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Experiences of psychosis may increase isolation and stigma, increasing negative perceptions of oneself. Social networks can be a source of support and strain in dealing with these difficulties. This research explored how individuals with experiences of psychosis make sense of their social relationships.

Interpretative Phenomenological Analysis guided design and conduct of semi-structured interviews with 7 Scottish mental health service-users with lived experience of psychosis, exploring positive and negative aspects of relationships and how they influenced personal recovery. Interviews were audio-recorded, transcribed and coded for subordinate and superordinate themes.

The superordinate theme, “She is more about my illness than me” highlighted normalisation of participants’ illness identity through family and support staff dominating social networks; their primary orientation being towards illness management. Subordinate themes; “without [Service] I wouldn’t know what to do”, “They wouldn’t talk, they will sort of control me in a way” and “She doesn’t see me as normal either with me getting help” evidenced benefits and tensions associated with these relationships.

The composition and nature of social networks can prevent individuals with experiences of psychosis from exploring identities unrelated to illness. Further research must identify ways to empower individuals and promote connectedness independently from illness management.

**Keywords:** psychosis, social support, relationships, illness management, identity
Introduction

Experiences of psychosis can be distressing and lead to significant disability (Oh et al., 2018). Social connectedness is recognised as being central to personal recovery (Bird et al., 2014). Reduced social networks are common and can influence feelings about oneself, and the resources one can mobilise to manage mental health difficulties (Palumbo et al., 2015). Accompanying reduced social networks, individuals may have less desire to engage with others (Galderisi et al., 2018) and difficulties synthesising information necessary to interpret social situations (Lysaker et al., 2011). Clearly, both reduced social networks and personal challenges to social interaction have a negative impact, yet first-person accounts of the influence social networks and psychosis have on each other are comparatively under-researched. Researchers have called for exploration of how individuals experience social relationships (Thornicroft et al., 2016), which may play a significant role in identifying how social connectedness can be increased.

Poverty, disrupted education and trauma, in childhood and through interactions with psychiatric services as adults, may limit the opportunities individuals have to engage in positive social relationships (Stain et al., 2012; Sweeney et al., 2018). Additionally, discrimination and victimisation are more commonly reported by individuals with psychosis than the general population, and this has been linked to their greater social distance with those close to them and wider society (de Mooij et al., 2015; Webber et al., 2014). Experiencing discrimination has also been linked to social anxiety and negative symptoms, including low motivation for social situations (Lysaker et al., 2010). Thus, individuals’ limited social opportunities, compounded with previous negative experiences, may lead to negative anticipation and further difficulties forming positive connections.
Many individuals with experiences of psychosis have fewer relationships, predating symptom onset (Gayer-Anderson & Morgan, 2013). Reduced social networks are associated with increased perceptions of loneliness, negative beliefs about oneself and others and feelings of low self-worth in social contexts, impacting on individuals’ anxiety, paranoia, and perceptions of self-efficacy (Lim et al., 2018; Jaya et al., 2017). These difficulties indicate that social networks might influence elements of personal recovery often unrelated to symptoms of psychosis. Social network composition appears an important contributor to disability, with fewer friendships/acquaintances detrimentally effecting psychosocial functioning (Erickson et al., 1998), and worsening as experiences of psychosis become longer-term (Degnan et al., 2018).

Social support, where interpersonal relationships offer practical and emotional resources, can buffer stress and positively influence psychological wellbeing (Thoits, 2011). Yet understanding how relationships influence personal recovery is complex. Aldersey and Whitley (2015) interviewed participants, including individuals with experiences of psychosis, and found supportive social relationships often facilitated improvements in individuals’ mental and physical health. In particular, being able to have conversations or undertake tasks unconnected to coping with mental illness facilitated recovery. However, participants added that mainly family, where they didn’t show understanding of their illness, were also a source of strain. This suggests that interpersonal relationships both positively and negatively influence individuals making sense of their identity, however this hasn’t been explicitly researched in this population.

This qualitative research investigated social relationships in mental health service-users living in the community with experiences of psychosis. It aimed to explore the positive and negative aspects of interactions and how participants’ meaning making about themselves and their personal recovery was impacted.
Method

Design

Interpretative Phenomenological Analysis (IPA) guided study design and analysis. This idiographic approach attempts to remain close to participants’ lived experience in the analysis (Smith et al., 2009) and appeared most appropriate to meet our aims. Semi-structured interviews were selected to allow exploration of participant experiences and conducted according to IPA guidelines.

