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Recovery perspectives and narratives of hope of young people experiencing psychosis

Section A: Experiences of recovery for young people with psychosis: A review of the literature. Word Count: 7957 (260)

Section B: A narrative exploration of hope and social inclusion with young people following experience of psychosis. Word Count: 8000 (340)

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Acknowledgments

'Human time is a storied affair' (McAdams, 1996)

Although this body of work has my name on it, it has come about through the support of many, some of whom I will mention, whilst being grateful to all.

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I am thankful for my supervisors, Sue Holttum, Sara Meddings and Clio Berry who have provided much needed advice and encouragement throughout. Thanks also to Diana Byrne for her support. Huge thanks to the research assistants and early intervention team who helped with recruitment.

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So Earth is lost to us?

No. There is always hope.

(Thor, Marvel)

Summary of MRP Portfolio

This portfolio comprises three sections:

Section A: A qualitative systematic review which explored the recovery stories of young people below the age of 30 years who had experienced psychosis. The search strategy is described which identified 12 qualitative papers. Common themes across the papers were identified, described and evaluated. Making sense of the experience of psychosis was an important part of moving forwards for young people. Therefore, being unable to make sense of psychosis represented a challenge to recovery. The recovery journey involved hopeful thinking, re-evaluation of goals and meaningful activity to promote inclusion and purpose.

Section B: A narrative analysis of young people's experiences of hope following an episode of psychosis. Ten young people consented to participate in interviews. These were transcribed and analysed using narrative methodology. The results suggested the importance of information to young people and the added value to this of meeting people with lived-experience. The absence of friendships was a salient feature throughout the narratives. The conceptualisation and experience of hope was consistent with the extant literature and this is discussed in terms of theoretical, research and clinical implications.

Section C: Additional supporting material, such as an abridged research diary and appendices.

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Section A:

Experiences of recovery for young people with psychosis:

A qualitative literature review

Accurate word count:

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Abstract

Introduction

There is a growing evidence base regarding recovery from mental health difficulties with a shift in recent years to recovery as a personal journey. The views of service-users are therefore increasingly important. The recovery experiences and preferences of young people are less clearly documented.

Method

This qualitative systematic review explored the recovery stories of young people below the age of 30 years who had experienced psychosis. Electronic databases were used to conduct a systematic literature search of published papers. The quality of the selected literature was appraised using the RATs guidance (Relevance, Appropriateness, Transparency, Soundness) for critiquing qualitative research.

Results

Twelve papers met the inclusion criteria and were included in the review. Five main headings were identified across the literature which formed the structure for the review. Making sense of the experience of psychosis was an important part of moving forwards. Being unable to make sense of psychosis represented a challenge to recovery. The recovery journey involved hope, re-evaluation and meaningful activity.

Discussion

This review considered the complexity of an experience of psychosis. By considering this age group a developmental perspective was acknowledged alongside the scarcity of research specifically focusing on the recovery experiences of young people. Further research would be beneficial to identify how underlying processes such as hope are conceptualised and maintained in this population.

Introduction

Definition of recovery

Recovery has been conceptualised as both a clinical and a personal concept with a shift in the last decade to the latter (Roberts & Boardman, 2013). In an article outlining this shift, Roberts and Boardman (2013) suggested three meanings of recovery; recovery as a natural healing process, clinical recovery understood bio-medically as an alleviation of symptoms, a discontinuation of medication and a return to life 'before illness'. The third meaning, personal recovery, focused on 'living well' in a hopeful, valued way with collaboration, choice and a sense of purpose which is a move away from a medicalised idea of recovery and symptom reduction.

Deegan (1988) writes from a perspective of lived experience and talks about 'the paradox of recovery' (p. 14). Coming to terms with a life which is different to what was expected means a process of readjustment including potential for the discovery of new strengths and experiences (Deegan, 1988). This suggested that recovery is not about returning to the same life as before mental health difficulties, but of adaptation, acceptance and new direction and emphasised personal recovery and 'living well'. Following a pilot study of service-user views on recovery, Whitwell (1999) warned against the 'mirage' of recovery as an end state as an 'over simplified medical model'. He suggested instead a process encapsulating new strength gained from the experience of mental ill-health: not a simple return to 'life as before' but a progression to new knowledge (Whitwell, 1999). Supportive of a growing emphasis on recovery as a journey, Perkins (2015) wrote about recovery as 'recovering a life' rather than as recovery from symptoms and deficits.

Anthony (1993) encapsulated this idea in an article outlining the assumptions of a recovery-oriented mental health system in the 1990s, in which he described recovery as:

> "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness." (p. 527, Anthony, 1993).

This has become an oft quoted definition of recovery and suggested the importance of understanding recovery from the unique and individual perspective of each service-user, again supporting the more recent suggestion by Roberts and Boardman (2013) of personal recovery. Leamy, Bird, Le Boutillier, Williams, and Slade (2011) suggested from their review of studies of service-user accounts, a comprehensive framework for personal recovery, including 'micro-processes' such as awakening of hope. The wider recovery literature suggests that hope is a 'prerequisite' for recovery as it contributes to attributing new meaning to the experience of mental health difficulties (Schrank, Stanghellini, & Slade, 2008). Therefore to support such 'micro-processes', practitioners need to understand both what 'living well' entails for each person, and whether micro- processes such as hope are recognisable and communicable by service-users of all ages.

The recovery movement

There has been a sustained rise in interest in factors associated with personal recovery in the context of mental health in recent years; partly due to an increasing focus on mental health and recovery within UK government policy (Department of Health, 1999, 2007, 2009, 2011; HM Government, 2006) and partly as an acknowledgement of the importance of involving service-users in decisions regarding their care and their recovery process (e.g. Department of Health, 2005; NHS England, 2013). Additionally the rise of what

has come to be termed 'the recovery movement' has been well documented (e.g. Care Services Improvement Partnership, Royal College of Psychiatrists, & Social Care institute for Excellence, 2007; National Institute for Mental Health in England, 2005).

However, despite a growing interest in personal recovery, an ongoing discrepancy between service users and professionals regarding an understanding of recovery has been highlighted within the literature. Gould's (2012) service-user led research identified the importance of hope-inspiring relationships; but suggested that when practitioners focused on service-led approaches this minimised the importance of service-user knowledge in meaningful recovery (Gould, 2012). This perspective is further supported by Le Boutillier et al. (2015) who held focus groups with multidisciplinary clinicians to gather perspectives on supporting recovery in the context of mental health services. Competing priorities were identified by staff of top down service infrastructure and the drive to save money, increase efficiency and 'tick the boxes' for clinical tasks making the recovery program more medicalised and less personal (Le Boutillier et al., 2015). A thematic analysis of focus group talk between mental health nurses and service-users also found different perspectives between the two groups on how mental health services were delivered. One of the conclusions was that the focus of recovery needs to shift to working collaboratively with service-users in order to inspire hope (Aston & Coffey, 2012). It would appear that the momentum of the recovery movement has gathered pace faster than it can be implemented with a tension between service-user and service-led priorities (Aston & Coffey, 2012; Gould, 2012; Le Boutillier et al., 2015). Perkins (2015) stated that although recovery is a personal journey, it occurs within a 'social and political context' and as such it is important to consider the relationships between service-user and service-led priorities and how these can be improved and, in particular the former, more supported.

How relevant is the recovery approach for young people?

For service-users, it has been suggested, recovery is not a 9 - 5, Monday to Friday service, but an enduring process requiring flexible working and recognition of each person as on a unique journey (Care Services Improvement Partnership et al., 2007; Deegan, 1988). With competing priorities evident within services it is important to acknowledge how mental health difficulties, and recovery, translate for young people. Deegan (1988) described recovery as 'marked' by an increasing understanding of the limitations presented by mental health difficulties. However, mental health problems are not always long-lasting; for example Harrow, Jobe and Faull (2012) conducted a longitudinal study into the long term use of anti-psychotic medication with a cohort of young people identified as experiencing early psychosis. The results indicated that at each follow up, 30 – 40% of young people were no longer taking medication and remained symptom-free (Harrow, Jobe, & Faull, 2012). However, young people who are just beginning to discover themselves as independent beings with potentially more freedom and fewer limitations, encountering mental health difficulties for the first time, such as psychosis, could encounter assumptions of long-term illness (Boyle, 2002). This may not be easy to face, indicating a need for recovery services to support a more hopeful outlook (Mackrell & Lavender, 2004; Marcia, 1980).

