Lived Experiences of Negative Symptoms in First-Episode Psychosis: A Qualitative Secondary Analysis

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Abstract

Aim: Exploring how negative symptoms are experienced and understood by individuals with lived experience of psychosis has the potential to offer insights into the complex psychosocial processes underlying negative symptom presentations. The aim of the current study was to investigate lived experiences of negative symptoms through secondary analysis of interviews conducted with individuals recovering from first-episode psychosis.

Method: Transcripts of in-depth interviews with participants (n = 24) recruited from Early Intervention in Psychosis services were analysed thematically with a focus on participants' experiences and personal understandings of features corresponding to the negative symptoms construct.

Results: Descriptions of reductions in expression, motivation and sociability were common features of participants' accounts. Several participants described the experience of having difficulty interacting as like being a 'zombie'. Some participants experienced diminished capacity for emotion, thought or drive as underlying these experiences. However, participants typically attributed reductions in expression, motivation and sociability to medication side-effects, lack of confidence or active avoidance intended to protect them from rejection or ridicule, sometimes linked to internalised stigma.

Conclusions: Personal accounts of experiences of reduced expression, motivation and sociability during first-episode psychosis highlight the personal meaningfulness and role of agency is these features, challenging the framing of negative symptoms as passive manifestations of diminished capacity.

Key words: lived experience; negative symptoms; psychosis; qualitative research; thematic analysis

Introduction

Reductions in expression, motivation and sociability are observed across the spectrum of functional psychoses (Lyne et al., 2012). These features consistently coalesce in factor analytic studies (Blanchard & Cohen, 2006) and are collectively referred to as negative symptoms. Negative symptoms are a significant predictor of poor recovery from first-episode psychosis (Austin et al., 2013; Hodgekins et al., 2015; Singh et al., 2000) and are a treatment priority for many service-users (Sterk, Winter van Rossum, Muis, & de Haan, 2013). However, the development of effective treatment options for negative symptoms is hindered by still limited understanding of their underlying mechanisms (Velthorst et al., 2015).

The importance of seeking to understand the experience of psychosis from the perspective of those with lived experience is increasingly accepted (Boydell, Stasiulis, Volpe, & Gladstone, 2010; McCarthy-Jones, Marriott, Knowles, Rowse, & Thompson, 2013). Qualitative methods have been used to provide insights into the experience of positive symptoms (Engqvist & Nilsson, 2013; Le Lievre, Schweitzer, & Barnard, 2011; Luhrmann, Padmavati, Tharoor, & Osei, 2015) and the personal meanings attributed to them (Hirschfeld, Smith, Trower, & Griffin, 2005; Larsen, 2004; Werbart & Levander, 2005). However, how negative symptoms are experienced and understood by individuals with lived experience has so far received little research attention.

Understanding personal constructions of negative symptoms is important given the potential for such understanding to facilitate improved intervention by offering clues to the mechanisms that underpin these debilitating symptoms. The current study aimed to explore how negative symptoms are experienced and understood by those with lived experience of

first-episode psychosis using thematic analysis of interviews conducted with individuals recruited from UK Early Intervention in Psychosis (EIP) services.

Methods

Context

Interviews were conducted as part of the Super EDEN study (Chief Investigator, MB; Qualitative Lead, AL), a follow-up to the National EDEN evaluation of UK EIP services (Birchwood et al., 2014). Participants in the study's qualitative component (n = 207) were invited to be interviewed every 12 months during the two year follow-up period. The study obtained NHS ethical approval before commencing and adhered to Good Clinical Practice guidelines.

Participants and Sampling

Participants were included in Super EDEN on the basis of having met the acceptance criteria for a participating EIP service; no additional inclusion criteria were imposed. The acceptance criteria of the participating services were in line with the Department of Health's Policy Implementation Guidelines for EIP services and included: presence of a psychotic disorder consistent with an ICD-10 diagnosis F20-29; aged 14 – 35 years; and no previous treatment for a psychotic episode.