Participants and recruitment

Participants were recruited by convenience sampling from a local mental health support service in Glasgow, Scotland. Support staff identified individuals meeting eligibility criteria, including having experiences of psychosis and mental and legal capacity to take part, and contacted them with leaflets describing the study. Although mental health diagnoses were not formally assessed, all participants contacted openly identified with experiences of psychosis, specifically diagnoses of schizophrenia. Interested individuals’ details were passed to the researcher, or potential participants could contact directly if desired. As IPA is suited for small samples (Smith & Osborn, 2008), we aimed to recruit 6-10 participants.

Procedure

Participants chose whether the interview took place at home or in the support centre, with all preferring a home visit. Choice over caregiver presence or absence seemed appropriate (Smith & Osborn, 2008), and one participant asked her husband to be present. The first author developed the interview schedule through reviewing literature and generating relevant topics. The first author conducted the interviews, asking
participants to explore positive and negative elements of their social relationships, how they made sense of their experiences and whether they felt they affected their recovery. Although the schedule aided exploration of the research questions, participants were encouraged to deviate in order to fully explore experiences.

To further exploration, participants were invited to construct a relational map using cardboard figures representing individuals important to them. The first and fourth author developed this to encourage visualisation and tracking of relationships; explore feelings of connectedness; differentiate between individuals and account for changes in feelings by allowing alterations of persons’ placement, without the need for drawing as in other techniques inspiring this methodology (Bagnoli, 2009). This was anticipated to allow a flexible and externalised exploration of potentially emotional experiences. Relationships identified in previous literature (i.e. family, friends, community members, and staff) were highlighted to increase the likelihood that the map was representative of participants’ lives. Interviews lasted between approximately 20 minutes and 1 hour and 20 minutes based on how long participants felt able and wished to continue. Interviews were recorded for transcription purposes and photographs were taken of each participant’s map.

Ethical considerations

This research received ethical approval from the University of Glasgow and managerial approval from the mental health service participants were recruited from. Participants provided informed consent, including permission for anonymised quotations to be used in any report. Participants were not obligated to participate and could withdraw at any time, and were offered no incentives to take part. After interviews the researcher highlighted their contact details, and encouraged discussion with support staff and processes for crises management in accordance with participant’s care plans if they felt
negative effects from taking part. None were reported. Participants were provided with a summary of the study’s results and a photograph of their relationship map.

**Data management and analysis**

Interviews were recorded, securely stored and destroyed after transcription. Transcriptions were anonymised, participants and their social networks given pseudonyms, and prominent place names omitted. Analyses followed IPA procedures (Smith & Osborn, 2008), with review and re-review of transcripts aiming to bring awareness of the meaning making ascribed to participants’ experiences and the impact this had on generating themes. Transcripts were annotated on a line-by-line and case-by-case basis, and to increase the trustworthiness of these interpretations (Yardley, 2008), the third author’s independent analysis of 4/7 transcripts was compared to analysis by the first author. The emergent themes were discussed by the first, third and fourth authors, with continual comparison between final and emergent themes and the raw data to explore differences in interpretations. The first and fourth author completed the write up of the data, where interpretation continued and final themes were agreed upon. There was not sufficient time within project constraints to discuss results with participants.

**Results**

Of 8 individuals contacted, 7 consented to participate in the research, comprising three females and four males aged between 36 and 64. When asked about recovery, some indicated they perceived mental health stability as indicative of recovery, and others believed recovery to be impossible for them. Participants highlighted social relationships including those with family and mental health professionals. As interviews progressed, additional people participants valued interacting with were added to their social network maps. One interview was excluded from analysis due to excessive
prompting by the interviewer and monosyllabic responses, where complete social networks and reflections on these could not be established. A full account of included individuals’ social networks established in interviews are described in Table 1.
Table 1. Social networks of included participants:

