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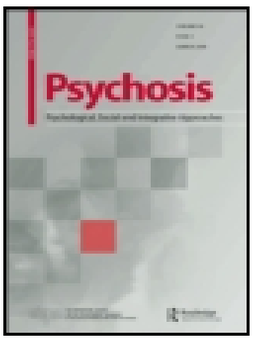

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Experiences of stigma in psychosis: A qualitative analysis of service users' perspectives

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Background: Psychosis is associated with a high degree of stigma. There is relatively little qualitative research exploring service users' experienced, perceived and internalised stigma and its impact on their lives.
Material: Data from semi-structured interviews with 12 service users with experience of psychosis were subjected to secondary qualitative analysis.
Discussion: Six overarching themes were identified concerning: understandings of psychosis; experiences of stigma; impacts on self; emotional responses; behavioural responses; and impact on recovery.
Conclusions: Stigma is a key concern for service users with psychosis. Detailed assessment of stigma should be considered in clinical services and interventions developed to reduce stigma.

Keywords: stigma; psychosis; schizophrenia; internalised stigma; qualitative; thematic analysis

Introduction

It is widely acknowledged that stigma is associated with having a psychiatric diagnosis (Crisp, Gelder, Goddard, & Meltzer, 2005). In particular, a schizophrenia spectrum diagnosis is associated with increased stigma, including public perceptions of dangerousness, unpredictability and permanence (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000; Crisp et al., 2005).

Research examining service users' subjective experiences of stigma in psychosis has increased our understanding of stigma. A recent review of the qualitative literature exploring service user perspectives identified that stigma is pervasive throughout the social systems of service users and can lead to: social exclusion, devaluation of difference, lack of power and control, lack of understanding, stereotyping and discrimination, inferiority and inequality, shame and secrecy and pessimism about recovery (Wood et al., 2015). Schulze and Angermeyer (2003) identified that stigma can present in psychosis across the four domains of interpersonal relationships, structural discrimination, public images of mental illness and access to social roles. More recently, Brohan, Slade, Clement and Thornicroft

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(2010) have conceptualised stigma as comprising three distinct categories of experienced, perceived and internalised/self-stigma. Experienced stigma is contact with overt discrimination (Brohan et al., 2010), perceived stigma is where a person believes stigma to be present in society and be reflective of them personally (Van Brakel et al., 2006); and internalised/self-stigma is the internalisation of perceived and/or experienced stigma (Corrigan & Watson, 2002). This approach arguably offers a more psychologically informed model of stigma which helps to understanding the impact of stigma at the individual level. To date there has been no study of stigma experiences from the theoretical model proposed by Brohan and colleagues (2010). Internalised stigma is of particular importance because it is associated with reduced psychological well-being and impeded recovery (Livingston & Boyd, 2010).

As part of another study (Morrison et al., 2015), a semi-structured interview measure of stigma (SIMS) was developed to assess and explore experienced, perceived and internalised/self-stigma (Wood, Burke, & Morrison, 2015). For the present study, data from SIMS interviews were subject to a secondary qualitative analysis with the aim of adding to the qualitative evidence base relating to service users' perspectives of stigma in psychosis.

Method

Design

Data were collected as part of a pilot randomised trial evaluating cognitive therapy for the treatment of internalised stigma in psychosis. Eligible participants aged between 16 and 65 were in contact with mental health services, and either met ICD-10 criteria for schizophrenia, schizoaffective disorder or delusional disorder, or entry criteria for an Early Intervention for Psychosis (EIP) service (operationally defined with the Positive and Negative Syndrome Scale; Kay, Fiszbein, & Opfer, 1987) in order to allow for diagnostic uncertainty in early phases of psychosis. Eligible participants demonstrated at least moderate difficulties with internalised stigma by scoring less than 60 on the Internalised Stigma of Mental Illness Scale-Revised (ISMI-R, based on Ritsher & Phelan, 2004 which has been demonstrated to have good psychometric properties (Brohan et al., 2010). More details regarding the trial are provided elsewhere (Morrison et al., 2015).