A purposive sample of transcripts of interviews with Super EDEN participants who participated in the qualitative sub-study described above was defined for the purposes of the

current study. In a prior study (Gee et al., 2016), latent class growth analysis was used to categorise EDEN participants into latent classes according to the severity and stability of their early negative symptoms. To ensure the purposive sample for the current study included participants who had presented with negative symptoms of the full range of severity and stability observed in the wider cohort, participants were selected from across the latent classes identified. The participants sampled from within each latent class were selected based on their demographic characteristics to maximise variation in gender, ethnicity and study site. Participant demographic and clinical characteristics are presented in Table 1. Pseudonyms are used to protect participant anonymity.

[Insert Table 1]

Data Collection

The interviews that generated the data explored in this secondary analysis explored a range of topics, including symptoms, relationships, treatment and recovery. Motivated by a desire to prioritise the interests and concerns of participants, and underpinned by the interpretive qualitative framework of medical anthropology (Bernard, 2006; Lambert & McKevitt, 2002), interview schedules were developed iteratively; schedules were amended to reflect themes participants had guided earlier interviews towards. Schedules were developed in collaboration with a panel of young people with personal experience of psychosis.

Written, informed consent was sought before interviews commenced and reconfirmed verbally after completion. Interviews were conducted by trained research assistants, either in the participant's home or a community venue according to participant preference. They were

designed to take around one hour but varied in length according to the level of detail participants chose to provide. Interviews were audio-recorded and transcribed verbatim.

Analysis

Qualitative secondary data analysis comprises utilising previously collected qualitative data to answer new or additional research questions (Heaton, 2004). Qualitative secondary analysis can generate new insights in a number of ways, including by 'prioritising a concept or issue that was present in the original data but was not the analytical focus' and selecting 'purposively from the sample used in the original study'(Irwin & Winterton, 2011). These strategies were used in tandem in the current study.

A thematic approach to analysis was adopted (Braun & Clarke, 2006; Notley, Green, & Marsland, 2014). Informed by critical realism, which recognises that each individual has a unique experience of reality (Danermark, Ekström, Jakobsen, & Karlsson, 2002), we sought to understand participants' perspectives through close engagement with individual narratives. Consequently, analysis was data-driven with coding drawing on the language used by participants themselves rather than an a priori analytic framework. The coding structure was refined and themes developed with the aid of qualitative data analysis software NVivo (QSR International, 2012). All transcripts were analysed by the first author and a small number of randomly selected transcripts independently analysed by the second author as a cross-check on the quality of the analysis.

Results

The phrase ‘negative symptoms’ featured in the transcripts only once. However, descriptions of experiences corresponding to the negative symptom construct, including diminished expression, motivation and sociability, featured in all but four participants’ accounts. Five themes in participants’ constructions of these experiences were identified: “like a zombie”, diminished internal experience, medication side-effects, “a confidence thing” and active avoidance.

“Like a zombie”

Some participants recounted difficulties interacting with others during their episode of psychosis, often recalling not talking as much as usual. Some described being unable to express appropriate emotions. The simile ‘like a zombie’ was used by several participants when describing these experiences:

> "I wasn't moving, I was sitting down … I wasn't talking. I was just like, you know, like a zombie, just sitting there … I'd just sit down and not interact with anyone". *Aisha, Birmingham*

> "I was just sitting all day and not speaking at all and not showing any reaction when people were talking to me … I didn’t even like say anything when my sister had a baby. I wasn’t even interested. I was just like a zombie". *Jennifer, Lancashire*

Several participants indicated that they felt remote from themselves as well as others during the experience. For instance, Callum commented that he was not himself (*“I’m not me”*) whilst in this zombie-like state. Thus, for some participants, disruption in the ability to interact with others appears to have led to discontinuity in identity.