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Those Initially Placed In Social Network</th>
<th>Those Not Initially Placed In Social Network but Later Mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ashley</td>
<td>Female</td>
<td>50</td>
<td>Local Cafe Owner Support Worker 5</td>
<td>Husband’s Mum Previous GP Cat CPN 1: Angie CPN 2: Kerrie Friend</td>
</tr>
<tr>
<td>Michael</td>
<td>Male</td>
<td>61</td>
<td>Sister 1: Cheryl Support Worker 3</td>
<td>Support Worker 2: Support Worker 4 Ex-Boyfriend Father</td>
</tr>
<tr>
<td>Umur</td>
<td>Male</td>
<td>54</td>
<td>Aunt: Social Worker</td>
<td>Support Worker 1: Support Worker 2: Scott Support Worker 4</td>
</tr>
<tr>
<td>Helen</td>
<td>Female</td>
<td>64</td>
<td>Daughter: Granddaughter</td>
<td>Support Worker 1: Support Worker 2: Support Worker 3 Support Worker 4</td>
</tr>
<tr>
<td>Martin</td>
<td>Male</td>
<td>36</td>
<td>Daughter: Support Staff</td>
<td>Support Worker 1: Support Worker 2: Support Worker 3 Brother</td>
</tr>
</tbody>
</table>

Groups: Support Staff, Family

Gender Not Specified: Psychiatrist, Consultant

* Categorisations reflect whether an individual or group was referenced, and to reflect gender where specified, to give additional context to un-named individuals.
“She is more about my illness than me”

The superordinate theme (represented by this quote from Gemma, P6,L7) emerged from the context in which social relationships took place, and highlighted how “the illness”, an object which served as a source of need and disability, was the main focus of the majority of participants’ relationships. Family members and mental health service support staff tended to dominate participants’ social networks, and these relationships were most extensively discussed.

Participants described a range of practically and emotionally oriented interactions related to managing life with a mental illness, including how mostly support staff “sorted out my finances”; “supports me with shopping”; “helps me about the house”, and “got medication for me”. Participants also highlighted how these individuals “keep me companion” and “reassure me”. In this sense, the primary function of most relationships perhaps inadvertently maintained the role of the participant as being in need of support, and participants taking a less active role in managing their affairs.

In discussing involvement in the lives of network members, reciprocity of providing support was limited, and only one participant described providing support to family members. Most participants acknowledged that their relationship with support staff had a professional capacity which perhaps limited opportunities to reciprocate support. Still, participants enjoyed learning about the lives of staff members, showing their understanding, and giving them small gifts such as food. This suggested that participants valued playing an active role in their relationships within these limitations.

It was striking, given the relative absence of similar experiences across interviews, that participants only discussed a few instances where family in engaged in roles unrelated to specifically supporting them with their mental health problems:
She just does what sisters do, your hair, dyes my hair, dries it up and things –
Gemma (P8,L3-4)

Friday night we have a movie night, that kind of thing. And that’s good fun –
Martin (p5,l15–P6,L1)

All but one participant identified at least one friend when describing instances of social support. None of these individuals were initially included in participants’ social network maps. It unfolded that many of these friendships were historical or referred to “my friends” generally. To further illustrate this point, only two participants described details of activities involving friends:

*We do a lot of watching telly... Maybe it’s programmes that I don’t watch but I will just sit with her just for the sake of having company –* Helen (P28,L2-5)

*Meet up every week and do stuff like go shopping and other stuff as well like watch movies and things –* Martin (P3,L10-12)

The absence of opportunities to engage in activities out with the role of being ill further illustrates how participants networks lacked interactions placing them in an active role not predominantly focused on managing mental health difficulties.

Throughout these descriptions it became clear that this context influenced participants’ perceptions of the social world, themselves and their capabilities, including their ability to take on non-illness related roles. Resultantly, three subordinate themes discussed below were identified, which highlighted the dependence on these relationships and therefore importance of their reliability; of autonomy in these relationships; and difficulties participants encountered in “appearing normal”.

