Title: Recovery and self-identity development following a first episode of psychosis

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Introduction

Research on recovery in the early phase of psychosis has risen dramatically in recent years (Santesteban-Echarri et al, 2017). A growing interest in understanding and treating the early phase of psychosis has brought forth a sense of optimism and hope of altering its course (Bonnett et al, 2018; Lower et al, 2015). The onset of psychosis typically develops during adolescence or early adulthood; a crucial period for forming peer networks, beginning the transition from family to independence, and developing a stable sense of self (Harrop & Trower, 2003). Chronicity of psychosis is often conceived of as a loss of self and of positive social roles and identity (McCarthy-Jones *et al*, 2012). Experiencing a psychotic episode in early adolescence often disrupts developmental tasks of establishing an identity and becoming more autonomous (Gumley & MacBeth, 2014).

Recovery from psychosis includes both symptomatic and functional components. Functional recovery has been found to lag behind symptomatic remission with many individuals remaining socially isolated with poor functional outcomes (Norman et al, 2017). Systematic review and meta-analysis of longitudinal studies of predictors of functional recovery emphasise the importance of early intervention and the use of novel treatments targeting cognitive deficits to improve functional recovery (Santesteban-Echarri et al, 2017). Psychosocial factors and negative emotion have been found to be strong longitudinal predictors of variation in subjective recovery, rather than psychiatric symptoms (Law et al, 2016).

Subjective experience of first episode psychosis

Alongside progress in demonstrating the efficacy of individual and group based interventions for treating the symptoms of psychosis and improving functional recovery (e.g. Coupland & Cuss, 2008; Fowler et al, 2017; Ochoa et al, 2017), further attention has been paid to understanding the subjective experience of first episode psychosis (Boydell et al, 2010; Windell et al, 2015). Gaining an understanding of how adolescents make sense of their experiences of psychosis allows service providers to gain a deeper insight in to how best to engage and support them (Brew et al, 2017). Researchers investigating the prodromal period using in-depth interviews with adolescents have identified a wide range of symptoms and behaviours including sleep difficulties, anxiety, problems with concentration, racing thoughts and social withdrawal (Corcoran *et al*, 2003; MacBeth et al, 2014; McCarthy-Jones *et al*, 2012). Studies focusing on the period during and following the initial psychotic episode have highlighted how adolescents search to find meaning for their psychotic experiences and adopt varied explanatory frameworks that evolve over time (Larsen, 2004; Perry *et al*, 2007; Werbart & Levander, 2005).

Self-identity and the recovery process

The process of recovery during early onset psychosis in adolescence has not been investigated with reference to its influence on self-identity. Identity formation in the form of secondary separation-individuation is recognised as a pivotal construct in adolescent development (Becht et al, 2016). This process is mainly characterised by the adolescents' disengagement from parental ties, enhanced autonomy and interpersonal relatedness, which requires a realignment of attachment needs (Gumley et al, 2014). Patterns of

recovery from psychosis varies from person to person and multiple dimensions of recovery are important when considering adolescents' subjective experiences (Bourdeau et al, 2014). Recovery is a complex and idiosyncratic process, which often involves post-traumatic growth, rebuilding self, emotional resilience and hope for a better future (Dunkley & Bates, 2015). Positive adjustment and successful individuation processes depend on how adolescents with early onset psychosis adapt and engage in their own personal journey of recovery. Such processes are likely to be influenced by adolescents' perceptions of self. Further work is needed to investigate adolescents' subjective experiences of recovery during early onset psychosis with reference to its influence on self-identity. This study aimed to explore adolescents' personal understandings and experiences of recovery during early onset psychosis. It sought to gain insight in to how adolescents' consider their subjective experiences of living with psychosis to have impacted on self-identify. With increasing awareness of the need for developmentally sensitive mental health services, it is essential to clarify how recovery and identity development are experienced and engendered by adolescents experiencing psychosis through exploring their first-hand accounts.

