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Social Networks and Psychosis

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Submitted in partial fulfilment of the requirements for the degree of

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College of Medical, Veterinary and Life Sciences

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FOREWORD – COVID19-RELATED VARIATIONS

The Covid19 pandemic and associated restrictions resulted in some deviations in the MRP project design from the originally planned study (ie. Chapter 2).

Our study initially aimed to recruit a larger sample of at least six young people with experiences of psychosis, across three main settings: early intervention services, (intensive) child and adolescent mental health teams, and local adolescent inpatient unit. Despite significant efforts to recruit, the services in which our recruitment took place experienced some of the most significant strains and adaptations in response to the pandemic and associated regulations, and were thus limited in the extent to which they could contribute to recruitment. Therefore, we required to continuously monitor and adapt our timelines. We have collected high quality, rich, in-depth data towards the intended work, but the amount of the data differs from what was planned in the initial proposal. The limited data set and tight time pressures also had an impact on data analysis. We did not complete the proposed quantitative social network analysis or qualitative structural analysis of the visual network maps. However, this allowed us to focus on reaching depth and quality of analysis of the qualitative interviews instead. Limitations of the analysis and resulting interpretations are addressed.

CHAPTER 1

A systematic review and meta-synthesis of qualitative studies exploring peoples' first-hand accounts of social networks in psychosis

Prepared in accordance with the author requirements for the Frontiers in Psychology Journal (Psychology for Clinical Settings) for Systematic Reviews <u>https://www.frontiersin.org/about/author-guidelines</u>

1. ABSTRACT

Background and Aims: Social connectedness is essential in recovery. In psychosis, people often report smaller network sizes, loneliness and difficulties with social integration. An interest in exploring these qualitatively emerged recently. Synthesizing such findings can highlight recurring themes and discrepancies across settings, stages of illness and age. We aimed to systematically retrieve, critically appraise and meta-synthesise qualitative research on types and subjective experiences of networks in psychosis across the lifespan and illness stages. Method: We conducted a thematic synthesis of 15 studies identified across major electronic databases from inception to September 2021. **Results:** We identified three broad themes: 1) people presented with key profile features of social networks, including dominance of family, professional and other service-user networks, pervasive social difficulties, and post-traumatic growth; 2) networks acted as a gateway to practical, emotional or socialisation resources, and also dynamically took on new roles in absence of other networks; and 3) participants experienced power imbalance in relationships with networks focusing primarily on illness, limited opportunities to reciprocate, high control from others, stigma and negative experiences of disclosures. **Conclusions:** Networks across systems influence recovery negatively and positively in complex ways. Changes over time, post-traumatic growth and the adaptability of networks to supplement each other support the role social integration has in recovery and beg for development and evaluation of multi-system social network interventions.

Keywords: qualitative meta-synthesis; thematic synthesis; lived experience; social networks; social capital; psychosis; schizophrenia; recovery.

2. INTRODUCTION

Psychosis and/or schizophrenia describe a group of symptoms characterised by altered or distorted perceptions of reality, disorganized communication and reasoning, reduced motivation, or blunted affect (Saha et al., 2005). Although low in prevalence as compared to other mental health difficulties, they are major contributors to the global burden of disease, affecting people across areas of functioning, physical health and quality of life, and ultimately reducing life expectancy (Saha et al., 2005; Brooks et al., 2022). Promoting recovery is thus essential and the interpersonal environment is one key target for supporting recovery.

Although conceptualisations of the interpersonal sphere are heterogenous, including often interchangeably used terms such as social networks, social relationships, or social integration/isolation (e.g., Palumbo et al., 2015; Wang et al., 2017), this review focused on Social Networks (SNs). We considered SNs as an umbrella term comprising the set of significant social relationships an individual is directly involved with. Social relationships in turn refer to interpersonal connections 'characterised by repeated interactions between the dyad members and a mental representation of the relationship' (Wrzus et al., 2013, p53), definition with excludes fleeting, incidental interactions. Social relationships are both impacted by and influence the wider SNs they belong to, social activity and social support. For example, an individual could have a poor social relationship with a partner but a supportive friendship network, overall feeling socially integrated and engaged in social activity (e.g., Wang et al., 2017).

According to previous reviews on SN concepts (Kelly et al., 2017; Wang et al., 2017; Wrzus et al., 2013), SNs can be characterised 'objectively' through structural/quantitative aspects such as network size, composition (e.g., predominance of different network types), or density (i.e. how many network members also know each other). SNs can also be characterised 'subjectively' through functional/qualitative aspects, such as perceived emotional connectedness, practical support, access to resources, ability to confide in others, experiences of loneliness (i.e. painful subjective experience resulting from a discrepancy between desired and achieved patterns of social interaction) or social isolation (i.e. an inadequate quality and quantity of relationships with others at individual, group, community and larger society level; Kelly et al., 2017; Wang et al., 2017). SNs, alongside the social resources and support systems they influence, form the individual's social capital (Salehi et al., 2019; Wang et al., 2017). Positive social capital (i.e. constructive and supportive social connectedness that fosters hope, empowerment, meaningful social roles) is important in recovery from severe mental illness (Salehi et al., 2019). For instance, bonding social capital (i.e. homogenous, intragroup, horizontal relationships characterised by high trust, intimacy and closeness, such as family)

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facilitates access to emotional and tangible practical support essential particularly during stressful, traumatic life events, whereas bridging social capital (i.e. weaker ties between heterogenous intergroups, characterised by less closeness, but greater access to diverse resources, such as organisations) can improve access to broader professional or mental health support for people with severe mental illness (Salehi et al., 2019)

It is now well established that many such aspects of SNs, including social connectedness and relationships also contribute to relapse and recovery in psychosis specifically (Pope et al., 2019). Qualitatively, for instance, expressed emotion involving high levels of criticism, hostility and blame from close family members is linked to poorer functioning, worse symptoms and relapse (Izon et al., 2018), as are experiences of discrimination, stigma (Gumley et al., 2020; Hansen et al., 2018) and loneliness (Michalska da Rocha et al., 2018). Quantitatively, SNs are reduced in size and predominated by family members (Michalska da Rocha et al., 2018). This disproportionate composition can in turn impede access to resources such as healthcare or employment, negatively affecting the recovery process (Salehi et al., 2019). Further understanding of the presentation and subjective experiences of SNs, particularly through the views of people with lived-experience, is therefore required.

In line with shifts towards a person-centred model in psychiatry, SNs have recently started being explored in individual studies with people with lived experience (Cheng et al., 2016; Karanci et al., 2017; McGuire et al., 2020) and also with wider systems (e.g., families, mental health professionals; Tee et al., 2020; White et al., 2019). Qualitative studies are particularly rich in data, capturing nuances such as positive versus negative SNs or SN configuration, which are often missed in quantitative instruments (Siette et al., 2015; Wang et al., 2017). Considered separately, qualitative studies have often been criticised for their lack of generalizability due to small sample sizes and specificity of their context (Noiriel et al., 2020). Collating and interpreting such findings through qualitative syntheses can improve their impact, by highlighting recurring themes and discrepancies across settings, generating information and guiding intervention, guidelines or policy development (Noiriel et al., 2020; Tong et al., 2012).

Several qualitative reviews were identified concerning either SNs or psychosis. Exploring recovery in schizophrenia, two reviews found social aspects such as access to social support, a sense of belonging, partnership-based close and equal relationships and mutual understanding as protective factors, whereas negative interactions, stigma, social rejection and isolation were challenges to recovery (Hansen et al., 2018; Soundy et al., 2015). Interpersonal factors were also identified in

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meta-syntheses on experiences of the prodromal phase (e.g., friendship loss and isolation from childhood to recovery; desire for new relationships with peers with similar experiences; Boydell et al., 2010), distress during first-episode psychosis (e.g., FEP; feeling disconnected, ostracised, fear of negative evaluation/stigma; Griffiths et al., 2019), and on post-traumatic growth following FEP (e.g., closer family bonds, involvement in peer-support actions; Jordan et al., 2018). As all reviews so far primarily focused on other topics, with SNs considered as secondary, some meanings and experiences of SNs could have been lost during synthesis, as cautioned by one of the authors (Soundy et al., 2015). Therefore, we identified one thematic synthesis that focused primarily on social bridging and bonding capital, including 19 studies published until 2015 with people with severe mental illness (Salehi et al., 2019). Findings revealed themes of imbalance, powerlessness in and exclusion from relationships, and the value of social supports beyond the illness. Nevertheless, the samples included psychosis/schizophrenia as well as bipolar disorder or major depression, potentially masking illness-specific opportunities and challenges. Moreover, only half of the studies focused on patients' experiences, whereas the remaining focused on other stakeholders' experiences (e.g., siblings, parents). Finally, new literature on the topic emerged since 2015 (e.g., Hansen et al., 2020; McGuire et al., 2020). Therefore, a deeper understanding into participants' firsthand experiences of SNs and their associated nuances in psychosis remains relatively unchartered.

The aim of this review was to systematically retrieve, critically appraise and meta-synthesise published qualitative research on types and characteristics of SNs and how patients experience them in psychosis across the lifespan and stages of illness.

3. MATERIALS & METHODS

3.1. Design

We conducted a systematic review and qualitative meta-synthesis of qualitative and mixed-methods studies on SNs and psychosis.

3.2. Inclusion/Exclusion criteria

We included studies that met the following four criteria: 1) *study design:* published empirical qualitative (e.g., focus group, interviews etc.) or mixed-methods studies (with a qualitative component sufficiently described for the authors to be able to assess its quality and extract the themes); 2) *language:* in English or Romanian, due to the researchers' linguistic skills; 3) *population:*

patients with experiences of psychosis or schizophrenia spectrum disorders, across the lifespan and stages of illness, or where they constituted at least 50% of the sample amongst other mental health difficulties; or where there was an approximate 1:1 ratio of patient: stakeholders perspectives; and 4) *social networks*: with a primary focus on experiences of SNs/social capital. Using conceptualisations described above, we defined SNs as the global web of social relationships surrounding an individual, including parents, siblings, friends, colleagues, spouses, community members etc. (Wrzus et al., 2013), which can be described by size, degree of closeness, interactional quality, directionality etc. (Wang et al., 2017). Studies were included if they investigated entire global SNs, or closer (e.g., family, friends) or peripheral (e.g., neighbours, professional) subnetworks using Wrzus' et al.'s distinctions (2013).

Due to the complexity and versatility of the SN concept, we excluded studies where SNs were secondary to a primary focus on other topics, such as stigma, work/academic reintegration, recovery, disclosure about illness, caregiving experiences, care-seeking, physical health, substance abuse, loneliness, impact of illness on SNs or ideologies about SNs without an actual exploration of SNs. We also excluded studies that focused on evaluations of social-based interventions. We excluded studies that focused primarily on stakeholders' experiences of SNs (e.g., peers' experiences of being friends of someone with psychosis) or on how professionals build relationships (e.g., therapeutic alliance techniques). With regards to the other criteria, we excluded studies with quantitative data only, unpublished dissertations and theses, as well as papers where psychosis did not comprise at least 50% of the sample or this could not be determined. Post-partum/puerperal psychosis was excluded due to its acute nature and significant life/network changes associated with birth besides psychosis. Studies with people at-risk of psychosis were also excluded.

A second rater (trainee clinical psychologist) checked approximately 20% of the full-text screening articles against inclusion and exclusion criteria. The inter-rater agreement was 86.3% and the minor noted discrepancies were resolved through discussion and involvement of the supervisor.

3.3. Search Terms

Two key search strategies were employed: 1) searches based on free text key words, and 2) searches based on index terms of key concepts in the database; both in title/abstract. Both strategies have been tested with a librarian with expertise in health and social care research over several rounds of discussions to assess for sensitivity and relevance. Preliminary searches used a combination of search terms employed by previous relevant systematic reviews (Siette et al., 2015; Salehi et al., 2019) and iterative piloting against results. The Population (i.e. psychosis/schizophrenia), Phenomena of Interest (i.e. social networks), Context (ie, qualitative research) PICo framework was further used, as recommended for qualitative research exploring lived experiences and meaningfulness of concepts (Munn et al., 2018). An example of the search strategy is: (Psychosis or psychoses or psychotic* or schiz*).ti,ab. AND (social adj1 (network* or contact* or capital*)).ti,ab. AND ((qualitative* adj1 (method* or research* or investigat* or analys*)) or phenomenological* or 'lived-experience*' or 'grounded-theor*' or 'thematic-analys*' or 'mixed-method*').ti,ab. A comprehensive list of search terms (including synonyms, abbreviations, and spelling variants) was compiled, and database checks of specific indexing terms used as controlled vocabulary. Index terms were further verified for definitions and narrower and broader concepts to ensure the relevant concepts are covered, and adapted to each database (e.g., 'exp social network analysis/ or exp social capital/"). Estimating a smaller number of qualitative studies, our search strategy is included in the Appendix 1 (page 73).

3.4. Database Searching

The Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) 2020 (Page et al., 2021) and Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ; Tong et al., 2012) guided the procedure of this review. Prospero and Epistemonikos were first searched for any ongoing reviews on the topic. None was identified. A study protocol was therefore registered on Prospero (CRD42021275355).

A comprehensive sampling approach was used, which is suitable for qualitative meta-syntheses (Booth, 2016). Searched databases included PsycInfo, Medline, Embase, Assia, AMED, ERIC, Cumulated Index to Nursing and Allied Health Literature (CINAHL), Sociological Abstracts and Scopus. To ensure the search was as systematic as possible, we additionally searched ProQuest Dissertations and Theses and OpenGrey/GreyNet. However, unpublished dissertations/theses were excluded later on, strategy deemed acceptable for qualitative reviews (Booth, 2016), as we could not ensure a consistent approach to thesis retrievals due to embargo and time constraints, and prioritised accessible peer-reviewed literature. Several relevant studies/reviews (e.g., Salehi et al., 2019) were informally hand searched by manually scanning through the reference list as a way of proofing our search strategy and identifying any omitted articles. Two further search strategies were used on Google Scholar due to its relevancy ranking: adapting the search syntax and using forward citation and 'related articles' sections of 15 key relevant articles. Once all articles across all databases/search engines were imported into the reference manager, deduplication was performed.

3.5. Data Extraction

Using a data extraction form based on previous research and pilot on the first three articles, we recorded descriptive features such as: author, year of publication, country, aims, sample characteristics (including size, diagnosis and stage, age), setting (inpatient, outpatient etc.), study design and analysis, materials (e.g., interview type, duration and content), and key findings. Due to time constraints, no inter-rater reliability was performed on data extraction; however, this is unlikely to have affected the quality of the form, as sought information was readily available in the articles.

3.6. Critical Appraisal

Each article was assessed for risk of bias and quality using the 10-questions Critical Appraisal Skills Program Checklist for Qualitative Research (CASP; Hannes, Lockwood and Pearson, 2010). The items cover questions about research design, sample strategy, researcher's reflexivity, data collection, findings or value of research. For each item, there are three possible answers: 'yes' (indicating high quality), 'can't tell' (indicating unclear quality) and 'no' (indicating low quality). This criteria guided our description of strengths and limitations of extant literature. CASP is the most frequently used tool in qualitative evidence synthesis, is brief, and is appropriate for a novice researcher and decision-maker (Majid and Vanstone, 2018). An independent trainee clinical psychologist assessed the quality of approximately 20% of the included studies. The inter-rater agreement was of 84%. Discrepancies were resolved through discussion and optional involvement of the supervisor.

3.7. Data Synthesis

Qualitative meta-synthesis was used. This attempts to integrate results from different but interrelated qualitative studies, using an interpretive rather than aggregating approach (Booth, 2016). A thematic synthesis approach was taken. This focuses on analytical themes that offer novel interpretations going beyond the primary studies (Thomas and Harden, 2008). Three steps were followed. First, the main author extracted the Results/Findings section (direct quotations and

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authors' summaries of evidence) with associated tables/figures from each paper and completed a free line-by-line coding. The line-by-line coding on the first article was reviewed in discussion with the second author to ensure the codes remained close to the primary data. Second, the free codes were synthesised and organised into descriptive meta-themes. Similarities and differences between codes guided grouping into broader, hierarchical themes. Residual codes were initially bracketed, then returned to for review and reintegration or addition as exceptions into the wider themes. Third, we interpreted and reorganised descriptive themes further to develop analytical themes, by comparing them against the research question, identifying recurring nuances, similarities and exceptions, or inferring interactions between discussed factors (Thomas and Harden, 2008). Across stages, we contrasted the themes against primary findings and codes to check for consistency of interpretation and internal homogeneity of the themes. Narrative summaries were constructed including illustrative quotes from the original articles. The process was completed by the first author, with feedback from the supervisor. Analysis was conducted manually in Microsoft Word.