*“Without the service I wouldn’t know what to do”*

This theme, highlighted by the quote above (Ashley P27,L22-23), is about the
importance of relationships having consistency, reliability, and regularity as a function of providing emotional support. It illustrates how participants relied on support from family and support staff to complete daily tasks such as “get round the supermarket”, and cope with difficult experiences such as feeling paranoid or anxious. When they had to “deal with this myself,” things could be difficult, and services in particular could be used “as a crutch” to cope. Having the support of family and support staff was therefore highly valued, and participants highlighted how support from those they could rely on consistently was intrinsically linked to feeling safe:

*I feel safe with Rick. I don’t like going out on my own. Because I get lonely you know* – Ashley (P18,L10-12)

Michael didn’t have much contact with family and friends and therefore his comment that “in a simple way they reduce my upsetting side of my mental illness. They reduce that because all I need to do is think of them” – (P50,L2-4) was very striking.

Here, relationships were key to reducing feelings of isolation:

*Family. They are all I have got... I have got [service], I am used to [service]. They are like family... I would be very cut off on my own without them* – Helen (P21,L11-P22,L3)

A key domain of support was the consistency and regularity of support from others. Martin emphasised the importance of regularity:

*that's one of the reasons we're constantly, kind of, well my mum and dad they're phoning me quite a lot and I phone them, I phone them every week and we arrange to meet up and that and then I'm talking to my sister on WhatsApp and all these things... and so I think that we're in kind of a habit of getting into regular kind of communication with each other* – Martin (P24,L4-13)
In contrast, when Michael placed one of his relationships away from the centre of his network he said: “I have said things to him and nothing has happened ... he said that he would contact social work and let her know about the chair not working.” (P8,L5-11). Inconsistent support highlighted to Michael aspects of his relationships, which dissatisfied him, and sometimes resulting in conflict:

*In the past I upset Lyndsay a lot over the phone... I made the slight something like this: ‘maybe if they were more concerned about me I wouldn’t be feeling like this’. Very selfish. I remember I was on my own all the time and that’s not to make up an excuse to send her a text like that but that’s where she will turn round and say everything is a lot of crap.* – (P40,L1-11)

Umar, who felt unable to rely on family, felt this contributed to his increased independence:

*I’ve got 40 years and I am on my own and I have just kept myself because I can’t say anything or be argue or be myself and tell them off.* – Umar (P27,L2-4).

Overall this suggests that participants placed high reliance on their social networks, and in turn strong feelings of dissatisfaction were evoked when support was inconsistent.

*“They wouldn’t talk, they will sort of control me in a way”*

This theme, represented by Umar’s above quote (P28,L3) highlighted the importance of feeling in control. Very few participants discussed times they felt entirely in control of decision-making, with only one participant (Martin) highlighting an active role in this through him and a family member deciding on activities “as a pair”. One salient example indicating that expectations for control in decision-making might have been generally low included Ashley, who after rejecting the option of going to hospital recounted the alternative offered to her by the Crisis Team was to increase her
medication while she rested in the house. As a result of this, Ashley felt reassured that her considerations had been taken into account and was satisfied with the overall outcome, although this alternative did not offer an opportunity for full control in decision-making. Ashley described how the positive outcomes she saw from speaking about her health with services and family made her more willing to speak about difficulties early on:

> See when I get unwell X.X., I contact [SERVICE] when I get really unwell, I don’t keep it boiled up inside me I let the lot out and I tell Patrick. – Ashley (P32,L3-6)

Across participants, the majority of decision-making appeared to take place with service users or family members being in control. Participants met these experiences with mixed responses, including highlighting the benefits of others taking over activities on their behalf such as being able to “get to all of my appointments”, and being “no longer in control of pain”. Participants did not express much reflection on what contributed to their lack of involvement in decision-making. One participant who did, felt he was to blame:

> I feel as if she is taking over maybe, taking the mother role, the parental role. Maybe I am too and have been too soft where she’s more or less to say you have not said anything so I will just say and do what I want. – Michael (P31,L1-4)

This perhaps indicated that, at least for Michael, being active in decision-making felt blocked because his views were no longer sought, and he implicates himself in this. Yet there was little acknowledgement of how difficult this could be. Sometimes, taking control in decision-making appeared blocked because participants saw others as a more reliable witness of changes in their mental health than they were:
I think since I got Leanne the support worker, I am much better and I can’t say but my doctor can. - Gemma (P14,L5-6)

It therefore seemed that most participants relied on others’ involvement during decision-making, and the lack of participants’ control in this process was to some extent normalised, which was perhaps entwined with participants’ lack of confidence in expressing their views. Some participants expressed dissatisfaction with their lack of control in decision-making. Umar did not tend to be involved in decision making about his health:

if I am out of character and they would go down to [Resource Centre] and report to my psychiatrist and my psychiatrist would come up here and section me and bung me into hospital. That’s what I have learned over the years that’s what family is like and that’s why they are not supportive. – Umar (P27,L6-11)

Lack of involvement in decision-making processes led to some participants having less positive perceptions of family and support staff and, in some instances, distancing themselves from those people. This happened in multiple ways, with Umar, for example, having significantly reduced family contact due to feelings that “they have got their problem and they don’t understand that they are not helpful” (P42,L1-2).