Diminished internal experience

A small number of participants reported that reduced expression was a result of reduced internal experience. For instance, Clara explained that she struggled to communicate because she felt 'numb' and 'blocked':

> P: "I couldn't really communicate with anybody. Erm it's difficult to describe myself".
> R: "Did you feel locked in? Or?"
> P: "I didn't feel like detached. And I, I didn't feel like anything".
> R: "Sort of empty? Or?"
> P: "Yeah. Erm numb. Blocked. My head was sort of blocked. I couldn't think, therefore couldn't speak, because I didn't know what to say".
> *Clara, Cornwall*

Another participant explained that her lack of emotional expression was symptomatic of a long standing absence of strong emotions, leading to a feeling of being disconnected from her body:

> "Do you know that twin towers, when it crashed, I didn't care. I sat watching it, I was like, oh yeah boring. But now, when I watch programmes on it, I was nearly crying because I was like oh it's so dramatic and emotional and everything. But I remember distinctly when it happened, I just sat there staring … I didn't have any feelings for any of it. It was horrible. It was like I'd been possessed by a demon or something, it was really weird. It was like I wasn't even in my own body".
> *Jennifer, Lancashire*

Similarly, some participants explained decreased motivation as a consequence of a profound reduction in their enthusiasm for life, aligning with characterisations of negative symptoms as indicative of reduced drive and hedonic capacity:

> "you do feel like you've had so much sucked out of you that, it's like that inner child it's a bit like someone's taken it by the neck, strangled it, it's just survived and then shaken it again and then said, right your life's never going to be the same again … we

> go to the park, we go out for lunch, we go into town and go to groups or whatever and I do do that but just not with as much gusto as I did before".
> *Isabella, Cambridgeshire*

Medication side-effects

Participants most commonly understood decreased expression, motivation and sociability to be side-effects of prescribed medications. Participants commented that anti-psychotic medications decreased their drive to engage in activities requiring relatively more effort and energy, imposing a trade-off between controlling positive symptoms and the ability to socialise and participate in activities:

> "Because my thoughts were racing in really weird directions, they thought that a more sedative tablet would be better for me. But, of course, then that meant that I wasn't going out very much. I wasn't socialising. I wasn't really doing the things that may have helped me".
> *Hayley, Cornwall*

For others, lack of motivation was seen as a side-effect of weight-gain associated with antipsychotic use.

> "When I was lighter I was more active and doing loads of things and I had motivation and everything. And now like - my motivation - like before I had loads of motivation. Now that my motivation isn't really there. It's like someone has to push me to do things".
> *Aisha, Birmingham*

"A confidence thing"

Lack of self-confidence was another explanation participants cited for decreased expression, motivation and sociability. For instance, Yasmin spoke about behaving during her episode of

psychosis in ways that she afterward viewed as inappropriate. This led to crippling doubt about her ability to navigate even simple everyday activities and interactions:

> "I don't talk to anybody that much and I haven't got confidence left in me, because I think, 'Oh, my God.' I'm not sure about things which I'm doing. Like, am I not, am I doing right or not, because, you know, like, when you're unwell, you don't realise, do you?".
> *Yasmin, Lancashire*

Whilst Yasmin described a global lack of self-confidence, other participants lacked confidence in a specific domain. For instance, Clara discussed her reluctance to engage in "intellectual" conversations due to reduced confidence in her cognitive capacities:

> "An intellectual conversation with someone, that scares me because I feel like I don't know. And perhaps that's a confidence thing. I know things that they don't know perhaps, but it just seems like I don't have that, that way of being able to process information or to capture the - to have that information that I had before".
> *Clara, Cornwall*

Active avoidance

Participants often presented decreased sociability as a deliberate strategy, intended to protect them from rejection or ridicule. Several participants spoke about deliberately cutting contact with friends or making fewer efforts to form new friendships than they would have done before experiencing psychosis:

> "When I had the psychosis and the problems I cut myself off from a lot of people, I withdrew and I lost a lot of friends through that".
> *John, Birmingham*

Some participants linked their social withdrawal to the stigma surrounding psychosis. Like Ben, most participants expressed that it was not stigma from others, but internalised stigma which contributed to their decision to withdraw:

> "My relationship with, erm, quite a few of my friends has changed in a negative way, and it's not been because of prejudice or lack of understanding on their part, it's because at first I felt very ashamed, and I deliberately cut them out of my life".
> *Ben, Birmingham*

Participants were often acutely aware of negative media portrayals of psychosis and this fed fears about how others might perceive them. Aidan, who spoke about having lost contact with all his former friends, expressed that he believed others would find him *'disgusting'* if he were to disclose his symptoms.