Psychosocial development during adolescence and young adulthood

The fifth and sixth stages of the life cycle as identified by Erikson (1968) outline the tasks relevant to adolescents in order to achieve successful transition from adolescence to young adulthood. These include the increasing significance of peer relationships, finding a role in society and individuation from parents which, if successfully achieved, lead to

intimacy and increasing commitment to others (Erikson & Erikson, 1982; Sebastian, Viding, Williams, & Blakemore, 2010). These stages may be characterised by several big transitions; from school to college or into employment, leaving the family home or making new friendships (Lenz, 2001). Failing to achieve these tasks during typical adolescent development is suggested to lead to 'identity confusion'(Erikson & Erikson, 1982; Erikson, 1968). Alongside this, mental health difficulties can lead to negative assumptions about prognosis and social exclusion or withdrawal. For example, Boyle (2000) has criticised the concept of 'schizophrenia' as entailing unsubstantiated negative assumptions about 'prognosis'. Increased sensitivity in adolescence to social exclusion could mean that the impact of mental health problems on the self may be greater than for adults. In a comparison study of adults and adolescents, Sebastian et al. (2010) examined the affective consequences of an experimental ostracism and found that typically developing female adolescents indicated greater levels of anxiety and lower mood following ostracism, to a greater extent than in adults. This indicated the importance of considering the differing tasks of each developmental stage as well as providing accurate and hopeful information when assessing the needs of young people.

Lenz (2001) offered a theoretical perspective about life stage transitions from a nursing perspective and described each transition as a period of 'disconnectedness' with the context in which the transition is occurring affecting the overall success of transition. This disconnectedness occurs naturally in the life stages of typically developing adolescents without the compounding variable of mental health. In a study of peer relationships in adolescents with experience of psychosis, Mackrell and Lavender (2004) reported that a disruption in peer relationships in early adolescence continued as unstable peer relationships through adolescence, with increasing social isolation into young adulthood.

Within a recovery approach, it is important to understand the impact of illness on an individual, but additional understanding of the interruption to transition tasks and how these may be supported to (re) commence may lead to greater empathy when working with young people and positive long-term gains, such as regaining a stable peer network.

Young people given a diagnosis of psychosis

Psychosis has been defined as a set of behaviours which include both process, such as hearing or seeing things not heard or seen by others, and content, such as holding delusional beliefs, and either experienced as one episode or reoccurring over time (American Psychiatric Association, 2013; Rethink Mental Illness, 2014). A common experience which fits with this definition is hearing voices, or believing that you are under surveillance. Statistics presented by Rethink Mental Illness (2014) suggested that approximately one in a hundred people will experience psychosis with eight out of ten of these experiencing this for the first time between the ages of fifteen and thirty years.

The impact of a psychotic episode is thought to vary depending on the level of support available, as well as duration of untreated psychosis and can impact on friendships, family life and college or job attendance (Mackrell & Lavender, 2004; Rethink Mental Illness, 2014; Yung & McGorry, 1996). This can be a frightening process as well as an accumulative effect leading to withdrawal and a reduction in a young person's ability to manage everyday tasks (Yung & McGorry, 1996). In a qualitative study, Mackrell and Lavender (2004) interviewed adolescents who had experienced psychosis-related symptoms and identified a process of increasing social withdrawal and gradual isolation from peers with the resultant limited social network having a negative effect on recovery from psychosis. An earlier age of onset (as being before 21 years) may influence more long-term negative outcomes such as disorganisation and anxiety (Malla et al., 2002). Qualitative research by Perry, Taylor, and

Shaw (2007) explicitly linked the importance of friendship to feeling hopeful and a sense of belonging. This suggests the importance of exploring experiences of psychosis in more detail to find out what is useful for adolescents in their recovery journey in order to halt social withdrawal and inspire hope for the future.

Mental health services for psychosis

External factors such as mental health services influence recovery, for example by facilitating symptom relief, offering family support and supporting access to resources and it is necessary to consider their role with young people (Jacobson & Greenley, 2001). The National Institute for Health and Care Excellence (NICE) guidance (2013) suggested that there is limited evidence for the efficacy of medication in the treatment of psychosis in young people. Alongside this, there is evidence of harm from metabolic disorder and weight gain that is particularly rapid in young people, often evident within six weeks (NICE, 2013). The guidance suggests a combination of psychological therapy and anti-psychotic medication as well as referral to a specialist mental health service such as an early intervention in psychosis service (EIP) (NICE, 2013). In recognition of untreated psychosis linking to poorer outcomes for young people, EIPs have been steadily introduced into the UK healthcare system since the early 1990s (Lester et al., 2011). EIPs often work with 'diagnostic uncertainty', focusing instead on issues relevant to young people such as education and employment (The Sainsbury Centre for Mental Health, n.d.). EIP staff work in a youth friendly way, for example using text messaging and flexible appointments to maintain engagement (Lester et al., 2009).

A longitudinal qualitative study of young people's views of EIP suggested that the family support offered by such services was a highly valued aspect of the service as well as the focus on youth-sensitive working leading to more consistent engagement (Lester et al.,

2011). Involving young people in treatment decisions allows a sense of autonomy as well as the opportunity to come to terms with the impact of mental illness and form, or reclaim, self-identity (O'Toole, Ohlsen, Taylor, Walters, & Pilowsky, 2004). Focus groups exploring service-users' experience of EIP validated the importance of working in this way to increase a person's confidence and independence as they move towards recovery (O'Toole et al., 2004).

Rationale for review

The importance of a recovery-oriented approach to mental health problems has a growing evidence base; however recovery preferences expressed by young people are less clearly documented. Although early engagement with mental health services appears to increase the likelihood of a positive outcome for young people following a first episode of psychosis (FEP), some young people may experience further episodes throughout their lives (Rethink Mental Illness, 2014). It is therefore important to understand the factors young people consider important in their unique recovery journey so that common features can be identified, alongside variations.

Quantitative research has captured the efficacy of some recovery approaches. For example, in a randomised controlled trial which explored associations between individual placement, support, working, clinical and social outcomes, Burns et al., (2009) reported better global functioning, fewer symptoms and less social disability for those who worked following mental health difficulties. However, qualitative research enables the in-depth variation in individual experience to be detailed, such as the perceptions young people hold about their mental health as well as particular aspects of their recovery journey which have helped or hindered (Byrne, Davies, & Morrison, 2010). Quantitative studies can tell us what occurred, but are less effective for understanding how or why.

Some qualitative studies have begun to look at personal recovery journeys; Leamy et al. (2011), conducted a qualitative review of personal recovery in order to provide a conceptual model. The model (known as CHIME) suggested five recovery processes along with thirteen recovery characteristics (Leamy et al., 2011). Byrn, Davies and Morrison (2010) summarised current qualitative literature of mental health service-users to provide a synthesis of service-user priorities for treatment. This study added an additional note to the scarcity of literature regarding direct service-user preferences for the outcome of treatment (Byrne et al., 2010). Both of these reviews highlighted important characteristics and preferences for personal recovery. However, both included a range of long-term mental health difficulties and a wide age range. A first episode of psychosis does not always lead to long-term mental health difficulties and research evidence suggests that early recognition of symptoms and engagement with services better supports recovery and long-term outcomes (Lester et al., 2011). Therefore, despite the growing evidence base to support personal recovery, there exists a gap in the literature for the additional evidence of how young people experience recovery following a first episode of psychosis. This may be qualitatively different from other mental health difficulties or the experiences of older, or more long-term, service-users. There may be some individual differences, or common themes, in this population which are missed.

Review

Aim

The aim of this review is to critically evaluate qualitative literature in relation to the experience of young people with FEP in order to identify how recovery is experienced in this population. Following on from this, this literature review seeks to identify whether common elements exist in the recovery experiences reported by young people.

Method

Eligibility criteria

This review sought to identify qualitative papers which explicitly described the first-hand recovery accounts of young people following an experience of first episode psychosis. The search terms used are described in Table 1.0. Papers were selected if they met the following inclusion criteria:

1. Qualitative design
2. First-hand accounts specifically focused on recovery from FEP
3. Participants were young people below the age of 30 years
4. Peer reviewed journal article

Literature search

Six electronic databases were searched in two separate searches; PsychINFO, Web of Science, ASSIA, Ovid, CINAHL and the Cochrane library (Figure 1). In addition, Google Scholar was used and the references of selected papers were hand searched.

