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Young adults' dynamic relationships with their families in early psychosis: Identifying relational strengths and supporting relational agency

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Objectives. Most existing research on the family context of psychosis focuses on the 'burden' of caring for people experiencing psychosis. This research is the first to ask young people experiencing early psychosis to 'map' and describe their experiences and understandings of their family relationships, and how they have related to their psychosis and recovery.

Design. The research took an inductive, multimodal hermeneutic–phenomenological approach (Boden, Larkin & Iyer, 2019, *Qual. Res. Psychology*, 16, 218–236; Boden & Larkin, 2020, *A handbook of visual methods in psychology*, 358–375).

Method. Ten young adults (18–23), under the care of early intervention in psychosis services in the UK, participated in an innovative relational mapping interview (Boden, Larkin & Iyer, 2018), which invited participants to draw a subjective 'map' of their important relationships. This visual methodology enables subtle, complex, ambivalent, and ambiguous aspects of the participants' experiences to be explored.

Results. Findings explore the participants' accounts of how they love, protect, and care for their families; how they wrestle with family ties as they mature; and their feelings about talking about their mental health with loved ones, which was typically very difficult.

Conclusions. This paper advances understanding of recovery in psychosis through consideration of the importance of reciprocity, and the identification and nurturance of relational strengths. The capacity of a young person to withdraw or hold back when trying to protect others is understood as an example of relational agency. The possibility for extending strengths-based approaches and family work within the context of early intervention in psychosis services is discussed.

Practitioner points

- Young adults experiencing early psychosis may benefit from support to identify their relational strengths and the opportunities they have for reciprocity within their family structures, where appropriate.
- Relational motivations may be important for a range of behaviours, including social withdrawal and non-communication. Services may benefit from exploring the young person's relational context and subjective meaning-making in regard to these actions.
- Young adults experiencing early psychosis may benefit from opportunities to make sense of their family dynamics and how this impacts on their recovery.

- Attachment-based and relationally oriented interventions that increase trust and openness, and reduce feelings of burdensomeness are likely to support family functioning as well as individual recovery.

In the UK, early intervention services (EIS) for psychosis are typically presented as multifaceted biopsychosocial services (NHSE, 2016), but in practice, they often struggle to implement even the best-evidenced, most protocol-driven relational interventions (e.g., Behavioural Family Therapy; Bucci, Berry, Barrowclough, & Haddock, 2016). Instead, the emphasis falls on biological and psychological interventions (see Byrne et al., 2020). However, the social context of recovery has started to receive more attention. It has a promising evidence base (Stafford, Jackson, Mayo-Wilson, Morrison, & Kendall, 2013), and there have been calls to embrace social factors within psychiatric research (Priebe, Burns, & Craig, 2013) and interventions (Johnson, 2017).

There are ideological challenges to working relationally. British adult mental health services tend to treat the person as a discrete and independent unit, resulting in interventions and policies that rarely acknowledge the relational context of distress and recovery (Pilgrim, Rogers, & Bentall, 2009). Although there have been recent attempts to encourage more relational thinking in UK policy (e.g., the Cabinet Office's *Think Family*, 2008; the Care Act legislation (2014), and interventions (e.g., Family Group Conferencing, De Jong & Schout, 2011; Open Dialogue, Seikkula et al., 2006), these are constrained by limited resources, a risk-averse culture, and 'production line' organizational structures (Tew, Morris, White, Featherstone, & Fenton, 2016).

First onset of psychosis typically occurs during emerging adulthood (Arnett, 2000), at a time of critical psychosocial development (Arnett, 2007). The emerging adulthood period is normatively marked by increasing individuation away from family, increasing self-responsibility and agency, as well as the opportunity for identity development, exploring love and sex relationships, and finding study or work roles (Arnett, 2000). This identity development occurs in a social context and involves a complex interplay of individual and social factors, including the influence of peers, guidance, and support from significant others and the broader cultural context (see Adams & Marshall, 1996; Baumeister & Muraven, 1996; Erikson, 1968). Emerging adulthood is therefore a period marked by instability and change, which can be especially challenging for those experiencing challenges to their mental health (Arnett, Žukauskienė, & Sugimura, 2014). In recognition of the specific challenges of this period, and unlike many adult services, EIS do *aim* to support social recovery. However, interventions that expose people to social situations and encourage them to expand their social repertoire are still targeted primarily at the individual. Where there is social network intervention, it often heavily relies on psychoeducation where the young person is still seen as the bearer of 'the problem'.

Relationships matter

Connectedness via stable, warm, and frequent relational contact is essential for well-being. However, relationships are instrumental in both 'the creation and amelioration of mental health problems' (Pilgrim, et al., 2009, p. 235) and people with enduring mental

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health needs report that close relationships can be both harmful and supportive (Green, Hayes, Dickinson, Whittaker, & Gilheany, 2002). Young people under the care of EIS are more likely to have experienced traumatic and abusive relationships or family adversity in early life (Mackrell & Lavender, 2004), which can be causal factors in their psychosis (Varese et al., 2012). Consequently, caution about others and interpersonal distress is common (Griffiths, Mansell, Edge, & Tai, 2019). Relationships seem to be harder to maintain: the process of losing social connections begins early (Boeing et al., 2007) and relates to the growing salience of psychotic experiences (Dodell-Feder, Shovestul, Woodyatt, Popov, & Germine, 2019). People experiencing psychosis therefore tend to have small social networks that more heavily rely on family members (Gayer-Anderson & Morgan, 2013; Palumbo, Volpe, Matanov, Priebe & Giacco, 2015).