Shame and stigma were also important to some participants' decisions to avoid romantic relationships. Several participants shared Jennifer's dilemma:

> "It'd be really really hard to establish a relationship because you wouldn't know when to say to them, 'I've got schizophrenia' because if you leave it too late, they'll say, 'Oh why didn't you tell me, you've led me on.' And if you say it too soon, they'd never even speak to you because they'll just assume you're mad and it's very very, that's very difficult".
> *Jennifer, Lancashire*

A lack of romantic relationships in individuals with psychosis is sometimes considered indicative of diminished capacity for emotional closeness. However, Jennifer's account offers the alternative explanation that some who experience psychosis may have simply given up hope of establishing an intimate relationship due to the perceived barriers imposed by stigma.

Some participants employed a strategy of avoidance in order to escape negative evaluation of their changed appearance following medication induced weight-gain. For instance, Clara explained that her weight increased rapidly whilst on antipsychotic medication and, as a result, she avoided social situations in order to protect herself from the critical gaze of others:

> I had my episode and was in the ward in London, then came back down. No one knew what had happened to me, but I was huge … I didn't want anyone to see me like that. I know it's sad, but I really didn't".
> *Clara, Cornwall*

Clara described her fear that her sudden weight-gain would alert others to her use of antipsychotics, thus exposing her to potential stigma.

Discussion

In a purposive sample of EIP service-users who followed varied negative symptom trajectories during their first-episode of psychosis, experiences corresponding to the negative symptoms construct commonly featured in participant's pre-existing accounts of psychosis. Participants' narratives challenge the widespread framing of negative symptoms as passive manifestations of diminished capacity, revealing the varied personal meaning of reduced expression, motivation and sociability.

Several participants used the simile 'like a zombie' to describe their experience of having difficulties interacting with the world around them, evoking a sense of otherness. For some, this experience led them to feel remote not only from other people, but also from themselves. Such accounts suggests that European phenomenological approaches to psychosis (Bürgy, 2008) may continue to be of relevance in understanding the subjective experience of negative symptoms. These approaches suggest that negative symptoms are not inherent deficit states

but are instead characterised by positive experiential disturbances stemming from core disturbances in the sense of self (Sass & Parnas, 2003).

Participants offered varying explanations of the negative symptom-like experiences they described. Consistent with research carried out with individuals with more chronic psychosis (Boydell, Gladstone, & Volpe, 2003; Le Lievre et al., 2011), reduced communication and lack of motivation were often viewed as medication side-effects. As such, it is possible that the experiences described by some participants do not relate to primary negative symptoms but to negative symptoms secondary to medication side-effects.

Some participants described decreased emotional experience, capacity for thought or drive as lying behind changes in their behaviour. This echoes Krupa et al.'s (2010) finding that some individuals recovering from psychosis describe a deadening of emotions and increased apathy, turning participation in previously valued activities and social interactions into experiences to be endured. Participants also identified lack of confidence as a reason for negative symptom-like behaviour. Previous psychotic symptoms and the perception of decreased cognitive capacities undermined participants' confidence in their abilities, leading to decreased activity and interaction. This finding supports quantitative evidence that pessimistic assessments of cognitive and social capabilities may be implicated in negative symptom maintenance (Campellone, Sanchez, & Kring, 2016; Oorschot et al., 2013).

Active avoidance was also frequently recounted. Several previous studies have identified withdrawal as a strategy used by individuals experiencing psychosis to minimise potential embarrassment or rejection (Boydell et al., 2003; Judge, Estroff, Perkins, & Penn, 2008; Mauritz & van Meijel, 2009; Redmond, Larkin, & Harrop, 2010). The apparent contribution

of internalised and perceived stigma to some participants' active avoidance is in accord with previous research suggesting that withdrawal is a common reaction to feeling excluded from society as a result of mental health problems (Boydell et al., 2003).