Methodology

Participants

A purposive sample (n = 10) was obtained, whereby participants were considered eligible for the study if they were: (1) aged between 16 and 18 years old; (2) recovering from early onset psychosis; (3) within 3 years of first contact with an Early Onset Psychosis Service; (4) were actively engaged in an Early Intervention Service; (5) able to provide

informed consent to their participation in the study; and (6) granted primary care-giver consent for their participation. Adolescents with drug and/or alcohol problems as a primary diagnosis were excluded from the study. Information concerning the adolescents' demographical background is detailed in table 1.

TABLE 1 HERE

Recruitment

The process of gaining access to research participants consisted of a number of stages. Firstly, ethical approval for the conduct of the research was sought from the research ethics committee in the Department of Clinical Psychology, University of Edinburgh. Ethical approval was granted on the basis of its academic merit, however, its conduct was conditional in that ethical approval had to be sought from the NHS Research Ethics Committee (REC). Ethical approval was sought and granted from REC and the Research and Development Department for Primary Care NHS Trust.

Adolescents were recruited from an Early Intervention Service in NHS Lothian. The British Psychological Society (BPS) Code of Ethics and Conduct was followed throughout the research process.

Despite extensive planning of the research, one of the most significant challenges in conducting the research concerned identifying and recruiting adolescents with experience of psychosis. As has been reported by other researchers working with vulnerable populations (Rimando et al, 2015), intensive and proactive networking with gatekeepers was needed to commence with the research. The process of initially

identifying and recruiting participants involved senior clinical staff in an early intervention service for psychosis in the Lothian area being provided with information about the study. Senior clinical staff then identified potential adolescents that they reported to be well enough to participate and to have the capacity to provide informed consent. Clinical staff initially approached such adolescents regarding their potential participation in the study and those who expressed an interest were contacted by the chief investigator. Adolescents were offered an opportunity to ask questions about the study. They were sent a copy of an information leaflet about the study with a covering letter inviting them to take part. This was followed by a phone call a week later asking if they were interested in participating in the study. Of the eleven adolescents that had initially showed interest in participating in the study, ten agreed to take part. Written consent was sought from all of the adolescents as well as their primary care-givers. Adolescents were offered a suitable time and date to engage in a semi-structured interview at the early intervention service. Conducting the interviews with adolescents required a great deal of thought and consideration; sensitivity was needed, with attention to ethical considerations, the developmental stage of the adolescents and appropriate forms of communication. It was anticipated that adolescents might have fears about disclosing information concerning their experience of psychosis. They were informed that they were free to withdraw from the study at any time and issues regarding confidentiality and the protection of their anonymity were discussed.

Research Process

The data was collected through individual, semi-structured interviews with each participant. The schedule was used to let participants tell their own stories of recovery and self-identity following early onset psychosis through exploring the following themes: (1) understandings of self and psychosis, (2) personal history, (3) impacts on diverse life domains, and (4) recovery process. The schedule was developed from a review of relevant research literature and designed for the specific purposes of this study. With the participants' consent, each interview was recorded using a digital audio recorder. A notebook was also used for keeping reflective field-notes.

The data was transcribed in full verbatim to ensure no data was lost that may have become significant in the wider analysis of the research findings. The primary interest was in the content of the interviews, therefore it was sufficient to transcribe what was being said (the words), although selective transcription notation was found to be useful. That is, occasions where reference to non-linguistic features of speech were considered to be of significance in the interpretation of what was being said by the participants, notations were made during the transcription process. This allowed inclusion of other issues relating to the setting in which the interviews took place, non-verbal communication and behaviour of the participants.

The qualitative data stemming from the transcripts was managed with the software programme NVIVO (Richards, 1999), which facilitates the storage, analysis and retrieval of textual information. Each data file stemming from individual interviews with adolescents (n=10) was imported into NVIVO and coded with a brief descriptor of the information contained in each file (i.e. adolescent who experiences psychosis, aged 18 years, male).

