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Early intervention in psychosis for first episode psychotic mania: the experience of people diagnosed with bipolar disorder

Short running title: Early intervention for first episode psychotic mania

Joanna Farr[1], John E. Rhodes[1], Ella Baruch[2] and Jonathan A. Smith[1]

[1] Birkbeck University of London, Malet Street, London, WC1E 7HX, United Kingdom

[2] Tower Hamlets Early Intervention Service, Three Colts Lane, London E2 6BF, United Kingdom

*Corresponding author information: Joanna Farr, Birkbeck University of London, Malet Street, London, WC1E 7HX, United Kingdom (e-mail: joanna.farr@bbk.ac.uk).

Abstract

Background: Early intervention for people diagnosed with bipolar disorder has been identified as a priority, but little is known about how existing early intervention services are experienced by this group or could be tailored to their needs. **Aims:** This study examined the experience of early intervention in psychosis (EIP) services for people diagnosed with bipolar disorder, following first episode psychotic mania. **Method:** Semi-structured interviews were conducted with 11 adults in EIP services and analysed using Interpretative Phenomenological Analysis. **Results:** One superordinate theme was formed, Rebuilding within EIP service, consisting of five subthemes: i) Piecing together episode through talking to staff; ii) Exploring other perspectives during CBT; iii) Empowered through shared decision-making; iv) Reconsidering future and purpose; v) Service as safety-net. EIP provision was pivotal in helping participants understand their episode, adjust their perspective, build confidence and progress. **Conclusions:** Aspects of the service that were valued, including person-centred relationships with staff, shared decision-making and the development of motivation and opportunities, reflect key principles of mental health care for young people following first episode psychosis. Furthermore, findings point to elements that may be particularly relevant to early intervention following first episode psychotic mania including managing mood escalation and individualised approaches to goals.

Introduction

Bipolar Disorder (BD) is a chronic affective disorder and a leading cause of disability in young people (Vieta et al., 2018; Vigo et al., 2016). One sub-type, BD I is characterised by episodes of mania and depression and has a lifetime prevalence estimated at 0.6% (APA, 2013; Merikangas et al., 2011). In BD I, 73.8% of individuals experience a lifetime history of psychotic symptoms, including hallucinations and delusions (van Bergen et al., 2019).

Early intervention following first episode mania in BD I is seen as a priority due to a high risk of episode recurrence which is, in turn, related to a higher rate of episode recurrence in the longer-term (Gignac et al., 2015a, 2015b). A higher number of episodes is also associated with deterioration in functioning, cognition and quality of life (IsHak et al., 2012; Vieta et al., 2013).

In the UK, recovery after first episode psychotic mania for people diagnosed with BD is likely to be managed within early intervention in psychosis (EIP) services, where this group make up 5-20% of caseloads (Macneil et al., 2011; Marwaha et al., 2016). EIP services aim to reduce the duration of untreated psychosis, prevent relapse and hospitalisation. Service development has been motivated by evidence of improved outcomes in people with first episode schizophrenia when treatment is initiated earlier (McGorry, 2015).

Evidence indicates that EI for BD is more clinically and cost-effective than standard treatment (Joyce et al., 2016; Kessing et al., 2013), but EIP interventions have been developed in line with evidence from studies focusing on first-episode schizophrenia and are not tailored for BD (Jauhar et al., 2019). Additionally, clinical guidelines offer limited advice on first episode BD or early episodes of mania (Chia et al., 2019). Recently, EIP staff have reported no clear care packages for BD, a lack of understanding of specific treatments and a

need to optimise care (Marwaha et al., 2018). To date no studies have examined how EIP is experienced by people diagnosed with BD.

EIP is delivered through assertive engagement for a period of up to three years. Key interventions offered by services include anti-psychotic medication, psychiatric input, cognitive behavioural therapy (CBT) for psychosis, family therapy and support for families and carers (NICE, 2016). Care coordinators have relatively small caseloads which enable them to be available and responsive to clients' needs. The wider support on offer includes employment, education advice, physical health checks and psychosocial recovery groups.