Measures

The SIMS was developed through systematic review of the qualitative evidence base and consultation with a service user reference group. It explored participants': understanding of stigma; experienced stigma; perceived stigma; and internalised/self-stigma (comprising self-esteem, safety behaviours/avoidance, emotional change, relationships, impacts on experiences of psychosis, treatments, positive impacts of stigma and recovery). The semi-structured design allowed for consistency of questioning across participants and exploration of areas of particular concern for individuals (see Table 1 for questions included in the SIMS).

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Table 1. Questions in the SIMS.

1. What does stigma mean to you?
2. How do you think a person with psychosis is viewed by society?
3. Have you had any direct experiences of stigma because you experience/d psychosis? What are these?
4. How do public views about psychosis and/or your experiences of stigma/discrimination make you feel about yourself?
5. Have you experienced difficult emotions as a result of stigma? What?
6. Has stigma impacted upon your daily life? How?
7. Has stigma affected your relationships with others? How?
8. Has stigma impacted on your experiences of psychosis? How?
9. Has stigma affected you accessing mental health services/treatment? How?
10. Has stigma had any positive impacts on your day to day life? What?
11. Has stigma impacted on your recovery? How?

Sampling

To reduce researcher bias in selection of interviews, data from consecutive SIMS interviews conducted at the baseline assessment of the trial were included in the analysis, starting with the first participant, and continuing to a point when thematic saturation was deemed to have been reached in the data; in this instance, at the twelfth participant. Sample characteristics of the resulting 12 participants are outlined in Table 2.

Table 2. Sample characteristics.

Ppt. ID	Gender	Age	Ethnicity	Employment status	Diagnosis	Interview length (minutes:seconds)
#1	M	27	White	U	Psychosis	46:59
#2	M	45	White	U	Schizophrenia	91:39
#3	M	20	White	FTS	Bipolar with psychotic symptoms	63:07
#4	M	62	White	U	Paranoid schizophrenia	95:40
#5	F	27	White	U	Psychosis – first episode	36:06
#6	F	55	White	U	Paranoid schizophrenia	59:56
#7	M	45	White	U	Schizoaffective disorder	91:02
#8	M	53	White	U	Paranoid schizophrenia	63:28
#9	M	40	White	U	Paranoid schizophrenia	75:20
#10	F	45	White	U	Psychosis – first episode	46:51
#11	M	54	White	U	Psychosis	69:04
#12	F	29	White	E	Psychosis – first episode	47:32

Ppt. ID, participant identifier; M, male; F, female; E, currently in paid employment; U, not currently in paid employment; FTS, full-time student.

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Procedure

Participants were interviewed alone and in person by the first author. Assessments took place either in the participant's home (n = 8) or at a local health service (n = 4). In two instances the interview took place on the second meeting between the interviewer and the participant; in all other instances the interview took place on their first meeting. The SIMS was introduced as an interview to explore and measure stigma related to psychosis. Interviews lasted between 36 and 96 min (mean = 66 min, SD = 20 min). Participants gave consent for interviews to be recorded and subject to qualitative analysis.

Analysis

Thematic analysis following Braun and Clarke's (2006) approach was adopted because this method is largely "theory-free" and was therefore judged to be suited to secondary analysis of a data set. Transcripts were read and re-read by the researchers and initial coding of successive transcripts was conducted separately and at the manifest level (i.e. interpretation did not extend beyond surface meaning). Further analysis was done through regular group meetings where the meaning of codes was discussed and semantically similar codes clustered into subthemes. Instances of subthemes were compared across successive transcripts. Saturation was deemed to have been reached when the group reached consensus that no new thematic information was being identified in successive interviews. Higher-order themes were proposed, developed and agreed upon by group consensus.

Results

Six primary themes, each comprising 3–5 subthemes, were identified (see Table 3). The following section presents a description of themes and subthemes with illustrative quotations.

Understandings of psychosis

This theme describes how participants perceived others to understand psychosis and their own attitudes and beliefs about stigma related to psychosis.

Lack of understanding. Participants described a general lack of understanding about psychosis among the public; they reflected that they themselves knew little about it before having their own experiences. Misunderstandings of schizophrenia as "split personality" and of psychosis as synonymous with psychopathy were cited. A lack of accurate information about the range of experiences that the term "psychosis" encompasses was felt to reinforce negative stereotypes: "people don't really want to understand what it is […] It's not really explained to people [...] everyone thinks it's the same for everyone" (Participant 1).