3.8. Reflexivity Statement

The first author is a doctoral trainee clinical psychologist with several years of clinical experience across the lifespan with people with moderate to severe mental health difficulties. The author's clinical work involves applying principles of third wave therapies, systemic theory, and community psychology to formulate experiences of distress and recovery. These often acknowledge that, although knowledge of reality is filtered through ones' perceptions/beliefs, knowledge can also approximate closely an external reality (e.g., living in deprivation; Smail, 2005). The author's sensemaking of the data has likely been influenced by these - for instance, in interpreting subjective experiences of distress through how proximal (e.g., family, work) and distant (wider culture) social structures exercise power and offer more or less capital to the individual (Smail, 2005). Through reflective discussions in supervision, efforts were made to stay close to the original data, particularly in the first two stages of the thematic synthesis process. Therefore, the author took an epistemological position aligned to some extent to both critical realism and scientific realism (Barnett-Page and Thomas, 2009). This maps with the critical realism stance of thematic synthesis and with its underlying assumption that, although allowing for some interpretation, the synthetic products correspond to a shared reality (Barnett-Page and Thomas, 2009). The second author and supervisor is an academic clinical psychologist and Professor of Psychological Therapy in the Doctorate in Clinical Psychology course at the University of Glasgow, and a Consultant Clinical

Psychologist in NHS Greater Glasgow & Clyde and researcher with extensive experience in qualitative research and psychosis.

4. **RESULTS**

4.1. Search Results

Our searches identified 3328 records across databases and one further article from hand-searching. Of these, following deduplication, 2215 unique records were screened against inclusion/exclusion criteria by title and abstract, and 149 were retained for full-text reading. Three of these were not available in full-text despite efforts to locate them. However, upon further inspection with the research team, they did not meet criteria due to being unpublished dissertations/theses. Of the 146 full-text readings, 15 were included in the final analysis (Figure 1. Prisma diagram, adapted from Page et al., 2021).

Figure 1. Systematic review: PRISMA diagram





Fifteen studies were included in the final analysis, covering data from 265 participants with psychosis or schizophrenia from across outpatient, inpatient and third-sector program settings, in eight countries: Australia, Canada, Denmark, Germany, Norway, Turkey, UK, and USA. Studies were published between 2001 and 2021, with the majority after 2015 and thus not included in Salehi et al.'s review (2019). Sample sizes varied between 5-100, with approximately half of the studies having 10 or fewer participants. FEP was included in seven studies, as was chronic/persistent schizophrenia, whilst two other studies included people that were in remission. Sample age varied between 16 and 73, the majority of studies using an adult sample, two studies including older adolescents, and a further three older adults. In terms of theoretical and methodological approach, only two studies were mixed-methods, with the remaining qualitative. Moreover, seven studies used thematic analysis, two of which were complemented by network mapping or team-based reflexive analysis; four used grounded theory; one used interpretive phenomenological analysis; one content analysis; one a phenomenological method; and one a descriptive mixed-method timeline profile. Fourteen studies employed individual semi-structured interviews, covering a range of questions about social interactions, social supports and role in recovery, experiences of networks before, during or after acute illness, activity-driven socialising, and negative social experiences. One study used focus groups. Three studies used additional visualisation methods (e.g., cardboard figures, concentric circles maps), two used additional questionnaires, and another time diaries, life history calendars and field observations. A comprehensive summary of the studies and their key findings is included in Appendix 2 – Data Extraction Table (page 74).

4.2. Qualitative Appraisal

The quality of the studies was generally high (Figure 2). The point most frequently absent was critically examining the researcher-participant relationship in potentially influencing research question development, data collection and materials, implications of responses during the study or data interpretation. Similarly, ethics considerations, such as informed consent or minimising power imbalance were not always clearly covered, although this may be assumed from statements on granted ethics approvals. Finally, the sampling procedure (e.g., purposive, convenience) was not always justified, particularly in relation to the research question and analytic approach. Although these limitations may reflect adherence to strict word limits for publishing, they induce potential bias. However, given the lack of consensus about the function and reliability of study quality assessment as part of systematic syntheses (Noiriel et al., 2020), no study was excluded based on quality. A summary of each study's rating across the CASP items is included in Appendix 3 (page 83).



Figure 2. Overall study quality based on CASP criteria

*Note: Green = Yes (High quality); Amber = Can't tell (Unclear quality); Red = No (Low quality).

4.3. Thematic Synthesis Results

Three major themes, with underlying sub-themes, emerged during the meta-synthesis: 1) key profile features of SNs composition and negative and positive social features; 2) SNs as a gateway to resources; and 3) power imbalance in SNs (Figure 3). SNs emerged as complex, dynamic, multifaceted and acting as both positive and negative influences on recovery across studies. The representativeness of themes and sub-themes across articles is presented in Table 1. A transcript extract illustrating our coding process is available in Appendix 4 (Page 85).

Figure 3. Experiences of SNs in psychosis: key themes and sub-themes



	1	1.1.	1.2.	1.3	2	2.1.	2.2.	2.3.	2.4.	3	3.1	3.2	3.3.	3.4.	3.4.1	3.4.2
Angell,																
2003																
Cheng et																
al., 2016																
Hansen et																
al., 2020																
Huckle et																
al., 2021																
Karanci et																
al., 2017																
Killian et																
al., 2001																
Lencucha																
et al., 2008																
MacDonald																
et al., 2005																
Mackrell &																
Lavender,																
2004																
Masse et																
al., 2020																
McGuire et																
al., 2020																
Nilsson et																
al., 2019																
Ogden,																
2014																
Pinfold,																
2015																
Pope et al.,																
2019																

Table 1.The presence of themes and sub-themes across articles

Note. Green = present; red = absent

4.3.1. Theme 1: Key SN features: cross-sectional snapshots and patterns at different life points

Fourteen of the 15 studies explored SNs features, offering time stamped snapshots on SN types and composition, and indications of negative (e.g., isolation, loneliness) and positive features (e.g., positive social withdrawal, post-psychosis growth) at different life points. These fell into the following three sub-themes.

4.3.1.1. Sub-theme 1.1: SNs types and characteristics

Network types and their characteristics, including composition, size, and degree of network closure, were discussed in 13 studies. Valued types of SNs included family, intimate partners, friends, acquaintances, occupational and professional networks (Lencucha et al., 2008). A specific profile emerged where family and professional networks dominated over friendship ones (e.g., McGuire et al., 2020; Pinfold, 2015), potentially reducing access to other sources of social capital such as work or education. Similarly, networks with other service users dominated over non-ill contacts and efforts to extend social life beyond service-user contacts were met with rare success, leading to feelings of helplessness over learning and conforming to typical social conventions (Angell, 2003). Although SNs with service-users were often valued for allowing people to experience a shared bond, acceptance, compassion, higher understanding and reciprocity, they were also disliked for reinforcing the focus on mental health difficulties as a common relationship ground, being incongruent with a healthy identity, acting as triggers of illness trauma, and bringing potential conflicts due to communication, attention or insight difficulties (e.g., Huckle et al., 2021, Pinfold, 2015).

With regards to SN size, some studies identified typologies of social integration. Some people were socially integrated within large sized, diverse and active SNs (Killian, 2001; Pinfold, 2015). These were characterised by frequent contacts, diverse social settings and were perceived as highly satisfactory and helpful in instilling belongingness, providing access to wider social capital and buffering against relationship losses (Pinfold, 2015). However, for some participants, large SN sizes were also portrayed as requiring more effort and active management, being emotionally taxing, and increasing chances of stigmatisation through more exposure to people (Pinfold, 2015). Another typology included people that were primarily integrated within a small family context with limited opportunity to expand SNs through structured activities, but with a helpful element of emotional connectedness. On the other extreme, some participants presented with a disintegrated profile, with sporadic social contacts, no non-kin SNs, and lacking elementary social competencies (e.g., Killian, 2001). For these, a sense of resignation to social ostracization permeated.

Other SN features such as the degree of network closure varied between people as well. For some, SNs were widely intertwined and interconnected, such network closure potentially fulfilling more emotionally-driven needs, such as trust and mutual support, but limiting access to divergent resources. Other participants preferred keeping groups of networks segregated as a way of reducing stigma, although such strategy could inadvertently perpetuate social isolation for those with formal and spare SNs (e.g., Lencucha et al., 2008, Pinfold, 2015).

4.3.1.2. <u>Sub-theme 1.2.</u>: Detrimental features across time: pervasive isolation and social difficulties

Negative features at different life stages were noted in 12 of the 15 studies. Isolation appeared more prominent later in life (Ogden, 2014). However, negative social experiences were reported to outweigh the positives across different life stages and as early as in childhood, and were further exacerbated by an experience of psychosis. For instance pre-psychosis, investigating peer relationships in adolescence, Mackrell (2004) identified inequity and instability in SNs, negative bias, conflictual family dynamics, hostility/bullying and rejection from peers as early as childhood. These persisted through early and late adolescence, leading to unfavourable social comparisons, stigmatisation, and eroded trust over time. Experiencing psychosis, including both positive and negative symptoms, such as paranoid delusions, diminished initiative, or avolition further directly damaged or broke relationships according to half of the studies. For instance, one study exploring life story narratives in the older age group described a participant who left his wife and daughter after God's voice told him to wander and heal people with prayer (Ogden, 2014). One's own strategies to manage symptoms further perpetuated relationship losses. The prominent example included social detachment or avoidance strategies, *([participant] spending evenings and weekends* alone because he became 'a little paranoid"; worried he might "feel uncomfortable" around others if he started to hear voices' (Ogden, 2014, p679). Psychosis effect on one's sense of self, such as feeling unable to cope, further led to relational absences for some participants, which in turn reinforced feelings of regret for lost life opportunities in the older age: "I can't cope with the problems that come with having a husband . . . [but] I'm sorry that I didn't have more children." (Ogden, 2014, p677).

Loneliness, which refers to a painful subjective experience arising from gaps between desired and achieved patterns of social interaction, was also discussed in nine of the 15 studies. Loneliness particularly featured across network profiles characterised by disintegration, limited social contact, isolation, or social contact with other service-users only (Killian et al., 2001; Pinfold, 2015). It also featured prominently in the older age population, where non-occurrence of typical age-and-stage SNs, such as spouses or children, created feelings of loneliness and regret over lost dreams of a social life (e.g., Ogden, 2014). This may suggest loneliness as secondary to cumulative relational losses and voids across time, that were exacerbated by psychosis and inadvertently perpetuated by one's own social withdrawal/avoidance strategies: *'her schizophrenia spectrum diagnosis had contributed to "a lot of loneliness—a lot of loneliness … I would have liked to have had a family … And I would have liked, in lieu of a family, to have some sort of decent sex life"* (Ogden, 2014, p677).

4.3.1.3. <u>Sub-theme 1.3.</u>: Favourable features across time: positive social withdrawal and posttraumatic growth

Positive features were noted in seven of the 15 studies. Positive social withdrawal was used as a strategy to manage social connectedness by many people, helping them recuperate and recharge to later engage with SNs. Social withdrawal thus could become *'a delicate and not negatively experienced balancing act consisting of elements distancing them from and relating them to the intersubjective sphere'* (Nilsson et al., 2019, p236). Moreover, in over a third of the studies, some people experienced post-psychosis growth with their closest SNs. Participants shared that psychosis tested and strengthened some relationships (Huckle et al., 2021). For some people, psychosis made them reconsider their attitudes, values and networks, leading to active decisions to adjust or terminate relationships incompatible with recovery, the majority of which related to what people perceived as contributing factors to the onset of psychosis, such as stressful conflicts or drug and alcohol consumption (Huckle et al., 2021; MacDonald et al., 2005). A minority of people felt satisfied with their SNs, did not identify any social gaps, and deemed a *'return to normality possible'* over time (Huckle et al., 2021, p11).

4.3.2. Theme 2: SNs as a gateway to shared and unique resources and supports

All 15 studies highlighted the shared and unique roles different SNs play in people accessing resources for recovery. These could include providing immediate pleasure, a sense of belonging and safety, or structure and routine. Types of support across key networks were captured under four sub-themes.

4.3.2.1. Sub-theme 2.1: Practical and instrumental support

Nine studies highlighted network roles, particularly family's, in offering practical support with basic needs, illness management, daily tasks, finances, solving practical problems or work. These helped participants gain more structure and maintain roles, which in turn built a sense of purpose and meaning. Friend SNs were also valued for offering mainly activity-led support, everyday distraction, advice and problem-solving (Pope et al., 2019). Finally, professional SN supports were particularly and uniquely valued for helping during crisis, promoting understanding of psychosis, case managing, filling forms, housing, offering therapy, monitoring and increasing public awareness (Cheng, 2016; Hansen et al., 2020; Karanci et al., 2017; Pope et al., 2019) However, the latter needs have not always been met, one study highlighting that participants felt *'lost in the system'*, disempowered and uninformed: *'when their troubles were explained in words that they did not understand or in ways that differed from how they themselves perceived the situation'* (Hansen et al., 2020, p82).

4.3.2.2. <u>Sub-theme 2.2: Emotional connectedness: a solid base to connect to the world from</u> Emotional support, to which family SNs were central, was specifically highlighted in 11 studies. A mix of positive and negative experiences was captured. Across informal family and friend SNs, showing interest in the person, offering stability, security and belonging, encouraging manageable autonomy, constancy and unconditional presence despite competing demands were highly valued by participants (e.g., Cheng et al., 2016; Huckle et al., 2021; Lencucha et al., 2008; McGuire et al., 2020). Re-enacting a circle of security, one participant described how settling down, marrying and buying a home with her spouse provided a secure base to connect to the world from (Pinfold, 2015). These positive attributes also applied to professional SNs who were seen as a crutch to cope (McGuire et al., 2020), and also uniquely provided a safe space for disclosures of private problems that would not otherwise be as easily discussed elsewhere (e.g., Pinfold, 2015).

Nevertheless, negative experiences of emotional support were also present. In some studies, conflicts, losing interest and emotional closeness, lacking understanding, and passivity indicated that emotional support was unavailable (e.g., Karanci et al., 2017; Pinfold, 2015). On the other hand, too high SN involvement was criticised for dominating to the point where SNs themselves – both family and professionals - became barriers to new opportunities to build connections and create a vision of an alternative future, both hindering recovery. Whether SN involvement was perceived as helpful or not appeared to depend on the level of control experienced by the participant (Pope et al., 2019).

4.3.2.3. <u>Sub-theme 2.3</u>: <u>Socialisation support</u>: <u>SN development through activities and</u> <u>interventions</u>

Rebuilding a social life and maintaining meaningful relationships in the context of routinised activities and social interventions, such as clubs, social groups, or hobbies (e.g., dance group 'family'; Masse, 2020), emerged as a key factor in 12 of the 15 included studies. Environmental proximity,

shared purpose, frequency of interaction, clear socials scripts and facilitation by professional SNs (e.g., staff-led groups) promoted such activities (Angell, 2003; Lencucha et al., 2008), although a preference for self-initiated activities, such as university or dating, and a dislike for professional SN involvement were also highlighted by some participants (Huckle et al., 2021). Some people used the prescribed roles offered through activities to maintain SNs, even when feeling pulled towards self-isolating: *"when I'm wearing my uniform [...] Then I have a part to play. Then I have to be a nursing student and I know what to say and what not to say [...] It's kind of like there are more written rules on how to behave, and that's more difficult when you're just being yourself."* (Nilsson, 2019, p235). For some people, activities filled social gaps, compensated for a lack of social connectedness and allowed development of other identities outwith the illness or social realm (e.g., an artist identity; Pinfold, 2015).

4.3.2.4. <u>Sub-theme 2.4: Needing different things from different SNs at different times: a play of</u> giving and taking responsibility

Five studies highlighted that SN responsibilities and functions were context, illness/recovery stage, age/development, and capacity dependant. For instance, professional help intensity changed over time, with high involvement in the acute stage and gradual withdrawal of support as the person simultaneously built on their mastery, confidence and independence skills (Pinfold, 2015). This involved a complex game of transferring responsibility for recovery between SNs and the individual – circumstances dependent – which was welcomed by many participants as a way to gain autonomy (Pinfold, 2015) and was deemed essential for and indicative of recovery: '*And think on your process, because I think the doctor cannot do nothing if you don't want to do it yourself* [...] *you can't help somebody that doesn't want to be helped.*' (Pope et al., 2019, p1303). Moreover, SNs jumped positions at times, substituting for gaps in people's social world. For instance, a new relationship with a social worker fulfilled the need for emotional connectedness lacking from their absent family for one participant (Ogden, 2014), and similarly, a close friend became a 'surrogate mother' for another participant, compensating for the lack of acceptance and support from their family (Pinfold, 2015).

4.3.3. Theme 3: Power imbalance: service users as 'less than' amongst SNs

A theme of existing power imbalance in relationships permeated through all 15 studies. Participants often took a 'less than' position in their social world. Reciprocity, control, dependency, stigma and relationships centred on illness were captured under four sub-themes.