Struggles with relationship maintenance are believed to relate to deficits in social cognition (Bertrand, Sutton, Achim, Malla, & Lepage, 2007), depressive and 'negative' symptomatology (Corcoran et al., 2011) (Cresswell, Kuipers, & Power, 1992), paranoia (Freeman, Garety, Kuipers, Fowler, & Bebbington, 2002), or social anxiety (Michail & Birchwood, 2010), and relationships are likely to be further disrupted by periods of hospitalization (Fenton et al., 2014; Hickman et al., 2016; Horan, Subotnik, Snyder, & Nuechterlein, 2006). Even when the young person has maintained a larger network, they may not perceive themselves as having access to correspondingly more support (Macdonald, Jackson, Hayes, Baglioni & Madden, 1998), and loneliness in psychosis is a fundamental issue (Fromm-Reichmann, 1990/1959) that remains poorly understood (Lim, Gleeson, Alvarez-Jimenez, & Penn, 2018).

Family relationships

The social networks of people with psychosis tend to include twice as many family members as friends (Palumbo et al., 2015). Between 60 and 70% of young adults first attending EIS either live with, or have close contact with family members (Addington & Burnett, 2004). Family relationships are more likely to be asymmetric and involve negative or ambivalent feelings compared to the general population (Randolph, 1998) and, understandably, often become strained (Corcoran et al., 2007). Indeed, much existing research on the family context of psychosis focuses on the 'burden' of caring for a young person with psychosis, which can be considerable and may result in family members becoming psychologically distressed themselves (e.g., Fadden, Bebbington, & Kuipers, 1987; Mittendorfer-Rutz et al., 2018). The argument for intervening to support families is clear (e.g., Addington, Collins, McCleery, & Addington, 2005). Young people with psychosis frequently see family members as a source of support; helping them to engage with services (Windell, Norman, & Malla, 2012) and avoid relapse (Lee, Barrowclough, & Lobban, 2014 and supporting their general well-being (Lal, Ungar, Malla, Frankish, & Suto, 2014).

The *family's* capacity to provide support is important. However, because caregiving and care-receiving are often viewed as mutually exclusive (Guest & Corrigan, 2018), the caring capacity, and relational experience more generally, of *care-receivers* has been overlooked. In policy and practice, caring relationships are constructed as uni-directional and devoid of their relational contexts (Moynaux, Butchard, Simpson, & Murray, 2011). This belies the complex realities of how caring happens within families (Barnes, 2012). The distinction between carer and care-receiver seems to be particularly stark within the psychosis literature, which draws primarily on family member's accounts (Henderson, 2001). However, two studies have explored how people experiencing psychosis

contribute to their families. Coldwell, Meddings, and Camic (2011) interviewed adults with diagnoses of schizophrenia, noting that when given opportunities to contribute, they felt psychologically rewarded. Allman, Cooke, Whitfield and McCartney (2018) interviewed younger adults under the care of EIS, noting that family members and professionals tended to overlook young people's positive familial roles.

While some studies have explored young people's perspectives on their social networks during early psychosis, including friendships (e.g., MacDonald, Sauer, Howie, & Albiston,) and romantic relationships (e.g., Redmond, Larkin & Harrop, 2010), there is little about young people's experiences of their family relationships. This understanding can support EIS to collaborate successfully with families, and the young people in their care. This paper draws from a wider project about young people's experiences of relationships during early psychosis and recovery. This paper specifically explores how young people experience and understand their family relationships at this time.

Method

Sampling, recruitment, and participants

After NHS ethical approval was granted (REC 15/LO/1821), participants were recruited from two EIS in a major British city with the support of staff. Sampling was purposive, aiming for an appropriately small and relatively homogeneous group of young adults under the care of EIS. Service users were excluded if they were currently experiencing acute distress, were unable to communicate in English, or had learning disabilities. Five men and five women participated (see Table 1). They were aged between 18 and 23 (mean = 20.5, $SD = 1.51$) and had been with the EIS for between 6 months and 3 years. They were of varying ethnic and cultural backgrounds (including Asian, Eastern and Western European and South American) and were of different nationalities, reflecting the local population. Six participants were currently living with family, two were in supported accommodation, one was homeless, and one was living independently. Participants gave informed consent, names in this paper are pseudonyms, and some details have been obscured to protect anonymity.

Data collection

Participants took part in a relational mapping interview (Boden, Larkin & Iyer, 2019; Boden & Larkin, 2020). This is an innovative interview method that supports participants to visually 'map' their important relationships. Interviews lasted between 30 and 120 min and were audio-recorded. The multimodal (talking and drawing) interview allowed subtle, complex, ambivalent, and ambiguous aspects of the participants' experience to be fore-grounded (Boden & Eatough, 2014). The interview follows an 'interview arc' addressing pre-determined 'touchpoints' followed up by prompts and probes to encourage the interviewee to describe and reflect on their lived experience and sense-making (see Boden & Larkin, 2020 for the interview schedule). This is similar to, though less prescriptive than, a semi-structured interview schedule. Each interview was unique, according to the experiences of the participants, but all asking about four 'touchpoints': how they saw themselves, their relationships with important others, the impact of psychosis and recovery on their relationships, and their relational hopes for the future. The interview begins by asking participants to represent themselves on a blank piece of paper: their 'map'. Participants are then asked to add important relationships in their life,