Analysis

The data was analysed in accordance with thematic analysis (Braun & Clarke, 2006). Firstly, this involved becoming closely familiar with the data by reading and re-reading the interview transcripts. Following this close reading, initial codes were generated through focusing on what the participants were saying in relation to their experiences of recovery and the impact on self-identity. This consisted of identifying meaningful extracts and coding them into themes. All the data relevant to each theme was extracted and a process of defining and naming the themes commenced. The themes were then refined in relation to the overall meanings that was captured for each theme. Themes are key characters in the story being told about the data (Clarke & Braun, 2018). Each theme being an active creation of the lead researcher that unites data that, at first sight, might appear disparate; capturing implicit meaning beneath the data surface (Braun, Clarke & Rance, 2014). Preliminary themes created by the lead researcher were cross-checked by the co-researchers who both had expertise working within the context of early intervention for psychosis. In line with the concept of 'participant validation' (Henwood & Pidgeon, 1992), adolescents were also offered the opportunity to read the initial thematic analysis of their own interview, to discuss it with the researcher, and to make any comments or changes they wishes. The purpose of this was to involve the adolescents more closely in the research process and to offer a further credibility check of the emergent themes. Quotes from the transcripts that captured discrete aspects of each theme were identified. This procedure resulted into three main themes that were largely present within all ten interviews. Differences between the adolescents' accounts are

highlighted. In illustrating the themes from the data, any names used in the interviews have been changed to pseudonyms. Words or phrases inserted to make meanings clearer are enclosed in brackets.

Findings

Analysis identified the themes of: (1) uncertain identities & status ambiguities, (2) decrease in referent points for identity, (3) unfavourable social comparison (loss, grief & self criticism).

Uncertain identities & status ambiguity

As adolescents drew upon their personal meanings and experiences of recovering from a psychotic episode, they described how their sense of self had become a matter of uncertainty. Quite apart from the problems of status ambiguity associated with being diagnosed with psychosis (as sick; ill patient; deviant) and the difficulties this created for them in terms of developing a coherent sense of self, there were other factors which exacerbated the uncertainty. This included "not knowing what I'm gonna do with my life" (Donna), "will I ever get rid of it (psychosis)" (Shona), and "will my mates think I'm mental, like, not right in the head" (Michael). All of the adolescents expressed concern in how having had an episode of psychosis impacted on their lives.

Half of the adolescents drew reference to how the onset of psychosis led to a loss of contact with reality; typically including delusions and/or hallucinations. This point was

illustrated by Stephen who described his experience of having lost a sense of trust within himself:

> Having been (psychiatrically) hospitalised for the first time, well, a good thing that I don't fully trust myself and believe all the delusions (pauses). I felt alone and like I had lost everything.

Adolescence itself was viewed as being a time when the certainties of the past (being cared for by parents; child status; having decisions made for you) gave way to a situation characterised by a greater level of ambiguity and skepticism. This point was captured by Jennifer who stated:

> I mean being this age is hard enough, like, trying to work stuff out and deciding what to do next, like to go to college or whatever (pauses), I guess that's not gonna happen now, cos I'm in here (early intervention service), I don't see the point now.

Living with psychosis said something about the adolescents' recovery and self-identity. It was not just a matter of what it symbolised to others, but of what it symbolised in terms of their construction of the self. They had different opinions in terms of what it said about self-identity. For a couple of the adolescents their experience of psychosis had set them aside from others and made them "special" (Shona & Mark).