4.3.3.1. Sub-theme 3.1: Relationships centred on illness

This sub-theme emerged across six studies and highlighted that many SNs were centred on an illness-identity, 'an object which served as a source of need and disability (McGuire et al., 2020, p131)'. *The* person was seen as ill, fragile, in need of support, not taken seriously, and lacking previously strong roles/identities. Lacking a shared understanding of the problem further reinforced tension and illness as a core identity within the person: '*Practitioners viewed him as mentally ill, whereas Bill viewed his problems in life as related to loneliness and being an outsider; he did not recognise a mental illness identity.*' (Pinfold, 2015, p78). A sub-type of relationships of particular interest here was that with other service users. Gravitating towards relationships with other service users was common (e.g., Angell, 2003), either as an active choice, or as the only means to fulfilling a need for belonging (Hansen et al., 2020). However, a longing for non-ill companions and a desire to lessen focus on mental illness as the common ground in relationships was also present (Angell, 2003).

4.3.3.2. <u>Sub-theme 3.2: Reciprocity: being cared for and caring for others through a symbiotic</u> process

Reciprocity emerged as an important need for self-actualisation across 10 studies. In many studies, participants valued helping others and helping themselves, taking personal responsibility, being treated by others as if they were important, and having a recognised role through which others depended on them, such as parenthood (e.g., Cheng, 2016; McGuire et al., 2020). People often accepted the dual role of being dependent on and giving back to others: "Sometimes I just feel depressed in my head . . . or just not good. It helps me to sit in there. It helps just to sit and listen . . . and I honestly like to help people out . . . The clients have their problems, and [I] give them advice . . . Give them feedback" (Ogden, 2014, p679). However, reciprocating was found to be dependent on the extent to which "they are capable of doing so, and this capacity may fluctuate over time" (Pope et al., 2019, p1303). Some participants even welcomed other SNs taking over responsibility over decision making about how to handle specific situations, particularly in the more chaotic acute phase of illness (Hansen et al., 2020). Balancing a desire to help with sensitivity to others' needs and care for not overburdening others was also highlighted: "there is a compatibility of understanding and respect for boundaries [...] I would really like to help her out as much as I can, but, in the same way, I don't want to become a problem; so, I have to be careful of how I am." (Lencucha et al., 2008, p344).

4.3.3.3. <u>Sub-theme 3.3: Control and dependency: 'when you are dependent, you're not</u> <u>autonomous anymore'</u>

Nine of the 15 included studies highlighted a complex trade-off between feeling controlled and feeling in control or autonomous. In many studies, participants expressed disappointment at either the little opportunity to get involved in decision-making (e.g., about medical treatment, McGuire et al., 2020) or overinvolvement particularly from families, both taking agency of action away from the person (e.g., Cheng et al., 2016). This in turn created perceptions of betrayal, disempowerment or resentment, which in some cases led to disengagement from services or families and thus relationships breakdown (McGuire et al., 2020). Contrastingly, reducing dependency increased self-reliance and agency for other participants: *"he came to feel more self-reliant and independent by moving away from the mental health system, even though this was not his personal choice at the time: I've learnt to survive and I am now strong emotionally.*' (Pinfold, 2015, p75). On the other hand, in some studies, participants valued such dependency on services as a way of accessing much needed emotional and practical support (McGuire et al., 2020), talked about a readiness for building independence, and argued against an all-or-nothing approach to SN involvement (Pinfold, 2015).

Both intrapersonal and interpersonal factors appeared to contribute to one's sense of perceived control/autonomy. Intra-personally, participants had little expectation of, agency and self-confidence to exert control, blaming themselves internally and retreating. These further fed into interpersonal factors such as others not seeking participants' views, considering participants as unreliable witnesses of change, or blocking people's involvement: *'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'.* (McGuire et al., 2020, p134). These interpersonal factors likely further inhibit participants' attempts to self-assert, trapping people in a transactional vicious cycle, although a wish to be seen as a unique person, with preferences, and an agent of their own lives persisted (Hansen et al., 2020).

4.3.3.4. <u>Sub-theme 3.4: Stigma from self and others: 'you're not right'</u>

Stigma from self and others was pervasive across participants' experiences in 14 of the 15 studies. Tensions between being seen as 'not normal' and a strong desire of 'passing for normal' resulted in complex responses, including fear and avoidance of disclosure. Both are captured under the following two sub-sub-themes.

4.3.3.4.1. <u>Sub-sub-theme 3.4.1: Being seen as 'not normal'</u>

Participants often felt that they were seen by both formal, informal, and service-user SNs as 'not normal', judged, belittled, labelled, rejected, subjected to unfavourable social comparisons, or

discriminated against: 'since I went to hospital and got help they always said like, if I walk inside a pub and they just say 'oh madman' so I don't keep them as my friends.' (Mackrell & Lavender, 2004, p475). Such stigmatised views demonstrating lack of hope and limited life expectations were also held about participants' future by professionals (Pinfold, 2015) and friends: 'they view me differently now you know, because I've become psychotic they think that you are now a waste of life or something. . . They just think you're a loony' (MacDonald et al., 2005, p137). Some degree of stigma was also noted in SNs with people with lived experience, whereby people criticised and distanced themselves from other service users 'who are in their eyes "crazier" than themselves' to preserve a 'healthy' identity (Killian et al., 2001, p550). Stigmatising reactions from the outside world reinforce messages that psychosis fundamentally changed who one is at their core: 'I wouldn't be the same person' (Huckle et al., 2020, p7). In turn, these led to internalised fears of criticism, anticipation of negative reactions from others, poorer confidence in one's ability to live up to SNs' expectations, or shame (Huckle et al., 2021), which further inhibited participants' seeking of social contacts and contributed to relational losses. For some, friendships were reminders of a lack of progress and stagnation, which was further self-stigmatising: "I didn't want to talk to them because I knew it would be all about going back to uni . . . it would remind me of all the good times that I'm missing out on." (Huckle et al., 2021, p9). Therefore, stigma both arose from SNs and contributed to SN losses.

However, not all participants experienced stigma across SNs. For instance, friends treating participants like 'healthy person', accepting them or avoiding discrimination was valued in Cheng et al.'s study (2016). Similarly, relationships with other service users were also often defined as accepting, free of fear of criticism or pressure to pass for normal in other studies: '*peers in the program "understand what illness we've got . . . so they are not going to make fun of you*''' (MacDonald et al., 2005, p135; Angell, 2003).

4.3.3.4.2. <u>Sub-sub-theme 3.4.2: Fear of disclosure as a response to stigma</u>

Whereas a minority of people responded to stigma with resilience and refusal to 'be beaten by prejudicial public attitudes and discriminatory behaviours' (Pinfold, 2015, p79), avoidance, detachment and concealment were more frequently noted across eight studies. Many feared that disclosing experiences of psychosis would lead to being seen as different, and actively avoided mental health topics, even when believing that concealment was at odds with steps needed towards recovery (McGuire et al., 2020).) However, for some, non-disclosure derived not from stigma but from a wish to prevent reliving trauma: "I don't like talking about it and when I do I get really upset and stuff like that so I don't like talking to people, even friends, about what happened, what I went

through" (Huckle et al., 2021, p8). On the contrary, a smaller number of people were keen to disclose about mental health to prevent relationships progressing on a false basis and breaking down later on: *"I wanted the truth to come out so that in the future if we get married, if he finds out he won't leave me or he won't get angry at me, so I told him from the start*" (Huckle et al., 2021, p8). Interestingly, one study distinguished positive and negative influences of disclosure based on network characteristics (Pinfold, 2015). Limiting disclosure was helpful for people with diverse networks which could present more sources of stigma, but could block connectedness and thus reduce the pool of resources to buffer isolation for those with sparse networks (Pinfold, 2015). Nevertheless, roles in tackling stigma through actions such as increasing funding and raising public awareness were attributed to both the service user, and closer and wider systems (i.e. government, third-party agencies, society as a whole; Pope et al., 2019).

5. DISCUSSION

5.1. Theoretical Discussion

This review of literature on SNs in psychosis highlighted key aspects about how SNs are affected by and influence, both positively and negatively, experiences of psychosis and recovery across stages of illness and ages from service users' perspectives.

First, with regards to network configuration, family and service networks predominated over non-kin ones, which is consistent with previous literature (Michalska da Rocha et al., 2018). Although this offers access to bonding capital (i.e. emotional closeness and trust with a highly interlinked network), it can limit bridging social capital (i.e. connections with dispersed, heterogenous groups), as also highlighted in a previous review (Salehi et al., 2019). Consequently, people may have fewer opportunities to resume valued tasks, maintain a healthy identity or develop new identities outwith illness, as highlighted in Salehi et al.'s review (2019). In addition to previous research, however, our study noted that more dispersed, large SNs are not always protective either, as they were perceived emotionally taxing and requiring active management by some participants.

Second, in terms of qualitative experiences of relationships, our findings mirror previous metasyntheses (Hansen et al., 2018; Salehi et al., 2019; Soundy et al., 2015) on protective interpersonal factors, such as having close emotional networks, reciprocity, adaptability for SNs to fulfil needs in absence other SNs, understanding and equity, as well as risk factors, including negative interactions, isolation, disempowerment and imbalance in relationships. However, our findings also partly contradict the observed decreased social support in acute stages of illness noticed by Salehi et al. (2019). On one hand, we identified that psychosis can lead to relationship breakdown and isolation, and therefore a decrease in quantity of social support which resembles Salehi et al.'s review (2019). On the other, however, we found that networks can become overinvolved particularly during the acute stages of illness. This involvement could then be experienced both positively and negatively depending on whether it impeded gradual transfer of responsibility from SNs to the person during recovery, phenomenon also captured in Soundy et al.'s review on factors influencing recovery (2015). To this end, both our and Salehi et al.'s review (2019) highlighted feelings of entrapment in controlling relationships, autonomy and independence loss with too high levels of social involvement. In addition to these reviews, our findings also highlighted the dual side of relationships with other service users, particularly negative aspects such as centring relationships on illness identity and within group stigma.

Our review further compares with a recent meta-synthesis on experiences of distress in psychosis (Griffiths et al., 2019) in that both identified psychosis as triggering relationships breakdown, fear of negative evaluation and thus hesitancy of disclosure, which in turn perpetuated isolation. Although both also identified not being treated as an individual, not being involved in decision-making, feeling dismissed and not being taken seriously as barriers to engagement, Griffiths et al. (2019) cited professional SNs as a frequent source of such distress. This was less prominent in our review as professional support was also valued by many.

Moreover, integrating our findings with reviews on post-traumatic growth following FEP (Jordan et al., 2018; Ng et al., 2021), overlapping themes included increased self-discovery, better insight into SN trustworthiness and reliability, acceptance and value of mutual support, closer and deeper bonds, and renouncing unhealthy, unstable or superficial relationships. Similarly, socially shaped internal factors such as personal identity emerged as central to recovery and experiences of post-traumatic growth here and in previous reviews (e.g., Ng et al., 2021; Soundy et al., 2015). Many people wished to maintain a 'healthy' identity and 'pass for normal' (Angell, 2003). However, experiences of stigma in particular, both overt and internalised, can send messages that psychosis fundamentally changes the person to their core, leaving them with a damaged or fragmented sense of self (Ng et al., 2021). This further perpetuates a rigid psychiatric identity, social anxiety, avoidance and hopelessness, and in turn limits the potential for post-traumatic growth, and thus recovery (Soundy et al., 2015). What reviews on post-traumatic growth highlighted that is missing from our

review was the positive changes in perception of one's role in society, particularly in supporting other people with experiences of mental health problems through peer networks (Jordan et al., 2018; Ng et al., 2021). This somewhat reflects the value of reciprocity identified in our review.

As compared to previous reviews above (e.g., Griffiths et al., 2019; Salehi et al., 2019; Soundy et al., 2015), our review also generated some novel findings, such as tentatively highlighting a pattern of isolation and social difficulties and cumulative SN losses with psychosis at different life points, leading to feelings of grief, missed opportunity and unaccomplished dreams particularly in the older age (Ogden, 2014), although these may also reflect typical SN loss cohort effects linked to death or retirement (Brooks et al., 2022). Loneliness was also commonly experienced and coincided with social disintegration and pervasive difficulties, mirroring previous findings (Michalska da Rocha et al., 2018). Social disintegration was further often preceded by social difficulties, inequity and mutual rejection between service users and networks pre-psychosis, mirroring experiences of rejection, hostility, harassment, abuse and social difficulties with peer and family in Noiriel et al.'s qualitative synthesis on FEP (2020). Overall, SN erosion may emerge over time, perpetuating subjective feelings of loneliness, with psychosis acting as an added non-normative destabilising factor.

A final important consideration emerging in our review is the wide range of roles and supports, including practical, emotional and socialisation, available to service users from key networks, such as family, friends and professionals. SNs often provided a circle of security for an individual to explore the world from. However, a subtle and dynamic negotiation of responsibility taking between the person and their networks was noted. Personal responsibility is important to recovery (Soundy et al., 2015), and was also valued by participants in our review. However, our review also indicated that individuals may not be able to take on responsibility unless enabled and trusted by their SNs to do so, albeit capacity-dependent. Interestingly, we identified that although SNs in psychosis had holes and losses, participants sought other SNs to fill in for their absence (Pinfold, 2015). Similar network reconfiguration strategies featured as a protective factors across mental health difficulties (Brooks et al., 2022).

5.2. Strengths and Limitations

This systematic review draws strength from including a complex range of generally good quality peer-reviewed studies of 265 patients across age and stage of illness, identified and evaluated through rigorous search strategy, quality appraisal and extraction methods, following PRISMA and

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ENTREQ guidelines (Tong et al., 2012). Synthesising qualitative studies brought to light nuances of SNs not captured otherwise through quantitative methods. However, the raw studies' and our review's methodological quality pose limitations. First, with regards to the included studies, based on CASP, most did not address researcher's reflexivity and relationship with the participants, which could have biased interview development, participant disclosures, or data interpretation towards authors' existing preconceptions. Similarly, the sampling procedure (e.g., purposive, convenience) was not always justified or clearly linked to the analytical approach, for which aspects of thematic saturation or information power were sometimes further missed. This raises questions on the comprehensiveness of findings across participant groups and settings. Finally, a key limitation revolves around the inherent heterogeneity and confusion in conceptualising SNs and related terms (e.g., relationships, isolation), as highlighted in similar reviews (Brooks et al., 2022; Siette et al., 2015; Wang et al., 2017) which also impacted on us defining our SN criteria. There is no gold standard assessment of SNs in psychosis, and qualitative aspects of SNs, such as negative features of ties, are sometimes missed from available measures and are methodologically more problematic to assess (Siette et al., 2015; Wang et al., 2017). Shared themes may thus have been missed due to inherent discrepancies in conceptualisation and assessment of SNs. Consequently, interpretations of our findings may be limited to experiences defined within similar parameters to ours, such as appraisal of types of SN support, but provide less relevance to other concepts such as social isolation. Second, with regards to our review limitations, our own biases and pre-existing knowledge may have influenced article selection and theme development. Some of the meaning and nuances behind the intended messages of the articles may thus have been lost, although we attempted, through iterative comparisons with the original data and review in supervision, to ensure we stayed close to the original findings. Moreover, claims about SN and patterns over time are only tentative and drawn from merging different cross-sectional studies involving retrospective reflections across age groups with one exception of a study that used longitudinal interviews (i.e. Masse, 2020). Although we aimed to stay close to the original data, which did make claims about patterns of SN changes over time, such reports could have been distorted by recall biases, particularly positivity bias whereby people tend to remember events more positively than they were (Adler & Pansky, 2020) and may thus partly account for more frequently reported negative social changes later in life. Third, we noted a disproportionate contribution from Pinfold's study (2015) during the synthesis. However, this appeared to reflect its methodological strengths, volume of findings, and that it was only one of two studies where themes synthesised during the review were fully populated.

