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ORIGINAL PAPER

Experiences of Mental Healthcare Reported by Individuals Diagnosed with Bipolar Disorder: An Italian Qualitative Study

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Abstract

This qualitative study explores experiences of mental health care by nine Italian users with a diagnosis of bipolar disorder. The findings from semi-structured interviews carried by professional researchers highlighted the following themes: mixed feelings about the diagnosis; lack of access to psychological interventions despite preferences of users; positive view of peer support, job as a safe haven, traumatic experiences of compulsory hospital admissions; need for crisis interventions as alternative to hospital admission. Most users' views look in accordance with evidence-based recommendations seldom implemented in practice. Future research directions, implications of users' expectations and experiences for service planning and quality improvement, are presented and discussed in the light of the qualitative available literature.

Keywords Bipolar disorder · Qualitative research · Mental health care · Psychosocial interventions · Italy · Users' view

Introduction

In last years a number of countries endorsed policies promoting user participation in various aspects of mental health care with increasing emphasis on the need to involve service users in decisions that concern them and to give greater weight to their preferences (National Institute for Health and Clinical Excellence 2011).

The users experience is recognized as an important factor in fostering excellence and recovery-oriented attitudes in mental healthcare, through better identification of their priorities (Thornicroft and Tansella 2005). Perspectives and views of individuals who use mental health services are relevant drivers of change in the system by offering insights into unmet needs and factors that can impact on the course of disorders. A bottom up approach to research, in which service users draw on their own experiential knowledge is now a legitimate focus of service-based studies (Wallcraft 2012), to better understand the feasibility, acceptability and impact of care delivery models, the potential facilitators and barriers to user engagement, and ways to improve service provision.

Although the available studies reflect the views of individuals with a broad range of mental disorders, few focused on people with a diagnosis of bipolar disorder (BD). Some studies explored the concept of recovery in BD (Mansell et al. 2010; Veseth et al. 2012; Perlick et al. 2001), examined the relation between peoples' own experiences and the impact of the disorder upon quality of life (Michalak et al. 2006), considered the impact of BD on the development of self and identity within a psychosocial developmental framework (Inder et al. 2008). In a large-scale study of the concept of "staying well", Russell and Browne (2005) concluded that the meaning of this term for people with BD varied, ranging from being asymptomatic and behaving "normally", to being able to take control of their lives and to separate themselves from their diagnostic label. Overall, few accounts of the subjective care experiences of this user groups are

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available and there is therefore a need to fill this knowledge gap (Seal et al. 2008).

This study aimed to explore the experiences of mental health care in a sample of Italian adults with BD, to gain a broad understanding of their expectations, views and evaluations of key aspects of services received.

Methods

We adopted a qualitative design based on material collected through semi-structured interviews with nine individuals with a diagnosis of BD.

Interview Process

Two researchers (MV and FR) defined the interview process and one of them (MV) conducted all the interviews. The structure of the interview did not follow fixed questions and the approach was flexible to allow adaptation to the subjective narrative style of each person. To begin the process, the interview started with open-ended questions about the individuals' first contact with mental health services or private mental health professionals. This format enabled participants to discuss their experiences according to their own agenda and was aimed at empowering participants to talk about what they felt most relevant. The interviews were conducted in a community mental health center.

The contents of the interview were chosen by the research team in the light of the recent literature on quality of care from services users perspective (Skelly et al. 2013; Wallcraft 2012; Barbato et al 2014). To investigate the relationship between people with BD and services four main topics have been addressed:

1. The individuals' relationship with mental health services or private clinicians. This considered the subjective experiences of care and their impact upon the participants (Proudfoot et al. 2009);
2. The impact of the illness on individuals' life and the involvement of family members (Pompili et al. 2014);
3. Psychosocial factors influencing the individuals' recovery process (Mansell et al. 2010);
4. Factors influencing access to care; suggestions, preferences and wishes for improvements of the care system to better meet the needs of individuals with BD (Barbato et al. 2016).

The interviews lasted approximately 60 min and were recorded (with consent) and transcribed verbatim, producing 78 pages for the analysis. Notes were taken during the interviews.

Thematic Analysis

Interviews were read by two researchers (MV and FR) who conducted the analysis. The discourse was coded and organized in a text document according to the themes.

In accordance with the thematic analysis methodology (Attride-Stirling 2001; Joffe and Yardley 2004), data analysis followed a process, in which the researchers read the transcripts carefully and systematically identified themes and subthemes that were associated focusing on the subjective experience of the interviewees. The researchers then had two analysis sessions in which they shared their preliminary thoughts and findings, discussed the thematic network and produced a synthesis document. Later, two other researchers joined the team and commented the analysis document. Finally, the data were interpreted and findings were reported as an outcome of a joint analysis process.