At the same time, all of the adolescents acknowledged that their larger cultural context holds pejorative viewpoints towards their "being psychotic" (John) and reported experiences of stigma and social exclusion within their social networks. They recognised that in telling other people about their psychosis they ran the risk of embracing an identity which, whatever it meant to themselves, was often seen as "mad" (Callum), "tainted" (Shona) and/or "dangerous" (John). For Alison, the fear surrounding psychosis was felt to have had a negative impact on how people perceived her:

> Stuff that I've been dealing with in my life so it's pretty normal to me (pauses) it's voices, I see things, it's hard for me to know what is and what isn't psychosis. I think if I say the word 'psychosis' to someone it sounds really big and scary. It's quite a big part of me, em, it affects the ways … people perceive me, I think if people think that you've got this (psychosis) you're not allowed in public with them because you're weird (pauses). It's like being damaged in some way.

Decrease in referent points for identity

One specific aspect of this context of uncertainty which had particularly significant bearing on the issues raised by all of the adolescents concerned their perceived decrease in referent points for developing their own sense of identity. Factors that served as referent points in the past (self; peer group; siblings; parents; school) no longer operated with the same force or clarity. While the majority of the adolescents placed importance on peer relationships, they all expressed their difficulties in developing and

maintaining friendships. Michael described his sense of feeling socially isolated following a psychotic episode:

> I feared being alone and that I would lose all my friends, well my old friends just disappeared, I mean I told some of them (about psychosis) but they just started going about with other people so (pause), I just lost friends.

One particularly problematic consequence of their experience of living with psychosis was the impact this had on establishing and maintaining referent points. In adopting a referent group, that being with other adolescents recovering from psychosis, they established a shared experience with others and reduced their tendency to feel alone. At the same time, this also created mixed feelings in terms of how this affected their developing sense of self. This point was illustrated by Donna who drew upon her experience of attending a therapeutic recovery group:

> They have similar problems to me (pause), that can be quite nice, you know to feel part of a community of people cos it can be quite isolating when you hear voices. It's also scary to be around people that can be struggling more than you are, like to think 'am I really like them?'. Suddenly you're getting locked away into that (identity) with no way out.

Their search for meaning and understanding their experiences of psychosis were critical to their paths to recovery. Callum described how he sought to make sense of his experience through engaging with his keyworker:

> When it (psychotic episode) happened to me I didnae even know what was happening, like that I was ill, like, I was just scared (pauses), I still don't know how it happened, or why me? My keyworker is trying to help me understand it and she understands it, so that makes me feel a bit better.

Unfavourable social comparisons (loss, grief & self criticism)

The adolescents tended to compare themselves unfavourably with past selves and others. They talked about their difficulties (of social life; going to college; getting a job) by invoking what they used to be able to do (comparison with past selves) and by highlighting what other people are capable of doing (comparison with peers, siblings, parents). A couple of the adolescents also compared themselves with people less fortunate than themselves (terminally ill; homeless people) to emphasise their existing strengths. However, these comparisons were experienced as counterproductive as they made them worry about their own futures. This point was captured by John in describing his concerns about not being able to progress with his life through fear of being psychiatrically hospitalised again:

> I can't really see me getting over it, like I worry about it all the time, I don't want to have to go back in (psychiatric) hospital again (pauses). My friends are all going to college or University and I'm just here.

The uncertainty and ambiguity associated with psychosis meant that social comparisons tended to emphasis loss and grief. All of the adolescents drew reference to how their experience of psychosis had contributed towards a sense of intense sorrow and mourning. They drew reference to feeling "sad" (Donna), "like a bit of me is dead" (Callum) and "I'm fading away" (Shona) and this further exacerbated their tendencies towards making unfavourable social comparisons (between self and others).

Losses were experienced by the adolescents in multiple domains of their lives (peer and romantic relationships; educational achievements) following their episode of psychosis. Apparent in the majority of the adolescents' accounts was a tendency to adopt a self-critical stance on factors contributing towards the onset of psychosis. Reference was made to their experience of psychosis as being "all my own fault" (Stephen), "I messed everything up" (Mark) and "I've put my mum through hell" (John). A sense of shame and negative self-appraisal associated with having had a psychotic episode was captured in Lisa's account:

> I guess like I blamed myself for what I was feeling and thinking and I felt kind of ashamed of myself for what I was feeling and thinking and I feel like I can't really do stuff I did before, you know, like going out with my pals or going to gigs. I often think it's all my fault.