Qualitative work examining the experience of EIP provision following first episode psychosis has focused on young people diagnosed with schizophrenia or schizoaffective disorder. Reviews of this area highlight the pivotal role of a person-centred relationship with staff, the impact of which is multi-faceted (Hansen et al., 2017; Loughlin et al., 2020). Personal relationships with EI staff that are warm, equitable, and where the person feels listened to, promote engagement, disclosure and help combat stigma (Jansen et al., 2018; Lester et al., 2012). Person-centred relationships also facilitate agency and control of symptoms, help rebuild identity and generate feelings of normalcy (Harris et al., 2012; Lester et al., 2012).

Further service-related aspects that are seen as helpful include continuity of care, developing hope and opportunities, and choice over treatment (Bjornestad et al., 2017; Eisenstadt et al., 2012). EIP staff can aid insight and understanding, particularly during the first months following first episode psychosis (Allard et al., 2018). Although single psychological interventions tend not to be a key focus, studies indicate that CBT, and to a lesser extent family therapy, is valued as part of overall treatment (Barr et al., 2015).

Understanding the needs of this group is important for the development of optimal care. This study will, therefore, explore how young people perceive their experience of EIP services following first episode psychotic mania.

Method

Recruitment and setting

Participants were sought from two NHS EIP services. Staff screened for study recruitment criteria and invited suitable participants who were euthymic (stable) to contact the researcher who sent the study details, information sheet and consent form, and invited them to participate. All participants gave written consent to be included in the study.

Participants

The study aimed for a homogenous sample. Inclusion criteria included a current diagnosis of bipolar disorder, a first episode of psychotic mania within the last two years, aged 18-35 and sufficient fluency in English to conduct an interview. Exclusion criteria included co-morbid psychiatric conditions. Eleven participants (8 men, 3 women) were recruited. Ethnicities included British African Caribbean, Asian, White British and White Other. All had been hospitalised (10 involuntarily; 1 voluntarily) for 1-6 months during their episode and the majority had a period of depression or low mood afterwards. Participants had been assigned a care coordinator and psychiatrist on entering the service, most had undergone CBT, and some had engaged with employment advice and support groups (see Table 1 below).

(Insert Table 1)

Ethical considerations

Ethical approval for the study was given by Camden & Kings Cross NHS ethics committee (15/LO/1875).

Data collection

Interpretative Phenomenological Analysis semi-structured interviews were conducted by the first author. Participants were asked about their recovery from first episode, including aspects of the service that helped or hindered their progress. The researcher was guided by the interview schedule, but participants were encouraged to talk freely. Interviews were conducted in a private room at the service, for 52-88 minutes (mean: 74 minutes) and were audio-recorded. Interviews were transcribed and anonymised. All participants interviewed were included in the analysis.

Analysis

The theoretical framework of Interpretative Phenomenological Analysis brings a focus on individual experience and is therefore well positioned to explore the meaning of EIP services for participants. The first author led the analysis following the procedure in Smith et al. (2009). The analysis was conducted case-by-case. The first case was analysed searching for points of descriptive, linguistic and conceptual note which were translated into emergent themes. This produced for the first case a list of superordinate themes with pointers to supporting evidence in the transcript. This was completed for each case. Finally, connections between theme tables were identified, leading to a master table of themes. Recognition of the researcher's position and how it differed from that of participants facilitated an awareness of its influence on the research process. This was supported by a second member of the team who verified the analytic process, checking the first author's interpretations against the data. Discrepancies were discussed and reconsidered by iteratively re-reading transcripts. Once consensus was reached, analysis was revised, if necessary. Themes illustrating participants' experience of the EIP service and recovery were identified; this paper focuses on the former.

