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ORIGINAL ARTICLE

Peer support in early intervention in psychosis: a qualitative research study

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ABSTRACT

Background: There is evidence that peer support can be helpful for people suffering from psychosis, but there is a lack of research describing peer support in the context of Early Intervention in Psychosis (EIP).

Aims: We aim to investigate the key elements of peer support in EIP and how peer support workers might best be recruited and supported in their work.

Method: We used purposive sampling to recruit seven participants for semi-structured interviews. Thematic analysis was used to analyse the data.

Results: Destigmatisation of psychotic experiences is a central concept that runs through all themes. Participants perceived peer support as a meaningful source of support that could provide benefits to peers (service users) and peer support workers. Themes included a "symbol of hope," "practical support," "mutuality and reciprocity," "bridge between service and peers," "ideal requirements of peer support workers," "delivering peer support," and "team-working and role clarification."

Conclusions: Peer support makes a strong contribution to destigmatising psychosis. Findings potentially contribute to developing peer support workers' roles in EIP. Future research is recommended to investigate the perspectives of ethnic minorities on this topic and practical applications of these findings.

Introduction

Early Intervention in Psychosis (EIP) was established in response to evidence demonstrating that timely provision of clinical care to individuals diagnosed with first episode of psychosis (FEP) reduces the debilitating impacts of this experience and improves outcomes (Craig et al., 2004; Jeppesen et al., 2005; Thorup et al., 2005; Santesteban-Echarri et al., 2017). In recent years, there has been growing interest in addressing functional recovery in FEP (Alvarez-Jimenez et al., 2016), and functional recovery is suggested to be the most valuable treatment outcome for FEP patients (Iyer et al., 2011). However, functional recovery still lags behind clinical remission for many service users (Lieberman et al., 1993). Research to enhance the ability of EIP to improve functional recovery is urgently needed.

People experiencing psychosis also suffer internalised stigma as a result of their symptoms (Payne et al., 2006; Sartorius & Aichenberger, 2005). Internalised stigma is described as "the state in which a person with severe mental illness loses previously held or hoped for identities and adopts stigmatising views" (Yanos et al., 2008). A large survey conducted by Brohan et al., (2010) reports that almost half of the participants across 14 European countries experience moderate to high levels of self-stigma, which is associated with reductions in hope and self-esteem (Yanos et al., 2008), self-efficacy (Vauth et al., 2007), quality of life and social support (Livingston & Boyd, 2010). Hence, a further understanding of how to address internalised stigma may contribute to the development of a targeted solution to improve functional recovery in FEP patients.

The UK clinical guidance for treatment of psychosis recommends the provision of peer support in EIP services (National Institute for Health & Care Excellence [NICE], 2014). Elsewhere, it has been suggested that unmet needs among people using EIP services can potentially be fulfilled by peer support (Gillard, 2019; Jones, 2015). Peer support is the provision of support by people who have had lived experience of mental distress to others with similar experiences, with an emphasis on empowerment and hope (Schutt & Rogers, 2009). The key principles characterising peer support are identified as relationship building, mutuality and reciprocity, application of experiential knowledge, choice and control, empowerment, and connection to community (Gillard et al., 2017).

There is evidence that frequent and regular peer support improves social support as well as increases self-efficacy and quality of life for people experiencing psychosis (Castelein et al., 2008; Mahlke et al., 2017). People with diagnoses of serious mental illnesses receiving peer support reportedly feel more in control, hopeful, and empowered to bring change into their lives (Davidson et al., 2012; Wilken, 2007). A systematic review by White et al. (2020) notes that one-to-one peer support may have positive impacts on psychosocial outcomes. Additionally, it is noted how peer support can be beneficial for peer support workers, improving their well-being, self-esteem, and feelings of self-efficacy (Bracke et al., 2008). Paid peer support workers may also influence organisational change, break down the barriers between staff and service users, challenge stereotypes in work environment and reduce discrimination (Faulkner & Basset, 2012; Pyle et al., 2018; White et al., 2017).