Half of the adolescents described how they sought to deal with such losses by accepting their diagnosis and treatment. Others placed importance on their quest to gain further information about psychosis and make sense of their individual experiences to aid their recovery process. The adolescents had been to "education groups" (Callum & Alison), "therapy" (Jennifer, John & Shona) or had read "leaflets about psychosis" (Mark) which they had found helpful in their attempts to understand their lived experiences. Apparent in all of their accounts was the evident need to continue exploring their emerging self-identities within the context of their recovery journeys.

Discussion

In exploring adolescents' understandings and experiences of recovery during early onset psychosis, this study aimed to gain insight in to how adolescents consider their experiences of living with psychosis to have impacted on their self-identifies.

Establishing a stable self-identity is considered to be at the heart of the recovery process (Connell et al, 2015) and is the core developmental task of adolescence (Crocetti, 2018). In drawing upon adolescents' personal accounts, the complexity associated with establishing a coherent understanding of their experiences of psychosis contributed towards their identities becoming a matter of uncertainty. This finding is similar to studies reporting on the experiences associated with early onset psychosis, whereby the core of the self is displaced by the multiplicity of 'selves' established in relation to different referent groups (Nelson *et al*, 2009; Norman et al, 2014). Given that there is often diagnostic (Adeponle et *al*, 2015) and prognostic (Benoit et al, 2017) uncertainty in

the first episode of early-onset psychosis, it is understandable that the adolescents experienced status ambiguity and struggled to establish a stable sense of self. When adolescents' experiences of psychosis are not validated by those closest to them and are discounted by others, their very status as citizens in their communities to which they belong can become threatened. At the same time, the uncertainty surrounding the developing sense of self in adolescence is a normative phenomenon, typically experienced by many adolescents as they negotiate the many transitions and roles leading them towards adulthood (Hurrelmann, & Quenzel, 2013). The extent to which adolescents find a stable identity is intertwined strongly with their psychosocial functioning and well-being (Crocetti, 2017). It is likely that adolescents that experience an early onset of psychosis are at increased risk to the emerging self and arrested maturational development (Braehler & Schwannauer, 2011).

As has been found in earlier work (Harrop & Trower, 2003; McCarthy-Jones *et al*, 2012; Romano *et al*, 2010), adolescents drew reference to the disruption to their lives following the onset of psychosis. A perceived decrease in referent points and attention to the negative social impact living with psychosis had on their developing sense of self contributed towards relationship breakdowns. Studies that have investigated peer (Mackrell & Lavender, 2004) and familial relationships (Fortune *et al*, 2005), emphasis the uncertainty surrounding the nature of such relationships before and during the course of psychosis. Some researchers have reported that individuals who develop psychosis experience pre-morbid difficulties in peer functioning in childhood compared to controls (Dworkin *et al*, 1994; Mackrell & Lavender, 2004). Others have presented evidence to suggest that social functioning and relationship deficits occur primarily during the pre-

onset phase (Macbeth & Gumley, 2008). Nonetheless, there is agreement that supportive peer and familial relationships are associated with adaptive functioning in psychosis (Attard et al, 2017). Indeed, the adolescents in the current study emphasised the importance of relationships despite the evident problems they experienced in developing and maintaining social networks. Given the developmental stage of individuation, when young people typically move away from familial relationships towards friends, the current findings suggest that supporting adolescents to find a relatable and supportive peer group is an important consideration for practitioners.