For the purposes of this study, a theme is defined as "a pattern found in the information that at minimum describes and organizes possible observations and at maximum interprets aspects of the phenomenon" (Boyatzis 1998). Dialogues were analyzed to determine the frequency of certain remarks, whilst respecting the wide range of perspectives and experiences reported. The data analysis procedure was as described by Veseth et al. (2013) and Crowe et al. (2015) and can be summarized in the following steps:

1. Reading of the transcripts to get an overall sense of the participants' experiences and of pathways of care identified as being important in promoting recovery;
2. Identification of units of meaning representing different aspects of the participants' experiences;
3. Development of codes for each unit of meaning;
4. Interpretation and labeling of meanings within coded groups of text
5. Organization of the coded meaning units in overarching patterns, summarizing the emerged themes;
6. AB identified primary themes and the first transcript was coded independently by another researcher (BD), who checked the accuracy of material identified. Discrepancies were resolved by consensus among researchers.

Setting

This study was carried out in the Community Mental Health Service of the Department of Mental Health of San Carlo Hospital Trust in Milan, Italy within the framework the ENBREC (European Network of Bipolar Research Expert Centers), a project funded by the European Union to foster collaboration among centers with expertise in the

clinical management of and research in BD (Henry et al. 2013), as part of an investigation on implementation of psychoeducation in mainstream mental health care.

Participants

Individuals were included if they fulfilled the following inclusion criteria: ≥ 18 years old, diagnosis of BD according to ICD-10 criteria corresponding to the code F31; 2 years or more of treatment by any mental health service. Exclusion criteria were: being in an acute illness episode, mental retardation. Participants were not paid for being interviewed.

In the framework of the ENBREC project a 1 year psychoeducation program was conducted in the community mental health service of the San Carlo Hospital Trust. Four groups consisting of 12 sessions held every 2 weeks were set up including a total of 43 people. The 24 participants of the last two groups were informed about this study and five of them expressed their interest to participate. At the same time online advertisements on the website of the RUL (Reti Utenti Lombardia, the Lombardy mental health users network) was posted and four more people were identified.

We continued recruiting and analysis until new themes emerged from interviews and theoretical saturation was reached as suggested by qualitative methodology (Trotter 2012).

Procedures

Potential participants received information about the study by telephone. Written informed consent was obtained prior to the interview by people agreeing to participate. Sociodemographic and clinical characteristics were recorded through a brief written form.

A clinical psychologist undertook 60 min individual video-recorded interviews between February and September 2015. Participants chose the location which would enable them to feel most comfortable. To maintain confidentiality, the names of participants or any identifying information were removed from the transcripts before any extracts were presented to the researchers.

The study was approved by the Ethics Review Board of the University of Pavia.

Results

Study Sample

Participants had a mean age of 46.2 years (SD = 6.6), ranging from 37 to 56. Five participants had a high school degree, three had a university degree and one had a professional diploma. Five participants were single, two were divorced and two were married; two participants had one or more children. Seven out of nine were fulltime (n = 3) or part-time (n = 4) employed and two did not work, receiving a disability pension. The mean duration of illness was 25.1 years (SD = 8.6), with first symptoms occurring between 16 and 40 years. With one exception, all participants reported at least three lifetime hospital admissions.

Core Themes

Five main themes emerged from the interviews: (1) Mixed feelings about the diagnosis; (2) Role of psychological interventions; (3) Job as a safe haven; (4) Relationship with clinicians; (5) Hospital admissions.

Theme 1: Mixed Feelings About the Diagnosis

The experience of receiving the diagnosis elicited feelings of both confusion and relief in most participants. The communication of the diagnosis was described as a critical moment and many participants stated that the communication of diagnosis was not accompanied by meaningful information. For some people the failure of diagnostic labels to give a meaning to subjective distress was perceived as puzzling.

> When the doctor told me about bipolar disorders I could simply recognize all the symptoms. I was sort of shocked and relieved at the same time: I could put a name to what I was going through.

Five participants highlighted the importance of involving family members during acute illness episodes, because they were unable to understand completely what was happening to them or absorb the provided information.

> When the doctor started to write down a long list of medications and all the instructions for starting the procedure for disability pension... I could not understand a word. I could see only his mouth moving fast, and my thoughts were so slow… it was like a silent movie… I would have given everything to have someone from my family… sitting close to me helping to understand what was happening!