Table 1. Pen portraits of the participants

Pseudonym	Pen portrait
Aaliya	18-year-old woman, living in a room within a supported housing building, planning to go to college to study arts the following year
Ajay	21-year-old man, living with parents and siblings, retaking his first year studying science at university
Ceri	21-year-old woman, studying social science at university and living in a shared house
Hari	21-year-old man, homeless (sofa surfing) following family break-up
Jake	19-year-old man, living with his mother, having dropped out of college
Karina	23-year-old woman, living with her mother and sister, hoping to go back to education
Lakshmi	21-year-old woman, living with her parents and brother
Manu	19-year-old man, living with his mother and brothers, attending college
Medea	20-year-old woman, living alone in a supported housing flat
Robert	22-year-old man, living back with parents after interrupting studying humanities at university

one by one, discussing each relationship as the map develops. Participants used a range of strategies – symbolic, pictorial and written – to include, and sometimes exclude, people of importance in their lives. Unlike some other social network mapping methods, this approach allows participants to visualize their relational world entirely subjectively, without researchers' assumptions preconfiguring what a relational network might look like. A series of questions were asked to explore the 'texture' and qualities of each relationship and their associated meanings with regard to psychosis and recovery. The first author, who is a psychologist and psychotherapist, conducted the interviews. Data were transcribed verbatim and electronic copies were made of the maps.

Data analysis

A hermeneutic–phenomenological approach was taken to analyse the transcripts and maps. The analytic method is described in detail in Boden and Larkin (2020), Boden et al., (2019) and Boden and Eatough (2014). The aim was to first consider each participant idiographically, rigorously coding the verbal data line by line, focusing on the participants' lived experience and their meaning-making processes. The maps were analysed using a theoretically coherent framework for visual material (Boden & Eatough, 2014), coding in a similar way for both what-it-is-like and what-it-means for the participants. Both stages of analysis were conducted at descriptive and interpretative levels, and the analytic coding from the visual and verbal data was integrated. Secondly, the analysis drew out commonalities from across the sample, synthesizing and refining the analytic insights into thematic structures in order to answer the research question. This phenomenological–hermeneutic analysis was supported by extensive reflexive practice, drawing on theories of embodied, and relational reflexivity (Finlay, 2005) and emotional reflexivity (Benson, Gibson, Boden, & Owen, 2016). Practically, this comprised detailed journaling and regular analytic discussion within the research team.

Findings

Three themes describe how the participants experience and make sense of their family relationships. These are: 'Loving and caring as relational strengths', 'Wrestling with family ties', and '(Not) talking about psychosis'.

Loving and caring as relational strengths

All participants described a range of relational strengths including empathy, love, and care for family members, especially mothers and younger siblings. Simultaneously, participants also often viewed family relationships as a source of confusion, ambivalence, and sometimes distress. Participants described caring *about* their families and also about caring *for* them. They took pride in these roles, despite their challenges. This theme describes how these young people loved and cared for their family members and is split into two subthemes, 'caring about mothers' and 'caring about siblings'.

Caring about mothers. While Karina, Manu and Lakshmi described some positive family experiences, more generally, the family picture was mixed. Mothers were typically described as having 'been through a lot'. Fathers were rarely mentioned and were sometimes the target of anger and disappointment. Only Robert, Lakshmi, and Ajay lived with their fathers. Other participants either did not mention a father-figure (Karina, Aaliya, Medea) or explicitly did not want them to be part of their relational map because they were not emotionally (Jake, Ceri, Hari) or physically (Manu) close. Siblings were important sources of support, as well as figures of concern.

For some participants, caring went beyond *caring about* and constituted *caring for* their mothers, including in ways that could constitute a young carer role. Jake, Hari, and Ceri cared for mothers with health and social problems, including taking responsibility for medication, sleep, eating, physical health, and psychological well-being. Their caring involved emotional responsibility and commitment, as well as confusion and ambiguity as interpersonal boundaries felt fuzzy or roles seemed reversed. Jake offered the most striking example of intensively caring for family, while managing his own well-being. Jake lives alone with his mother who has mental and physical health needs:

Jake: She's been through a lot herself and any time she's been down, upset or anything like that we've kind of switched roles where I'm like the parent and she's like the child. And even sometimes when she's fine, it's kind of like role switch [. . .] I tell her to go and eat, and she says that I sound like her mother. [. . .] I have to be there for her, I feel like it's my job. [. . .] I can't actually think of myself, even at all, any time she's upset.

Jake takes his caring responsibilities seriously ('it's my job') to the detriment of self-care even when his mother is well. On the one hand, 'role switching' is his normality, yet he also recognizes that caring for her can overshadow his own needs. However, he welcomes it as beneficial to his well-being: 'I do like the feeling that if I can help someone, it makes me feel glad'.

Hari also cares about his mother's needs, especially since they both became homeless. Like Jake, Hari feels a responsibility to look after his mother, but also thinks he has let her down. Illustrating their interrelationship, he draws himself as a small star and his mother as the universe:

Hari: 'Cause I love her more than anything in the universe. [. . .] on Christmas I didn't really get to see her and stuff because she's having a hard time, 'cause she has nowhere to live. [. . .] But I want to get to that stage where I should be helping her, d'you know what I mean? [. . .] because I haven't really done that, but I will do that [. . .] and give her everything.