However, there is still limited understanding on the effects of peer support, how peer support workers might work and best be supported in the EIP context prior to formal evaluation in a clinical trial (Chien et al., 2019). Research studies have indicated a lack of clarity in reporting of what peer support workers do and the mechanisms by which they may bring about change (Pitt et al., 2013; Lloyd-Evans et al., 2014). Another vein of research identifies workplace challenges for peer support workers, including low wage, inflexibility, identity and clarification of the their role, lack of understanding, support and appropriate training from mental health services, which potentially dilute the processes and impacts of peer support (Davidson et al., 2012; Gillard et al., 2014; Pyle et al., 2018). Therefore, further exploration of the implementation of peer support is needed, especially in different clinical settings and populations (White et al., 2020).

This paper reports a qualitative interview study that aims to understand peer support workers' experiences of working in EIP services and their views on how peer support works and may best be supported in that context. The term *peers* is used in our study to indicate service users who are supported by peer support workers.

Methods

Recruitment and participants

We used purposive sampling to recruit peer support workers who had a range of experiences of working in EIP. They are verbally fluent in English and willing to provide informed consent. There are currently relatively few peer support workers working in EIP teams in England, which means we could only identify a small sample. However, a small sample size is not unusual in qualitative analysis where the focus of the analysis is on complexity and nuance within the data (Braun & Clarke, 2016).

Procedures

Ethical approval for the study was granted by the UCL Research Ethics Committee (14649/001). Interviews were either on telephone or face-to-face, recorded using a digital recorder, and transcribed verbatim by an independent third party. Field notes were made during the interviews to enrich the data and aid analysis.

We developed a topic guide for semi-structured interviews, informed by the principles framework cited above (Gillard et al., 2017). We followed the consolidated criteria for reporting qualitative research (COREQ; Tong et al., 2007) to ensure the quality of the study.

Data analysis

Interview transcripts were imported into NVivo 12 software and analysed using thematic analysis (Braun & Clarke, 2006). The first author read through the entire data set and identified possible patterns. Themes were discussed and reviewed by the authors until a satisfactory thematic map was finalised. The first author then coded all transcripts. We used both deductive and inductive approaches, generating themes that answer *a priori* research questions and exploring new themes directly emerging from the data (Fereday & Muir-Cochrane, 2006). Our analysis focused on the latent meanings in the data, in which the researchers took on an interpretivist position to understand participants' experiences.

Before publication, the analysis section was returned to participants for validation – we asked whether the analysis reflected their views and whether they had any comments or suggestions for improvement. Three participants gave full approval without suggestions for change; the remaining four participants did not reply to our request.

Results

Participants

Seven participants were recruited to the study; interviews lasted an hour on average. All participants are aged 36 to 51, White British, spoke English as their first language, and have lived experience of psychosis, consisting of three men and four women. All participants had experience of providing peer support in EIP, with five currently employed to do this. Three had experience of receiving peer support. Of these three, all had received both group and one-to-one peer support. Two had received online peer support. Only one received peer support in EIP. Their years since first experience of psychosis ranged from 2.5 to 33 years, their years since first contact with mental health services ranged from 2 to 32 years. Years since receiving diagnosis ranged from 1.5 to 33 years, and years of experience of delivering peer support ranged from 1 month to 6 years. Five were heterosexual, one was gay and one preferred not to disclose sexual orientation.

Overview of findings

Results were categorised into four thematic domains (Table 1).

Table 1. Four thematic domains.

Domains	Domain descriptor	Themes
1. The benefits of peer support in EIP	The distinct advantages of peer support in facilitating peers' recovery journey and empowering peer support workers.	1a. Symbol of hope 1b. Practical support 1c. Mutuality and Reciprocity 1d. Bridge between services and peers
2. The ideal requirements of peer support workers	Desirable specifications in peer support workers' recruitment.	No sub-themes.
3. Effectively delivering peer support	Participants' opinions on how to train and effectively deliver peer support, including views on teamworking, management and supervision.	3a. Peer support in the context of EIP 3b. Training 3c. Team-working and role clarification
4. Working alongside peers	Participants' experiences of building relationship with peers they support and involving peers in shared decision making.	4a. Relationship building 4b. Providing support and coping strategies

A central concept that emerged and ran through all themes was the importance of destigmatisation of psychosis. One participant considered psychosis a "survival gift" (understanding psychosis as providing a way of psychologically surviving abuse and trauma). Experiencing and recovering from psychosis could change and enhance the knowledge participants hold about psychosis, facilitating beliefs about self-efficacy. This central concept and the key themes are discussed below.