Results

One overarching superordinate theme consisting of five subthemes were formed:

(Insert Table 2)

Rebuilding within EIP service

Piecing together episode through talking with staff

Participants entered the EIP service at a time of vulnerability as they struggled to grasp what had happened and why. Being listened to by staff, and drawing on professionals' expertise was pivotal in helping piece together their episode and its implications.

For Alex, many questions needed answering:

> [CBT therapy] was useful to talk about the things that have happened with someone that I had no prior relationship with, so I was able to talk about my feelings, what went on, what possibly caused it? […] where did it come from? Is it something that's always been there?

For Alex, speaking to someone with whom he has no 'prior relationship' allows him to consider 'what went on' and his feelings in relation to this. Inseparable from this process are significant questions of 'what possibly caused it?' and 'has it always been there?' that require professional expertise.

Similarly, Steve struggled to make sense of his episode:

> By talking to [care coordinator] that's how I was able to put the pieces together, I mean, what is the significance of it all? […] Because I had to

> still be able to talk it out with a person rather than internally within my mind. Once you say something, actually it becomes, it echoes differently in your mind […] I could actually deal with the internal. […] Once I started talking to him, I start remembering I'll get a flash of an event.

Like Alex, Steve needs to remember what has happened and consider the implications. An essential part is being able to 'talk it out' by voicing it to another person and being listened to. Through this, he pieces 'together' his episode, not only starting to remember, but beginning to see it differently. Like most participants, Steve's interview suggests he feels unable to talk to close others about his episode, making the service the only recourse he has to vocalise his experience and manage psychologically.

Exploring other perspectives during CBT

After first episode, most participants struggled with depression or low mood along with beliefs that might destabilise them. CBT helped them to develop insight into the way they interpreted their situation and the impact this had on their feelings, enabling them to take steps to change.

Edward developed an awareness of his own perspective:

> The way I was thinking of things is always like glass half empty […] their approach was sort of to step out of yourself and think what would someone else think, what would like, like a normal-headed person think? […] Just had feelings of like hopelessness and, umm, like I'm a failure and yeah, they, umm, definitely, I think, like, boosted my morale.

Edward learns to 'step out of' himself and adopt what he considers a 'normal-headed' perspective. This is a comparative process, during which he begins to appreciate that his way

of thinking may not be shared by others, enabling him to consider an alternative, more positive standpoint. Through recognising his perspective and learning to change it, not only is his sense of failure alleviated, but his morale is 'boosted'.

Dave felt CBT taught him about his own responses to others:

> The therapy's [CBT] helped me to see that they [other people] probably don't even notice, they're probably more preoccupied with what they're doing, that's in all honesty, they're not even thinking about you. But I'm understanding more now that's where my problem lies, cos I'm thinking like, what are they thinking about me? So, I'm over-thinking [....] so it's when you think about it, that's when you're almost feeding it.

Compared to Edward, Dave feels less concerned with how he sees himself, and more concerned with how others see him. His first episode was characterised by feelings of paranoia about others and he sees CBT as helping him to recognise that by 'over-thinking' his worries, he has been 'feeding it'. Like Edward, an awareness of his perspective reveals alternative possibilities where other people are no longer 'thinking about you'.

As Jenna became conscious of her changing perspective, she felt wary of taking an overly positive view:

> As soon as abnormal thoughts would come back or something, I would understand that something is wrong and I would no longer chance it and think I'm powerful, you know, extra powers that I have. I would probably the first thing I would do is obviously contact Jack [her care coordinator].

Like the others, Jenna emphasises gaining insight into her way of thinking, but in contrast, describes a wariness of seeing herself as 'powerful'. Rather than attempt to

change this, she refuses to give credence to those thoughts and raises the alarm by contacting her care coordinator. Unlike Edward and Dave, who evaluate their perspective to activate mood change, Jenna scrutinises her thoughts to maintain stability and prevent escalation into mania.

In contrast, Craig struggled to reconsider his view:

> [The psychologist] will be questioning me about, like, how much do you believe that? I saw it [hallucinations] with my own eyes which is, um, I can, I can never unsee it sort of thing […] I still have it at 80 to 100%, it happened. […] I feel like I understand the spiritual game and I understand the biggest thing about the human race on this planet.