These findings highlight the role of agency in negative symptom presentations, echoing Corin's reframing of negative symptoms as 'positive withdrawal' (Corin, 1990): a recovery strategy characterised by the deliberate maintenance of distance from normative social roles and relationships. They also intersect with cognitive models of negative symptoms which contend that apparent deficit presentations are often underpinned by active psychological processes (Rector, Beck, & Stolar, 2005; Staring, Ter Huurne, & van der Gaag, 2013).

Limitations

Since the study used qualitative secondary analysis, participants were not specifically asked about their experience of negative symptoms. Had an interview schedule specifically designed to elicit accounts of negative symptoms been employed, further insights might have been gained. However the use of secondary data also conferred advantages, making it possible to observe the extent to which negative symptoms were brought up spontaneously and the explanatory frameworks used by participants themselves.

The timing of data collection could also be considered a limitation. Participants were interviewed for the first time towards the end of their time with EIP or following discharge, in some cases several years after their index episode. It is possible this hindered participants' ability to recall their experiences. However, time having passed since the onset of their psychosis might also have afforded participants more time to reflect on their experiences.

Clinical Implications

The findings indicate the potential value of exploring clients' personal understandings of their negative symptoms and suggest that particular attention should be paid to the possible impact of medication side-effects, diminished internal experience, low self-confidence and avoidant coping strategies. Clinicians should also consider the possible contribution of internalised stigma to negative symptom presentations. That participants often described active psychological processes as underpinning the negative symptom-like experiences they described supports the potential for tailored psychological interventions to ameliorate negative symptoms.

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Tables

Table 1. Sample demographic characteristics and mean negative symptom severity scores

Pseudonym[a]	Study Site	Ethnicity	Age[b]	Mean Negative Symptom Score[c]		
				Baseline	6M	12M
Daniel	Norfolk	White British	20	4.00	4.43	4.00
Max	Cheshire	White British	27	4.00	3.43	2.71
Nathan	Birmingham	White British	26	3.43	3.29	2.57
Yasmin	Lancashire	Asian Pakistani	28	1.57	3.29	2.57
Tom	Cambridgeshire	White British	20	1.71	2.29	2.14
Hayley	Cornwall	White British	28	3.00	2.86	2.86
John	Birmingham	White British	31	2.57	3.00	2.57
Jacob	Birmingham	Black Caribbean	28	3.43	3.43	1.00
Aisha	Birmingham	Asian Pakistani	28	3.29	2.00	1.43
Oliver	Cornwall	White British	30	3.14	1.29	2.00
Stacey	Cornwall	White British	27	4.29	2.29	1.29
Aidan	Norfolk	White British	25	3.00	3.43	2.14
Steve	Lancashire	White British	27	2.86	3.71	2.14
Philip	Norfolk	White British	37	1.00	1.29	1.29
Nazir	Lancashire	Other Asian	21	2.29	2.29	1.86
Alexander	Devon	Other White	32	1.00	2.57	1.00
Shelly	Birmingham	Black Caribbean	28	1.29	1.57	1.29
Isabella	Cambridgeshire	White/Asian	35	1.57	1.14	1.14
Jennifer	Lancashire	White British	30	2.14	1.57	1.00
Ben	Birmingham	White/Caribbean	27	2.43	1.57	1.14
Kelly	Norfolk	White British	22	1.43	1.57	1.71
Clara	Cornwall	White/African	30	2.14	1.00	1.00
Jack	Cambridgeshire	White Irish	29	1.71	1.00	1.00
Callum	Cheshire	White British	27	1.14	1.00	1.00

[a]Pseudonyms are used throughout to protect the anonymity of participants.

[b]Age at initial interview.

[c]Mean negative symptoms score (min 1; max 7) for the seven PANSS items ('blunted affect' (N1), 'emotional withdrawal' (N2), 'poor rapport' (N3), 'passive social withdrawal' (N4), and 'lack of spontaneity and flow of conversation' (N6), 'motor retardation' (G7) and 'active social avoidance' (G16)) found to indicate the negative symptoms construct in a factor analysis of data from the EDEN cohort.