Ashley described how an experience of not being listened to about her desire to change medication led her to disengage from support completely:

I said I am getting no help from you at all, you seem to put my medication up and I am like a complete zombie. I can’t do my shopping and I can’t keep my house clean, I can’t do this and I can’t do that. She said I am sorry you feel that way. I said just get out and I got myself another CPN. – Ashley (P37,L15-20)

This highlights that although participants discussed similar decisions in relation to their illness, such as changes in medication and hospitalisation, how this was
communicated was integral to whether participants perceived these acts as controlling. To what degree participants appeared confident in expressing their views appeared linked to whether they subsequently modified their interactions when participants lacked control.

“*She doesn’t see me as normal either with me getting help*”

This theme, represented by Helen’s above quote (P17,L8-9), highlights participants experience of “stigma”, where critical comments made them feel judged and ultimately, not “normal”. This unfolded in a context where participants’ relationships function in part so others can monitor their mental health, and participants felt it necessary to managed others’ impressions of them.

Gemma for example described how a family member saw her behaviour as childlike, “*saying no listen you will need to waken up. yeah mum does that and she says you have went the way back to when you are ten*” (P14,L12-14). In comparison to these statements when a support worker told Gemma “*you are stable with your mental illness and that’s about all she said*” (P14,L15-16) this had a significant influence on Gemma’s sense of self and her relationship with this person. Ultimately, for Gemma this signified being treated “*like a normal person really and not mentally ill*” – Gemma (P5,L9-10).

Umar described his experience of unfavourable social comparisons:

> and now they don’t respect you they lower your dignity like mocking you up making fun and laughing and taking the mickey in other words. Things like that not respecting you because they have houses and they have jobs in restaurants and they are married or they can have a car and they think that is all successful but to me I’ve got 40 years and I am on my own. – Umar (P26,L11-P27,L3)
These experiences affected how participants acted around family and support staff, with a strong desire to appear normal being highlighted. This was most noticeable in participants’ own monitoring and change of their behaviour in response to others:

*I find out what she is doing and go from there how I should behave* – Helen (P27,L8-9)

*I have learned from that experience just to keep quiet and get on with it* – Umar (P29,L6-7).

At times this resulted in conflicting experiences for participants. Michael mentioned that he avoided discussing his mental health despite acknowledging that this was a large part of his life:

*Everybody knows I have got the problem but if I am not talking about it to them I don’t have a problem but there in lies the problem because what do I talk about?* – (P12,L18-21).

Similarly, Umar highlighted that he could not share with family his desire to undertake roles out with that of being ill, because his family would perceive this to mean he was unwell:

*If I said to him I am going to do my highers, go to college, do my [COURSE]. He would be like you can’t do that you are over it… I say that I can’t express myself to my family because they will then report me* – Umar (P36,L9-14)

Participants’ avoidance of discussing their true reflections appeared to fulfil more than just the role of avoiding criticism, but particularly for Helen it served to avoid relationships ending because of negative perceptions of her illness:

*I think about them a lot… How I appear to them and that I am not too bad, not much Jamie as Debbie, how bad I appear* – (P9,L7-10) …
I couldn’t imagine not having them and I worry that Debbie you know cuts me off – (P19,L10-11)

Even in relationships where she felt understood, Helen perceived this to be related to other individuals’ ability to tolerate her behaviour and seemed less about having a shared experience between her and these individuals:

*I don’t worry what they think of me. They are used to people like me…. They are more understanding, I won’t get slagged… If I get a bit annoyed or upset. They wouldn’t hold it against me.* – (P10,L13-P12,L14)

This suggests that disclosure in participants’ relationships was mostly contingent on the level of stigma and monitoring they experienced. Expectations of critical commentary influenced participants’ level of self-disclosure and often this felt at odds with steps they wished to take to improve their mental health. Additionally, the absence of criticism was often seen as sufficient for relationships, but there was little evidence of how this improved the ability of participants to fully express themselves.