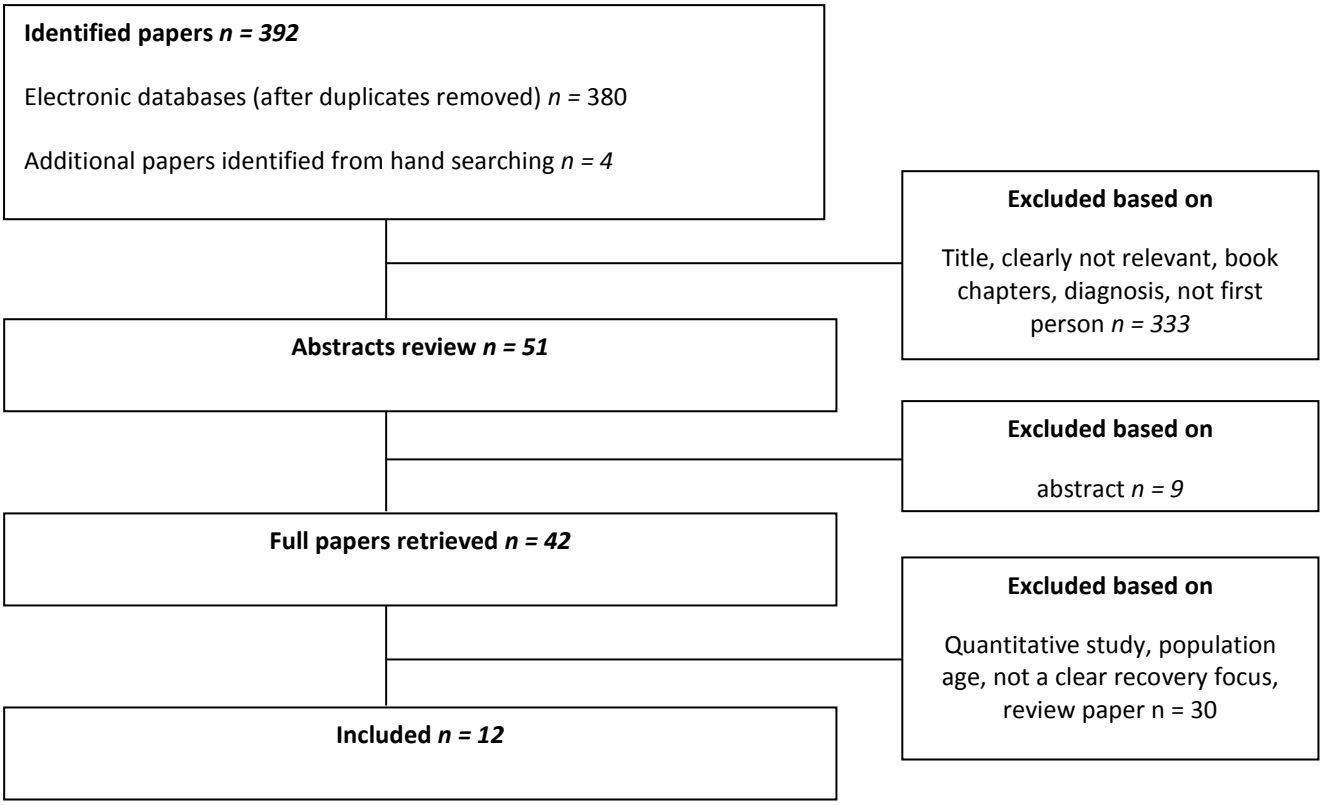
Based on the eligibility criteria, twelve papers were selected for inclusion in the review (Table 2.0).

Table 1.0 Search terms used in the review

Search Terms - all combined with AND
Psychosis OR schizophrenia OR psychotic
Recov*
Adolescents OR "young people" Or teenagers OR "young adults" OR teen*
Qualitative OR "subjective experience" OR experience OR phenomenol* OR meaning OR "grounded theory" OR thematic OR themes OR narrative OR stories

Selected papers

Figure 1. PRISMA Flowchart of search process (Moher, Liberati, Tetzlaff, Altman, & Grp, 2009).



Quality assessment

These studies were appraised using RATs guidance (Relevance, Appropriateness, Transparency, Soundness) for critiquing qualitative research (Clark, 2003). See Appendix 1 for a full list. Statements answered positively, for example, 'are characteristics of the study group and setting clear?' were added together to give an overall score out of 23 (Appendix 2).

Synthesis of the literature

This review employed a narrative synthesis of the literature in order to explore relationships within the data (Booth, Papaioannou, & Sutton, 2014).

Popay et al. (2006) proposed four steps for synthesis (not necessarily a linear process);

1. Developing a theory: generate a theory or test existing theory
2. Develop a preliminary synthesis
3. Explore relationships in the data
4. Assess robustness of the synthesis

This review sought to add to the understanding of recovery in young people and as such was based on existing theory. The preliminary synthesis involved data extraction (see Tables 2 and 3) and development of initial descriptions of the studies. This involved intensive reading of the selected studies to collate all the elements associated with recovery in each paper (Appendix C). The third stage, exploring relationships in the data, involved 'grouping' elements between papers to establish overarching strands and detail consistencies, or inconsistencies, between studies (Booth et al., 2014). This stage was the most time-consuming and involved re-reading of the literature, grouping elements and reflexive discussion with the supervision team to avoid mis- or over-interpretation of the data which

has been a criticism of a more traditional narrative review approach (Booth et al., 2014). The quality assessment of the included literature (Table 2) ensured that the review was robust and based on research evidence of medium to high quality.

Table 2 Papers included in the review *(n= 12)*

	Full reference	Country	Study aims	Method and analysis	Main findings	Quality rating
1	Braehler, C. & Schwannauer, M. (2011). Recovering an emerging self: Exploring reflective function in recovery from adolescent-onset psychosis. *Psychology and Psychotherapy,* 85, 48 - 67	UK	To address two main questions: 1. Main processes involved in adaptation to psychosis? 2. How does reflective function influence adaptation?	Semi-structured interviews (n = 8) and adult attachment interviews Grounded theory	Moderate reflective function was linked to positive adjustments whereas impaired RF was associated with difficulty in making sense of psychosis and less successful individuation	20
2	Connell, M., Schweitzer, R., & King, R. (2014). Recovery from first-episode psychosis and recovering self: A qualitative study. *Psychiatric Rehabilitation Journal,* 37, 1 - 6	Australia	An exploration of the early stage of recovery following a first episode of psychosis	Semi-structured interviews (n = 20) Interpretive phenomenological analysis	Making sense of psychosis, supportive relationships and a sense of personal identity were related to subjective improvements in recovery	19
3	Connell, M., Schweitzer, R & King, R. (2015). Recovery from first-episode psychosis: A dialogical perspective. *Bulletin of the Menninger Clinic,* 79, 70-90	Australia	To understand the process of change in self following a first episode of psychosis	Semi-structured interviews (n= 12) Interpretive phenomenological analysis	Loss of a sense of self was associated with little autonomy and loss of role. A strengthening of self was strongly associated with a sense of agency	18
4	Eisenstadt, P., Monteiro, V. B., Diniz, M. J. A., & Chaves, A. (2012). Experience of recovery from a first-episode psychosis. *Early Intervention in Psychiatry*, 6, 476 - 480.	Brazil	To understand the subjective factors involved during recovering following a FEP	Semi-structured interviews (n = 16) Interpretive phenomenological analysis	Recovery was related to a sense of agency, decrease in psychotic symptoms and renewed independence	16
5	Gearing, R. E., DeVylder, J .E., Chen, F., Pogge, D.L. & Buccolo, M. (2015). Changing perceptions of illness in the early course of psychosis: Psychological pathways to self-determination and self-management of treatment. *Psychiatry: Interpersonal and Biological Processes,* 77, 344 - 359.	USA	1. To identify subjective pathways to understanding and self-management 2. To examine common elements of 1. 3. To explore strategies and treatment recommendations that are influential to 1.	Semi - structured interviews (n=12) Content analysis	Five dominant themes were evident; symptom recognition, awareness of change, negative appraisal, positive appraisal and self-management of treatment.	19
6	Grealish, A., Tai, S., Hunter, A. and Morrison, A.P. (2013) Qualitative exploration of empowerment from the	UK	To examine empowerment in relation to young people with psychosis	Semi-structured interviews (n= 9)	Young people attributed being listened to, being understood and behaving autonomously as contributing to	22