Craig struggles with being questioned about the validity of his visions. For him, the sticking point is that he saw them with his 'own eyes' and cannot acknowledge them as hallucinations. Unlike the others, Craig feels unwilling to question his perspective because it gives him a superior level of understanding and purpose. While the others are keen to alleviate their suffering or prevent relapse, Craig has limited motivation. However, by being encouraged to consider his own viewpoint, he tentatively admits the possibility of an alternative reality.

Empowered through shared decision-making

Most participants underwent enforced treatment when hospitalised, leaving them distrustful of services and disempowered. Being involved in decisions around their care within EIP generated feelings of agency, promoting engagement in treatment.

Jane felt her opinion mattered:

> I felt like I was in charge […] I felt like my opinion was definitely taken
> into account of what I wanted... it was never, 'You have to take this
> medication'. […] I came off the medication earlier than they suggested, and
> it was always what would work for you and Dr Garesh [psychiatrist] was
> very, you know I felt very listened to, I was treated like a, like a person, I
> suppose empowering.

Jane stresses the importance of feeling 'in charge' which, in contrast to detainment, made her feel 'like a person'. She attributes this to the change from having 'to take medication' to 'what would work for you'. Through being listened to and involved in decisions, she feels respected.

Alex welcomed a more collaborative approach, having had treatment enforced when hospitalised:

> When things are most difficult, then you get seen more frequently, times
> when kind of more self-sufficient and doing well, then they'll, I don't need
> to see them as often. I think it was something that adapted to where I was
> and respected the choices that I wanted to make. And so, I felt empowered
> enough to take my medications.

Alex feels empowered by being involved in decisions, but his sense of agency also derives from flexibility over treatment intensity. Emphasising that his recovery journey is not linear, he relies on the adaptability of the service to allow self-sufficiency during well periods and intensive support at others. It is this adaptability which empowers Alex to take medication.

While Dave appreciated choices, he also valued staff expertise:

> You get the chance to express your feelings and concerns. So, it's in that, in
> that sense, you know I feel I have a choice, but you know you gotta do the
> right thing too cos it's kind of up to you in the end. But, just sometimes you
> just have to believe what they [the practitioners] say and just, just try and
> that just take it.

Dave feels his interactions with staff encourage him to speak openly, inviting his input. Like the others, by being included in decisions, he feels acknowledged. However, he feels that both parties must do 'the right thing' together. He feels responsible for making the 'right' choice, but recognises that sometimes he must defer to the team. Here, Dave illustrates a collaborative process, involving flexibility on the part of client and practitioner.

Reassessing future and purpose

First episode posed a major disruption to the participants' future and the service played a key role in reassessing their plans. For some, this involved working towards new goals, but others, disregarded them.

Dropping out of university during his episode, Liam struggled with a loss of purpose. The opportunities at the service encouraged him to reassess:

> My employment specialist got me on to being a peer support worker for
> charity called the Advisory Projects, which has been really helpful like
> getting out there and into the community and actually trying to like, do
> some sort of work […] I can achieve what I want to achieve without a
> degree and I can always go back and I didn't really, I don't really, I don't
> really care about that anymore […] [Care coordinator] really pushes me to
> like, actually to do things whilst I'm there, like call people and write emails
> and stuff whereas you feel, you know, I don't want to call anyone.

Liam feels rejuvenated by pursuing new goals. Where previously he felt lost, with the help of the employment specialist, he has made progress towards 'some sort of work'. Liam describes taking practical steps, proving to himself that he can pursue a future without a degree and no longer sees dropping out of university as a setback. Though Liam recognises his progress, he stresses the role of his care coordinator in encouraging this.