**Discussion**

This research aimed to explore positive and negative aspects of social interactions and how relationships impacted on participants’ meaning making about themselves and ultimately their personal recovery. Participants valued receiving emotional and practical support, and consistency, regularity and reliability of support determined participants feelings of safety and isolation. Lack of this, and other aspects of social interactions, particularly stigma and monitoring, appeared to influence participants’ desire to modify their behaviour in order to reduce contact or appear “normal”. Yet lack of involvement in decision-making, and non-illness related interactions further normalised participants identities as being ill, and they had low confidence in their judgement of their health, and limited expectations for change or recovery. Arguably, this context also provided
limited opportunity for participants to act assertively, with withdrawal or ending of relationships sometimes being the only way participants appeared to meet some of their needs.

**Interpretation of findings**

These findings are consistent with other studies identifying positive and negative aspects of social relationships. Cavallo et al. (2016), for example, suggests relationships are most supportive of recovery when they are tailored to the needs of individuals when they need support. Equally, stigma has been shown to impact on self-esteem and hope (Lysaker et al., 2007), which are identified as important components for personal recovery (Bird et al., 2014). This suggests that while the presence of close relationships may facilitate connectedness, this alone is not necessarily sufficient for personal recovery, and in many cases, social relationships in the current study may have even contributed to poorer recovery outcomes.

Service disengagement has also been linked to similar factors in previous research, including whether individuals felt their wishes, experiences and views of illness had been acknowledged in decision making (Priebe et al., 2005). The current study demonstrates a further distinction between disengaging from services in these contexts, and the detachment that may occur when participants are too reliant on services to disengage. While detachment may less noticeably effect service utilisation, the factors leading to participants detaching from services appeared to profoundly affect identity and personal recovery.

**Implications for practice**

To identify ways of rebuilding positive social identities, work is needed across families, communities and services rather than focusing exclusively at the individual level to
promote recovery (Tew et al., 2012). Within services, a partnership model of therapeutic decision making is increasingly recommended as an important way of helping individuals act more autonomously (Priebe et al., 2005; Dixon et al., 2016). The need to experience roles unrelated to being ill perhaps suggest a need for peer support, which has been identified to help individuals engage more with the community and improve self-efficacy (Gillard et al., 2015; Mahlke et al., 2017).

**Strengths and limitations**

The level of engagement with the cardboard figures indicates that the methodologies used encouraged visualisation and reflection, supporting participants to elaborate on a nuanced representation of their social relationships. In this sense, these findings may inform clinical practise for a group whose views have been historically under-represented (Sündermann et al., 2013).

However, this sample was a small group receiving long-term support from a third sector organisation supporting community integration and preventing rehospitalisation. Therefore, these findings are not necessarily applicable to other persons recovering from experiences of psychosis, including first episode psychosis, or when living independently from community services. Caregiver presence in one interview may have also influenced that participant’s report, however as this participant felt uncomfortable being interviewed alone, refusing caregiver presence would have resulted in losing her valuable contributions. Notwithstanding, the interview setup apparently allowed this participant to explore experiences, many of which could be perceived as portraying social networks in a non-desirable way, although negative experiences with her caregiver directly may have been avoided.

This study relied on verbal expression of relationships, where other methodologies may have been more effective in understanding these phenomena, (e.g.
photo elicitation, ethnography). Involvement of individuals with lived experience in design and analyses may have also improved this work.

Conclusion

This study found that for individuals with long-term experiences of psychosis, social support was associated with positive outcomes, including feelings of safety and being less isolated. However, the dominance of family and support staff relationships which were illness-oriented, and which in turn participants depended on, resulted in participants role of “being ill” becoming normalised. Furthermore, feeling “normal” was limited by experiences of stigma, monitoring and lack of autonomy and at times these experienced lead to distancing or disengagement from relationships. In order to build relationships which are supportive of recovery, researchers and clinicians should consider the role of peer support and shared decision-making to promote empowerment.

References