5.3. Research Implications

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First, more consensus on core SN definitions is needed in further research. Our evidence-based conceptualisation of SNs as the web of social relationships centred on an individual, that can be looked at objectively 'from above' (i.e. size, composition) and subjectively 'from within' (i.e. people's perceptions of support types, access to resources, reciprocity, loneliness etc.) could offer a conceptual template for further use. Adding an agreement on an appropriate time frame (e.g., SNs in the last month/ last 6 months) would further help compare results across literature. Such consensus is however likely to be challenging (Siette et al., 2015), particularly for qualitative research, which is intrinsically bound by the specific setting and context in which it takes place and therefore requires flexibility in fine tunning such SN definitions to the specific research question, purpose, specific aspect of SNs investigated in depth, context and available resources. A compromise may be reached by embedding existing instruments, such as the Interview Schedule for Social Interaction (ISSI; Henderson et al., 1980) into a wider qualitative interview to highlight key topics for further in-depth discussion, whilst maintaining consistency on some of the key definitions. Moreover, although our review included articles from different cultural areas, articles from Englishspeaking countries were overrepresented, limiting representativeness of findings to primarily Western individualistic settings. Comparing these with collectivistic countries and socio-economic status should be further explored as they can influence social capital (Hansen et al., 2018; Karanci et al., 2017; Salehi et al., 2019). Beyond the scope of our review, further research could synthesise other stakeholders' perspectives on the topic and triangulate these with our participant-led findings to provide further insight into the processes and motivations behind interpersonal transactions. Future research could also clarify the role and impact of social, environmental and cultural factors in facilitating or hindering post-traumatic growth and how this phenomenon varies over time with stages of illness through longitudinal designs. Tentative speculations on patterns of pervasive social difficulties and isolation across time, particularly in the older age, call for further longitudinal qualitative research following people across life stages to identify any potential cohort effects or risk factors. Next, our methodological assessment points to further improvements for individual qualitative studies, such as more explicitly addressing the researcher-relationship and potential power-imbalance and using more sensitive measures of SNs. Social Network Analysis, including developing visual network maps, is a promising avenue to this end in accessing quantitative and qualitative information, and has successfully been drawn on in one of the included studies (i.e. Pinfold, 2015), with positive feedback from participants. Finally, preliminary evidence for SN interventions exists (Brooks et al., 2022). Our study further reinforces the need for rigorous evaluation of such interventions, including patient and public involvement and cost analysis, to understand and optimise implementation, promote uptake and acceptability, and assess outcomes.

5.4. Clinical Implications and Conclusions

This meta-synthesis adds further evidence and novel knowledge on people's experiences of SNs in psychosis/schizophrenia, capturing preliminary findings of changes over time, individual differences determining social integration profiles, post-traumatic growth and the adaptability of networks to complement and supplement each other. All network systems were identified to influence recovery negatively and positively, in complex ways. Clinically, these ask for individualised assessments of the quality and quantity of social experiences, focusing particularly on the person's position in relation to various SNs, transfer of power and responsibility within and between networks, assessing and monitoring readiness for resuming roles in social contexts, and changes in networks over time. The pattern of pervasive social difficulties across time further prompts towards timely involvement and early intervention to buffer for social losses due to normative events particularly later in life. Moreover, social isolation was present for many, and understanding this phenomenon was complicated by people's own positive social withdrawal strategies. Therefore, developing a shared formulation of individuals' views on aspects such as isolation or positive withdrawal and their driving forces, and expanding awareness of any helpful and unintended consequences should be routinely addressed clinically. Moreover, previous research indicates that typical strategies such as increasing social involvement and supports are often ineffective (Michalska da Rocha et al., 2018) or have small to moderate effect sizes when compared to usual mental health care (Brooks et al., 2022). This further emphasises the need for service-user involvement in understanding their appraisal and motivations, acknowledging when social withdrawal may become protective. This would also positively instil a sense of control, agency and reciprocity that was highly valued across our studies. Furthermore, noted SN replacements point towards a need for services to focus on collaboratively identifying unmet needs by absent networks and flexibly drawing on available (in)formal supports, roles or activities to fulfil them (Brooks et al., 2022). Finally, our review supports previous findings that, to shift whole networks, improve social integration, increase awareness, reduce stigma and reestablish non-ill identities/roles, efforts need focused outside of mental health services (Brooks et al., 2022) to include interventions drawing on all systems (e.g., family, work, friends) and meaningful activity.

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CHAPTER 2

Mapping and Understanding Social Networks in Young People with Psychosis: A Mixed-Method Social Network Approach Study

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PLAIN LANGUAGE SUMMARY

Title

Mapping and Understanding Social Networks in Young People with Psychosis: A Mixed-Method Social Network Approach Study

Background

Social networks include any relationships in a person's life, such as family and friends. Although being helpful in recovery following psychosis, many people report small networks and loneliness. Changes in networks happen naturally as people navigate through life stages and may be more challenging for young people with psychosis, who need to solve key tasks of building a self-identity and forming peer relationships whilst managing symptoms. However, this topic has received little research attention.

Aims and Questions

The study aims to explore: (a) the size, composition and characteristics of people's social networks (quantitative), and (b) their meaning-making of how these networks help or slow down recovery (qualitative).

Methods

Participants

Three participants aged 19-23 with experiences of psychosis within the past two years and capacity to consent were interviewed.

Recruitment

Participants were recruited through their key workers in early intervention for psychosis services in Scotland. Participants were provided with detailed information about the study and consented prior to the interviews.

Study Design

The study used a mixed-qualitative and quantitative-methods design, informed by a thematic analysis and social network approach. Thematic analysis ensured we stayed close to the participants' experience whereas the social network approach directed our attention to how network structures shaped access to resources for the participant.

Data collection

We conducted one-to-one semi-structured interviews lasting between 1.5-2.5 hours. Participants first listed all network members they have been in touch with over the past month. Then, they characterised these networks, based on role, gender and most frequent type of contact. Next, using four concentric circles, participants placed themselves in the centre, and their network members in rings closer or farther away from them, according to level of closeness. The nearer to the centre, the closer the relationship. Finally, participants reflected on how psychosis influenced relationships and how these relationships helped or hindered recovery of valued roles and tasks, such as university or work.

Main Findings and Conclusions

Participants named between 13 and 57 network members, mostly close and extended family, and friends. We found four themes: 1) Supportive networks were available, offering practical, emotional and illness management help; 2) factors related to the participants themselves, such as anxiety or social difficulties growing up or their experience of psychosis, as well as 3) factors related to the networks, including difficult upbringing and stigma, influenced recovery; and 4) all wished to resume valued roles/identities and activities.

These findings help systems around the person, such as family and clinicians, understand what people with lived experience find helpful and unhelpful towards recovery. This can inform mapping social risks and protective factors, which can then guide intervention. Our visual circles materials could further be used clinically and in research to encourage tracking and evaluation of relationships and recovery, and spot gaps and strengths in social supports. Participants valuing contact with same-age and psychosis-experienced others, particularly during crisis, points to the use of peer support networks for adolescents.

1. ABSTRACT

Objectives: Social Networks (SNs) play a key role in psychosis recovery, yet their influence in adolescence/young adulthood and thus developmental tasks of peer belongingness, independence and identity have rarely been explored qualitatively. We aimed to explore networks quantitatively, through size or composition, and qualitatively through first-hand perspectives on their role in resuming and achieving developmental milestones. Design: We employed a mixed-methods, crosssectional design, guided by a social network approach and thematic analysis. Methods: Three participants aged 19-23 from early intervention for psychosis services completed a semi-structured interview, which identified all networks present within the past month, visually mapped them based on closeness, and explored key relationships' role in recovery. Results: Network sizes ranged between 13 and 57, and close and extended family and friends predominated. Thematic analysis revealed four themes: 1) Supportive SNs, providing security, practical, emotional and illness management support; 2) intrapersonal factors, such as pre-existing social/emotional difficulties, psychosis symptoms and a need for solitude, and 3) interpersonal factors, including family context and stigma, influence recovery; and 4) a persistent desire for resuming SNs, roles/identities and activities. Conclusions: Our findings provide a person-centred insight into good working principles for systems involved in intervention and inform systemic formulation of risk and protective social factors in recovery. Our visualisation materials have potential to be used clinically in developing reflexivity and managing track recovery and transitions, spotting gaps and strengths in social supports over time. Valued engagement with same-age and psychosis-experienced others points to the use of peer support networks for adolescents.

Keywords: social networks; psychosis; early intervention; adolescence; recovery; mixed-method research; qualitative research

2. INTRODUCTION

Psychosis is a mental illness characterised by positive symptoms, such as disturbances of perception (e.g., delusions, hallucinations) and negative symptoms, i.e. an absence or reduction of affective, social and behavioural expression (e.g., avolition, anhedonia), that often starts in adolescence or early adulthood (Arciniegas, 2015). Psychosis can be highly traumatic, with negative consequences on daily functioning and quality of life, such as disability, loneliness, unemployment (Hansen et al., 2020; McGuire et al., 2020; Ng et al., 2021), as well as reduced life expectancy (Brooks et al., 2022). Supporting people in their recovery from psychosis is therefore imperative. One key influence on recovery is connectedness through social networks (Leamy et al., 2011; Palumbo et al., 2015). Social networks (SNs) refer to an individual's web of significant relationships, including family, friends, colleagues, communities or professionals. In efforts to move away from an individualistic approach, novel social network approaches focus on how such SNs dynamically mobilise in response to health problems that extend beyond an individual's own capacity to self-manage (Brooks et al., 2020).

The role of SNs in psychosis is of particular interest, as different networks act as gateways to distinct resources and social capital (Brooks et al., 2020), and can thus play different roles in promoting engagement with services and personal recovery (Pope et al., 2019). However, individuals with experiences of psychosis often encounter challenges in forming and maintaining networks (Palumbo et al., 2015). Quantitatively, their networks are reduced in size (Bjornestad et al., 2019; Michalska da Rocha et al., 2018) and are disproportionately made up of family members (Palumbo et al., 2015). This is important as different networks fulfil different functions (Wrzus et al., 2013). Qualitatively, according to self-determination theory (Deci & Ryan, 2008), people are inherently agentic, curious and motivated to achieve new skills, and such motivation is promoted by satisfaction of key psychological needs for relatedness and autonomy, which are influenced by one's social realm. Autonomy for instance captures a perceived sense of control and/or choice; however, people with psychosis often feel out of control and excluded from decision making (Salehi et al., 2019). Relatedness refers to a feeling of social or emotional connectedness to others; however, loneliness is reported in up to 80% of people with psychosis and rated by a third as their biggest hinderance to recovery (Lim et al., 2018). Furthermore, poorer perceived social support and absence of confidants have been reported both in long-standing and first-episode psychosis (FEP) compared to the general population (Sündermann et al., 2014).

The link between poorer networks and psychosis is complex. On one hand, it has been suggested that onset of psychosis creates a SN crisis (Michalska da Rocha et al., 2018). Negative symptoms such as poor motivation and reduced anticipatory pleasure (Bjornestad et al., 2019), increased paranoia

and avoidance (Lim et al., 2018), frequent hospitalisations and severity of illness (Palumbo et al., 2015) impact SNs. However, there is also evidence that shrinkage of networks may pre-date the onset of psychotic symptoms (Mackrell and Lavender, 2004; Robustelli et al., 2017). For instance, individuals at ultra-high-risk of developing psychosis report less diverse networks, poorer peer and family relationship quality, and increased loneliness (Robustelli et al., 2017). Furthermore, increasing isolation from, inequity in, perceived negative bias of, and rejection by and of peer relationships were noted pre-psychosis, across childhood, early and late adolescence in a qualitative study on FEP (Mackrell & Lavender, 2004). Overall, individuals with higher vulnerability for developing psychosis and/or social difficulties may be caught in a self-perpetuating cycle of exclusion, whereby psychotic experiences such as paranoia impact on access to and quality of networks. This may then lead to the erosion of social support, increasing sensitivity to rejection and reinforcement of negative expectations of others. In turn, these heighten psychotic experiences, which further exacerbate social withdrawal (Michalska da Rocha et al., 2018). Nevertheless, relationships between networks and development of psychosis are likely to be complex, iterative and multifactorial.

Networks naturally change across the lifespan, quickly developing until young adulthood followed by a steady decrease through old age; with family networks remaining stable throughout the lifespan (Wrzus et al., 2013). First, according to the socioemotional selectivity theory, this trend is attributed to perspectives on how much time one has left to live (Wrzus et al., 2013). During adolescence and young adulthood, when remaining lifetime is perceived as unlimited, individuals' goals are to seek information and knowledge, rather than meet emotional needs for closeness that characterise later life. Second, according to Erikson's psychosocial stage model of development (Newman & Newman, 2015), young people need to solve dilemmas such as peer group affiliation versus alienation, independence, and identity definition versus confusion through experimenting with their roles and values. Both theories highlight goals that are achieved best by developing diverse relationships in large networks. A nonnormative life event, such as acute psychosis, likely affects goal attainment, influencing young people's views on life, values, self-identity (MacDonald et al., 2005) and prioritisation of emotional closeness over work/study-based goals (Lam et al., 2011). To this end, observed decreases in networks following a psychotic episode may be actively sought in line with personal values and balancing needs, rather than emerging as a negative consequence of psychosis (Nilsson et al., 2019). However, the opposite can also be true as psychosis brings uncertainty over one's development of expected roles and missed opportunities around education and employment (Grealish et al., 2013).

In addition, Dunbar and colleagues (Dunbar, 2008; Roberts et al., 2009) highlight that SN sizes and configuration are dependent on what people can maintain at any given level of intensity (Roberts et al., 2009), ability which is likely affected by psychosis. Networks gravitate around the person in concentric circles, with an innermost emotionally intimate layer typically averaging 5 members as it requires significant effort to maintain; and the next layer out capturing weaker ties the person has at least monthly contacts with, averaging 12-15 members, and which provide access to wider resources building on social bridging capital. Individual characteristics further influence such network sizes. For instance, people who are single, without children, with a highly sociable personality or with higher socio-economic status tend to have bigger network sizes and diversity, one's network is dominated by the same gender, and network size tends to decline in older age (Roberts et al., 2009; see also Wenger, 1993).

To capture the complexity of SNs, recent efforts were directed at obtaining first-person accounts of the changes, functions and meaning of SNs for people with psychosis (McGuire et al., 2020; Pinfold et al., 2015). For instance, a mixed-methods social network analysis study, including SN mapping and in-depth interviews, explored the phenomena in adults with severe mental illness, including psychosis (Pinfold, 2015). With regards to young people with psychosis however, based on our review above (Gatej & Gumley, unpublished), only a few studies included adolescents alongside young adults (Hansen et al., 2020; Mackrell & Lavender, 2004), and FEP in younger and middle adulthood (Huckle et al., 2021; MacDonald et al., 2005; Masse et al., 2020; Pope et al., 2019). Hansen et al. (2020) interviewed ten young adults with FEP about their experiences of relationships in recovery. Key themes included being seen as a unique person, being supported when feeling lost, having supportive families, and having diversity in friendships, different SNs having complementary roles and offering access to different recovery capital components. Similarly, Mackrell and Lavender (2004) specifically explored peer relationships amongst 12 adolescents with FEP using semistructured interviews. General family adversity and positive and negative peer experiences were highlighted. However, networks were underpinned by an increasing sense of social isolation, inequity in peer relationships and rejection of/by peers over time, which was exacerbated by psychosis onset. Similar themes of withdrawal from and by peers due to psychosis were noted in Huckle et al.'s study on friendships in FEP (2021) and MacDonald et al.'s study on young people attending a recovery group programme in an early-intervention setting (2005). The latter also highlighted that young people valued receiving family support, being understood and building relationships with other peers with psychosis through a staff-facilitated group programme. However, individual differences were also noted in regards to experiences of SNs. Masse et al.'s mixedmethods study (2020) for instance identified two distinct profiles characterising the evolution of SNs over time. One profile featured rich and stable SNs, had better metacognitive skills and was less reactive to psychosis onset. The second profile presented sporadic, unstable SNs, almost exclusively focused on substance use, that were more disrupted by psychosis and lost at normative transition points. Adding to previous studies, Pope et al. (2019) collated patients' and stakeholders' views on roles and responsibilities of SNs for supporting people with FEP primarily via focus groups. Different roles at different points in recovery were assigned at all levels, including patient, immediate family SNs, macro-level stakeholders (e.g., governments) and society. Tensions between valuing agency and personal responsibility versus the need for SN involvement and a need for coordinated efforts were amongst the key themes identified. Due to the emerging complexity of SNs, further in-depth exploration of young people's first-hand perspectives is needed.

To our knowledge, no study to date has investigated the quantitative and qualitative experiences of networks in young people with psychosis using a mixed-method social network approach. Therefore, this study aims to explore (a) the composition, structure and characteristics of networks amongst young people with psychosis and (b) their meaning making around how these networks support or hinder their recovery of valued roles and developmental tasks.

3. MATERIALS and METHODS

3.1. Design

A mixed-methods, cross-sectional design was employed, guided by a social network approach. This is based on social network theory, which highlights that the structure of the networks shapes the flow of resources and opportunities, influencing individual behaviours and attitudes (Herz et al., 2015). Quantitative aspects such as network size or composition, and qualitative in-depth narratives of network formation and supports were included. The primary findings are focused on the qualitative data, which was analysed using Thematic Analysis (TA). This idiographic approach aims to remain close to participants' experiences, whilst allowing for nesting within a social network approach. More details on the originally planned methodology are provided in Appendix 1 – MRP Proposal (online; page 88) and more comprehensively in Appendix 2 – IRAS proposal (online; page 89).