Permanence and embeddedness. Participants spoke about how psychosis was viewed as a permanent problem and that the associated stigma was also thought to be permanent: "it's seen to be something that you know you never recover from, you might never recover from, certainly the stigma, the stigma will probably never go away" (Participant 2).

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Table 3. Thematic structure.

Primary theme	1. Understandings of psychosis	2. Experiences of stigma	3. Impacts on self	4. Emotional responses	5. Behavioural responses	6. Impact on recovery
Subtheme	1.1. Lack of understanding	2.1. Treated differently	3.1. Sense of abnormality and difference	4.1. Shame and embarrassment	5.1. Heightened awareness and threat monitoring	6.1. Barrier to Recovery
	1.2. Permanence and embedded/ness	2.2. Treated badly	3.2. Reduced self-confidence & self-worth	4.2. Fear and vulnerability	5.2. Avoidance and social withdrawal	6.2. Making psychosis worse
	1.3. Prejudice and stereotyping	2.3. Social exclusion and increased marginalisation	3.3. Change in identity and self-image	4.3. Worry and preoccupation	5.3. Disclosure, secrecy and guardedness	6.3. Reduced functioning
				4.4. Depression and hopelessness	5.4. Masking / hiding	6.4. Compassion and self-acceptance
				4.5. Anger and frustration		

Participants reported that while negative public attitudes towards mental health problems like anxiety and depression had reduced in recent times, psychosis was viewed as "a different kettle of fish" (Participant 4). Stigma regarding psychosis was thus understood to be more firmly embedded in society.

Prejudice and stereotyping. Public understandings of psychosis were believed to be influenced by negative stereotypes, including those of abnormality, unpredictability and ineptitude. Participants believed that others were likely to pre-judge them based on such stereotypes. Of particular concern was how the mass media perpetuated stereotypes and promoted fear by conflating psychosis with violence and dangerousness:

> ... if I was to go off what I see in the media you often, you never, you don't see much about a schizophrenic who's been working hard for charity and done some really nice things, but you will see one sword-wielding maniac, so I think that could spread fear ... (Participant 9)

Although widespread prejudice and stereotyping was reported, participants highlighted the non-judgemental support they received from loved ones: "the way I feel, as long as my family […], my best mate, a close group, they're alright with it. I can live with that" (Participant 1).

Experiences of stigma

This theme describes participants' lived experiences of stigma and discrimination.

Treated differently. Participants reported that others treated them differently because of their mental health problems. Although perhaps not amounting to ill-treatment, this differential treatment was nonetheless unwanted: "I don't think it's something that they want, to treat me differently but even if they are being nice about it it's still being treated differently" (Participant 5).

Such experiences included family, partners, friends, mental health professionals and other members of the public being patronising, acting warily when around them and a general sense that people behaved "not the same" (Participant 12) towards them.

Treated badly. More negatively, participants described ill-treatment and overt discrimination directly related to their having experiences of psychosis. Examples included being ignored, dismissed, insulted, humiliated, excluded and bullied. Such experiences could have significant impacts on well-being: "my ex-wife, my ex mother- and father-in-law. They were just a nightmare, erm, they would erm, say very demeaning things to me. Erm. It was hell-on-earth actually" (Participant 11).

Social exclusion and increased marginalisation. Participants reported exclusion from social and family circles including having friends "disappear" and family members distance themselves: "it made me feel like an outsider, friends that I had known since 13/14 [...] and 5 years later they didn't want to know me because I'd been inside [psychiatric hospital]" (Participant 6).

Participants reported exclusion from life opportunities and a sense that they were "never going to get the chance" (Participant 12) in areas of life that others took for granted. Such marginalisation was most notable with regards to employment. Being unemployed and reliant on state benefits was a significant source of preoccupation and distress for many and was associated with low self-worth: "I feel a bit ashamed that I'm not working but I can't kind of erm I can't say to people that I am not

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working because I have mental health problems [...] that's a stigma thing" (Participant 8).

Impacts on self

This theme describes how stigma related to psychosis was internalised by participants, with negative consequences for their beliefs about themselves.