Diagnostic terms as ‘hypomania’ were viewed as difficult to understand, a sort of ‘empty word’, without a clear meaning. Some were not informed about the treatment implications of their diagnosis and felt that diagnostic terms were not useful to describe their experiences.

> I took medication regularly and the quality of my sleep improved quickly, but lithium cannot do anything with the sense of shame, embarrassment and frustration.

Delay in diagnosis or misdiagnosis emerged as a relevant theme. Many people said they had received different

diagnoses over time, with seven participants reporting at least one other diagnosis before that of BD. Some reported that this had caused distress and led to inappropriate treatments.

> I was very young and the first psychiatrist I met after a short interview told me that I was depressed and gave me antidepressants...then something very bad happened and after this nothing was like before...[suicide attempt] For the next two years I was stamped with the label "schizophrenic". Four years ago I finally met my current psychologist and he started talking about bipolar disorder...that moment was my turning point.

This theme was related to a key problem: the lack of information about evidence-based care and available treatments.

> I did not know what to do, what could be the interventions recommended for bipolar disorder, if I could recover from this illness. Was it just taking medication every day? Once, a woman I met at the emergency room told me about psychoeducation, but I did not know where (to get it), and who could provide it to me.

Theme 2: Role of Psychological Interventions

Most of the participants said that they had little access to psychological interventions in public services; those who received psychotherapy usually paid private professionals.

> I spent many years very depressed and lithium was completely ineffective. I decided to start a psychotherapy thanks to my parents who supported me financially. I could not afford it alone and the psychologist of the mental health center could only see me once a month, or sometimes once every two months.

Users wanted to have more time to discuss their complex problems and not to be given pills and 'sent home'.

> In the mental health center where I went for my routine visits, I asked my psychiatrist if I could have some psychological support, but I felt like I was asking for a pot of gold. I would like to know if there were some treatments that could help me to recover in addition to medication.

One individual reported that the (re)construction of a solid sense of self required a long process.

> I began to realize that there is life beyond the illness. I was more than just "bipolar". I am a good cook, I can speak three languages, I am an aunt, I am a good friend when I am not ill... and other many things. I worked hard with my therapist. Now when I speak with other people I choose to say that "I have a bipolar disorder because it reminds me that I am not limited to the label, I am definitely more than this!"

Four persons had access to a psychoeducational group focused on general provision of information; problem-solving and communication skills, early detection signs, management of manic and depressive symptoms.

Participants noted the importance of informal or non-specific elements of the group sessions, reporting that they benefited from learning from others, and that they felt less isolated and lonely.

> Looking at the other group participants, I saw myself where I was before the psychotherapy…angry, chaotic, confuse and deeply alone. On the other side, some members of the group helped me in determining what kind of person I would become in the future. One of the best parts of this group was the interaction with other participants… sharing experiences, as most people cannot understand in everyday life.

The possibility of exchanging personal experiences within a supportive context was considered a key positive factors. Meeting other people with BD normalized their self-representation, offered a sense of solidarity, and was de-stigmatizing.

> It was nice to be around people who know how you feel and what you have been through, I felt like I was being "protected". I am still in contact with a couple of people, for my birthday they sent me a pretty birthday card: I was really touched!

A couple of participants underlined the positive aspect of having a group format in which people were at differ stages of the disorder, suggesting that it promoted peer learning.

> We were eight people and everyone had their own story. I felt lucky listening to other stories. I have a family that emotionally supports and loves me, but some people were completely alone. I felt bad for them, especially for a young woman who lived in a residential facility, she could not even take her cats there! I felt very miserable and touched by her story; although she had a very hard life, she always had a word of comfort and kindness for all of us.

Theme 3: Job as a Safe Haven

Seven people currently full or part time employed described work as a protective factor with advantages, not only in terms of financial gain and economic independence, but also in terms of social inclusion, wellbeing and mood stability.

The most frequently highlighted benefits were the positive impact of work routines on self-esteem and opportunities to increase skills and knowledge.

> Despite dark times of mood instability, of many ups and downs […] I've always considered my work an important part of who I am, through the years having a job helped me to monitor my mood […] when I am down it gives me a reason to wake me up and go out.

Five participants reported that, as they often felt isolated in their neighborhood or community, the relationships in the workplace were the most frequent social contact outside family.

> When I decided to do a sort of "coming out" about my illness, in my office people reacted differently. Some people were great, others withdrew very quickly because they felt scared by the mental illness. My boss wrote me a long email saying she was there for me any time I needed and we could think of any work adjustments to help me. I was very positively impressed!

Two participants, who had been unemployed for many years, reported that professionals in mental health services showed a low appreciation of the importance of work for individuals with BD.