3.2. Participants and Recruitment

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Participants included young people 1) aged 14-24 years old, 2) with experiences of psychosis over the last two years, 3) who were open to and supported by NHS secondary care mental health services (i.e. early intervention for psychosis services, adolescent inpatient units, and CAMHS/ICAMHS) in Scotland, 4) with good level of English, defined as the referring clinician providing care in English without the use of a translation service, and 5) with capacity to provide informed consent. Participants experiencing acute psychosis and/or lacking capacity to consent, as deemed by their keyworkers through their clinical care or the researcher during informed consent, were excluded due to risk of destabilisation. Although we estimated variations in the composition and structure of networks across developmental stages due to our initially wider age range, potentially reducing sample specificity and limiting conclusion-making (Malterud et al., 2016), we proceeded with it to facilitate recruitment. We aimed to recruit 6-10 participants, taking into consideration information power factors such as the in-depth idiographic analysis strategy, broad aims and predicted strong quality of dialogue (Malterud et al., 2016) and comparing with similar qualitative studies on SNs (e.g., MacDonald et al., 2005; McGuire et al., 2020). Initially, we attempted to purposively sample younger participants in CAMHS and the adolescent inpatient unit. However, only one person was identified as eligible and they did not proceed with the study. Consequently, we extended recruitment towards the older age-ranges in the early intervention for psychosis services, which provide multidisciplinary care for young people aged 16-35 following FEP.

The lead researcher provided clinicians at the relevant recruitment sites with information about the study. Clinicians then identified people meeting eligibility criteria and provided further information, including a study leaflet, to ascertain initial interest in being approached for informed consent. Interested people's details were passed to the researcher, who made contact and provided further information about the study, including a Participant Information Sheet (PIS; Online Appendix 3, page 90) detailing the study procedures, risks/benefits, and participants' rights (e.g., confidentiality, right to withdraw, data management), which was discussed directly with the participant via a 30-45 minutes remote appointment. Following this, we sought informed consent (see Online Appendix 4 and Online Appendix 5 for consent forms, pages 91-92). Recruitment spanned four months (October 2021-February 2022). Eight eligible participants were initially named by clinicians in the early intervention services. Of these, two did not wish to proceed due to recent deterioration in their mental health, one due to temporarily having moved homes, one due to holiday travels, and another due to other commitments. The final sample included N=3 participants (two males, one female; age range: 19-23). One participant was studying at university and lived with flatmates in private accommodation, another was an ex-university student and current volunteer and jobseeker, living

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with parents, and a third was an ex-university student who had recently returned to his parental home from hospital following acute psychosis.

3.3. Procedure and Materials

Based on participants' preferences, interviews were conducted face-to-face or remotely via a routinely used NHS video consultation platform. Following informed consent, one-to-one semistructured interviews were conducted over one-two sessions. An interview lasted between 1.5-2.5 hours (average approx. two hours) and was conducted by the lead researcher. The interview focused on social networks within the past month. The first part of the interview included the quantitative interview and social network mapping (Online Appendix 6 – Interview Schedule1, page 93). Three social network analysis elements were covered. First, the Name Generator, adapted from Crossley et al. (2017) prompted participants to name as many people present in their networks within the last month. A range of network categories were covered, including significant persons networks (i.e. people who are important to them), exchange/support networks (i.e. people that may offer help with work/school), and networks based on the role of the relationship (e.g., friends, neighbours etc.). Second, a Name Interpreter provided follow-up questions about the demographic characteristics of the identified SN members (e.g., role, gender, online-only versus face-to-face contact). Third, the researcher presented an online blank visual network map consisting of the Four Concentric Circles interpersonal psychotherapy inventory, with each ring located at an equal varying distance from its neighbouring rings (Mufson et al., 2011). The participant was positioned in the centre and independently placed all members of their personal networks across the concentric rings from most to least involved; closer rings to the centre indicating a closer relationship to the participant. Each ring could be assigned a rank of 1-4 (where 1-closest to centre; 4 – person is known but not close; distant; furthest from centre). The researcher did not influence participants' choice, but encouraged them to ask for clarification or reflect aloud. Visual representation of personal networks has been used in a similar study and found to increase recollection, raise awareness of resources, help identify gaps and vulnerabilities, and instil reflections on future plans (Pinfold, 2015). The Network Canvas tool was used to collect all the information above and add members to the concentric circles sociogram, the researcher sharing their computer screen with the participant. Network Canvas is a free, novel, GDPR-compliant and open-source software designed to support researchers collect social network data in a more user-friendly, fast and interactive manner.

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The second part comprised of the qualitative interview on young people's meaning-making around their networks diagram and role in recovery, whilst and after working through the personalised sociogram (Online Appendix 7 – Interview Schedule2, page 94). Participants were advised to choose freely up to eight members they wanted to discuss in their in-depth reflections to allow for richness of data. Interview prompts were compiled by the lead researcher from interpersonal psychotherapy guidance on concentric circles and literature on developmental milestones, recovery, and SNs in psychosis and reviewed in research meetings with supervisors. Topics included SN changes during crisis point and recovery from psychosis, SN roles in meeting developmental tasks (e.g. independence, seeking employment/studies), and future goals/hopes. Anecdotes and concrete examples were sought. Participants were encouraged to digress from the questions to fully explore experiences. The interviewer wrote reflexive notes during and following each interview. A debriefing sheet with a summary of the study and contact details for further supports was offered at the end of the interview for participants' records.

3.4. Data Analysis and Research Team

Interviews were audio-recorded for transcription purposes, securely stored, and destroyed after transcription. Transcriptions were anonymised (e.g., <pseudonym1><location1><friend1>). Quantitative data was analysed using descriptive statistics to obtain the size and configuration of SNs (e.g., counts of the global networks, family, friends etc.) and SN member characteristics. Anonymised visual network maps were also presented. Qualitative analysis of in-depth interviews employed a reflexive thematic analysis (TA) strategy. TA was chosen over other methods such as Interpretative Phenomenological Approach (IPA) because, in line with our research question, we aimed to identify key themes across cases on the truths of people's contextually situated experiences and behaviours, rather than unique features of individual cases (Braun & Clark, 2021). TA can be used with smaller or larger datasets with samples with homogenous or heterogenous experiences, accommodating our small N sample and any potential heterogeneity related to recovery and age-stages between participants. TA also prioritises a fluid approach to interviewing to resemble real-world conversations which fitted with our semi-structured interview approach (Braun & Clark, 2022). It is further theoretically flexible and suitable for mixed-methods designs; thus, could be nested within the broader social network approach used (Braun and Clarke, 2006) whilst allowing to remain close to participants' individual experiences through its phenomenological, idiographic approach. Finally, due to time and resource constraints, it could be completed by a single analyst and allowed for inevitable subjectivity, as long as the focus was on richness and depth of data (Braun & Clark, 2022).

An inductive, semantic, and critical realist approach to TA was used. The inductive approach allowing for coding and theme development to be directed by the content of the data was preferred because of the limited research with adolescents, lack of an available theoretical coding framework, achieved richness and depth of the interviews, and to limit the influence of analytic preconceptions driven by the researcher's interest. Our approach leaned towards the semantic end of the semantic-latent spectrum, to allow codes and themes to reflect the explicit content of our broad topics and rich data, although such themes inevitably unite implicit or latent meanings due to researcher's subjectivity and reflexive approach taken (Braun & Clark, 2021). The critical realist approach aimed to give clearer, concrete conclusions on the SN phenomenon experienced as the reality for participants. This assumed that participants verbalisations represented a close approximation of an external reality that is also filtered through one's own beliefs (Braun & Clark, 2022). Six phases were followed: 1) multiple readings/listening of the interviews and noting down initial ideas/reflections; 2) generating initial codes with their relevant data; 3) collating codes into potential themes; 4) identifying recurring themes, generating a thematic map of the analysis; 5) defining and naming themes; and 6) write-up, where interpretation of data continued (Braun and Clarke, 2006). Key themes and illustrative quotes were presented. Preliminary codes, themes and write-up were reviewed in supervision. No member checking or qualitative structural analysis (QSA; Herz et al., 2015) of the visual network maps were conducted due to time constraints. Both researchers who reviewed the data have training in clinical psychology, clinical interviewing with participants with mental health difficulties, and qualitative methods. The supervisor has extensive experience in psychosis research.

3.5. Ethics

The study received Ethics Approval from the West of Scotland Research Ethics Service (REC Reference: 21/WS/0089) and health board managerial approval (R&I reference: GN21MH127P; see copies of approval letters in Appendix 8, page 95). Issues such as confidentiality, right to withdraw, data privacy, anonymisation and use of quotes in reports, risks and benefits, and safety management were extensively covered throughout contact with participants. Participants were given a week in between initial contact and PIS discussion appointment and another week before the interview to carefully consider their wish to participate and provide informed consent. Consent was verified several times due to the nature of remote appointments. Participants were encouraged to consult with a trusted adult about the study if wishing to, seek support from their keyworkers or discontinue participation if feeling distressed and were reminded of their right to withdraw at any point. No issues were reported, and participants expressed positive feedback about the interview experience.

Participants were offered a summary of the study's results, a copy of their sociogram and a £10 honorarium. Data was securely stored as per ethics and university guidelines.

4. **RESULTS**

4.1. Quantitative Features of SNs

Table 2 presents the SN size, composition and attributes (i.e. gender, contact type) for each and across the three participants. Each participant's visual network map is presented in Figure 4. There was great variation between participants on network sizes and composition, with more non-kin and wider SNs present for the participant that appeared furthest in their recovery based on their return to typical activities and roles (i.e. Kate). Network members from each group took positions across all circles of closeness. Informal SNs, such as family and friends were generally positioned closer to the participant than more formal SNs, such as work and school relations.

	SN characteristics	Dan	Kate	Oliver (19,	Average	Average
		(23,	(23,	male)	(N)	(%)
		male)	female)			
Overall	SN total	29	57	13	33.0	100.0%
Network						
Size						
Network	Close family	4	7	4	5.0	15.2%
Composition	(parents, siblings)					
	Extended family	4	7	2	4.3	13.1%
	(grandparents,					
	aunts, uncles etc.)					
	Partners/ Spouses	0	1	0	0.3	1.0%
	Friends	7	27	1	11.7	35.4%
	Professionals	2	3	3	2.7	8.1%
	Work/School	7	5	1	4.3	13.1%
	Others	5	7	2	4.7	14.1%
	(neighbours, ex-					

Table 2. Quantitative characteristics of networks

	partners, pets,								
	youth/groups,								
	organisations etc)								
Most	Online	12	5	2	6.3	20.0%			
frequent	Face-to-face	11	35	9	18.3	57.8%			
contact type	Mix: online &	6	13	2	7.0	22.1%			
	face-to-face								
Gender	Male	12	18	7	12.3	37.4%			
distribution	Female	9	35	6	16.7	50.5%			
	Non-binary	0	3	0	1.0	3.0%			
	Transgender	3	0	0	1.0	3.0%			
	Other gender	5	1	0	2.0	6.1%			

Note. For Kate, four members were added after completing the Network Canvas interview, so not all their characteristics (i.e. gender) were noted. Percentages are calculated across the whole sample.

Figure 4. Visual network maps for each participant





4.2. Qualitative Features of SNs

Qualitative TA revealed four themes that captured SNs in recovery (Figure 5). Each participant described recovery in their unique way. For Dan, recovery meant 'pursuing my goals again. [...] opening up, . . .{{3sec}} being more involved in things like, --yeah, taking up some of my hobbies that I maybe gave up when I started studying' (L486-487). For Kate, 'psychosis was like a big explosion' and recovery 'as like picking up those pieces, and putting them together, and putting them together in a way that is different to what I did before[...] that makes my life better' and reconfiguring complex relationships (Kate, L311-312). Finally, for Oliver, recovery meant being OK with their own thoughts.

Figure 5. Themes and sub-themes across cases



4.2.1. Theme 1: Supportive SNs: a safety net holding the young person

All participants chose important professional and non-professional networks that played a role in recovery and have experienced this involvement positively overall. Participants' experiences fell into two sub-themes.

4.2.1.1. Sub-theme 1.1: SNs as a 'backdrop and sense of security': shared and unique roles

All three participants identified support from both professional and non-professional SNs as vital in recovery. Support took varied roles, from practical to emotional to managing symptoms.

Emotional support, including being available for the young person to discuss important things with, encouraging and praising progress, instilling hope, offering unconditional support *'without an agenda'* (Kate, L367), normalising distress, and sticking with the young person at challenging times were valued indications of emotional connectedness for all participants. Emotional support was provided primarily by family and close friends, although professional SNs took a unique role here in allowing safe space for disclosures that would otherwise not be discussed with informal SNs and instilling hope for the future: *'I had quite like a bleak idea of what my future is gonna be (uh-hum)*.

Like, I thought I was gonna be really unwell and long-term unemployed and stuff (yeah). [...] I think MENTALHEALTHSERVICE1, like, I feel it gives me a lot of security.' (Dan, L293-295, L297).

Practical support was also described by all participants. This was offered primarily by family and professionals, including help with job/university applications, or engagement in meaningful solitary and social activities: 'she [sister] kinda pushes me to do stuff like, apply, she helped me apply for the provisional license recently (yeah) and she says I should apply for the theory test (uh-hum). So I have something to work towards.' (Dan, L80-82), which appeared to instil a sense of purpose. However, participants highlighted the importance of SNs being attuned to the person's readiness for action, for regaining valued roles/activities, and thus limiting expectations and pressure. Albeit to a lesser extent, friend SNs took a more prominent position in activity-led socialisation, such as games, parties, jokes and sharing of similar interests for most participants.

Illness management support was additionally mentioned by most participants. This included immediate support such as keeping the young person safe during the acute phase, visits at hospital, or advocacy support with treatment decisions, as well as longer-term intervention. Professional SNs played a unique role in increasing awareness of helpful and unhelpful behavioural patterns, monitoring distress and progress, reassuring the networks around the person, and ultimately helping the young person understand psychosis, i.e. *'unpacking those really twisted things I said when I was really unwell, where that came from and what do I do with that [...] dealing with the way things might have changed with people, the way things have changed with my relationship, with myself.' (Kate, L299-300, L322). Joint working between SNs was particularly valued for updating SN on the person's wellbeing, attenuating potential unintended consequences of psychosis symptoms and bringing SNs, such as previously distant family members, closer together to support the person. However, some segregation between professional and informal SNs was also welcome, as it allowed having <i>'just my perspective, or, I can talk about relationships which might be quite complicated or quite difficult to someone who doesn't know about them in a personal sense, because it is kinda objective I guess.'* (Kate, L493-495).

4.2.1.2. <u>Sub-theme 1.2: SNs experienced qualitatively - Mattering</u>

All three participants were seen as an active contributor, valued, understood, accepted, paid attention to, held in mind and forgiven by their SNs. Reciprocity played a big role in mattering. For instance, one participant talked about the importance of building skills for their future role as carer for their parents: 'One of the things about being independent is, I think, learning how to cook (uh-hum). [...] if I was a carer (uh-hum), I think cooking meals would be a really useful skills.' (Dan, L375-378). Nevertheless, the wish to reciprocate was at times paired with low self-confidence and

uncertainty about how to do it: '*I'd like to help but I may not be the best person to deal with -to be sympathetic or whatever.[...] I don't really know how to help or deal with it.*' (Oliver, L327, L329-330). Being understood, accepted and forgiven were also indicators of mattering across participants. Networks with other service users took a special position in this regard. All participants appreciated the value of a shared sense of isolation, relatedness, inspiration and hope gained from witnessing others' recovery journey: 'She [friend] gets on with her life in spite of difficulties she has had with her mental health and that of those around her. [...] So I felt very understood by her (yeah), and like I could explain the really weird things about my mental illness, or like you know, the strange things when I was psychotic, like how I behaved, and the things that even if I was close to them, I would have had hesitancy sharing with other people because they didn't have direct experience with it (yeah).' (Kate, L413-416). A need for forgiveness particularly permeated through Kate's experience with close SNs, when psychosis symptoms were directed at them: 'she's one of the only people I feel I can 100% be me and it's not a problem, cause she knew it wasn't really me speaking.' (Kate. L230-231).

4.2.2. Theme 2: From the inside out - intrapersonal factors influencing SNs and recovery All interviews highlighted a range of intrapersonal factors both pre- and post-psychosis that shaped SNs, described under three sub-themes:

4.2.2.1. Sub-theme 2.1: Social and emotional difficulties pre-psychosis

All participants reported one or more experiences of anxiety, depression, low confidence and social difficulties, specific health-related worries about developing psychosis due to family history of severe mental illness, or general unhelpful behaviours relating to the self or others pre-psychosis: 'before I was psychotic, and I was unwell in a different way, I was depressed and anxious periodically, there were certain ways I behaved, in my relationships or work, relationship with myself, all these things, that were not making me mentally well.' (Kate, L312-314). One participant specifically highlighted their Asperger diagnosis as a contributor: 'I'm not one for keeping in touch, really, just sort of drift away from people (uh-hum). That's what I do. [...] not good at socialising or –I've got Asperger's so maybe that may be a factor.' (Oliver, L294-295, L298-299). Such difficulties also made it harder to reciprocate, resulting in relationships that were described as 'one-sided' (Dan, L690).