In contrast, Karen felt she benefited from being allowed to stand still:

> [The psychiatrist] puts my mind at rest, also gives me some recommendation, umm, as to how to think about things and how you should kind of try and move forward and think ahead, but also would, um, I suppose just tell me it's alright to not be moving at all. Again, it's normal […] you don't have to get back to, the high functioning self if you feel not ready to so, well, it's kind of a relief to, to, hear things from a professional's mouth.

Karen values reassurance from staff that 'it's alright to not be moving at all'. On hearing this from a 'professional's mouth', she feels released from the pressure to return to her 'high functioning self'. Her escalation into mania during first episode followed from the need to perform at work and she is not ready to go back. Like the others, she found it reassuring to have her situation normalised.

Service as safety net

All participants stressed the safety that came from being in the service. For Jane, this came from being supported by a diverse team:

> Feeling OK is down to them [EIP team], pivotal […]. I feel like I've been held by a great team people, different disciplines and different ways,

whether it be the doctor in terms of medication, and that kind of thing, or
whether it's, you know, it's like psychology therapy weekly, or Carl [care
coordinator] just literally checking in on me.

Jane attributes 'feeling OK' to being 'held by' a diverse team. Her choice of the
word 'held' expresses the sense of safety she feels in being cared for by a team of
professionals, providing holistic care. This involves a multifaceted approach to her
needs, from 'medication' and 'psychology therapy' to 'checking in on me'.

Edward also felt a sense of safety, but attributed it to a different aspect:

They [EIP team] were always looking out for you, umm, like, whether it be
by telephone conversation or, umm, you know, whenever you came in to
see them here […] closely monitoring everything. If, like, I'd even hint at
that, that I was, err, swinging one way or the other.

Whereas Jane felt safe in having access to a network of experts, Edward feels protected from
relapse by being closely monitored. He stresses the degree of scrutiny he receives over 'even'
a 'hint' of change – nuances that might have passed unnoticed.

Discussion

The participants' experience of reassessing and rebuilding themselves and their lives within
EIP encompassed a range of interventions and relationships which enabled them to
understand what had happened, gain insight into their perspective, develop agency,
reconsider the future, and feel safe.

On entering the EIP service, participants initially struggled to understand what had
happened to them and why. Articulating episode experiences and drawing on staff expertise
played an important role in prompting memory, finding clarity and making sense of their

diagnosis. One study on first episode psychosis suggests that the search to understand and normalise episode experiences dominates the early stage of EI and is a precursor to progress (Allard et al., 2018). In our study, most participants struggled to talk to close others about their episode, so the opportunity to talk with someone at the service was key. Studies on BD suggest that secrecy is common following mania, despite a keen desire to share experiences (Ouwehand et al., 2019).

A recent meta-analysis of CBT for BD indicates that CBT is effective in improving depression symptoms, mania severity and lowering relapse rates (Chiang et al., 2017). Further work, however, is required to understand the relative benefit of CBT in early-stage BD (Ratheesh et al., 2023). In this study, CBT facilitated an awareness of alternative perspectives which helped manage low feelings, anxiety and risk of mania. The benefit of CBT reappraisal techniques for mood management has also been highlighted by other qualitative work focusing on individuals at later-stages of BD (Joyce et al., 2017). Not all participants report changes in mood or thinking post-CBT, however. Consistent with this, in our study, Craig remained invested in his belief that his visions were proof of his superiority, despite testing his perspective. According to reviews, CBT may be less effective in modifying beliefs related to grandiose delusions because they tend to be held with the highest level of conviction, bringing significant meaning (Knowles et al., 2011). Evidence suggests that for individuals with BD, beliefs in a grandiose self predicts a worse response to cognitive therapy (Lam et al., 2005). There is a need for further investigation of CBT in EIP for psychotic mania, where grandiose delusions are common.