	perspective of young people with psychosis. *Clinical Psychology and Psychotherapy,* 20, 136 - 148.			Interpretive phenomenological analysis	personal empowerment which in turn contributed to recovery.	
7	Henderson, A.R. & Cock, A. (2015). The responses of young people to their experiences of first-episode psychosis: Harnessing resilience. *Community Mental Health, 51, 322 - 328.*	Australia	To describe and explain the responses of young people to FEP	Semi-structured interviews (n=10) Constant comparison method	Psychosis was experienced as an interruption resulting in perceived loss of control. Recovery was enabled through acknowledgment of FEP, help-seeking, regaining control and harnessing resilience	19
8	Lal, S., Ungar, M., Leggo, C., Malla, A., Frankish, J. & Suto, M. (2013) Well-being and engagement in valued activities: Experiences of young people with psychosis. *Journal of Occupation, Participation and Health,* 33, 190 - 197.	Canada	To understand how engagement in valued activities contributes to well-being following an experience of psychosis	Semi-structured interviews (n=17) Grounded theory and narrative enquiry	Well-being was enhanced through activity by enabling making sense of psychosis, expressing thoughts and feelings, cultivating skills, social inclusion and feeling valued.	21
9	Lam, M. M. L., Pearson, V., Ng, R. . K., Chiu, C. P. Y., Law, C. W., & Chen, E. Y. H. (2010). What does recovery from psychosis mean? Perceptions of young first-episode patients. *International Journal of Social Psychiatry,* 57, 580 - 587.	Hong Kong	To explore recovery experiences following FEP and the meanings people attach to this experience	Focus Group (n = 6) Content analysis	Participants' view of recovery was broader than that of psychiatrists. Participants were concerned with medication and stigma, but were generally optimistic about the future	14
10	Romano, D. M., McCay, E., Goering, P., Boydell, K., & Zipursky, R. (2010). Reshaping an enduring sense of self: The process of recovery from a first-episode of schizophrenia. *Early Intervention in Psychiatry,* 4, 243 - 250.	Canada	An exploration of ways in which people with FEP describe their process of recovery	Semi-structured interviews (n = 10) Grounded theory	A theory of the process of recovery which incorporates identity prior to FEP, an interruption due to FEP, engaging with services and moving towards the future by re-establishing identity	21
11	Tan, R., Gould, R. V., Combes, H. and Lehmann. S. (2012). Distress, trauma and recovery: Adjustment to first-episode psychosis. *Psychology and Psychotherapy: Theory, Research and Practice,* 87, 80 - 95.	UK	To understand the experiences people with FEP are adjusting to and identify perceived barriers to recovery	Semi-structured interviews (n = 8) Grounded theory	A theoretical model was developed with a core category of distress as people adjust not only to FEP but also to stigma, challenged identity and past experiences	20
12	Windell, D. & Norman, R. M. G. (2012). A qualitative analysis of influences on recovery following first-episode of psychosis. *International Journal of Social Psychiatry,59, 493 - 500.*	Canada	To examine factors that contribute to or hinder recovery of people with FEP	Semi-structured interview (n = 30) Thematic analysis	Factors contributing to recovery were identified as social support, medication, valued occupation and lifestyle change. Hindrances were stigma, substance misuse and side effects.	17

Summary of the literature

The first point to note, in line with Byrne et al. (2010), is the scarcity of literature specifically on young people's views of their recovery experience from FEP. Of the twelve studies identified, eight specifically used the term recovery when discussing young people's accounts of psychosis (Braehler & Schwannauer, 2012; Connell et al., 2014; Connell, Schweitzer, & King, 2015; Eisenstadt, Monteiro, Diniz, & Chaves, 2012; Lam et al., 2011; Romano, McCay, Goering, Boydell, & Zipursky, 2010; Tan, Gould, Combes, & Lehmann, 2014). Gearing, DeVylder, Chen, Pogge and Buccolo (2014) discussed changing perceptions of psychosis as young people move towards self-management. Grealish, Tai, Hunter and Morrison (2013) considered how young people developed a sense of empowerment as they moved towards recovery and in a similar manner; Henderson and Cock (2015) considered the development of resilience as young people established a new direction following their experiences of psychosis. Finally, Lal et al. (2013) suggested the value of engagement in activity as a contributory factor in the recovery and well-being of young people with psychosis.

All twelve articles presented first-person accounts which considered the impact of psychosis on young people alongside factors which helped them come to terms with this and move beyond a first episode of psychosis. Table 3 details participant demographics.

Table 3: Participant demographics

Title of paper	Number of participants	Mean age	Gender	Recruitment
Braehler, C. & Schwannauer, M. (2011). Recovering an emerging self: Exploring reflective function in recovery from adolescent-onset psychosis.	n = 8	18.6	Female (n = 4) Male (n = 4)	CAMHS (Child and adolescent mental health) early-onset psychosis support service
Connell, M., Schweitzer, R., & King, R. (2014). Recovery from first-episode psychosis and recovering self: A qualitative study.	n = 26	21	Female (n = 6) Male n =20)	Three Early Psychoses services
Connell, M., Schweitzer, R & King, R. (2015). Recovery from first-episode psychosis: A dialogical perspective.	n = 12	21	Female (n = 3) Male (n = 9)	Three Early Psychoses services
Eisenstadt, P., Monteiro, V. B., Diniz, M. J. A., & Chaves, A. (2012). Experience of recovery from a first-episode psychosis.	n = 16	23 (1 participant 37, 15 participants <30)	Female (n = 4) Male (n = 12)	A First-psychotic episode service
Gearing, R. E., DeVylder, J .E., Chen, F., Pogge, D.L. & Buccolo, M. (2015). Changing perceptions of illness in the early course of psychosis: Psychological pathways to self-determination and self-management of treatment.	n = 12	19.3	Female (n = 6) Male (n = 6)	An adolescent inpatient service of a private psychiatric hospital
Grealish, A., Tai, S., Hunter, A. and Morrison, A.P. (2013) Qualitative exploration of empowerment from the perspective of young people with psychosis.	n = 9	16.4	Female (n = 4) Male (n = 5)	CAMHs
Henderson, A.R. & Cock, A. (2015). The responses of young people to their experiences of first-episode psychosis: Harnessing resilience.	n = 10	Range - 19 - 28	Female (n = 3) Male (n = 7)	Advertisement in a newspaper and flyers

Lal, S., Ungar, M., Leggo, C., Malla, A., Frankish, J. & Suto, M. (2013) Well-being and engagement in valued activities: Experiences of young people with psychosis.	n = 17	22	71% male	Specialist early intervention program for psychoses and a youth mental health program
Lam, M. M. L., Pearson, V., Ng, R. . K., Chiu, C. P. Y., Law, C. W., & Chen, E. Y. H. (2010). What does recovery from psychosis mean? Perceptions of young first-episode patients.	n = 6	25	Female (n = 3) Male (n = 3)	An outpatient clinic of the early assessment service for young people with psychosis
Romano, D. M., McCay, E., Goering, P., Boydell, K., & Zipursky, R. (2010). Reshaping an enduring sense of self: The process of recovery from a first-episode of schizophrenia	n = 10	23	Female (n = 5) Male (n = 5)	Two clinics with a first-episode in psychosis program
Tan, R., Gould, R. V., Combes, H. and Lehmann. S. (2012). Distress, trauma and recovery: Adjustment to first-episode psychosis.	n = 8	24.25	Female (n = 2) Male (n = 6)	An early intervention service
Windell, D. & Norman, R. M. G. (2012). A qualitative analysis of influences on recovery following first-episode of psychosis.	n = 30	25.87	Female (n = 7) Male (n = 23)	A preventions and early intervention program for psychosis

The main areas covered in each paper constitute five main headings which will form the structure for the following review (Appendix 3). The five headings are 1. Life before psychosis, 2. Making sense of psychosis, 3. Moving forwards: recovery, 4. Re-evaluation and 5. Meaningful activity. To ensure maximum clarity, these headings have been presented in a way which could imply a chronological order to the process of recovery. However recovery is not conceptualised as a linear process and people may experience all, or some, of these processes at different times, with differing impact (Leamy et al., 2011).