4.2.2.2. Sub-theme 2.2: Psychosis changed SNs: a 'make-it or break-it' point

All three participants named at least one negative impact of psychosis on their SNs. For some, it increased dependency on SNs, although for one this was only in the initial/acute stage of

Conversely, two participants' reflections indicated experiences of post-traumatic growth following psychosis. Close core SNs, such as family, long-term friendships and romantic relationships solidified and grew even closer following psychosis, both in relation to the participants and also between themselves, and reflected progress, whereas distant or unhealthy SNs were happily dropped by participants: *'for some of my relationships it was kind of a breaking point. Not that I was doing this consciously at the time, but it was like 'let's get rid of that friendship because it isn't really serving me.'* (Kate, L287-288). For one participant, psychosis allowed expressing long-term bottled feelings and thoughts about abandonment and rejection, as illustrated in the above quote. This was experienced as a release, removing *'blocks on friendships'* (Kate, L280).

4.2.2.3. Sub-theme 2.3: Social detachment and a need for solitude

Some of the social difficulties present pre-psychosis followed through post-psychosis for two participants. Participants described isolating themselves, being non-committal, not keeping in touch or not thinking about relationships: *'I think I didn't think about getting in contact with people (uh-hum) and kind of, I relied on them to kind of like get in contact rather than me reaching out (yeah). It is kind of one-sided, which is bad for, you know, . . . {{4sec}} relationships.' (Dan, L682-684). This however proved helpful in terms of avoiding relationships that were incompatible with recovery (e.g., friendships were drugs/alcohol were consumed), reducing shame and allowing for time to recharge. Even more, one participant reported feeling <i>'ok with spending time on my own'* and assumed responsibility for his limited SNs: *'I think it's just my own doing, that I don't have, cause I don't actually*{*4sec*} commit to spending time with people that –sometimes I do, but very, very *rarely.*' (Oliver, L249-251). Nevertheless, even for this participant, a fear of 'too much solitude' was present.

4.2.3. Theme 3: From the outside in - interpersonal factors influencing recovery

All interviews highlighted a range of interpersonal factors both pre- and post-psychosis that have shaped their experience of psychosis and recovery, including SNs. These fell under two sub-themes:

4.2.3.1. Sub-theme 3.1: Family context: 'I had what she had'

A family history of schizophrenia and alcohol dependency leading to intense worry and rumination was believed to have contributed to developing psychosis by Dan: '*My aunt is very unwell with psychosis, she's had it before, she's like –very bad, and like, that worried me a lot, I worried about that (yeah). And I've kinda, like, --we are quite similar, me and my aunt, and I kinda thought I had what she had.' (Dan, L232-233). Witnessing his relatives' struggles with long-term unemployment and isolation perpetuated worries about Dan's own future, ability to work and rebuild relationships. Another participant (Kate) briefly touched on their experiences of an unstable upbringing as being reflected in psychotic symptoms. However, for this participant psychosis brought previously segregated parts of her close family together.*

4.2.3.2. Sub-theme 3.2: Stigma and fear of disclosure

Two participants experienced some level of rejection and stigma. One participant's friends 'would not invite me and stuff (uh-hum). . . . {{4sec}} It was probably, they didn't want to do it because I was acting kinda strange' (Dan, L341-342). Talking about ex-romantic partners, Kate also revealed how insensitive jokes, comparisons with less severe/enduring mental illness, and not engaging her in group conversations minimised her distress and left her feeling inferior and devalued: 'I would sit with them [partner's group], and feel quite out of the loop and inferior (hmm). And he [partner] wouldn't really talk to me, he would be quite off, distant, so that would always make me feel kinda devalued (uh-hum).' (Kate, L395-396).

Hesitancy to disclose about psychosis emerged across all interviews. One participant did not disclose about their symptoms at first, another remained hesitant to talk about psychosis with people without lived experience, and a third wished not to disclose specifically about psychosis, but was comfortable disclosing about mental health problems in general. These were linked to shame and one's own lack of understanding of psychosis and expectations that other people will understand it even less: '*1 just wouldn't be that specific, ehmm. . . . {{6sec}} I might feel a wee bit ashamed about it [...] I don't really understand it myself. (I: so do you think other people would understand even less?)* Yeah. --But if I just say that I've got problems with my mental health, that is a bit more general and a bit more people can relate to that.' (Oliver, L273-274, L277-280)

Despite these nuances, all of the participants in fact denied being stigmatised by others, and felt understood and accepted as illustrated in sub-theme 1.2. Moreover, all participants acknowledged the contribution of non-illness related factors in relational losses, such as personal circumstances (e.g., sickness, moving towns, personal problems) or simply a lack of shared interests and values: ' *with ExFriend2, I don't think she's been a bad friend with me, I think we just don't necessarily click. And it is like those sorts of people, where I knew for years that our friendship wasn't really working but I didn't wanna say and I didn't know how to say it. [...] I kinda just like phased her out I suppose*' (Kate, L88-90, L94). These highlighted the dynamic evolution of relationships naturally phasing out.

4.2.4. Theme 4: Future recovery: resuming valued SNs, activities and roles

All participants reflected on their wishes for the future, both regarding SNs and wider activities. Two sub-themes emerged:

4.2.4.1. <u>Sub-theme 4.1. An interplay between strong wishes to resume life and sense of agency</u> <u>over this process</u>

All participants wished to resume lost activities or engage in new roles/activities (e.g., employment), gain independence, expand their SNs (particularly close friendship or intimate SNs) alongside competing demands, and maintain intimacy with existing SNs. SNs trusting the young people to take on risks, despite their own worries, particularly immediately post-discharge from hospital, was nurturing for Kate: *'with Flatmate1, I think she struck a balance between being supportive but letting me get on with my normal life (uh-hum), and like, yeah –so, I think I slowly gained back that independence, and I actually feel more independent now then I did before I was psychotic.' (Kate, L456-458)*. However, allowing independence appeared linked to the stage of recovery, as Oliver, our youngest participant with the most recent experience of acute psychosis, was accepting of his family believing he was not ready to live independently. Ability to progress towards desired goals was further tainted with low self-confidence in managing increasingly competing demands for Dan, whereas Oliver feared the opposite, i.e. not having enough purpose/activity. As indicated in theme 1, SNs can take a valued role in holding or resolving such worries.

4.2.4.2. <u>Sub-theme 4.2: SN development through activities: having something to work towards</u> Participants accessed SNs through organised and self-initiated activity, such as youth sport clubs, volunteering, university or employment. These provided participants with a sense of purpose, responsibility, routine, and opportunity to meet like-minded peers. Some participants were more dependent on SNs to initiate or facilitate activity involvement: 'the union has some kind of routines and, like, regular meetings. Uhmm... MENTALHEALTHSERVICE1 gives me a routine as well. But on my own, I think I'm quite dependent on, yeah, maybe my parents and others for routines.' (Dan, L494-496). Another participant highlighted the importance of varied enjoyable hobbies and activities 'to keep perspective on university' (Kate, L350), which was a previously significant stressor, and create a structure in the absence of the lost main student role. Peers were identified as central to enjoyable activities such as dinners and lighter parties, 'giving me a sense of normality and social life' (Kate, L355-356). Finally, pacing return to activities, including socialisation, was highlighted as essential to build confidence and resilience and avoid reaching a sense of overwhelm which previously contributed to psychosis: 'I don't wanna get, like, jump in too much, cause when I was studying, I kinda jumped in (uh), I was getting involved in a lot of things, and that was partly why I was unwell.' (Dan, L197-199)

5. DISCUSSION

5.1. Theoretical Discussion

The study explored SNs quantitatively through network size, composition and member attributes, and qualitatively through in-depth interviews on young people's experiences of SNs in recovery following psychosis. There was great variation between the network sizes and composition, with the presence of more non-kin and wider SNs potentially indicative of further recovery. All participants benefited from and valued practical, emotional and illness management support from both formal and informal SNs. Simultaneously, participants also valued growing independence, autonomy, relationships that enabled reciprocity, understanding and forgiveness, and taking on activity/role-based opportunities that would allow them to build on social identities. Our findings are in line with existing literature on the complex influences of both structural and qualitative aspects of SNs in psychosis recovery across age groups and stages (Hansen et al., 2020; Lencucha et al., 2008; Macdonald et al., 2005; Mackrell and Lavender, 2004; McGuire et al., 2020; Pope et al., 2019; Salehi et al., 2019) and with the CHIME recovery framework which highlights the need for positive connectedness and empowerment through agency and personal responsibility (Leamy et al., 2011).

With regards to SN structural features, such as size and composition, all our participants had people support them in crisis or with important things, and averaged a network size of 33, which is much higher than previously reported average of 10 in reviews (Siette et al., 2015). Moreover, all

participants had smaller innermost/close ties than the wider ties, which adds evidence to previous studies on an existing cap in maintaining SNs at a given level of intensity (Roberts et al., 2009). We speculate that the increase in network size between our participants may link to being further along in recovery. To this end, crisis points, such as experiencing acute psychosis, likely prioritises emotional closeness with a smaller network to best meet one's complex needs and affected abilities in social cognition, mentalising and memory (Dunbar, 2008). Family often predominated in offering such closeness and this has been highlighted in previous psychosis research (Michalska da Rocha et al., 2018). However, this may also reflect the fewer costs and effort required to manage kin ties as compared to non-kin relationships (Roberts et al., 2009). Similarly, as in previous studies (Dunbar, 2008; Roberts et al., 2009; Wenger, 1993), a gender bias appeared for our participants, whereby male participants' networks included more males and vice-versa, and our female participant tended to have larger networks, potentially reflecting socialised capacity for intimacy (Wenger, 1993).

Interpreting the network maps, all but one participant, both of which were further along in recovery, had different groups of networks (e.g., family, professionals), providing access to unique and more diverse resources, according to social network theory (Herz et al., 2015). This meets the expected developmental needs of adolescence and young adulthood, when, according to socioemotional selectivity theory, one's goals to seek information and knowledge (Wrzus et al., 2013) are best met by developing diverse relationships in large and relatively distinct networks. Comparing the maps with previous SN typologies (e.g., Killian, 2001; Pinfold, 2015; Wenger, 1993), Kate's network map – the largest in our sample - resembles an integrated, diverse and active SN typology, characterised by wider community-focused support networks, regular social contacts across settings, presence of close emotional bonds, feelings of integration into regular social life, and predominantly informal or non-ill contacts (Killian, 2001; Pinfold, 2015). Such typology allows for new identity formations through experimentation with roles and relationships and wider access to resources, but can also require more effortful management and create more sources of stigma (Pinfold, 2015). Comparatively, Dan's network map appeared to match a locally integration-oriented SN typology, which presents with regular social contacts in different settings, particularly through organised activity and community involvement in groups such as youth clubs with other service users, and with a persisting fear of disintegration and wish for more bonds and typical social activities (Killian, 2001; Wenger, 1993). Finally, Oliver's map, which had the smallest network size, identified primarily with a family-dependent support network typology (e.g, Killian, 2001; Pinfold, 2015; Wenger, 1993). Such typology is characterised by stable, close family bonds and lack of diversity in obtaining social capital from non-kin sources (Wenger, 1993; Pinfold, 2015). Whilst helpful offering a sense of structure,

short-term safety net, emotional support, too high family involvement can inadvertently dominate SNs, perpetuate a sense of dependency and limit vision of an alternative future (Pinfold, 2015). Interestingly, across all participants, strong, close family SNs and several long-term solid friendships appeared to follow the young person despite challenges, adding to evidence that the innermost layer of the network is maintained over time (Wrzus et al., 2013)

With regards to relational qualities, in line with a psychosocial model of development (Newman and Newman, 2015), a desire for independence, reciprocity, responsibility taking, augmenting intimacy with or expanding SNs and resuming developmentally typical activities and roles emerged, mirroring previous systematic reviews on social capital in severe mental illness (Salehi et al., 2019). Personal responsibility and identity are seen as central to recovery (Pope et al., 2019; Soundy et al., 2015). Depending on capacity and stages of recovery, a positive cycle of passing responsibility to and from the young person, whilst being attuned to their needs and preferences, offering forgiveness, and blaming the illness rather than the person, were supportive of recovery for our participants. From a self-determination theory perspective, responsibility taking augments control and choice, reinforcing a sense of autonomy, whereas intimacy with others increases relatedness, and these are key psychological needs towards self-motivation and wellbeing (Deci & Ryan, 2008). Considering that amotivation is common in psychosis (Arciniegas, 2015), SNs supporting increasing autonomy and relatedness becomes particularly relevant. Participants valuing building on autonomy and responsibility is however, at odds with previous suggestions that psychosis shifts developmentallyexpected goals towards a preference for emotional closeness over work/activity/study-based goals (Lam et al., 2011). This discrepancy may, however, be explained by the fact that all of our participants appeared to have emotional closeness needs already met through access to a solid base of close SNs which further allowed them to turn to task-based goals. This may also explain why loneliness, a frequently reported experience in psychosis (Lim et al., 2018; Michalska da Rocha et al., 2018), did not feature in our participants' reports. This hypothesis is supported by previous quantitative research findings that good social support, access to a confidant, less internalised stigma and fewer experiences of perceived discrimination protected against loneliness (Lim et al., 2018; Michalska da Rocha et al., 2018).

Comparing our findings to previous qualitative studies of young people in particular, Hansen et al. (2020) identified similar protective factors of mattering, receiving practical and emotional support from families and support in understanding and managing psychosis from professionals, and having access to diverse resources at different points in recovery, as well as risk factors, such as negative experiences of rejection and fear of disclosure. To this, our study added knowledge on what young people valued about relationships with other psychosis-experienced peers, such as greater acceptance and understanding driven from these networks. The second identified qualitative study on young people highlighted a pattern of increased isolation over time, inequity in peer relationships and rejection of and by peers, which were exacerbated by psychosis (Mackrell and Lavender, 2004). This pattern was only somewhat reflected in some but not all of our participants' experiences, where social and emotional difficulties, including social detachment, preceded and, to some extent, were temporarily exacerbated by psychosis. However, participants both in our study and previously (Ogden, 2014; Nilsson et al., 2019) were noticed to willingly reconfigure their SNs following psychosis, including increasing self-awareness and actively distancing themselves from SNs incompatible with recovery, adding to the post-traumatic growth in psychosis literature (Ng et al., 2021). This also fits with hypotheses that capacity for close, intimate networks is limited and that people need to sacrifice other networks to allow time for close relationships (Dunbar, 2008). Importantly, relationships with psychosis-experienced peers could either contribute to or hinder this growth, through modelling of either recovery and instilling hope, or stagnation and hardship respectively.

5.2. Strengths and Limitations

This study draws strength from its' social network guided mixed-methods approach and theoretical grounding, rich interviews and rigorous application of data analysis. Our data richness and thickness, capturing nuanced qualitative information about feelings, reactions, personal meanings, circumstances, contexts and narratives centred on the participants viewpoints, added to informational power and this was facilitated by analysis of the person's networks and strong quality of dialogue. The use of Network Canvas and concentric circles as a visualisation tool encouraged reflection and provided an overview of how SNs are positioned based on level of closeness, complementing qualitative reports. This adds to literature on the promising use of visualisation tools for eliciting reflections on SNs in psychosis research (McGuire et al., 2020; Pinfold et al., 2015).

However, we noted several limitations and deviations from the proposal. First, due to time constraints and Covid19-related negative impact on services, our sample size was significantly smaller than predicted and comprised participants on the older end of our age range. Critical developmental tasks and differences may have therefore been masked. Although all participants appeared at different stages of recovery, strengthening representation of the broader young population with experiences of psychosis, these are only speculative and we cannot extend learning

from their experiences to adolescents with different characteristics. Due to the small dataset, the analysis methods also have limitations. Although TA, and particularly an in-depth approach like ours, can be used with smaller samples (Braun & Clark, 2022), our small sample's informational power may be limited due to the relatively broad research question and inductive/exploratory approach used (Braun & Clark, 2022; Malterud et al., 2016). Moreover, TA reveals meaning across cases and these may have been impacted by the low number of interviews, albeit rich in content. However, we did not aim to achieve saturation as it conflicts with the core assumption that there is always potential for new understandings in a reflexive, in-depth analysis approach (Braun & Clark, 2022). The recruitment setting of multidisciplinary early-intervention services, whose role is to support recovery of valued roles/tasks, may have further influenced participants' views of and access to services and supports, and thus findings may be less relevant to people who do not access such intensive support. Furthermore, although we took effort in staying close to the raw data and reviewed themes in supervision and through each TA step, our own theoretical and clinical knowledge of adolescent development, psychosis, systemic interventions, recovery and focus on strength-based approaches inevitably guided the interview and choice of salient themes and extracts, potentially towards over-recognition of positive experiences. Involving people with lived experience in design and analyses, as initially considered but not achieved due to time constraints, would have strengthened our interpretation. Finally, guotes from two participants (Dan and Kate) were used more frequently; this was due to the richness of answers better illustrating the themes, and all participants' information was attributed equal weighting towards theme development.