Figure 1. Aaliya's drawing of herself as a flower. The ground and grass are her mother (see Boden et al., 2019 for further analysis).

The star-universe metaphor could illustrate a normatively ordered and hierarchical mother–son relationship – the universe contains the star, as the mother cares for the son – but Hari's description indicates a relational reversal, whereby he is responsible for his mother.

Aaliya, who had been living in supported housing since being discharged from hospital similarly indicates uncertainty about her relationship to her mother. She showed this in drawing herself as a flower (Figure 1), which '*can be easily crushed*' and her mother as the ground. Like Hari's image, this could represent a normative mother–daughter hierarchy, yet Aaliya's description indicates the ambiguity in their relationship: '[the ground] would probably be my mum, and someone that I kind of like rely on for support. And she needs me to be stable for like beauty to grow underneath her and stuff'. While saying that she relies on her mum, Aaliya also indicates uncertainty over which element of her drawing (flower or ground) is '*underneath*' and who needs to be stable. Perhaps, as with Jake and Hari, Aaliya feels she has to care for her mother (who also has mental health issues), more than her mother cares for her.

Caring about siblings. Hari, Robert, Ajay, and Manu described trying to protect their families through working hard and becoming responsible. Robert describes this sentiment, which has been particularly impressed upon him by his father: 'You have to become a man, you have to get a job, you gotta get healthy, you know, you gotta be a contributing member of society'. Participants were similarly concerned about protecting their siblings. Manu saw himself as a 'guardian', someone who could 'comfort [his sister] or someone who's there for her'. Ajay similarly described 'protecting [his brother],

making sure he's alright'. In two cases, sibling relationships were impacted by the young person during their psychosis: Lakshmi and Karina both worried that they had failed to protect their siblings from their behaviour during acute episodes and described attempts to repair those relationships. Lakshmi's relationship with her brother changed during her psychosis:

Lakshmi: My brother, erm he was probably my partner in crime during the childhood days. [...] I'd obviously spend most of my time with him [...] My relation to him during that zombie state was just non-existent. [...] when it came to the psychotic period I was completely, I don't know what it was, but I couldn't be around males, I just couldn't, it was the sense of, either I felt unsafe or I felt that I might do something that might harm them for some reason.

Lakshmi's fears culminated in an incident between them that had lasting impact:

Lakshmi: My sister told me the other day that he was crying about it [at the time] and I was like, I didn't know he cried [...]

Interviewer: What about now? Have you been able to talk about that with him?

Lakshmi: Yeah, we often laugh about it but if you look at it it's not a funny thing to laugh about.

Lakshmi seems to recognize that, while superficially she and her brother have repaired their relationship, their laughter may be masking the seriousness of what has happened between them. In contrast, Karina described a process of repair that seems to have deepened the relationship with her sibling:

Karina: When I had psychosis, we used to have fights, where we used, where I used to hurt her with words, err say mean things to her because I didn't really, I wasn't really in my proper mind and a couple of months ago she came to my room and she started talking to me [...] from that moment I knew that I had my sister. [...] from then on our relationship started becoming like a flower. I'm going to draw a flower. Basically from a tiny, tiny flower it became a really big and beautiful flower [...] we're really, really close now.

Karina's imagery of a flower blossoming, which she represents on her map, positioned between her and her sister, represents how the relationship has flourished since the conflict that typified her acute psychosis.

All participants expressed care for their mothers and siblings, and in some cases, this extended to emotional and practical responsibility for others' well-being. The participants' caring persisted despite complex relational strains (e.g., homelessness, illness), ambiguity about their role within the family, and their own distress.

Wrestling with family ties: Holding on and venturing away

This theme explores how participants felt about the prospect of becoming more independent from their families. Participants' relationships with parents seemed to be shaped by the binary discourse of in/dependence. While this echoes normative developmental concerns during the flux of emerging adulthood, the specifics of their familial relationships and psychosis experiences exaggerated the ambivalence of moving away from family and 'growing up'.

While some participants considered themselves self-sufficient, presumably as an established survival strategy, others felt that they were being steered towards greater independence. All though indicated some ambivalence about venturing away from family. Jake's concerns related to caring for his mother:

Jake: Whenever I'm ill I usually inform my mother that I'm not feeling well and if it's absolutely serious I tell her what's happening, but I try and make sure it's me that's dealing with it and not them. I feel like I have to be dependent, otherwise I can never advance or grow up, because I still feel like a child.

Jake seems to both feel held back ('I can never advance') and also 'pushed into' independence too soon ('I still feel like a child'). He describes feeling like he has to be 'dependent' where 'independent' would seemingly fit his statement about managing his mental health alone. Perhaps his slip of the tongue indicates a deeper desire to have family on whom he can depend. Jake drew himself as a tiny character at the very bottom corner of