Life before psychosis

Connell, Schweitzer and King (2015) interviewed twelve young people about their experiences of psychosis and identified two superordinate themes; loss of self and strengthening of self. Connell, Schweitzer and King (2015) noted that it is as important to understand the experiences of young people who experience multiple difficulties following FEP as it is to understand the experiences of those who do well. Within the accounts presented, experiences prior to psychosis were two-fold. In 'loss of self' the focus was directed to the past when the young person considered themselves to have greater respect from others and greater independence, *"[I'm] having to rely on other people more"* whereas within the theme of 'strengthening of self', the focus was more present with the sense of an improved life, "*I'm a totally different person, I used to always be this negative, depressed person...I'm seeing the beauty of the world..." (*Connell et al., 2015, *p.83*). What appeared less explicit in this polarisation of self, are the mechanisms by which young people were able to move from a position of little hope, to one in which the future had possibilities.

An awareness of life before psychosis, and positive change, was evident when considering the effects of substance misuse and trauma; *"I realised I have to straighten out my life and get off drugs", "my ex-boyfriend, he was very violent"* (Tan et al., 2014; Windell & Norman, 2012). Tan et al., (2014), identified a main category of recovery as 'the effects of past experience' with distressing and stressful life events culminating in psychosis-related symptoms. For these young people, the experience of psychosis appeared as a catalyst for change opening up possibilities. This was also consistent with research by Romano et al., (2010) in which participants identified their lives prior to psychosis as stressful. The sense of recovery

was in moving forwards in a new direction and learning from past experiences, rather than reclaiming what was (Romano et al., 2010; Tan et al., 2014).

Reclamation was implicitly positive when young people referred to previous strengths being acknowledged or used, e.g. 'existing coping skills' (Grealish, Tai, Hunter, & Morrison, 2013). This appeared to serve the purpose of reconnecting the young person with a sense of capability despite the experience of psychosis (Grealish et al., 2013). A study in Hong Kong which utilised a focus group to discuss recovery from psychosis incorporated both a 'returning to life as before' perspective as well as an 'improved self' (Lam et al., 2011). This was a small study of only six participants, recruited over a very short time period, but the reported experiences add to the understanding of psychosis as a turning point towards a more positive future. Four of the six participants spoke of psychosis as 'life enhancing'; it is an interesting point that these four participants had all received tertiary education, compared to the remaining two who had secondary education and indicates a somewhat biased sample. Additionally, the focus group was led by a psychiatrist and it is unclear from the authors whether this was a treating clinician for these participants, which could introduce unhelpful power dynamics.

Returning to life as before was less to do with wanting an identical life, but rather returning to previous cognitive functioning which participants felt had been disrupted by psychosis, for example being able to concentrate and think clearly, '*quicker in response'* (Lam et al., 2011). This does not seem to correspond with Deegan's (1988) personal account of recovery as an increasing understanding of the limitations of mental ill-health but is concordant with research supportive of recovery from FEP and suggested that at this stage, young people may be more hopeful of their experiences being a single episode (Harrow et al., 2012; MacBeth, 2014). Young people also described being unaware that what they were experiencing

was not 'normal' and found it hard to recognise a change from 'life before' to an experience of psychosis (Henderson & Cock, 2014) and therefore needed other people to make the suggestion of seeking help (Gearing, DeVylder, Chen, Pogge, & Buccolo, 2014; Henderson & Cock, 2014).

Loss and uncertainty

For many, loss and uncertainty was the experience of psychosis and rather than a main theme, these were implicit in many of the comments as young people moved from life before psychosis towards making sense of psychosis. This period seemed characterised for some young people by loss of a sense of self and uncertainty about the future and was identified by Henderson and Cock (2015) as the 'basic psychological problem' of psychosis. For some young people this period led to thoughts of suicide and a sense of hopelessness (Gearing et al., 2014; Romano et al., 2010). Gearing et al. (2014) interviewed 12 young people between six months and five years following a period of hospitalisation. The authors described their sample in detail and noted that the participants were highly-adherent with treatment which limits generalisability of findings to within a population who are already self-managing their recovery to some degree. The authors described the data analysis in detail and showed evidence of reflexivity, which is a strength of this study and suggests the findings within this cohort are robust. The sense of loss experienced by these young people related to a belief of insanity, loss of hope and general uncertainty about what was happening.

Gearing et al. (2014) also interviewed parents and carers as part of this research and it is an interesting facet of these interviews that parents shared a sense of loss as well as role confusion as they returned to more actively caring for their adolescents than was age-appropriate: *'how much supervision do you give, when you're looking at their age versus the*

psychiatric condition?' (Gearing et al., 2014). The sense of loss evident within this research was possibly linked to the experience of hospitalisation, rather than psychosis per se, although some of the young people also described hospitalisation as a time of stabilisation, a sense of order following a period of uncertainty (Gearing et al., 2014).

Connell, Schweitzer and King (2014) provided accounts of two young people who associated the hospital experience as one in which independence was necessary instigating a *found* sense of self as strong and capable following earlier feelings of uncertainty and loss. This study focused on the first month following FEP and as such provided insight into a sense of self in these very early recovery periods. In contrast, the paper by Tan et al. (2012) focused on a longer time period and their participants reported that hospitalisation and loss of privacy contributed significantly to the distress and trauma of FEP; *'the experience of being in hospital was more traumatic than the episode itself'* (Tan et al., 2014).

Not all young people with FEP experience hospitalisation, but the experiences of these young people also seem reflective of the experiences of young people who are not hospitalised. Braehler and Schwannauer (2012) interviewed eight young people within a child and adolescent mental health service (CAMHs) in order to construct a hypothesis about the process of adaption from FEP. Within this research, feelings of loss and uncertainty were characterised by confusion, losses of a sense of self, hope, valued activities and motivation. Impaired reflective function, described by Braehler and Schwannauer (2012) as 'the ability to infer one's own and others' mental state', threatened the developmental process of individuation as young people experienced uncertainty of living independently; *'I'm not looking forward to it [growing up] that much, I'd rather stay at home all the time...I did want to move out...last year, before I got ill'* (Braehler & Schwannauer, 2012, p.60). However, as the authors

acknowledge, they are unable to ascribe causality to their findings and it is possible that earlier life experiences, ongoing societal stressors, or continuing medication, play a contributory role within these developmental processes and ability to reflect.

Linking to life before psychosis, several papers identified loss of friendships as young people described uncertainty as to how to explain their experience, fear of stigma and social withdrawal in order to make sense of psychosis (Braehler & Schwannauer, 2012; Connell et al., 2014, 2015; Eisenstadt et al., 2012; Romano et al., 2010; Tan et al., 2014). This time was also marked by becoming increasingly dependent on family for support and gradual social withdrawal (Romano et al., 2010).

Making sense of psychosis

Making sense of the experience of psychosis was salient throughout the twelve papers. Being unable to make sense of their experiences appeared to prolong a period of uncertainty for young people, and heighten the sense of loss; '*I'm never going to get better, I don't even understand how I got like this,'* (Tan et al., 2014). Braehler and Schwannauer (2012) suggested that difficulties understanding their experiences, linked to low reflective function (RF), related to difficulties with peers and family relationships. Individuals with moderate to high RF assimilated the psychotic episode as part of their self-identity which led to better adaptation from FEP (Braehler & Schwannauer, 2012). However, only three young people in this sample indicated moderate to high RF and as such it is difficult to draw firm conclusions about the key role of RF in understanding and adaptation from FEP (Braehler & Schwannauer, 2012)

Sense-making was expressed by young people as a process of engaging in services, being able to talk to others, assimilating the reactions of others and coping with medication

and hospitalisation and was one of the first steps towards recovery (Eisenstadt et al., 2012; Henderson & Cock, 2014; Tan et al., 2014; Windell & Norman, 2012). Grealish, Tai, Hunter and Morrison (2013) interviewed nine young people between 14 - 18 years about their experience of psychosis and understanding of empowerment. Part of this conceptualisation was in making sense of psychosis; a process which happened through gaining some control over treatment choice and having access to information specifically written for young people (Grealish et al., 2013). One young person explained '*They would keep explaining things until I understood them and they didn't use big words'* (Grealish et al., 2013, p. 141) thus facilitating feelings of empowerment and in turn recovery. Young people experienced poor communication as a loss of voice and autonomy which delayed sense-making. This is a robust study meeting all but one of the quality guidelines (possible selection bias). Parents attended interviews alongside their children which possibly helped to minimise difficulty recalling experiences during the confusion of psychosis although may also have led to some reticence on the part of young people to fully express some of their stories.