Consistent with previous studies (Braehler & Schwannauer, 2011; Gumley *et al*, 2010), social comparisons tended to emphasis loss and grief. A tendency towards adopting a self-critical stance in describing losses in diverse areas of their lives may be linked to negative self-appraisals (Gumley *et al*, 2008). Indeed, a large body of research has highlighted the persistent and disabling consequences of both self-stigmatising (Karidi *et al*, 2009) and stigmatising attitudes of others towards people who experience psychosis (Burke et al, 2016; Rusch et al, 2014). The findings of this study emphasise the important relational component of others modelling non-stigmatising attitudes, recovery and normalising psychosis in planning and implementing early interventions for psychosis.

The need to feel accepted by others is a normative component of developing a stable sense of self in adolescence (Braehler & Schwannauer, 2011; Gumley, et *al*, 2010); early onset psychosis is likely to interrupt this process at a pertinent developmental period (Harrop & Trower, 2003). It is likely that psychotherapeutic interventions that encourage the development of self-reflection, compassion towards the self (Braehler &

Schwannauer, 2011; Dudley et al, 2018; Gumley & MacBeth, 2014; Laithwaite *et al*, 2009) and acceptance of the experience of psychosis (Attard et al, 2017; Gumley et al, 2017; Vilhauer, 2017; White & Gumley, 2010; White *et al*, 2011) will aid the recovery process.

In considering the limitations of the current study, it is important to acknowledge that the analytical process is based on the subjective interpretation of the themes extracted from the data, which are inadvertently influenced by the researchers' knowledge and assumptions as clinical psychologists. It is also important to note that according to some studies (Pedersen et al, 2017; Shek *et al*, 2010), persons who are acutely psychotic may have substantially impaired decision making abilities, including problems with reasoning. Consequently, adolescents who's lives were most severely affected by their experience of psychosis were not included in the study. Such adolescents may be more inclined to experience difficulties in terms of developing a stable sense of self. Indeed, preliminary discussions with senior clinical staff who assisted with recruitment reported this to be the case. With this in mind and given the small sample size the current findings do not represent a comprehensive picture or generalisable results. Future research incorporating other key informants (e.g. key workers; family members, peers) could provide a more holistic stance. While rich and informative findings have emerged, the study population were predominantly of white, low to middle class origin. Future work exploring social, clinical and demographical differences amongst adolescents experiencing early onset psychosis is essential, in that research and interventions must be varied to allow for diversity in race, culture and ethnicity (Cicero & Cohn, 2018). Encouraging and supporting adolescents that have

387 experienced an episode of psychosis to re-engage in their communities
388 encompasses acceptance, and the work of personal and social recovery (Fowler et al,
389 2017). Indeed, full membership in society, involves the "5 Rs" of citizenship:
390 rights, responsibilities, roles, resources, and relationships, accompanied by a sense of
391 belonging (Rowe et al, 2012). Adolescents that have experienced psychosis are often
392 excluded from the 5 Rs. By the time they enter early psychosis services, they are often
393 experiencing increasing detachment from the world around them (Hansen, Stige,
394 Davidson, Moltu, & Reseth, 2017). The importance of human reconnections, advocacy
395 and community reintegration, as well as continued public mental health campaigns to
396 tackle the stigma surrounding psychosis are essential steps to assisting people in their
397 recovery journeys. Such developments would help inform and advance public mental
398 health initiatives and education to assist adolescents recovering from psychosis.
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Table 1: Background information relating to adolescents with experience of psychosis

PIC	Age in years	gender	Presenting problems (accompanying psychosis as primary diagnosis)	Contact with mental health services in years	Number of hospitalisations
Donna	18	Female	Anxiety & interpersonal difficulties	4	2
Shona	18	Female	Anxiety	2	1
Alison	17	Female	Depression & anxiety	1	0
Jennifer	18	Female	Mania & low mood	3	1
Lisa	18	Female	Anxiety	2	1
Michael	18	Male	Substance misuse	2	1
Stephen	17	Male	Aggression & attention difficulties	1	0
Mark	16	Male	depression	2	0
John	18	Male	Mania & low mood	5	1
Callum	18	Male	Social anxiety	1	0

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