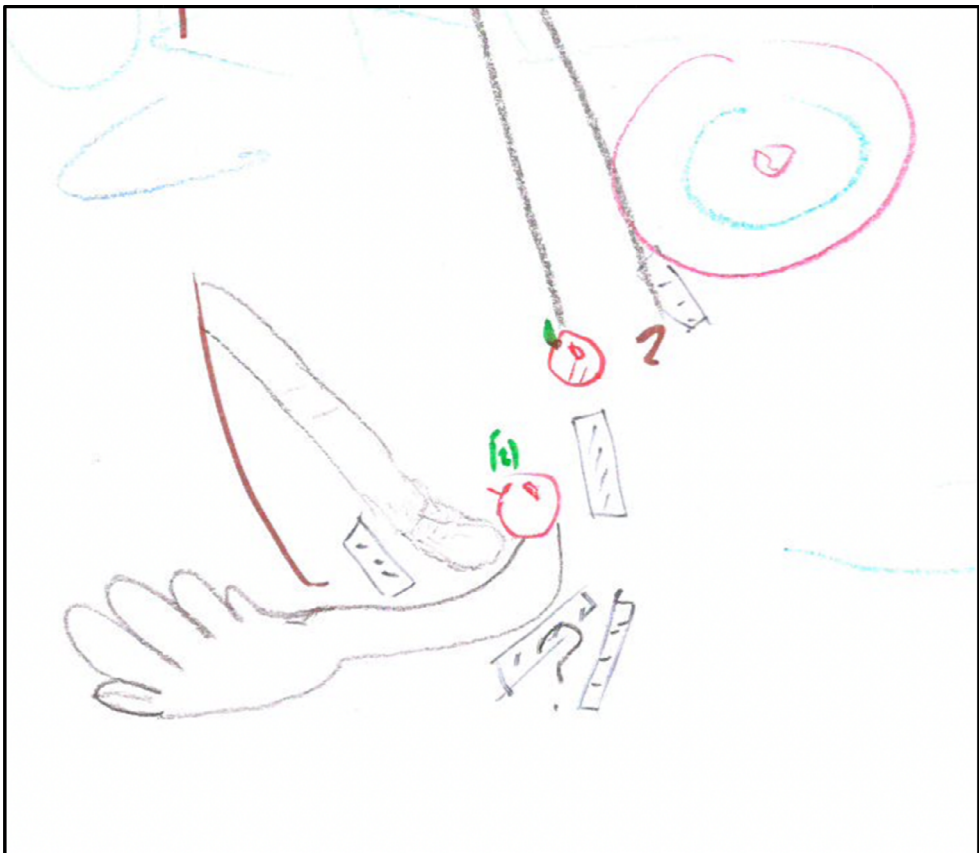


Figure 2. Extract from Robert's drawing of his 'family tree'. This section of Robert's image shows half of the bottom of the trunk, with the fallen apple (Robert) being kicked away by a leg protruding from the tree trunk. Robert added a second target close to the tree trunk. There are also mirrors (rectangles), question marks, and Robert's arm attempting to hug the tree, expressing his confusion about who is helping who in his family.

the page, with just four other people represented separately across the page with no inter-relationships described or drawn. He reflected on feeling the pressure to become independent from his father, with whom he had distrustful relationship, when choosing not to include him on his map: 'I'm constantly reminded by my father that he and my mother won't be around for much longer and I have to figure out how to live on my own'.

Robert similarly describes anxiety about being 'pushed' into independence and adulthood by his father. Robert is concerned with 'work[ing] towards becoming, erm, like self-sustaining and independent, all that kind of thing', which he describes as: 'what you have to do, isn't it? When you grow up'. He drew his 'family tree' as a literal apple tree (see Figure 2), with himself as a fallen apple. His metaphor is rich with symbolism: the apple of the parent's eye, the poisonous apples of fairy stories. His fallen status perhaps indicates he views himself as cast out or morally failing.

From the trunk of the 'family tree', he drew a leg to illustrate the way he felt his father was kicking him away:

Robert: There's like a leg coming out the tree trying to kick, you know, me, the apple, as far away from the tree as possible, but in a good place I guess.

Interviewer: So, you're the apple just here and the leg's coming out of the family tree, and trying to kick it away..?

Robert: Yeah but like you know, I don't know, erm so... er... [draws a target at the far side of the page]. Like a specific target... [..] so otherwise, I could just get, you know, kicked into the vast ocean [draws waves and a shark] Sharks or something.

Interviewer: So, you're being kicked out towards the target, but maybe you might be falling into the ocean

Robert: Mmm, so yeah so... that's why I'm sort of thinking you know maybe... get rid of this [drawing a line through the target] and stay clear of this [pointing to the sharks] and bring the target a little bit closer [drawing a new target next to the tree trunk]

Interviewer: Would that be better? If the target was a little bit closer to the family tree?

Robert: Yeah.

Robert describes how he (the fallen apple) is kicked away from the family tree towards independence and being 'grown up'. The kicking is pertinent in its derogatory nature, despite Robert's guess that it might aim him towards 'a good place'. As his metaphorical narrative develops, Robert revises his drawing, rendering it more hopeful, but also exploring his fears about his independence. First, he draws a 'far away' target and a shark-infested ocean, seemingly exploring his fears around not meeting his father's expectations (the target). Later, he moves the target closer to the tree, and there is a shared sense of relief.

In contrast, Karina, Lakshmi, and Manu, who felt their parents were broadly *supportive* during their crises, spoke more positively about independence. For example, Manu believed his mother saw him '*as the man of the house*' with a position of responsibility within the family (his parents were separated and his father had moved overseas), but then:

Manu: Since my diagnosis – that's when [mum] started caring a lot, being more caring and treating me more like a child [..] I felt patronised [..] I felt like my freedom was going to go away and I had to get it back.

Manu seemingly felt infantilized at first. By the time of the interview, he felt ready for independence, at a manageable level: 'I'd like to handle situations that I can alone'. In turn, his mother responded to him as he recovered:

Manu: She's pushing me to do more things by myself again. So, everything's getting back to normal.