Sharing the experience of psychosis with others was a common element between the twelve studies and this helped the young people make sense of their mental health. Eisenstadt et al. (2012) conducted a pilot study to understand the recovery experience in an early intervention programme in Brazil. Although this study only met 16 of the 23 quality criteria, for example these authors did not include any direct quotes, they provided some insight into the benefits of psychoeducation in less developed communities. The authors summarised that participants found the experience beneficial due to the shared experience and common language used between the young people. This is concordant with the research presented above citing the importance of good communication (Eisenstadt et al., 2012; Grealish et al.,

2013). Sharing the experience with others in a similar situation seemed to remove the sense of isolation and introduced some understanding of their current situation in turn instigating the possibility of a more hopeful future (Eisenstadt et al., 2012).

Moving forwards: recovery

Hope

Hope was mentioned in the recovery stories of young people as they considered moving forwards; Connell, Schweitzer and King (2015) refer to 'an attitude of hope' and Eisenstadt et al. (2012) suggested hope as contributing to recovery by enabling young people to become more active and involved. Windell and Norman (2012) suggested that 'messages of hope' contributed to a belief in recovery and had an additional role in moderating the effect of stigma. Feeling hopeful appeared to contribute in many ways to young people moving forwards and having a renewed sense of control over their own lives which in turn led to the development or recognition of personal coping strategies and engagement in 'normal' activity (Grealish et al., 2013; Tan et al., 2014). Connell, Schweitzer and King (2014) suggested that young people who had made some sense of their experience expressed more hope for the future as they incorporated psychosis as an aspect of personal growth. Therefore, making sense of psychosis appeared to instigate hope and precede the process of moving forwards, towards recovery. This is consistent with a qualitative study by Perry et al., (2007) in which a search for meaning was fundamental to maintaining hope. Conversely, in accounts reported by Tan et al. (2014), being unable to understand their experiences reportedly led to young people experiencing hopelessness and presented a challenge to moving forwards.

Recognition was also evident across this literature of the importance of service providers giving hopeful information and expectations of recovery; '*my case manager would reiterate...things get better*' (Henderson & Cock, 2014). Romano et al. (2010) interviewed ten young people twice using a grounded theory approach, and in addition, interviewed ten individuals who the young people named as influential to their sense of recovery. Moving forwards for these participants was described as increasing optimism through sense-making and 'messages of hope' from clinicians. This led to the development of new skills therefore positioning hope as part of a cognitive construct involving future planning (Romano et al., 2010).

Hope was not explicitly mentioned within the accounts presented by Henderson and Cock (2014), however friendships with those with shared experiences were important, with understanding seeming to facilitate hope for recovery, *'this...lets me talk to other people about my experience....I know that somebody understands and I understand them', 'he [fellow service-user] did slowly recover and now he's fully recovered so I know it can happen'* (p. 495, Henderson & Cock, 2014). The final stage of harnessing resilience suggested by Henderson and Cock (2014), that of 'being resiled', involved young people pursing their chosen goals, which is consistent with research suggesting elements of hope involves goals, a sense of agency and pathways (e.g. Snyder, 2002). Although many of the papers reviewed implicitly refer to hopeful activity, for example Romano et al., (2010) suggested that establishing new short-term goals enabled a 'reshaping of an enduring sense of self'; few mentioned how agentic participants considered themselves or identified specific ways pathways.

Support

Several papers refer to the role of parents as one of support, either in recognising early mental health changes prompting the seeking of treatment or providing encouragement (e.g. Gearing et al., 2014), in helping the young person understand and have control in the treatment process (e.g. Grealish et al., 2013) or being generally supportive as recovery progressed, *'[mother] is the one who's always talking to me...she's guiding me along I guess'* (e.g. Henderson & Cock, 2014). Tan et al. (2014) described the shock for young people of being in psychiatric system considered as an adult, but feeling in a position of dependence and needing a parent to buffer the loss of self-identity: one 19 year old described how *'I wanted my mum to stay with me on the first night really'.* This raises interesting clinical considerations of the role of parents for young people post-18. Participants in the research by Romano et al. (2010) reported a period of renegotiation of their relationship with their parents, as they reconnected with their sense of self. Young people also reconnected with seeking independence. Several papers suggested the importance of maintaining a developmental perspective for this client group, not only to support the young people, but also in recognition of the changing role of parents and carers (e.g. Romano et al., 2010; Tan et al., 2014).

Service providers delivered information about treatment and support, such as new coping techniques, which in turn empowered young people to take 'back' some control and begin to employ a range of strategies (e.g. Grealish et al., 2013). A sense of control seemed to increase confidence, which in turn reduced confusion and anxiety and the ability to develop other coping strategies (Grealish et al., 2013). Clinicians were also viewed as supportive if they encouraged young people to make life-style changes and provided support to the wider family network (Grealish et al., 2013; Henderson & Cock, 2014; Romano et al., 2010).This is supported

by early intervention service statistics indicating that young people who received support, for example about managing physical health and maintaining employment or education, after the first episode of psychosis are more likely to make a full recovery (Rethink Mental Illness, 2014).

A further facet of support was the role of lived-experience in which young people felt a sense of empowerment when sharing their experience by offering or receiving support to those sharing similar difficulties (Eisenstadt et al., 2012). This was also experienced by some young people as having a role model, which they described as inspiring hope and providing a sense of belonging within a social context (Windell & Norman, 2012).

Re-evaluation

Within moving forwards participants referred to making 'better choices' following their experience of psychosis and again the sense of psychosis as a catalyst for a new way of managing life (Romano et al., 2010). Lam et al. (2010) supported these conclusions as participants in their focus group in Hong Kong considered re-evaluating priorities for living to be more relevant to recovery than a symptom and illness narrative. Although a small study with some methodological limitations, it gives a sense of cross-cultural similarities in the priorities of young people moving forwards towards a future with possibilities (Lam et al., 2011).

In the theme of 'strengthening of self' young people re-evaluated their life choices and values by recognising where changes had to be made which led to positive action in moving forwards; *"I'm miserable, so things have to change"* (p.81, Connell et al., 2015).

Meaningful activity

Engaging in meaningful activity, defined by Lal et al. (2013) as a diverse range involving both communal activities, going to church and solitary activities, such as individual art-making,

helped young people reconnect with their sense of identity and appeared to initiate hope for the future. Meaningful activity was also used by some young people as a means of processing their experiences and in this way overlaps with making sense of psychosis. Lal et al. (2013) interviewed 17 young people between the ages of 18 and 24 years in order to examine the role of valued activities in relation to well-being following an experience of psychosis. Participants perceived creative activities such as writing and art as meaningful and for creating a space to process their experiences, in turn leading to less uncertainty; 'writing really helps...I'll read from the box from things like two years ago...and then I relate it to [life now]', 'I don't have to feel that way anymore because it's recorded for me' (Lal et al., 2013, p. 193). Being able to express some of the experiences associated with this time appeared to ameliorate feelings of loss. This study represented a diverse range of socioeconomic and ethnic backgrounds as well as a range of educational attainment and living situations and again gives a sense of similarities amongst young people experiencing FEP (Lal et al., 2013). This also fits with the study by Grealish, et al. (2013) which suggested that young people felt disempowered, and recovery was delayed, with the absence of meaningful activity. What is less explicit within this literature is how the concept of meaningful activity may vary within this population or which aspects of meaningful activity specifically aid recovery.

Windell and Norman (2012) also identified meaningful activity as critical to recovery and referred to opportunities for 'normative' activity as part of the development of a framework for understanding the experience of psychosis. These researchers interviewed thirty young people, a large sample size for qualitative research, however all were also enrolled in a longer longitudinal study so may have been representative of a more engaged cohort.

Meaningful activity was also linked to enhanced self-esteem and providing a sense of worth (Windell & Norman, 2012). Connell et al. (2015) associated the 'resumption of normal activities' with a move towards functional recovery and Romano et al., (2010) identified that pursuing their interests led to participants' sense of self enduring and therefore increased resilience. Henderson and Cock (2014) interviewed thirty young people about factors which were influential to recovery, and within this, recovery processes were referred to as gaining resilience. This involved a process of gaining control [over their own lives]. Within this paper, there is also acknowledgment of the future possibility of mental ill-health; *'I do keep in mind I have a mental health concern, so I don't want to over burden myself'* and the need to pace activity to maintain well-being (Henderson & Cock, 2014). This was evident also in participants suggesting that they followed their goals and activities 'in spite' of symptoms of mental ill-health, *'I haven't recovered, I'm resilient'* (Henderson & Cock, 2014).