Themes

The benefits of peer support in EIP
Symbol of hope. All participants affirmed that meeting someone who had been through the same experiences could potentially provide peers with hope and motivation. Peer support workers incorporated role-modelling, in which their recovery helped alleviate the pessimistic narratives and assumptions of chronic disabilities which could be associated with psychosis.

> It's very easy to be blown away by the negativity that can come with psychosis. (Participant C)

> You know, you're able to get up in the morning and come to work, and all those things speak volumes without actually me having to say anything. And I think that really offers people hope. (Participant E)

Practical support. All participants believed peer support workers could provide peers with pragmatic advice and coping strategies. Due to peer support workers' own experience of the condition, their guidance was often highly relevant and useful.

> So, it's about kind of signposting them, and navigating around those obstacles that I may have bumped into in the past and stuff, and that's the beauty of that lived experience. (Participant D)

Several participants also emphasised the significance of emotional validation, which helped peers feel valued, acknowledged the impacts of their trauma, and thus created a safe space for them to work on their healing progress.

> And I think sometimes just having somebody who's prepared to just witness how overwhelmed and devastated you feel, who can

tolerate that and is sending the message that your pain matters, your feelings matter. (Participant A)

Additionally, participants reported that peer support workers could reduce the extent of isolation for peers. As psychosis is a very stigmatising disorder, self-isolation is common and addressing this problem is an important step towards both clinical and functional recovery.

> Because a lot of people become isolated and think that (the) world outside their own house is a horrible place. So, they need to be re-educated that not everybody is horrible (…). (Participant F)

Mutuality and reciprocity. Most participants felt that similar experiences of psychosis created a sense of *mutuality*, a shared identity between peers and peer support workers. This supportive connection led to feelings of reciprocity where peer support workers felt fulfilled and empowered in their work, in which their difficult experiences of psychosis became a powerful tool to help others.

> To feel like you're using your experience for the good, and you're doing good in the world, and, ultimately, that is what I've always wanted to do, even before I became unwell. (Participant E)

Bridge between services and peers. Many participants suggested that peer support reduced the barrier between professionals and peers, allowing peers to share their own stories and struggles in an accepting, non-judgmental context.

> And I don't think they're necessarily given that opportunity so much with a CPN [community psychiatric nurse] or with a psychiatrist because of time constraints and because they're not peers at the end of the day. (Participant E)

Due to their own experiences of psychosis, peer support workers had a less clinical view of peers' struggle. This enabled them to offer companionship and hope at times where recovery almost seemed impossible. Several participants described that peers often felt more comfortable getting support from peer support workers, as they were not convinced that other professionals had a realistic understanding of what they were going through.

> It ends up annoying them, rather than helping them [peers] because they [clinicians] don't understand. (Participant F)

Furthermore, some participants suggested that peer support workers incorporated a more compassionate and hopeful perspective into their approach.

> People can live with psychosis and lead very fulfilling, good lives. (Participant E)

The presence of peer support workers in the NHS sent a positive message regarding healing progress in psychosis and shifted the service focus towards functional rather than clinical recovery.

> You know, when a doctor will talk about functioning, and things like that, 'oh, that person's level of functioning has deteriorated', and then you think to yourself, but they are still doing these things, or they are still achieving these things …. (Participant D)

The ideal requirements of peer support workers

Almost all participants felt that it was ideal to have peer support workers who mirrored the symptom characteristics of peers. As psychosis consists of unique and terrifying experiences, having a peer support worker with similar types of experiences can offer peers a sense of mutuality and facilitate interpersonal connections.

> I guess the advantage of my experience with psychosis is that I guess things that I've struggled with through the years, that I can have maybe more relatable conversations with those people. (Participant C)

One participant mentioned that people of various backgrounds had different needs which could be more comfortably met by peer support workers of similar demographic.

> I think ideally it would be good to have peer support workers who mirror the demographic of the client group. (Participant A)

Another desirable specification described by two participants was that the peer support workers should have prior experience of psychiatric services. Having this experience could help peer support workers be more mindful of the power difference between staff and peers.

> I think if you've used services, you might be more sensitive and aware of power over versus power with. (Participant B)

Delivering peer support
Peer support in the context of EIP. One participant suggested that peer support groups in EIP should be extended to peers who had been discharged from the service and people outside the designated geographical area, which could improve peers' social network and promote long-term recovery.