Given the participants' developmental stage and mental health status, it is perhaps unsurprising that they described struggles around in/dependence. Participants reported tensions between moving away and staying connected with family, wrestling to balance their needs for closeness and separateness, and the expectations of others with regard to maturity and recovery. Those participants who expressed most ambivalence around greater independence were those who felt most concerned about their family members and were most involved in caring for them. Those who were ready to embrace independence seemed happier about their familial relationships more generally and described feeling more supported.

'I don't want to open that can of worms': (Not) talking to family about psychosis

This theme explores the relational complexities of talking to family members about experiences with psychosis, which was distressing and frustrating for most participants, both during crises and in recovery. One key aspect of this was hiding their experiences for fear of upsetting others. For example, Medea avoided talking to her mother so as not to compound the distress she believed she had already caused: 'I feel like me and my mum should talk about the past a bit, just to fully get over it [...] but then we never do. [...] last time we brushed over it she started to cry'. Similarly, Ceri felt since she's recovering, 'there's no point worrying her [mother] over it now'. Jake's concern was with overburdening his mother:

Jake: With her I have to be this calm, collected person. It's almost, well it's not even almost, I have to hide all of this from her 'cause I know it upsets her to think of me like that. I mean I tell her about the conditions and everything, but I never go into detail about anything, because I don't know how she'd handle it. I don't think she needs many more upsets. I don't know how she'd react if she knew about half of the things that I've been through, even in past.

Jake's fear of his mother's fragility and the unpredictability of her capacity to tolerate his experiences means that rather than avoid talking to his mother, he censors his experience ('never go into detail'), talking to her in a sparing – perhaps medicalized, rather than emotional – way ('the conditions' rather than the 'things I've been through').

A consequence of feeling unable to talk about difficult experiences for fear of upsetting others was that sometimes the burden of explanation (and shame) fell upon the young person. Medea's fears about talking about the events prior to her hospital admission left her with unresolved questions and anger:

Medea: I don't want to like open a can of worms again [...] going into the past and talking about the bad things that happened. I don't even know what I did to be honest, that's what annoyed me the most. I don't know what I did wrong.

In addition, most participants also reported that they felt unheard and let down by family members when they did attempt to talk about their experiences. For example, Ajay wanted more support from his parents, a feeling of being understood, and the opportunity to ‘talk sensibly’ with his father instead of arguing. He also felt his mum was too busy to hear him:

Ajay: [Mum] was doing her daily life, activities, that she was prioritising more. I was trying to open up about my situation. [...] I was just trying to get them to see that I’m in a state where I need help and they weren’t really listening.

Ajay’s frustration with his parents (‘I was trying...’) and his need for support was echoed by other participants, including Medea, who wished her aunty ‘could have been there a bit more [...] just tried to sit me down and shake it out of me’. Both participants emphasize the struggle they had to start talking about their experiences, and their wish that others could have better supported them in that process. In contrast, Lakshmi praised her sister, who found an idiosyncratic way to communicate with her:

Lakshmi: I didn’t speak for a good month and a half. Not a word to anyone. I’d be in the same room, I’d just try and pretend I wasn’t there, kind of thing. But yeah, I’d speak to [sister] [...] I couldn’t speak to anyone physically, so she told me to write to her, so I’d write up on my laptop, I’d write on my hand.

Participants also described *struggling to talk* about their experiences during their recovery. Several people noted that the interview provided a novel opportunity to talk, as elsewhere in their lives these experiences were generally silenced. Echoing Ajay’s concern that he was not a priority, Karina describes not talking about her experiences:

Karina: ‘We don’t really speak about this. No one takes the time to talk about it pretty much. [...] it’s just time consuming for them to listen, it just like may be, like, too much of a hassle. [...] The other person is going to get bored’.

Only Karina and Medea mentioned family intervention, which Karina found very helpful (Medea felt accused). Despite this support though, she still felt that her experiences were ‘too much’ for others to hear about.

Only Manu described feeling universally positive about conversations with family, including with his father who shares his diagnosis:

Manu: He’s always been there and supportive. Certainly, when that diagnosis hit me, he started being a lot more supportive and asking, you know, asking questions and making sure everything was okay

Nearly all participants stated that talking about their psychosis experiences was personally and relationally risky, and while some tried to initiate conversations, others avoided talking to family about their mental health altogether. For some, this included keeping their mental health status a secret or minimizing it significantly; for others, it was avoiding revisiting ‘bad’ experiences, even when they felt it might help them. Only one participant described a supportive discussion about psychosis with a family member. Most felt their mental health experiences were burdensome, and so they silenced themselves, perhaps at least partially, as an act of care for others.

Discussion

Despite difficult circumstances, the young people in this research actively cared about (and sometimes cared for) family members and were seeking to feel cared for by them. Their caring, and struggles with in/dependence and communication have significance developmentally and with regard to their mental health.