Involving the participants in treatment decisions helped rebuild agency and trust; particularly for those who felt disempowered after detainment. When young people are excluded from decisions in EIP services, they feel powerless; by becoming active agents, their agency and responsibility is promoted (Harris et al., 2012; Lester et al., 2012; O'Toole et

al., 2004). A recent qualitative review of psychological interventions for BD recommends that interventions focus on empowerment rather than solely mood stability (Davenport et al., 2019). Early-stage BD was not the focus of the studies examined, however. Meanwhile, other research highlights that decision-making over medication requires a collaborative approach that recognises the expertise of both client and clinician (Inder et al., 2019). This study extends this, suggesting that shared decision-making may promote medication adherence in young people following first episode psychotic mania.

Returning to work or education has been found to be a source of hope for young people following first episode psychosis (Perry et al., 2007). EIP provision supports occupational spheres and promotes renewal of goals at a time when young people feel they are missing out (Lester et al., 2012; van Schalkwyk et al., 2015). In this study, the role of progressing goals in providing future hope was emphasised by most participants but some benefitted from disregarding them. The recovery of the participants in this study (reported elsewhere, see Farr et al., 2023), highlights the motivation generated through goals, but also their potential to instil pressure, contributing to manic relapse. This highlights the value of a flexible approach to goals that recognises both their benefits and the relationship between goal-directed behaviour and BD episode recurrence (Alloy et al., 2012).

Strengths and limitations

This study's key strength is that it is the first to explore the experience of EIP services for people diagnosed with BD. Its phenomenological approach captures the individualised experiences of EIP and identifies what matters, something that is not possible via standardised measures. Participants were identified via the service, meaning the perspectives presented are likely to be representative of people who are positively engaged in EIP. This overlooks disengaged individuals with, potentially, more negative views along with those

who declined participate. Although no gender differences were identified, further consideration of gender and how it might influence experiences would be valuable. Due to the use of an in-depth qualitative approach, findings are not generalisable. Yet insights provide implications for understanding EIP for this group. The interview timing varied and not all participants had been through the full range of interventions offered by EIP.

Conclusions

Findings highlight the benefit of multi-faceted support afforded by EIP, including person-centred relationships with staff, open discussion of episode experiences and treatment decisions, the development of agency, future opportunities and the provision of safety. These align with the priorities of personal recovery in BD (Jagfeld et al., 2021), highlighting their relevance to EIP for BD and psychotic mania. Moreover, these aspects seem to reflect the basic principles underpinning service delivery for young people with first episode psychosis and may have transdiagnostic value. What may be particularly relevant for people diagnosed with BD is shared decision-making for treatment adherence, the benefit of CBT in evaluating overly positive thoughts and feelings and the value of individualised approaches to goals. These point to the potential benefit of a tailored approach to BD and the need for further research.

Data availability statement

Due to the confidential nature of this research, supporting data of interviews is not available.

Declaration of interest

No potential conflict of interest.

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Tables

Table 1. Table of participant information

No.	Name[a]	Gender	Age	Diagnosis	Post-episode mood self-report	Months in EIP at interview	CBT
1	Edward	Male	22	BAD F312[b]	Depression	20	Yes
2	Alex	Male	27	BAD F312	Depression	19	Yes
3	Jane	Female	25	BAD F312	Depression	20	Yes
4	Dave	Male	26	BAD F312	None	20	Yes
5	Karen	Female	32	BAD F312	Depression	12	No/waiting
6	Steve	Male	30	BAD F312	Depression	14	Yes
7	Jenna	Female	24	BAD F312	Low mood	24	Yes
8	Joel	Male	26	BAD F312	Low mood	15	No
9	Craig	Male	35	BAD F312	Low mood	10	Yes
10	Eric	Male	21	BAD F312	Depression	3	No/waiting
11	Liam	Male	24	BAD F312	Depression	15	Yes

a Pseudonym
b Bipolar Affective Disorder, current manic severe with psychotic features

Table 2. Superordinate theme and subthemes

Overarching superordinate theme	Subthemes
Rebuilding within EIP service	Piecing together episode through talking with EI staff
	Exploring other perspectives during CBT
	Empowered through shared decision-making
	Reassessing future and purpose
	Service as safety net