> It strengthens the group in different ways, people willing to do that, so that's one idea. (Participant B)

Additionally, two participants highlighted that peer support in EIP should be holistic and cover all essential aspects of an individual's life rather than solely recovery-oriented or focusing on one specific stage or symptom.

> And being able to provide that service over a longer period of time helps that person to explore the different areas that they

want to explore within their life, so whether it's (a) job, you know, new relationship, whatever it might be. (Participant D)

Training. Participants suggested that training should contain elements that enabled peer support workers to be effective in their roles and challenge stigmas around psychosis. Participants mentioned signposting resources as useful information to be included in training, such as "Hearing Voices Movement, The Paranoia Network" (Participant A). They also suggested training on how to maintain professional boundary and one's well-being, improving communication skills, and teamwork.

> Boundary training. I would say sharing one's story: When it's appropriate, when it's not, and how much to share. Keeping one's self well at work. Keeping one's self well in the context of hearing distressing information. Working collaboratively with a team. I would say reflective practice, skills and reflective practice. Counselling skills, because you do a lot of that. A lot. Listening and counselling. Communication skills. (Participant E)

Team-working and role clarification. Participants reported that good team-working gave them the opportunities to off-load and receive valuable advice from colleagues, especially when their work became challenging and emotionally draining.

> But it's just about having conversations with your colleagues that have that experience and seeking out a voice and hoping they will guide you in that type of situation, rather than dealing with it in your own head. (Participant C)

Several participants noted that in EIP teams where staff did not have extensive knowledge about peer support, new peer support workers needed to take the initiative in establishing their roles. To do so, they should first be able to understand their key responsibilities and what they could bring to the team. Thus, role clarification was described as an essential aspect of peer support workers' employment.

> So maybe, initially, a better understanding of what a peer support worker is, and maybe how a peer support worker could potentially be used. (Participant C)

Most participants explained that management was essential in providing them with reasonable adjustments during employment and helping them establish their role within the team. Additionally, effective supervision reduced their risks of burning out and supported them in managing their caseload.

> I think it can be really, really draining, painful work, and I think that's why a lot of people end up getting burnt out, because they're not getting proper support themselves. (Participant A)

Working alongside peers
Relationship building. All participants deemed relationship building with peers as a core aspect in peer support, which was rooted in mutuality and empathy, as participant D explained:

> I kind of look at it now, a little bit more like peer support being about human connection (…). And I think that makes it a little bit more easier for somebody to understand, you know,

sort of that there are other people out there that maybe have experienced similar things in that way.

Different perspectives from participants included: (1) establishing a shared identity with peers, (2) validating their feelings and struggles, (3) sharing conversations about daily life topics, not just mental health, (4) doing social activities together, and (5) providing them with a realistic but hopeful perspective of recovery. All in all, the support provided should resemble meaningful, real-life interpersonal connections that peers did not often receive in the clinical context.

> I'll play squash with somebody, or we go to the cinema, or we go out for a coffee, or we go to go and snooker. (…) It depends on what they want to do, but I'll obviously try to work on the issues that they have, but trying to do normal things and support them, and just be normal with them. (Participant C)

Providing support and coping strategies. Several participants suggested that when peers were acutely unwell, they might not have sufficient resources to handle practical advice and work on personal goals.

> I guess it's remembering what was helpful when you were in the startling phase. I guess for me, it's being gentle and authentic and present and listening and being non-judgemental and accepting. (Participant B)

Regarding shared decision-making, participants suggested that peer support workers should first recognise each individual's perception of recovery. In cases where their expectations seemed unrealistic, peer support workers could encourage peers to make reasonable compromises in achieving these goals.

> Like, it doesn't have to be exactly the same as it once was, and it doesn't mean that you're any less of a person or any less good at your career. It just means that you need to adapt to change. (Participant E)

All participants suggested that peer support workers should consistently encourage peers to engage in positive risk-taking during their healing journey. This included supporting peers in building social relationships, living independently and taking responsibility for their recovery. However, self-stigmatisation could potentially be a detrimental barrier to peers' independence, as they might be ashamed and self-conscious about their psychotic experiences. Thus, one participant suggested that increasing peers' sense of self-efficacy was crucial. Feelings of discomfort should not be avoided, as they were a major learning factor in helping peers manage their difficulties.