Reciprocity and relational strengths

Young people experiencing psychosis are frequently understood as a 'burden' to their families and the participants in this research also saw themselves that way. This discourse of 'burden' perpetuates an evidence base that ignores the contributions that a person experiencing psychosis can make to their families (Allman et al., 2018; see Ahmed & Boisvert, 2006) and dismisses the reality that 'most people are, at some time, a 'carer' and at others 'cared for'; and often both at the same time' (Bowlby, 2012, p. 2102). Asymmetric care can be 'dehumanizing and disempowering' (Tanaka & Davidson, 2015) and reciprocity should be a significant aspect of any caring relationship, regardless of context (Barnes, 2012). Despite understanding themselves to be burdensome, the participants in this research were also proud and vocal about their active involvement in the emotional and sometimes practical care of their loved ones. Within family settings, this type of reciprocity offers a source of 'everydayness' that helps normalize the extraordinary nature of these families' circumstances (Guest & Corrigan, 2018). People with experience of distress have identified reciprocity as helpful for recovery (e.g., Ådnøy Eriksen, Arman, Davidson, Sundfør, & Karlsson, 2014), and it is recognized and supported within peer-oriented settings (e.g., peer support services, clubhouses, therapeutic communities). However, reciprocity is less frequently acknowledged or supported within families, which remain important relational constellations for young adults attending EIS (Addington & Burnett, 2004).

The positive practical and emotional contributions that people with psychosis make to their families are just starting to be being evidenced (i.e., Allman et al., 2018; Coldwell et al., 2011), and this research adds to that literature. Unfortunately, societal stigma and the deficit model of medical care mean that these contributions are often undervalued or under-acknowledged by families, which can then be internalized by person themselves (Allman et al., 2018). In this research, caring about and for family members was both a source of self-esteem and a marker of normality, as well as a source of distress. In some cases, the degree of caring responsibility participants was undertaking went beyond normative expressions of kinship love, and involved more or less explicit roles as informal carers for parents with health and social problems (a finding echoed in Allman et al., 2018). Young carers are known to have higher risks of experiencing psychological distress than non-caring young people (Dharampal & Ani, 2019) putting them at additional risk. Given their developmental stage of emerging adulthood (Arnett, 2000), how young people experience their relationships to their families will be in a state of flux. Recognizing that where and when (developmentally) caring takes place, as well as acknowledging the relational dynamics in which it happens (Bowlby's, 2012 'caringscapes'), enables a nuanced analysis of how these young people expressed care for their families and what may be done to support them.

Holding back, withdrawing, and relational agency

Social isolation and loneliness are significant risks in early psychosis, when people are likely to have diminished social networks and reduced perception of social support (Lim et al., 2018; Michalska da Roscha, Rhodes, Vasilopoulou, & Hutton, 2018; Sündermann, Onwumere, Kane, Morgan, & Kuipers, 2014). Loneliness may be both a potential contributing cause of psychosis (e.g., through increasing anxiety and depression which may exacerbate psychosis, or through perpetuating negative beliefs about self and others) and a consequence of psychosis (through stigma and exclusion, deficits in social cognition, lack of social skills, or the impact of symptoms including depression, paranoia and social anxiety, and periods of hospitalization). However, the exact mechanisms that link social isolation, loneliness, and psychosis are likely to be bidirectional and currently remain unclear (Badcock, Addery, & Park, 2020; Michalska da Roscha et al., 2018). Following the view that during psychosis intersubjectivity is experienced as threatening (Laing, 2010/1960; Lysaker, Johannesen & Lysaker, 2005), one proposed mechanism suggests that social isolation in early psychosis is self-protective, insulating the person from the stress of interpersonal relationships (Cresswell et al., 1992). More recently, Seeman (2017) recognized that while social withdrawal and solitude can be a way of managing social anxiety, it can also be a positive choice, supporting recovery, for example, through connecting with nature, spirituality, or creativity. This research extends this idea by indicating that there may be relational reasons why a young person withdraws from others. Reluctance to disclose mental health experiences or to ‘go back over’ past experiences – forms of holding back and withdrawing – was frequently described as acts of care, with the explicit intention of protecting loved ones from distress. This withdrawal meant participants often relegated or ignored their own needs, in order to prioritize caring for others.

Several explanations for this are possible. Firstly, protecting family is normative, socially sanctioned behaviour. It is developmentally normative too: as young adults mature and child–family dynamics shift, the young person typically takes on more responsibility for others within the family system. Therefore, withdrawing or holding back information may be an attempt to benefit the family group in line with altruistic societal ideals. Secondly, specific challenges within strained family structures, such as low levels of trust, low parental tolerance of distress, porous intergenerational boundaries, and ‘parentification’ (see Chase, 1999) may contribute to the young people’s choice to self-isolate, as this may appear to be the best option for their own and their loved ones’ well-being. Thirdly, given the prevalence of ‘carer burden’ discourse, it is perhaps unsurprising that young people may conclude that talking about their mental health will contribute to their families’ suffering. Withdrawing and holding back may represent a young person’s agentic attempt to counter the perception of themselves as a drain on family resources, but may also contribute to reducing intimacy and trust in familial system, increasing isolation. Lack of a confidant has been shown in particular to increase loneliness in early psychosis (Sündermann et al., 2014) and loneliness in turn corresponds with increases in suicidality, depression and hearing voices (Michalska da Roscha et al., 2018; see Hawkey & Cacioppo, 2010).

Considering agency as a relational rather than individual attribute may help further understand this process. Agency and autonomy rest on ‘the nature of our interdependence with others and how this shapes our mutual interactions’ (Burkitt, 2016, p. 331). Interdependence means that we rely on each other for emotional, sexual, economic, social, and political needs, with corresponding inequalities and imbalances, forces, and constraints (Elias, 1978). The young people in this research can be seen as active moral

agents within their family systems, taking action for the greater good, with corresponding impacts on their own self-esteem and identity. They are affectively and relationally engaged, seemingly even at the height of their distress. Further research is necessary to explore how relational agency, empathy, and altruism may, paradoxically, contribute towards social withdrawal and isolation in the context of families experiencing mental health challenges.