5.3. Research Implications

Further research should attempt to include younger teenagers' experiences to explore quality of SNs, particularly in school settings, which tend to expose people to larger but highly interconnected SNs, as compared to work or volunteering later in life; and across other community mental health services. Loneliness in young people also warrants further attention as our study's sample had close social bonds and no reported experiences of loneliness, and may not be representative of teenagers experiencing adversity where such bonds are potentially lacking. Considering our analysis limitations, first, alternative qualitative analysis such as IPA could have been suitable for our small, relatively homogenous, purposive sample and interview-based data (Braun & Clark, 2021). Going beyond cross-case themes, IPA would have additionally focused on unique details and depth of each case before looking for themes, added latent comments reflecting formulations of the participants' narratives as understood by the researcher, and focused on linguistic features (e.g., pauses, fluency,

metaphors; Braun & Clark, 2021). Second, the planned QSA of the network maps was not completed. QSA consists of a narrative discussion of the visual maps, by forming interpretational hypotheses based on broken down aspects of the map (e.g., What ties predominate? Are there any ties which (de)stabilise the network? Are there regions with more ties and others with holes?; Herz et al., 2015). These hypotheses could further sensitise for external relationship elements within the indepth TA (Herz et la., 2015). Third, incompletion of the planned extensive quantitative analysis (e.g., calculating degree of closeness) provides opportunity for further statistical analyses of the network maps. Concepts such as constraint (i.e. higher score indicating fewer structural holes and more network closure) or closeness (i.e. member's distance from the centre expressed through the X-Y coordinates of their position on the concentric circles) can be measured as a figure between 0-1 and can be calculated as mean values. These could further be calculated and compared across time points in longitudinal research (e.g., pre- and post-SN intervention) as in Anderson et al.'s study (2021) on SNs in alcohol and drugs recovery. Triangulating participant data further with other stakeholders' views would add a multifaceted, multi-informant formulation of social risk and protective factors in recovery. Finally, the valued relationships with other psychosis-experienced young people prompts further research on identifying associated facilitators and barriers to involving peers in recovery and whether these influence experiences of post-traumatic growth.

5.4. Clinical Implications and Conclusions

Our insight into young people's perceptions of helpful and unhelpful transactions with SNs provides a preliminary person-centred checklist of good working principles for professionals and non-informal SNs involved in approaching intervention. It further informs systemic formulation of risk and protective factors in recovery. Our visualisation materials have potential to be used clinically in developing reflexivity, helping track recovery and transitions, and spotting gaps and strengths in social supports over time. This further informs the use of more novel approaches such as Cognitive Interpersonal Therapy for preventing relapse through drawing on an individual's social context amongst others (Macbeth et al., 2020). Moreover, participants valued engagement with same-age peers and enjoyed interactions with psychosis-experienced others. This points to a potentially promising use of peer support networks for adolescents. The use of peer support in mental health is well established (Ibrahim et al., 2020) and may be particularly relevant for young people with preexisting social vulnerabilities, for whom psychosis can be more destabilising. However, due to developmental stage, this may need more systemic facilitation and training (Ibrahim et al., 2020). Finally, our study identified that everyone has a role in recovery, and although there is overlap, focusing on assessing the quality rather than quantity of such networks is essential in informing recovery-focused work.

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APPENDICES

Appendix 1 – Systematic Review Search Strategy Sample

APA PsycInfo <1806 to August Week 5 2021>

(Psychosis or psychoses or psychotic* or schiz* or halluc* paran* or delus*).ti,ab.
 184807

2 exp Psychosis/ or exp Affective Psychosis/ or exp Schizophrenia/121014

3 1 or 2 190045

4 (social adj1 (network* or contact* or assessment* or capital* or isolat*)).ti,ab. 44947

5 exp social network analysis/ or social networks/ or exp online social networks/ or exp interpersonal interaction/ or exp professional networking/ or exp social capital/ or exp social interaction/ or exp sociograms/ 711103

6 exp interpersonal influences/ or exp interdependence/ or exp peer relations/ or exp interpersonal relationships/ or exp relationship satisfaction/ or exp "social and interpersonal measures"/ or exp social exchange/ 292426

7 4 or 5 or 6 729918

8 3 and 7 12812

9 ((qualitative* adj1 (method* or research* or investigat* or analys* or explor*)) or phenomenological* or 'lived-experience*' or 'grounded-theor*' or 'focus-group*' or 'thematicanalys*' or 'mixed-method*').ti,ab. 170787

10 exp qualitative methods/ 17835

11 9 or 10 174509

12 8 and 11 486

Appendix 2 – Systematic Review Data Extraction Table

Table 3. Data extraction table

Study & Country	Sample	Setting/ Context	Aim	Method and analysis	Materials/ data collection	Key Findings
Angell (2003); USA	N=20 adults and older adults (age: 20+) with chronic schizophrenia and schizoaffectiv e disorders	Assertive Community Treatment (ACT) program	To explore the contexts and processes in which clients' social relationships are developed.	Grounde d theory	Individual semi-structured interviews; 1-2 sessions. Questions about social interactions; how social relationships developed in various contexts, such as work and residence, as these distinctions emerged as salient.	-Aside from contacts with family members and providers, participants' interactions with fellow mental health clients tended to dominate social interactions; pattern appeared to be influenced by both the concentration of social opportunities in daily activities of service utilization and the ACT program emphasis upon facilitating relationships between clients.
						-Relationships with other mental health clients primarily positive; yet several participants expressed dissatisfaction and desired greater integration into mainstream social networks
Cheng, Tu & Yang (2016); USA (Chinese sample)	N=49 adults (mean age=34) with recent and long-standing: Schizophrenia, schizoaffectiv e disorders, or psychosis	Chinese bilingual psychiatric inpatient units	To understand forms of social support experienced by Chinese immigrants with mental illness.	Grounde d theory (mixed- methods)	Individual semi-structured interviews; questions adapted from the Experience of Stigma Questionnaires: ("Have you been treated fairly by others who know that you have this condition?" and "Have people been supportive and understanding when they learn that you have this condition?")	-The most common forms of social support were belonging and companionship, perceived emotional support, social control, and perceived instrumental support, while self esteem and sense of mastery were the least common forms. -Family and friends were the main sources of support.

Hansen,	N=10	Early	To explore how	Thematic	Individual semi-structured	Professional helpers
Stige,	adolescents	detection	young adults with	analysis;	interviews; 40-150 minutes	-Theme 1: being seen as a unique person with
DavidsonL	and adults	team for	FEP experience	team-	(mean=84 minutes);	preferences: "simply being met"
øberg, &	(age: 16-32)	psychosis	relationships	based	questions on health and life	-Theme 2: getting help when you are lost: "A
Veseth	with First-	(university	inside and outside	reflexive	situation (including their	personal assistant"
(2020);	episode	hospital)	mental healthcare	analysis	experience of developing	
Norway	psychosis		services related		psychosis); perceptions of	Family and Friends
	(FEP)		to their early		pathways into mental health	-Theme 3: supportive family networks:" I know they
			recovery		services; previous or current	are out there cheering for me"
			processes; and		contact (and way out of the	-Theme 4: they cannot understand everything: "after
			how these		services, if relevant) with	all, it's my problem"
			relationships		mental health services; and	-Theme 5: different kinds of friendships: "friends
			complement each		factors that were helpful or	with whom I am just myself"
			other.		hindering to their recovery	- /
					processes inside or outside	
					the mental health system.	

Huckle, Lemmel & Johnson (2021); UK	N=14 adults (age: 19-34) with FEP	NHS early intervention service for psychosis	To explore experiences of friendships, focusing on any perceived changes in their friendships or approach to peer relationships as a result of the illness, on perceptions about what was helpful or unhelpful about friendships in their recovery; and perceived role for services in the establishment or maintenance of friendships.	Thematic analysis	Individual semi-structured interview guide; 2 sessions (30-45 minutes); experiences of friendships during the acute phase of illness and in the path to recovery, the impact of friendships on illness experience and of illness on patterns of social contact, and the potential role of services in supporting people with friendships	 Friendship losses -1. Self stigma: Participant directed loss of social contact: 1.1 Anxiety; 1.2 Talking about illness. -2. Symptoms ended friendships as I knew them: 2.1 Symptoms directly affected friendships; 2.2 Rejection by others; 2.3 Friends moved on. -3. Friendships incompatible with recovery -4. Getting better: What can friends do to help?: 4.1 Everyday support and distraction; 4.2 Play a unique role -5. Assessment of current social situation: 5.1 Absence of romantic relationships; 5.2 Absence of shared history; 5.3 Feeling back to normal socially again; 5.4 Friendships stronger and closer Moving on from here -6. Making new friends: 6.1 Conscious effort; 6.2 Ego strengthening and reciprocity; 6.3 Getting life back on track. -7. The role of services: 7.1 Facilitate sharing of experiences; 7.2 A need to step away from services.
Karanci, G ök, Yıldırım & Borhan (2017); Turkey	N=32 adults (age: 22-60, mean=42) in remission from schizophrenia	Schizophrenia community support associations	To investigate what is perceived as helpful social support in a predominantly Muslim and collectivistic culture.	Thematic analysis	Individual semi-structured interviews; what is perceived as supportive and not supportive from the family, relatives, friends from outside the association and friends from the association (e.g., 'How do you feel about your relatives in general?', 'Among your relatives, who supports you the most?', 'By doing what?')	Three themes: -Instrumental support: Basic needs; Material support; Information support; Daily tasks; Illness management -Emotional support: Interest and concern; Reciproca sharing/giving support Understanding and patience; Moral support/ instilling hope; Excessive control and interference; Belittling/ rejection/ labelling -Socialization support: Social context; Companionship/leisure activities

Killian, Lindenbac h, Lobig, Uhle & Angermey er (2001); Germany	N=100 adults (age: 18-65) with chronic schizophrenia	Outpatient private practice, community mental health services	To examine participants' perceptions of their social integration	Content analysis	Individual problem-focused semi-structured interviews; 90-180 minutes (2-3 sessions); description and the subjective evaluation of central domains of life such as family, social contacts, work, housing conditions, activities, and the subjective assessment of the availability and quality of medical and non-medical psychiatric services	Participants can be classified in five different groups according to their self-perceived degree of social integration: Integrated, Integration-Oriented, Integrated in psychiatric consumer relationships, Family context, and Disintegrated. First, the person feels either fully integrated in normal society or not; second, the person reports having social contacts in more than one social setting or not; third, the person describes their social contacts as frequent or as sporadic; fourth, the person reports having at least one close emotional relationship or not; fifth, the person feels able to establish new social relations to people who are not mentally ill or not.
Lencucha, Kinsella & Sumsion (2008); Canada	N=8 adults and older adults (age: 30-72) with chronic schizophrenia	Outpatient community mental health services	To explore how individuals form and maintain social relationships.	Grounde d theory	Individual semi-structured interviews; 30-55 minutes; identify relationships that "really stand out". The participants were asked what stood out, how they met, how the relationship developed over time or how they stayed connected, shared occupation with the person; Broad questions: "What makes up an important relationship?', "What do you feel you give to this relationship?"	Four types of social relationships were depicted as important: family, intimate, associate and occupational. Five core themes are important dimensions in the formation and maintenance of social relationships. -Environmental proximity -Routine environment -Reciprocity -Constancy=hope -Understanding

MacDonal d, Sauer, Howie & Albiston (2005); Australia	N=6 young adults (age: 19.5-25.25, mean= 21.99) with FEP	Outpatient recovery group program at the Early Psychosis Prevention and Intervention Centre	To explore young people's experiences of social relationships during the recovery phase FEP in order to facilitate their social relations.	Phenom enologic al analysis	Individual in-depth phenomenological interviewing; 2x 20-30minutes session; times spent with a person, the things they did, and the times they spent with other people; what they experienced and what it was like for them; and the feelings they attached to these experiences.	Five themes: -Hanging out with people I like and who understand me -Valuing families and other supports -Spending less time with old friends -Something happened to me – feeling and being perceived as different -Building new relationships in the recovery phase of their illness.
Mackrell & Lavender (2004); UK	N=12 teenagers and adults (age: 16-30) with FEP, schizophrenia, polymorphic disorder (with symptoms of schizophrenia) or bipolar disorder with psychotic symptoms.	Early onset psychosis service; adolescent inpatient unit	To explore how those recovering from a FEP described and understood the impact of their peer relationships before, during, and after the onset of psychosis.	Grounde d theory	Individual semi-structured interviews and concentric circle visuals; 40-85 minutes. Described important people:, "How did you meet this person?" and "How do you spend time together?", "what makes this relationship close or distant?"; explored networks during childhood, early adolescence, later adolescence, and after the onset of psychosis; reflections on changes in networks over time.	A process of increasing isolation from peers. Negative experiences outweighing positives across the lifespan. Childhood (5-11 years) – inequity in peer relationships describes a perceived negative bias in peer relationships. Early adolescence (11 to 15 years)—instability in peer relationships. Late adolescence (16 – 30 years)—becoming isolated and increasing isolation. During late adolescence, and before the psychotic episode, participants were becoming isolated. After the experience of psychosis, participants described a process of increasing isolation.

Masse, Paquin, Lysaker & Lecomte (2020); Canada	N=10 adults (age: 18-35; mean=24.4- 26.6) with FEP, schizophrenia, schizoaffectiv e disorder, psychosis-NOS	Inpatient FEP clinic within a psychiatric hospital	To identify different patterns of evolution of social networks and association with metacognitive abilities and substance use	Mixed- methods; timeline profiles	Individual semi-structured interviews, 30 mins; prompt the recall of friendships that were subjectively significant to the participant, as well as information regarding both quantitative (number of friends, substance using status of friends, etc) and qualitative information (experience of interpersonal dynamics); how they perceived their place in the group, conflicts, who initiated activities, activities shared, influences on friendship of moving, graduating, substance use, illness, proximity and reciprocity	Distinct and stable profiles: -Profile 1 presented with overall better metacognitive abilities, and varied on the onset, conclusion and diversity of relationshipsProfile 2 showed poorer abilities, and completely changed social networks at transitions. The presence of mutually supportive relationships and of personal interest contributing to friendship formation differentiated profiles. Individuals in both groups reported bullying at school or difficult family issues
McGuire, Melville, Karadzhov, & Gumley (2020); UK	N=6 adults (age: 36-64) with psychosis	Outpatient local mental health support services	To explore the positive and negative aspects of interactions and how participants' meaning making about themselves and their personal recovery was impacted.	Interpret ative phenom enologic al analysis (IPA)	Individual semi-structured interviews and visual relational maps using cardboard figures of the participant and their networks; 20minutes – 1hour 20minutes; positive and negative elements of their networks, how they made sense of their experiences and whether they felt they affected their recovery.	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 the 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.