> Because until you acknowledge them, it's really hard to embrace them and learn to know yourself more and how to move out of that comfort zone. (Participant A)

Participants expressed that as peers slowly gained back confidence, they became willing to learn skills that would benefit them in the long run.

> Trying to make them not blame themselves for those struggles, and say, well, you have become unwell, and you've got to learn to build these skills again. That could be an agonising process. In time, if you don't just hide from them, that things can get

better. Who knows how much better, but better all the same. (Participant C)

Discussion

Peer support and EIP

Our study reflects findings elsewhere which indicate that peer support can provide people with experiences of psychosis, especially in EIP, with self-management strategies, increased social support network and reduced barriers between services and peers (Castelein et al., 2008; Mahlke et al., 2017; Faulkner & Basset, 2012). Peer support workers can act as an example of living well with psychotic symptoms and reducing stigma surrounding psychosis among professionals (Faulkner & Basset, 2012; Pyle et al., 2018). Similar to previous studies in mental health services more generally, our findings suggest that peer support in EIP mutually benefits peers and peer support workers (Bracke et al., 2008).

We found that hope is a pivotal factor in recovery from psychosis, echoing the findings of Davidson (2020). As described by Wilken (2007), peer support workers may support the belief that *recovery is possible* and facilitate peers' *willingness to act*, thus motivating peers to engage in activities and establish goals which have previously seemed pointless. Our results show that perhaps one of the benefits of peer support is that it offers peers a sense of meaningful connection to others and the community through interpersonal interaction with others who shared the same source of distress (Gillard, 2019). This can potentially reduce loneliness and social disability, which is reported to profoundly affect people with psychosis (Hodgekins et al., 2015; Lim et al., 2018). Furthermore, the narratives in our study indicate that peer support can potentially facilitate functional recovery in peers, increasing their ability to live independently.

Our analysis finds that it is ideal to have peer support workers who match the symptomatic and demographic characteristics of peers. Having prior experiences of mental health services is helpful, as peer support workers become more aware of the power dynamics between professionals and patients (White et al., 2017). This indicates a possibility for peer support workers to use their experiential knowledge both of psychosis and working in mental health services to bridge this gap (Oborn, Barrett, Gibson, & Gillard, 2019). Finally, for peer support workers to be effective and feel supported in their work, EIP teams need to have a shared understanding of their roles within the service, echoing the findings of Gillard et al (2014).

Our participants' understanding of peer support and its benefits seems to closely align with the principles characterising peer support (Gillard et al., 2017), which suggests that the implementation and benefits of peer support in EIP may be similar to peer support in mental health services more generally. It would be interesting for future research to explore how peer support can be specifically tailored to the EIP context.

Addressing internalised stigma

Our data suggest that peer support may reduce the stigmatised assumptions of unavoidable disability and overwhelming pessimism around psychosis. Furthermore, peer support allows peers to have open and honest conversations about their experiences, symptoms and diagnosis without fear of judgment and psychological distress (Burke et al., 2016). Our analysis suggests that meeting others with similar experiences can also lead to normalisation of psychotic experiences, reducing internalised shame. As internalised stigma has been demonstrated to be severe and common among people with psychotic disorders (Brohan et al., 2010), peer support in EIP may contribute towards an effective solution for this problem.

Strengths and limitations

Our paper focuses on understanding the role and support required for peer support workers in EIP from the peer support workers' perspectives. Further research should usefully complement this by exploring the experiences and views of people receiving peer support in EIP services as well as other members of EIP teams.

We took steps to increase the validity and credibility of the research, such as collecting detailed demographic information, following the COREQ guideline (Tong et al., 2007), and adopting a team approach towards data analysis.

All participants are White British; this is a limitation of the study. Future research should attempt to capture black and ethnic minority perspectives on peer support in EIP, especially given the over-representation of people from black ethnic groups in psychosis services more generally (Morgan et al., 2004; Singh et al., 2007).

Conclusions

Our findings show that peer support has the potential to contribute to functional recovery, provide a sense of hope, increase self-efficacy and social connection, and facilitate the reduction of self-stigmatisation in EIP services. Findings also provide insight into the specific role peer support workers might play, and the support and training required to deliver these benefits.

Disclosure statement

No potential conflict of interest exists.

Data availability statement

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

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