diagnosis and treatment.

4.2. Strengths and Weaknesses

IPA provided a flexible and sensitive framework that allowed for novel areas to emerge. One of the strengths of this piece of research was that participants were recently diagnosed, which is likely to have been a key factor in the richness and detail with which participants could recollect their experiences. Furthermore, as recommended by Smith et al. (2009), this study benefited from having a relatively small sample size, which allowed for an in-depth analysis where the voices of all participants were heard.

In terms of weaknesses, it is possible that the sample was slightly biased towards people who have had positive experiences of receiving a diagnosis. Most participants either fully or partially endorsed the diagnosis. This could be a result of a selection bias by local clinicians towards service users who endorsed the diagnosis they had received. However, in recruiting, efforts were made to emphasise that the aim of the study was about people's experience (both positive and negative) of being given a diagnosis of bipolar disorder regardless of the perceived accuracy of the diagnosis.

4.3. Suggestions for Future Research

This is a small study with novel findings. A larger quantitative study, investigating the impact of diagnosis of bipolar with a more representative sample would be interesting. In addition, the therapeutic relationship is vastly under-researched in relation to how diagnosis is imparted, and future research would undoubtedly benefit from exploring this further. As this type of research relies mainly on the subjective experience of the participants, future research may also benefit from inviting 'experts by experience' to have a more formal role in developing the interview schedule, analysing the data and co-authoring the paper.

4.4. Conclusion

Receiving a diagnosis of bipolar disorder can lead to both positive and negative experiences. The findings from this study suggest that service users were less likely to experience stigma or reject the diagnosis if a trusting therapeutic relationship is established in which diagnosis is a negotiated process and information is clearly given. This, in turn, appeared to increase service users' feelings of empowerment and their willingness to engage with services.

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