Sense of abnormality and difference. Experiencing psychosis and being labelled "mentally ill" left participants with a distressing sense of difference and abnormality: "since they said I've got psychosis, it makes me feel weirder like I stand out [...] like I'm a big, glow-in-the-dark object sort of thing" (Participant 1).

Participants reported feeling different to others, "like a fish out of water" (Participant 11), which put a strain on interactions and created difficulties in day-to-day life.

Reduced self-confidence and self-worth. Public stigma and discrimination about psychosis had a notable negative impact on participants' self-worth: "it made me feel really degraded and downtrodden and it really made me feel pretty worthless and useless that other people can really see me like that" (Participant 11).

Participants spoke of themselves disparagingly and described losing confidence in themselves and their abilities, leading to lowered expectations of life: "I don't think I'm able to do it, I put myself down a bit" (Participant 4).

Change in identity and self-image. Participants reported feeling that they had undergone a change in themselves, their identities or personalities: "I don't feel like I'm the same person anymore" (Participant 5). This sense of a "changed self" was reflected back in the comments and behaviour of others: "my friends always say that I'm not as chatty or as outgoing as I used to be, before I got diagnosed with psychosis" (Participant 10).

Emotional responses

This theme outlines the negative impact of stigma on participants' emotional well-being.

Shame and embarrassment. Participants reported shame and embarrassment related to experiencing psychosis and its impact on their lives: "the embarrassment, I always saw, people talked, they were talking about me, like 'You're a nutcase'" (Participant 11).

This was reinforced through exclusion by others and encouraged avoidance and secrecy in participants: "being kind of ashamed […] I'm not inclined to tell people that … I've been in a psychiatric hospital" (Participant 8).

Fear and vulnerability. The stigma associated with psychosis left many participants feeling vulnerable and a likely target for harm and/or exploitation

> ... you could be victimised and especially, I was living in a council estate just down the road there, and em well any excuse it seems for the locals, mainly teenagers I'd say and maybe a bit older, but to em, to display what would you say, you know hatred towards people [...] so I was then very nervous for myself ... (Participant 9)

Some participants' reported an emotional fragility and lack of resilience; a sense that they would "go to pieces" (Participant 6) if faced with adversity. Avoidance and withdrawal were often ways of coping when feeling thus exposed.

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Worry and preoccupation. Stigma was a significant source of worry for participants who described being preoccupied with what others might be saying or thinking about them. This could become overwhelming: "if you start worrying about what other people think, you just, it spirals" (Participant 12). Preoccupation with stigma was identified as an unwanted accompaniment to improved mental health: "The more I've got myself better, the more I've started thinking about it" (Participant 5). Reducing preoccupation was associated with hope for the future and reduced distress: "You can't dwell on the past, you have to look forward" (Participant 7).

Depression and hopelessness. Stigma was described as a source of unhappiness and low mood, frequently expressed in hopelessness about the future: "it's just another nail in the coffin is stigma" (Participant 4). It contributed to participants feeling pessimistic and reluctant to take chances in life: "you just think "Oh, well there's no bloody point anyway [...] it quite saddens me really" (Participant 2).

Anger and frustration Participants reported that stigma made them angry and frustrated. This could leave them highly-aroused, overwhelmed or depressed: "I get that frustrated, that angry and I've got nowhere to direct that anger apart from inwards, it just sort of all congests in my chest" (Participant 12).

Anger was expressed towards society about the injustices of stigma, and towards mental health systems who contribute to stigma through diagnostic labelling: "I got angry with the psychiatrist when she wrote on my notes 'Paranoid Schizophrenic', I got very angry with her [...] because to me it's a stigma and it's something I don't want to be labelled with" (Participant 4).

Behavioural responses

This theme describes participants' behavioural responses to stigma.

Heightened awareness and threat monitoring. Based on past experiences and beliefs, participants anticipated stigma in interactions with others and reported being on high alert for it:

> ... it makes you more cautious, you don't go into anything with your eyes shut, erm, you make sure you're ready to handle any sort of situation that you might come into, erm, and that's down to stigma in the past making you, you know, relating to the future or the present ... (Participant 7)

This heightened awareness was likened to an "extra sense" (Participant 6) and was described as adaptive, that is, a way to keep safe in a threatening world where the potential to experience stigma was pervasive.