> I think there's a prejudice among mental health professionals, especially psychiatrists, towards work. My clinician believed that a job was a source of too much stress for people with bipolar disorder and he wanted to protect me by delaying the moment I could go back to work. He did not consider all the positive aspects for me of having a job.

In addition, employed individuals may view medications negatively, because of their side-effects and the stigma associated with taking psychotropic drugs.

> The list of medication changes in my life is very long. I suffered from many side effects, for some periods I could not even go to work. Two months ago, I decided to stop my medication for a while… I felt relieved not to hide from my colleagues that I had to take my pills, I felt so miserable in those moments.

Theme 4: The Relationship with the Clinician

A supportive relationship was described as a necessary requirement to trust mental health professionals. An essential ingredient in this alliance was the creation of an atmosphere in which the individual feels free to discuss all aspects of the illness, including dissatisfaction with medications or other treatments.

> My therapist is aware of my feelings before I tell him…. When I am standing at the door before entering in his office, I know he can understand at first sight if I am going up!

Seven participants with a long illness duration expressed the need to approach several doctors to find the one they felt to be not only competent, but also empathetic and ready to help. Three persons reported they were reluctant to discuss personal issues with clinicians, fearing that their disclosures might lead to hospital admission.

> Sometimes I feel my thoughts running, my sleep starts to be very fragmented, I become more talkative... I can work better and faster. I can get so much done. I can recognize some of the early signs of hypomania, but you know it's a sort of poisoned red apple... it's so attractive, I am afraid of telling my psychiatrist because you know what are the options: medications or hospitalization!

One woman reported that she spent many years wanting to become pregnant, but her psychiatrist recommended not to because it might increase the risk of relapse.

> The psychiatrist said that pregnancy could have dangerous effects on mood and increase risk of relapses and the responsibility of being a good parent could be very stressful for me. I was depressed and I followed her recommendations for many years. Four years ago, she moved to another service and my new psychiatrist understood immediately my deep desire to become a mother. We made a plan and three months later I became pregnant! My little child is growing well, she is a joyful and smart young girl.

Two women with children said that decisions regarding medications during pregnancy must be made on individual basis and emphasized the importance of considering non-pharmacological interventions such as psychotherapy, support groups such, sleep scheduling and nutrition counseling.

Theme 5: Hospital Admissions

Seven people reported a prior history of distressing compulsory admissions. Some were completely unaware of what was happening and reported feelings of failure, social isolation, disempowerment and shame. Two persons did not want to give any detail because they did not wish to relive the experience.

> Everything should be done to avoid hospitalization: the staff there are generally not interested and offer no psychological support. I was forced to take medication...next morning my admission I was getting dressed because I wanted to leave…my cats were waiting for me at home... I spent most of the day in my bed... So it was a terrifying place and my experience was very traumatic...I was thinking I was in prison and I asked myself several times for what crime?

However, three persons reported they felt also relieved by the admission because they felt protected and safe.

> …when I arrived to the hospital, I knew I was in the right place and I stayed there. I made a lot of friends in the hospital ward… At the beginning, it was a bit frightening with all the strange behaviors going on.

Four participants suggested that an immediate support, such as a 24-h crisis intervention providing psychological help and additional pharmacotherapy, could be very useful to avert relapses offering an alternative to a psychiatric admission.

> Two years ago I had one of the worst weekends of my life. In 48 hours, I spent more money than during the rest of the year. On the internet, I bought many items I cannot even remember.! The day after I realized everything and I felt so desperate about what I had done… I went to the front door of the mental health center very early in the morning waiting for it to open.

According to some people who had experienced several hospital admissions, 24-h crisis services might help to manage early warning signs of relapse and prevent the onset of full-blown manic episodes.

> I spent weeks trying to repair all of the damage I had done in that terrible weekend; maybe if the mental health center had been open, it wouldn't have happened.

Discussion

The first issue addressed by participants was the feeling of despair and hopelessness associated with the idea of a lifelong illness. This is consistent with previous studies reporting the negative effect of a diagnosis of BD coupled by a pessimistic outlook (Proudfoot et al. 2009; Delmas et al. 2011).

A recurrent theme for people who had received a BD diagnosis five or more years before was concern about the delay in diagnosis and the several other diagnoses received before being told they had BD. This problem reflects the findings from several studies (Cerimele et al. 2014; Matza et al. 2005), suggesting that over 60% of individuals with BD had received between 1 and 4 prior diagnoses, with a delay between first onset of symptoms and diagnosis ranging from 4 to 10 years. It is not clear if our subjects presented different problems before the onset of BD, or if BD was misdiagnosed. Anyway, they felt to have suffered for years from incorrect treatments with associated distress due to a wrong diagnosis.