Challenges

Progression to recovery was not a linear process through each of these themes, rather a process of negotiation and assimilation of experience and challenge into a new, reconnected or 're-shaped' identity. A perceived lack of support or understanding exacerbated feelings of isolation and social withdrawal; *"I didn't really get the support I needed from them [clinicians] so it made it [experience] a bit harder"* (p.89, Tan et al., 2014).

A common challenge throughout the literature was the impact of stigma on the young people interviewed. Perceived stigma led to withdrawal, distress, social isolation and avoidance of help-seeking (Grealish et al., 2013; Tan et al., 2014; Windell & Norman, 2012). Paradoxically, close friendships alleviated the impact of perceived stigma (Connell et al., 2014) but perceived stigma was a barrier for some young people to confiding in friends and attaining social support

(Braehler & Schwannauer, 2012; Lam et al., 2011). This is concordant with Leamy et al. (2011) who categorised overcoming stigma as part of a recovery process. However, they also found this to have a greater effect when combined with the stigma associated with race, culture and ethnicity. Being isolated from peers may have a greater impact for this age group as these friendships are a key ingredient in the process of individuation from parents and development of self-identity (Mackrell & Lavender, 2004).

Medication was also a common theme throughout this review. The accounts presented vacillated between challenge and aid. Where medication was perceived as a challenge, this related to side-effects and perceived loss of control which were detrimental to a young person's sense of self, and precluded social inclusion in some accounts (Grealish et al., 2013; Windell & Norman, 2012). However, medication also contributed to a sense of recovery and optimism for the future; '*Things started to change for me...I no longer heard voices...it was better...'*(Romano et al., 2010).

Being involved in treatment choices and managing medication gave some young people a sense of autonomy and improved coping skills, however, as Gearing et al. (2014) acknowledge the nature of their sample may have represented a more adherent population than other young people experiencing psychosis. Medication was also seen as a measure of recovery, with some young people expressing that they did not feel recovered whilst on medication (e.g. Lam et al., 2011) or hoped for a medication-free future (e.g. Romano et al., 2010). Ambiguity regarding the helpfulness of medication is echoed in other service-user research; for example Gould (2012) stated that 59% of respondents described medication as supporting their recovery 'a lot' but that the majority of focus group members made negative comments about the effect of medication within their lives.

Discussion

The aim of this review was to evaluate the literature to increase understanding of how young people with FEP experience recovery and identify whether common factors existed in these recovery experiences. The twelve papers included in this review highlighted the complexity of psychosis and associated recovery journey. Apparent across this literature was the acknowledgement of a life before psychosis, a period of loss and uncertainty followed by the need to make some sense of the experience in order to be able to move forwards with a recovery journey. Young people who were able to make sense of their experience developed a continuing narrative of a self with a future and a sense of hope. Sense-making was aided both by supportive parents and service providers.

Hope, support, meaningful activity and re-evaluation were all important topics evident across the literature when considering moving forwards. For the young people within this research, making some sense of their experiences and integrating this into a sense of self appeared to instigate hope for the future. This is concordant with previous research by Perry et al. (2007) which highlighted links between individual meaning and sustainment of hope. Schrank et al. (2008) identified four components of hope; affective, cognitive, behavioural and environmental and although explicit within the wider recovery literature, these components of hope were less explicit within these twelve papers. This makes it less clear how hope can be inspired and supported by clinicians or which of these components are most relevant for young people.

Engaging in meaningful activities also appeared prevalent in the narrative of a more hopeful future; however, it was less explicit in the literature what contributed to this sense of hope and which activities were construed as meaningful. Additionally it was unclear which

came first, hope that life can be better, or engagement in activity. For many young people, the experience of psychosis presented the opportunity for a re-evaluation of life choices and a 're-shaping' of self-identity. By gaining understanding, assimilating psychosis as part of their identity, engaging in services or talking to others, young people (re) gained some control and independence over their lives which led to moving forwards.

Challenges to recovery were also evident. Young people unable to make sense of their experience appeared 'stuck' in an illness narrative of loss which for some young people was exacerbated by medication side effects. Individuals who struggled with their sense of self reported a loss of agency which resulted in social withdrawal. Perceived stigma led to social withdrawal and loss of friendships which suggests that some key developmental tasks, such as individuation and conflict resolution, might be interrupted as these are generally achieved through integration with a peer group (Erikson, 1968).

Although presented under separate headings, many of these elements of recovery overlap and intertwine: For example the experience of loss and uncertainty was evident throughout as was the experience, or lack, of hope. This emphasises the importance of qualitative research in supporting the understanding of the 'how' and 'why' as well as 'what' when considering which factors facilitate a recovery process.

The elements of recovery prevalent within this literature review also highlight the importance of collaborative working and the need for professionals to listen to young people, as emphasised within the recent BPS guidelines (2014) for understanding psychosis and schizophrenia. Listening to young people explain their wider context, beyond psychosis-related symptoms, can enable construction of a coherent narrative for both the young person and those in a supportive capacity.

Strengths and limitations

Focusing on young people following a first-episode of psychosis adds to the understanding of this developmental stage and offers a different perspective to that of recovery literature which focuses on the impact of longer term mental ill-health. There were a range of time periods within these twelve papers from one-month to five years post FEP which therefore incorporated a range of experiences. Although there were a greater number of male participants, young females were also fairly well represented within this body of literature. Participants were selected from a limited number of mental health services which may have excluded harder to reach young people who were approaching their recovery, or managing their experience, in alternative ways.

Clinical implications

These accounts accentuated the importance of clear, developmentally appropriate, support and the availability of clinicians to spend time building a rapport with young people to understand their individual experiences. Helping young people understand their experience seems to initiate a process of moving forwards and recovery. These experiences of recovery from young people share commonalities with the recovery model proposed by Leamy et al. (2011) but also extend this review by considering the unique developmental considerations of this younger population.

Research implications

Moving towards recovery appeared differentially affected by sense of self, loss and hope which is supported in the wider research literature (Anthony, 1993; Leamy et al., 2011). Further research on the conceptualisation of hope, what it contributes to a young person's

recovery process, how it manifests and how it can be engendered and maintained would provide a clearer picture of what initiates recovery for this population. Further understanding of how young people conceptualise their experience, including additional understanding of what young people value and what constitutes meaningful activity, would be beneficial in understanding how best to support young people facing mental health difficulties.

Conclusion

This review considered young people's experiences of recovery from FEP and identified factors which are meaningful in the recovery journey for this population. There is a scarcity of research specifically focusing on the recovery experiences of young people and further research is needed to identify how underlying processes such as hope are conceptualised and maintained in this population.

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Section B:

A narrative exploration of hope and social inclusion with young people following experience of psychosis

For submission to the Journal of Mental Health[1]

Accurate word count

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Abstract

Background: Recovery focus has shifted in recent years towards understanding the impact of mental health difficulties on the wider individual context. This includes focus on social inclusion, engendering hope and peer support. For adolescents, psychosis and mental health treatment may interrupt typical developmental tasks such as individuation and successful stage progression and it is unclear how hope may be initiated or maintained in this population as part of the recovery process.

Aims: The aim of this research was to expand understanding of how young people with psychosis experience hope. This included how hope was experienced in specific domains and to which factors young people attributed changes in their hopefulness.

Method: The study employed a qualitative non-experimental design, using a semi-structured interview schedule developed in accordance with narrative methodology. Ten young people between 16 - 26 years old were interviewed.

Results: The experience of hope as an overarching strand throughout the narratives had three common elements; a sense of belonging, the importance of information and the significance of planning and occupation in relation to hope. Work was often a goal within domain-specific hope, and friendships seemed to be less apparent.

Conclusions: For some young people, psychosis can act as a turning point towards hopeful thinking. Information can both promote and hinder hope and the importance of meeting others with lived experience in engendering hopeful thinking and greater social inclusion should be considered when working with young people.

Declarations of interest: None

Keywords: *psychosis, hope, recovery, narrative, social inclusion*

Introduction

Psychosis

Psychosis is a term used to describe unusual experiences which may include hearing voices (sometimes termed hallucinations), holding beliefs that are not commonly held by others (delusions) and is often characterised by a sense of confusion (British Psychological Society, 2014; Rethink Mental Illness, 2014). A first episode of psychosis (FEP) usually occurs between the ages of 15 years and 30 years (Rethink Mental Illness, 2014). An experience of psychosis or associated stigma and discrimination can impact on social inclusion, sense of identity, self-esteem and hope (Boydell, Stasiulis, Volpe, & Gladstone, 2010).