Nilsson, Urfer- Parnas, & Nordgaard (2019); Denmark	N=5 adults (age: 24-52, mean=33.4) with schizophrenia and schizotypal disorder	5-year follow up of people with first- admission in a psychiatric facility	To explore a less ill subgroup of schizophrenia spectrum patients' ways of navigating the social world and examine potential links to anomalous self- experiences by applying.	Thematic analysis (mixed- methods)	Questionnaires and individual semi-structured interview; open-ended questions eliciting descriptions of quotidian experiences and behaviour. Main topics covered: experiences of meaning and subjective importance pertaining to the patients' interpersonal relations, professional life, and online behaviour.	6 themes identified: -Social detachment -Void time, positive withdrawal -The importance of particular activities or circumstances -The organising function of social engagement -The positive effect of clearly defined roles to alleviate social discomfort and help people stay embedded in a social milieu. -Positive withdrawal
Ogden (2014); USA	N=8 adults and older adults (age: 56-73, mean=66.3) with chronic schizophrenia	Outpatient/ non-profit (residence unit and a day treatment program for persons with serious mental illnesses); inpatient psychiatric service	To explore how people understood and expressed their life stories in the face of life course and present time adversities and resilience, focusing on narratives of interpersonal relationships.	Thematic narrative analysis	Multiple interviews conducted over several months, time diaries and life history calendars, and systematic and detailed field observations; average 1 hour (4-6 sessions);	Five core shared themes: -relational losses -relational voids -need for solitude -relational adjustments -relational adaptations. Participants attributed their interpersonal experiences either directly to their psychiatric diagnosis or indirectly to the consequences they connected in their narratives to the diagnosis. Strong relationships connected to feelings of safety and life satisfaction, whereas interpersonal challenges were felt profoundly, even after many years

Pinfold (2015);	N=41 adults (age: 21-64)	Primary care; secondary	To understand how network	Thematic analysis;	Individual semi-structured interviews and concentric	Formal and sparse networks: the quality, not quantity, of social ties was key in terms of supporting
UK	(age. 21-04) with severe mental illness: schizophrenia and psychosis (65%); bipolar disorder (35%)	care (early intervention services, community mental health services and recovery teams)	types developed exploring agency within networks and role of others, changes over time and impact of features such as stigma and severity of illness.	network analysis mapping (mixed- methods)	circles; Each participant was presented with their visual network emotional closeness map, from the first interview, and their three network descriptor words to anchor the interview initially in the data previously provided. The topic guides then progressed to questions about changes over time and what participants did to help themselves stay well.	 well-being needs; strategies to stay well sometimes meant limited social or community engagement; Stigma was a feature of formal and sparse networks, partly explaining network choices to reduce engagement within the community <i>Family and stable networks:</i> motivation to control and choose social connections, but poor motivation or reluctance to become more independent and worries over the consequences of illness or stigma. Family support crucial or disempowering. Where family ties are challenging (or absent replacement relationships could be established. Families generate stigma. Lack of diversity in obtaining social capital from different sources.
						Diverse and active networks: Valued social support encompassed a range of contacts. Incorporated people at different stages of recovery. These networks were dynamic and varied in content, diversifying social capital. Stigma was recognised as a barrier. Network segmentation was a strategy adopted to keep parts of the network separate to preserve/ manage non-illness identities and reduce the impact of stigma.

Pope,	N=13 adults	Outpatient,	To explore the	Thematic	Focus groups: 5-7 participants	Participants across stakeholder groups assigned a
Malla, Iyer,	(age: 18-35)	community-	views of	analysis	each; open-ended questions	range of responsibilities to individuals with mental
Venkatara	with FEP	oriented	individuals with		about who participants felt	health problems, stakeholders in these individuals'
man, &		program	FEP, their		should be responsible for	immediate and extended social networks (e.g.,
Jordan		within a	families,		supporting individuals with	families), macro-level stakeholders with influence
(2019);		specialised	treatment		mental health problems and	(e.g., government), and society as a whole. Perceived
Canada		early	providers, policy		what responsibilities they	failings of the health care system and the need for
		intervention	makers about		attributed to these parties.	greater sharing of roles and responsibilities also
		service for FEP	who is			emerged.
			responsible and			
			how to support			
			service users.			

Appendix 3 – Systematic Review Quality Appraisal

Table 4. Quality appraisal of included studies using CASP

Study	1.Was there a clear statement of the aims?	2.Is a qualitative methodology appropriate?	3.Was the research design appropriate to address the aims?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideratio n?	8. Data analysis is rigorous & supports interpretations ?	9. Is there a clear statement of findings?	10. How valuable is the research?
Angell (2003)										
Cheng et al.(2016)										
Hansen et al. (2020)										
Huckle et al. (2021)										
Karanci et al. (2017)										
Killian et al. (2001)										
Lencucha et al. (2008)										
MacDonald et al. (2005)										
Mackrell & Lavender (2004)										
Masse et al. (2020)										

McGuire et al. (2020)					
Nilsson et al. (2019)					
Ogden (2014)					
Pinfold (2015)					
Pope et al. (2019)					

*Note: Green = Yes (high quality); Amber = Can't tell (unclear quality); Red = No (low quality).

Appendix 4 – Systematic Review Thematic Synthesis Sample

Table 5. Thematic synthesis steps sample

Original transcript	Line-by-line coding for each	Broader preliminary	Preliminary	Final
	study	descriptive themes	analytical reflections	themes/sub-
		across studies		themes across
				studies
"She is more about my illness than me"	Illness over person			
The superordinate theme (represented by				
this quote from Gemma, P6, L7) emerged				
from the context in which social				
relationships took place, and highlighted	Relationship/needs focused	3.SNs role/characteristics	Other's perceptions	3.1. Relationships
how "the illness", an object which served	on illness/ main driver in	- 3.1. centred on illness/	of one's Identity =	centred on illness
as a source of need and disability, was the	relationships.	illness identity	illness	
main focus of the majority of participants'	SNs = family and mental	2.SN composition		1.1.A unique
relationships. Family members and mental	health professionals	disproportionate: 2.1. SN		profile of SNs:
health service support staff tended to	dominating	types: family +		composition and
dominate participants' social networks,		professionals > others		degree of closure
and these relationships were most				
extensively discussed. Participants	Managing life with a mental			2. SNs as a
described a range of practically and	illness	4.SN support types:	SNs' roles relating	gateway to
emotionally oriented interactions related	Practical-oriented	4.1. practical (finances)	illness identity:	resources (2.1.
to managing life with a mental illness,	interactions:		-practical	practical support;
including how mostly support staff "sorted	Support with finances,		-emotional	
out my finances"; "supports me with	shopping, medication,			
shopping"; "helps me about the house",	household chores.			
and "got medication for me". Participants				
also highlighted how these individuals			Maintaining social	
			factors of illness	

"keep me companion" and "reassure me".	Emotionally-oriented	4.2 emotional (company)	identity: power	2.2. emotional
In this sense, the primary function of most	interactions: keeping		imbalance, inactive,	connectedness)
relationships perhaps inadvertently	company, reassurance.		disempowerment in	
maintained the role of the participant as	Function of relation –	3.SNs role/characteristics	relationships, lack of	3.1. Relationships
being in need of support, and participants	maintains ill role; Participant	– 3.1. centred on illnes	reciprocity, all of	centred on illness
taking a less active role in managing their	seen as ill/in need of support		which reinforce ill	
affairs.	Participant – less active		identity. Person stuck	
			in this ill role?	
"She doesn't see me as normal either with				
me getting help"	SNs see participants as 'not	3.SNs role/characteristics:		3.4. Stigma →
This theme, represented by Helen's above	normal'	3.5. Stigma – seen as 'not		3.4.1. Being seen
quote (P17, L8–9), highlights participants		normal'		as 'not normal'
experience of " <mark>stigma"</mark> , where critical				
comments made them feel judged and	Stigma (critical comments) >		Relationship –	
ultimately, not "normal". This unfolded in a	feeling judged > 'not normal'.		centred on ill identity	
context where participants' relationships	In context of SNs function to	3.1. illness focused SN \rightarrow	> reinforcing stigma	3.1. relationships
function in part so others can monitor their	monitor mental health/ where	more stigma		focused on illness
mental health, and participants felt it	SUs felt need to manage			→ 3.4. stigma
necessary to manage others' impressions	others' impressions of them.			
of them.				
[]			Maintaining social	
Umar described his experience of			and interpersonal	
unfavourable social comparisons: and now	Unfavourable social	3.5. Stigma = seen as 'not	factors:	3.4. Stigma →
they don't respect you they lower your	comparisons: 'they don't	normal': Unfavourable	Stigma (actual	3.4.1. Being seen
dignity like mocking you up making fun and	respect you, lower your	social comparisons,	criticism, little trust	as 'not normal'
laughing and taking the mickey in other	dignity'; others have	childlike, judged	in participants,	
words. Things like that, <mark>not respecting</mark> you	jobs/marriage/car/houses			

			,,	1
because they have houses and they have	(=being successful) versus		comparisons with	
jobs in restaurants and they are married or	participant being on their own		others)	
they can have a car and they think that is			Self-monitoring:	
all <mark>successful</mark> , but to me I've got 40 years			managing	
and I am on my own. – Umar (P26, L11 -			impressions through	
P27, L3)'. These experiences affected how			behaviours (e.g.,	
participants acted around family and	Stigma $ ightarrow$ Participants acting	3.5. Stigma $ ightarrow$ 'desire to	avoiding disclosures).	3.4. Stigma →
support staff, with a strong desire to	with SNs: desire to 'appear	appear normal' 🔿	Unintended	3.4.1. Being seen
appear normal being highlighted. This was	normal';	behaviours examples:	consequences:	as 'not normal'
most noticeable in participants' own	e.g.,		cannot talk about	
monitoring and change of their behaviour			illness which is part	
in response to others: I find out what she is			of getting better.	
doing and go from there how I should				
behave – Helen (P27, L8–9); I have learned	-copying others' behaviour,	→keeping quiet;		3.4.1. Fear of
from that experience just to keep quiet and				disclosure
get on with it – Umar (P29, L6–7).	-keeping quiet and getting on,			
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: <i>Everybody</i>	-avoiding discussing	ightarrowavoiding mental health		
knows I have got the problem but if I am	participants' mental health	disclosures or disclosing		3.4.1. Fear of
not talking about it to them I don't have a	despite it being a large part of	interest in non-illness		disclosure
problem but there in lies the problem	their life > little left to talk	roles \rightarrow reduced recovery		
because what do I talk about? – (P12, L18–	about			
21).				
		1		

Note. Excerpt from McGuire et al., 2020. Of note, the wider preliminary descriptive themes across all studies were further re-organised, taking into account the preliminary analytical reflections, so the theme and sub-theme numbers do not correspond with the final themes. Colour was used to highlight key codes/ideas in the original findings.

Appendix 1 [Online] – MRP Proposal (for Proceed to Ethics approval) https://osf.io/x6apu Appendix 2 [Online] – MRP Proposal (for IRAS submission) https://osf.io/6qh24 Appendix 3 [Online] – MRP Participant Information Sheet https://osf.io/byfk9 Appendix 4 [Online] – MRP Consent Form (ages 14-15) https://osf.io/yjgxu Appendix 5 [Online] – MRP Consent Form (ages 16-24) https://osf.io/a2jpg

Appendix 6 [Online] – MRP Interview Schedule 1 https://osf.io/shf37

Appendix 7 [Online] – MRP Interview Schedule 2 https://osf.io/6xjtb

Appendix 8 – MRP Copies of Ethics and NHS Board Approval Letters



Research & Innovation

Grahamston Road Paisley, PA2 7DE

Scotland, UK

Dykebar Hospital, Ward 11

Administrator: Mr Scott Broadley Telephone Number: 0141 314 4001 E-Mail: Scott.Broadley@ggc.scot.nhs.uk Website: https://www.nhsqqc.org.uk/about-us/professionalsupport-sites/research-development/

05 October 2021

Alexandra-Raluca Gatej University of Glasgow, 1st Floor, Administration Building Gartnavel Royal Hospital, 1055 Great Western Road Glasgow, G12 0XH

NHS GG&C Board Approval

Dear Alexandra-Raluca,

Study Title:	Mapping and Understanding Social Networks in Young People with Psychosis: A Mixed-Method Social Network Analysis Study
Principal Investigator:	Alexandra-Raluca Gatej
GG&C HB site	NHS GG&C - CAMHS, Skye House Adolescent Inpatient Unit, ESTEEM Early Intervention Service
Sponsor	NHS Greater Glasgow & Clyde
R&I reference:	GN21MH127P
REC reference:	21/WS/0089
Protocol no: (including version and date)	Version 0.3, 25/06/2021

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant Approval for the above study.

Conditions of Approval

- 1. For Clinical Trials as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (<u>www.nhsggc.org.uk/content/default.asp?page=s1411</u>), evidence of such training to be filed in the site file.

2. For all studies the following information is required during their lifespan.

- a. First study participant should be recruited within 30 days of approval date.
- b. Recruitment Numbers on a monthly basis
- c. Any change to local research team staff should be notified to R&I team

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Board Approval_GN21MH127P



- d. Any amendments Substantial or Non Substantial
- e. Notification of Trial/study end including final recruitment figures
- f. Final Report & Copies of Publications/Abstracts
- g. You must work in accordance with the current NHS GG&C COVID19 guidelines and principles.

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study.

Yours sincerely,

Mr Scott Broadley Senior Research Administrator

Page 2 of 2

Board Approval_GN21MH127P





Professor Andrew Gumley Professor of Psychological Therapy; Honorary Consultant Clinical Psychologist; Director NRS Mental Health Network University of Glasgow & NHS Greater Glasgow & Clyde Mental Health and Wellbeing Research Group, 1st Floor, Admin Building, Gartnavel Royal Hospital 1055 Great Western Road Glasgow G12 0XH

West of Scotland REC 5 West of Scotland Research Ethics Service Ward 11, Dykebar Hospital Grahamston Road PAISLEY PA2 7DE

Date

05 October 2021

Direct line E-mail 0141 314 0213

WoSREC5@ggc.scot.nhs.uk

Dear Professor Gumley

Study title: Mapping and Understanding Social Networks in Young People with Psychosis: A Mixed-Method Social Network Analysis Study REC reference: 21/WS/0089 IRAS project ID: 296413

Thank you for Miss Gatej's letter received on 10 September 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The <u>UK Policy Framework for Health and Social Care Research</u> sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of <u>research transparency</u>:

- 1. registering research studies
- 2. reporting results
- informing participants
- 4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS</u> <u>management permission (in Scotland) should be sought from all NHS organisations involved in</u> <u>the study in accordance with NHS research governance arrangements.</u> Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at: <u>https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/</u>

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: <u>https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/</u>

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: <u>Reporting requirements</u>

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at <u>https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/</u>.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Email - Managerial Approval - SCS]		04 May 2021
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Email - Managerial Approval - ESTEEM]		21 May 2021
Copies of materials calling attention of potential participants to the research [Leaflet/Poster - Invite to participate]	0.3	11 June 2021
Covering letter on headed paper [Cover Letter REC Comments]		

Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsors Insurance - University of Glasgow]		26 July 2021
GP/consultant information sheets or letters [GP letter]	0.3	17 May 2021
Interview schedules or topic guides for participants [Interview Schedule 1]	0.2	23 March 2021
Interview schedules or topic guides for participants [Interview Schedule 2]	0.2	23 March 2021
IRAS Application Form [IRAS_Form_05072021]		05 July 2021
Letters of invitation to participant [Email/Letter Invite for Clinicians]	0.3	04 June 2021
Letters of invitation to participant [Email/Letter Invite for Participants (pre-consent)]	0.3	03 September 2021
Letters of invitation to participant [Tracked_Email/Letter Invite for Participants (pre-consent)]	0.3	03 September 2021
Letters of invitation to participant [Initial Appointment Letter]	0.5	03 September 2021
Letters of invitation to participant [Tracked_Initial Appointment Letter]	0.5	03 September 2021
Letters of invitation to participant [Subsequent Appointment Letter]	0.4	03 September 2021
Letters of invitation to participant [Tracked_Subsequent Appointment Letter]	0.4	03 September 2021
Other [Notice of Intent (14-15yo)]	0.3	25 June 2021
Other [Data Management Plan]	0.4	18 June 2021
Other [Email/Letter for Clinicians - Notice of Participation]	0.2	04 June 2021
Other [Data Analysis Example Form]	0.1	23 March 2021
Other [Debriefing Sheet for Participants]	0.3	04 June 2021
Other [Opt-In for Results Sheet]	0.2	25 June 2021
Other [Proforma - Contact Details and ID log]	0.2	04 June 2021
Other [REC_Comments for Reviewers_Provisional Opinion]	0.1	10 September 2021
Participant consent form [Consent Form (14-15 years old)]	0.5	03 September 2021
Participant consent form [Tracked_Consent Form (14-15 years old)]	0.5	03 September 2021
Participant consent form [Consent Form (16-24 years old)]	0.5	03 September 2021
Participant consent form [Tracked_Consent Form (16-24 years old)]	0.5	03 September 2021
Participant information sheet (PIS) [Participant Information Sheet (PIS)]	0.6	03 September 2021
Participant information sheet (PIS) [Tracked_Participant Information Sheet (PIS)]	0.6	03 September 2021
Referee's report or other scientific critique report [UoG Proceed to Ethics Letter]		15 December 2020
Research protocol or project proposal [IRAS_Protocol_NHSGGC]	0.3	25 June 2021
Summary CV for Chief Investigator (CI) [AuthorsCV_AG]	0.1	04 May 2021
Summary CV for student [AuthorsCV_ARG]	0.1	03 May 2021
Summary CV for supervisor (student research) [AuthorsCV_LB]	0.1	14 May 2021
Summary CV for supervisor (student research) [AuthorsCV_MmcC]	0.1	04 May 2021

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <u>http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/</u>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities— see details at: <u>https://www.hra.nhs.uk/planning-and-improving-research/learning/</u>

IRAS project ID: 296413 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Mrs Naomi Hickey Chair

Enclosures:	List of names and professions of members who were present at the meeting and those who submitted written comments
	"After ethical review – guidance for researchers"
Copy to:	Dr Colette Montgomery Sardar, University of Glasgow
	Lead Nation - Scotland: gram.nrspcc@nhs.scot