Avoidance and social withdrawal. Participants reported withdrawing from others due to experienced and/or anticipated stigma. They avoided socialising, participating in work or education and carrying out routine tasks. Self-consciousness and fear of prejudice, discrimination and having to make disclosures about their mental health resulted in some participants becoming almost completely withdrawn: "I was diagnosed as socially phobic, em that comes from having no self-confidence it comes from the self-stigmatisation" (Participant 9). Over time, social withdrawal and "self-ostracisation" (Participant 3) resulted in weakened or lost friendships; re-establishing these was perceived as challenging. Forming new relationships was also perceived as difficult because of the risk of rejection: "if I did get into relationships then I could be rejected, that's why I keep myself to myself" (Participant 4).

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Disclosure, secrecy and guardedness. While some participants felt willing and able to talk about their mental health difficulties with others, there was a more prevalent pattern of secrecy, a sense that psychosis was "a skeleton in the closet" (Participant 8) and that disclosure would result in rejection; "the second they'd find out, they'd go running" (Participant 12). Psychosis was described as a taboo subject to be "brushed under the carpet" (Participant 2) lest it shame the person, their family and community.

Autonomy over disclosure was important. Participants reported making limited disclosures; not using the words "psychosis" or "schizophrenia" but talking about experiencing anxiety or depression, because these were perceived to be less-stigmatising mental health problems: "I probably wouldn't mention the schizophrenia word or psychosis [...] it's not something you'd bandy about really, because of the connotations of it [...] but they know like I've got some mental health problem" (Participant 2).

Masking/hiding. Participants described feeling self-conscious, monitoring their behaviour and making efforts to hide distress and external indictors of experiences of psychosis from others. They described feeling unable to be themselves, lest they were judged negatively: "I'm very successful at hiding it from people [...] I'm constantly trying to be somebody I'm not basically" (Participant 4).

One motivation for masking and hiding difficulties was to protect loved ones from burden, distress and potential "stigma-by-association": "you definitely don't want her [participant's daughter] to have a different life than anybody else" (Participant 9).

Recovery

This theme describes how stigma influences the participants' journey of recovery.

Barrier to recovery. Stigma was spoken about as a significant impediment to recovery: "I think it's weighed me down a lot, I think if I hadn't had the responses that I have had through an awful lot of people, I think I would be on the way to recovery" (Participant 6).

Stigma was reported to hinder participants in "getting on" and "getting over things" (Participant 2), thus making recovery more difficult to realise.

Making psychosis worse. Stigma was reported to contribute to participants' experiences of psychosis, particularly fuelling feeling of paranoia: "it's like planting a seed in your brain, [...] you end up like building a plot in your head where em, you get paranoid from it and it's all down to the stigma" (Participant 7).

Voice-hearing participants reported that stigma could trigger an increase in the frequency and intensity of negative voices, which might mock and insult them about their mental health problems: "the louder they get, the more I want to tell them to shut up" (Participant 1).

Reduced functioning. Participants' functioning and ability to carry out "normal daily things" (Participant 5) was compromised by stigma, often due to the aforementioned avoidance and withdrawal it promoted: "I do go to the hairdressers, it takes a lot of strength to get there [...] I really, really have to push myself to go" (Participant 6).

In the long term, this reduced functioning was reflected in some participants' reported sense of "missing out" (Participant 4) on important aspect of life others may take for granted, such as having friends, partners, careers and families.

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Compassion and self-acceptance. Through lived experiences of psychosis and the related stigma, participants reported having developed compassion and understanding for themselves and others in similar circumstances: "I can understand what's going through their mind because of stigma, and they feel like no-one understands them" (Participant 7).

Participants spoke about rejecting stigma and accepting themselves; offering support and understanding to others was said to enhance personal self-esteem and self-acceptance: "it makes me more compassionate towards other people, I like to try and help people [...] I feel like I've given something back" (Participant 11).