Implications for intervention and research

This research indicates that young adults experiencing early psychosis may have many relational strengths and *can* be actively involved in and concerned about their families (acknowledging that others cared for by EIS may have little or no involvement with family, or feel otherwise towards them). A metasynthesis has demonstrated that young people who use EIS identify relationships as essential to their recovery and particularly value opportunities for reciprocity and togetherness (Hansen, Stige, Davidson, Moltu, & Veseth, 2018), yet acknowledging that the ‘patient’ can also be a caregiver seems difficult for professionals and/or services. This may be because it does not fit with the biomedically oriented views of psychosis that most staff hold (Morera, Pratt & Bucci, 2017). The powerful ‘illness identity’ stops staff from seeing how much young people positively contribute to their families (Allman et al., 2018) and this filters down to families and the young people themselves. Just asking about the positive contributions a young person makes can help change the negative perception of their value within the family, but services need to change their own perceptions first (Allman et al., 2018).

Rather than focusing on social deficits, interventions, and services that develop the young person’s pre-existing relational strengths (empathy, care, protectiveness) may help the young person negotiate the complexities of their family systems. It may also support them to develop their own explanations for their social withdrawal, silences, anger or confusion, supporting both intra- and interpersonal growth. Strength-based approaches have been used in EIS to support social and occupational goals (Kelly, Wellman & Sin, 2009) and to develop adaptive responses to stress (Meyer-Kallos et al., 2018), but a greater focus on *relational* experiences may be beneficial. A relational strengths approach reinforces the person’s prosocial capabilities and provides opportunities to develop self-esteem and build a positive self-identity that does not hinge on ‘illness’. There are challenges in services moving from an illness-based to a well-being-based model (Slade, 2010); however, it may lead to gains in both social and clinical recovery, provided it is done with acknowledgement of the complexities, risks, and ambivalences within the family system. *How* this is done is also important. Relational strengths-based interventions need to be *delivered relationally*, with an emphasis on dialogue and shared decision-making. On ethical and empowerment grounds, this should be led by the young person as far as possible, who should be actively involved in their care, and should be consulted and listened to with regard to their relational views, values and goals. Services may want to pay particular attention to the possibility that young adults they care for may also be managing caring duties of their own and may even be considered a ‘young carer’. Recognizing that a care-receiver can have a dual identity as a caregiver seems difficult when there are binary expectations of how each role should function (Henderson, 2001); however, it opens up avenues of support.

Family intervention for psychosis is supported by NICE guidance (NHSE, 2016) and our research suggests services could further develop this work to help family systems tolerate distress, increasing the potential for openness, intimacy, and trust. Positive family

environments, and especially emotional warmth, protect against relapse (Lee et al., 2014), and family work could acknowledge the potential role that the young person themselves can play fostering positive feelings within the family system, as well as being a recipient of others' regard. Where families are unable or unwilling to take part in interventions, EIS staff may be well placed to support young adults to identify other trustworthy confidants, or offer that role themselves. Attachment-informed design and delivery (Bucci, Roberts, Danquah, & Berry, 2015) and awareness of the developmental needs of emerging adults may support the EIS to provide stable relationships for those who are relationally deprived. Our research suggests there are currently few opportunities for young people to talk about their psychosis and to make sense of family dynamics. Developing an evidence base for the effectiveness of relationally oriented psychological therapies for psychosis would provide more options (see Taylor, Gianfrancesco, & Fisher, 2019). Struggling to trust others and the feelings of burdensomeness these participants identified are both risk factors for suicidality (Benson, Gibson, Boden, & Owen, 2016; Van Orden et al., 2010). Interventions that increase trust within significant relationships and that address beliefs that the young adults are burdensome to others may reduce suicide risk, in this high-risk population (e.g., Pompili et al., 2011).

Conclusion

As this paper is based on a small, exploratory study, further research is needed to understand more about how young people experience their relationships with important others, including family members. The sampling in this study was likely influenced by the necessity to recruit via clinical gate-keepers, who may have had their own understanding of which clients would be suitable to talk about their relational lives, or who would want to take part in an interview that requested drawing a relational map. Those EIS clients who were most acutely distressed were not able to take part in the research due to ethical restrictions; however, it is possible that these people may have different experiences of their family relationships. As such, the findings in this paper can only offer a snap-shot of the familial experiences of ten young people under the care of EIS. However, this research adds to an emerging literature, which argues that in the context of psychosis, many young people's relational strengths and the contributions they can make to their families are overlooked.

Despite numerous challenges, not least their distress, the young adults in this research were empathic and caring individuals who described choices which were relationally motivated. Family conflicts, frustrations, and ambivalences were apparent, especially in relation to individuating away from the family system, but so was loyalty, protectiveness, and love. Interventions that support and develop relational strengths may offer EIS an additional route towards social and clinical recovery.

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Conflicts of interest

All authors declare no conflict of interest.

Author contributions

Zoë V R Boden (Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Writing – original draft; Writing – review & editing) Michael Larkin (Methodology; Supervision; Writing – review & editing) Chris Harrop (Resources; Writing – review & editing).

Data Availability Statement

Research data are not shared.

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