Participants valued psychotherapy but complained the scarce possibility to receive it in the public system. People able to afford private therapy reported benefits such as increased awareness and development of self-monitoring and self-management of symptoms. Therefore, the cost was the main barrier to accessing psychotherapy. The limited access to psychological service provision was a very critical issue. This is at odds with evidence suggesting that a variety of psychotherapy models are effective in preventing relapses, improving social outcomes, reducing subjective burden, and lowering suicide rates in individuals with BD (Miklowitz and Scott 2009; Vallarino et al. 2015). Low access to psychotherapy is a problem in public mental health services in Italy, as shown by recent surveys (Barbato et al. 2016; Lora et al. 2011).

The importance of the therapeutic relationship was strongly highlighted. Emotional support was mentioned as an essential component, especially when trying to cope with acute episodes or the aftermath of a relapse. The participants reported that time constraints placed on routine psychiatric visits did not allow them to feel their experiences fully addressed. Empathy, trust, respect and willingness to discuss care plan, especially with regard to medications, were key elements for building good relationships with clinicians.

Participants who attended a psychoeducation group reported a range of positive experiences. They noted that group fostered coping skills and self-efficacy. This is in accordance with research showing positive outcomes of group psychoeducation (Colom et al. 2006; Biseul et al. 2016), although some studies conducted in real world practice suggested that the duration of benefits could be short (Kallestad et al. 2016). Since these meetings were bound by the rules of confidentiality, people experienced the group as a safe space for sharing feelings and connecting with others going through similar experiences and difficulties, as reported in qualitative studies about peer support and positive interpersonal feedback in group psychoeducation for BD (Poole et al. 2015; Asad and Chreim 2016).

High levels of distress was evident in traumatic accounts of compulsory hospital admissions. This confirms that coercive experiences and lack of safety during hospital admission are main barriers to the formation of a trustful relationship with care providers (Gilburt et al. 2008; Ridley and Hunter 2013).

Crisis services, often linked to home based interventions and shared joint crisis plans between clinicians and patients have been recommended to reduce hospital admissions (Wheeler et al. 2015). This study suggests a strong support of patients to this approach.

All participants mentioned positive role of work in their everyday life. The advantages of work and employment for people with mental health disabilities are well documented (Cook and Razzano 2000). Subjective ratings of quality of

life were shown to improve significantly in employed people, although access to work does not necessarily reduce the relapse risk (Jackson et al. 2009).

Limitations

Some limitations of this study should be considered. First, the recruitment of a small convenience sample of highly educated adults with a very long duration of illness (25 years) and a high age range (37–56 years) limits the generalization of our finding. Second, we relied on diagnoses reported in case records and did not perform a structured diagnostic assessment. Third, we did not assess the symptomatology and comorbidity with other psychiatric disorders. Last, as most participants came from a single service, this is a potential source of bias, because the organization and culture of this service may have influenced many of the experiences described. However, this is a common issue in qualitative studies and means that recommendations may be more relevant to local mental health services than to a broader range of care settings (Davison and Scott 2017).

Conclusion

Despite its limitations, this study adds to a growing body of research focused on experiences of service users (Skelly et al. 2013; Gilburt et al. 2008). The timely provision of meaningful information about the disorder and its treatments within a recovery-oriented framework, the provision of psychosocial interventions and the access to peer support, affect the users attitudes towards care and their engagement. The accounts of this sample of people diagnosed with BD confirm their need for information and wish for psychological interventions, self-help and active roles in illness management (Powell et al. 2000; Pontin et al. 2009). Qualitative studies focused on professionals might in the future clarify the interplay between patient-level, clinician-level and system-level barriers to implementation of shared care models and effective interventions (Piat et al. 2008).

User involvement in the care process and feedback about their preferences and expectations should therefore inform service planning and development (Elgie and Morselli 2007). This is especially important in Italy where, despite the implementation of a community care model, user contribution to service delivery and evaluation, with few exceptions, lagged behind until few years ago (Barbato et al. 2014). From this study the following suggestions for improvement of mental health services can be drawn:

- A person-centered organizational culture that respects users' preferences, their perceived needs and offers active involvement in decision making;
- Access to peer support and psychological interventions in individual or group format;
- Access to crisis services as alternative to acute hospital admission;
- Interventions helping users to gain and maintain regular jobs.

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Compliance with Ethical Standards

Conflict of interest The authors declared no conflicts of interests with respect to the authorship and/or publication of this article.

Ethical Approval Ethical approval were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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