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Discussion

Results contribute to the qualitative evidence base and support previous research identifying stigma as a significant concern for people who experience psychosis (Pyle & Morrison, 2013). Participants perceived public understanding of psychosis to be limited and dominated by negative stereotypes. They reported a broad range of negative experiences from many sources. This supports previous research suggesting that stigma is pervasive across the social system and operates through multiple processes (Wood et al., 2015).

This study provides information on internalised stigma and its effects. Stigma was negatively associated with self-image and self-confidence, and increased perceptions of abnormality. Shame, fear, worry, depression and anger were identified as key negative emotional responses to stigma. Previous research has found that service users who feel highly stigmatised are more likely to experience more significant emotional distress (Schulze & Angermeyer, 2003). Negative emotions and changes in self-perception are already highly prevalent in those with psychosis (Birchwood, 2003; Smith et al., 2006). Debate exists in the literature regarding conceptual clarity on the construct of stigma, including whether it can genuinely be separated-out from emotional distress and disruptions to identity/sense of self. Results of this study may be said to illustrate the problem of disentangling the true nature of the relationship between the internalisation of stigma and other psychosocial variables (Livingston & Boyd, 2010).

Results identified behavioural responses to stigma including hypervigilance, avoidance, secrecy and masking. These have been documented as "safety behaviours" in psychosis (Morrison, Renton, French, & Bentall, 2008). Such behaviours have unwanted and sometimes paradoxical effects. For example, it has been identified that maintaining secrecy about diagnoses limits relational closeness and likely compounds isolation and perceptions of difference (Howe, Tickle, & Brown, 2014).

Clinical implications

Stigma was identified as a significant barrier to participants' recovery, with negative impact on psychological well-being (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). It is consequently important for clinicians to routinely assess the role stigma may have in the presentation of people with psychosis, in order to better plan for provision of care. Although further research is required to investigate its validity and utility, the SIMS may be a useful clinical tool to begin conversations about stigma with service users.

Results suggest that reducing internalised stigma may be a worthwhile goal for psychosocial interventions. A number of small-scale studies have explored the impact of internalised stigma interventions, such as psychoeducation and cognitive behaviour therapy (Knight, Wykes, & Hayward, 2006; Lucksted et al., 2011). Evidence suggests that having a more positive way of understanding experiences of psychosis can defend against the pathologising influence of stigma (Brett, Heriot-Maitland, McGuire, & Peters, 2013). Clinicians can play a key role in promoting such understandings to service users, and in recognising harmful conceptualisations within mental health services.

Limitations

This study has a number of limitations. It is a secondary analysis of data collected using the SIMS which was developed as an assessment, rather than a research tool. Themes identified in the analysis reflect the areas of questioning included in the SIMS, which was based on a search of the literature and specifically explored experienced, perceived and internalised/self-stigma. A less-structured interview methodology may have elicited additional unexpected information, so it is acknowledged that these results may not represent the broadest range of service user experiences. Being a secondary analysis, with limited contextual information about the lives of the participants, may have limited the richness and complexity of the results.

The sample comprised individuals who had at least moderate levels of self-stigmatisation and therefore the results of this study do not generalise to all people who experience psychosis. It is possible that those who report high levels of internalised stigma may be more likely to have developed negative coping strategies. This might explain why potentially more adaptive coping strategies (e.g. education, righteous indignation) to mitigate against the negative impact of stigma were not identified. Additionally, although heterogeneous in terms of age and diagnoses, the sample was biased towards males and all participants were of white ethnicity. More research with females and with those from black and minority ethnic communities is needed, given that results highlighted issues of social exclusion and marginalisation, which may be especially pertinent for these populations. Similarly, the majority of participants in the sample were unemployed and thus stigma related to unemployment may have compounded and/or interacted with stigma related to psychosis. A final limitation worth highlighting is that findings were not validated with study participants, nor was a service user with experience of psychosis part of the research team for reflection and input.

Conclusion

In conclusion, this study describes the wide range of negative effects stigma can have on the lives of service users who experience psychosis. The implication is that assessment of stigma should be routine in services so as to inform appropriate intervention. Further research is needed into the most effective ways to reduce stigma in the wider system and to support service users to reduce the internalisation of stigma.

Disclosure statement

No potential conflict of interest was reported by the authors.

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