Early Intervention in Psychosis

Young people who have experienced psychotic symptoms are commonly referred to an early intervention in psychosis service (EIP) whose role is to implement 'phase-specific' treatment to either prevent progression or enhance recovery (Marshall, Rathbone, & Rathbone, 2011). EIPs therefore work with diagnostic uncertainty; the term 'first-episode psychosis' indicating a motivation to reduce further episodes, rather than a diagnosis as such.

Psychosocial development during adolescence into adulthood

In order to understand the full impact of a first-episode of psychosis on young people, it is helpful to appreciate the relevant developmental tasks for this stage. Erikson (1968) identified adolescence through to adulthood as a period of seeking identity, intimacy and generativity with the antithesis of these as confusion, isolation and stagnation. The issues experienced within each stage, whether resolved or not, then form the basis for the following stage, or regression to an earlier state (Erikson & Erikson, 1982). Adolescence can be marked by friendships, leaving school, higher education, first jobs and first loves all contributing to

'successful' stage progression. Arnett (2000) proposed a new stage for 18 - 25 year olds of 'emerging adulthood', characterised as a time of possibility and exploration and being neither adolescence nor adulthood, more a time of 'trying out'. Typically adolescence, or emerging adulthood, involves a move from family to peer groups as a testing ground for opinion, ideas, conflict resolution and exploration (Kroger, 2007; McAdams & Olson, 2010). Therefore a first episode of psychosis, and how it is responded to, may cause an interruption to typical developmental progression, such as individuation, within this stage.

Recovery

Successful progression through developmental tasks occurs in a social context and therefore, for young people recovering from mental health difficulties, social inclusion is an important element of recovery. Based on a review of qualitative studies, Leamy, Bird, Le Boutillier, Williams, and Slade (2011) suggested a comprehensive framework for recovery encompassing the recovery processes of connectedness, hope, identity, meaning and empowerment, which can guide clinical interventions. The argument for an encompassing meaning of recovery, a move away from symptom focus, is widely supported by people with lived experience (e.g. Gould, 2012; May, 2009), professionals (Shepherd, Boardman, & Slade, 2008) and government (Department of Health, 2011).

Although the recovery journey of young people is less clearly documented in the literature there is some concordance with the main recovery literature: recovery involves hope, meaningful activity and a re-evaluation of life choices (Connell et al., 2015; Grealish et al., 2013; Lam et al., 2011; Windell & Norman, 2012). However, this literature has also highlighted gaps in the recovery evidence base for young people, specifically how underlying processes such as hope are conceptualised and maintained in this population.

Hope

Theories of hope are described as both multi-dimensional and cognitively driven. Following research with survivors of cancer, Dufault and Martocchio (1985) described hope as:

> 'a multidimensional dynamic life force characterised by a confident yet uncertain expectation of achieving a future goal...which to the hoping person is realistically possible and personally significant' (p.380, Dufault & Martocchio, 1985).

This definition is also concordant with the idea of personal recovery in mental health as being both an individual and personal process. Snyder, Feldman, Shorey, and Rand (2002) suggested that hope comprises a hierarchical system of general dispositional hope (trait hope), domain-specific hope, state hope (moment-to-moment) and goal-specific hope. Global hope and domain-specific hope bear similarities to generalised and particularised hope proposed by Dufault and Martocchio (1985). However Snyder (2002) conceptualised hope as a cognitive rather than an emotion-driven process. Snyder (2002) posited that an individual's perception of the reality of gaining desired goals influences subsequent emotions and behaviour. Snyder (2002) proposed that hopeful thinking is initiated by future-oriented expectations (goals) which lead to planning (pathways) and a belief in capability (agency). Hope is then maintained by the realisation of some of these goals (Snyder et al., 2002; Snyder, 2002). Successfully achieving desired goals leads to positive emotions, but it is thinking which drives the process.

In an integrative literature review, Kylmä, Juvakka, Nikkonen, Korhonen, and Isohanni (2006) suggested that hope contributed to treatment compliance and adaptive coping strategies for individuals given a diagnosis of schizophrenia, which is consistent with a review of adolescent hope specifically in which Esteves et al. (2013) found that hope was predictive of health practices such as self-care. Research focusing specifically on adolescent hope suggested

that hope is also positively related to life satisfaction (Esteves, Scoloveno, Mahat, Yarcheski, & Scoloveno, 2013), sense of purpose (Burrow, O'Dell, & Hill, 2010), and faith in the future (Perry et al., 2007). Becoming hopeful has also been referred to as a 'turning point' towards a sense of agency (Deegan, 1988). Throughout the recovery literature, hopelessness is associated with anxiety and depression (Schrank, Bird, Rudnick, & Slade, 2012), caregiver burden (Kylmä et al., 2006), fear of relapse and as a hindrance to recovery (Law & Morrison, 2014). The utility of hopeful thinking in the recovery journey is evident, but fewer studies have focused specifically on adolescent hope. Some of the negative experiences associated with mental health difficulties (e.g. self-stigma) may also impact on recovery and treatment outcomes through a reduction in hopefulness (e.g. Corrigan, Larson, & Rüsch, 2009). Thus, as well as considered a central component of recovery, hopefulness is a key contender for limiting or repairing the impact of psychosis on people's lives, activities and conceptualisations of self.

Snyder et al. (2002) suggested that hope may fluctuate between different domains, such as work or friendships. The ability to generate goals and envision pathways to achieve these is based on the premise that 'the world is stable and predictable' (Snyder et al., 2002). This is possibly not the case for young people experiencing symptoms of psychosis, and therefore it is less clear how agentic or hopeful thinking is engendered for this population. Therefore increasing understanding of how young people prioritise different aspects of well-being and negotiate goals may also inform developmentally appropriate interventions.

Social inclusion

The National Social Inclusion Programme described inclusion as 'active participation in the community, as employees, students, volunteers, teachers, carers, parents, advisors and residents'(p.2, National Institute for Mental Health in England, 2009). Wilcock suggested that

'doing' is intrinsically linked to well-being, therefore not doing, or lack of meaningful occupation, can lead to social isolation, low self-esteem and uncertain self-identity (Wilcock, 1999). Berry (2013) explored internal influences on social inclusion in a cohort of young people with psychosis. She found that young people with psychosis had smaller social networks and cultural inclusion than other young people, which was mediated by level of hope. In a further study investigating the therapeutic relationship and professional expectations for social inclusion, Berry and Greenwood, (2015) found that greater domain-specific hope predicted social inclusion in psychosis and both a positive therapeutic relationship in EIPs, and some form of vocational activity influenced hopefulness. Both social withdrawal and loss of hope are associated with anxiety, depression, reduced quality of life and difficulty managing psychosis (Berry, 2013; Schrank et al., 2012).

Lloyd, Sullivan and Williams (2005) asked young people recovering from mental health difficulties about the impact of their difficulties on their social relationships. During these focus groups, young people described how their feelings about themselves impacted on their social relationships, but also how other people treated them differently and having less control over decision making. This period of their lives involved a greater dependency on close family and reduced social opportunity.

In order to reduce social withdrawal and encourage people to have greater autonomy in their own recovery by reinforcing strengths rather than deficits, Recovery Colleges have been established (Perkins, Repper, Rinaldi, & Brown, 2014). This has been achieved by moving from a therapeutic approach in which a focus is on problems or deficits, to an educational approach with a focus on skills, resources and increasing knowledge (Perkins et al., 2014). Recovery Colleges aim to redress the power balance between those with mental health difficulties and

professional services and encourage collaboration and inclusion (Meddings, McGregor, Roeg, & Shepherd, 2015). Students at Recovery Colleges have reported the value of collaborative relationships with peer trainers, structure, increased social opportunity and acquiring new knowledge and understanding (Meddings, Guglietti, Lambe, & Byrne, 2014). Further research is needed to assess the specificity of Recovery College to young people, but nonetheless, these are one step towards organisational change and helping people with mental health difficulties to (re) establish their sense of self (Perkins et al., 2014).

Changing societal views on mental health is important, but slow; the importance of challenging young people's perceptions of themselves, their social network and their future is also evident. Encouraging a hopeful outlook from others, such as professionals and employers may be important and go some way to improving self-perceptions and hope of, and for, young people. Further understanding of what motivates young people, how they maintain or re-establish hope and where they place value may be essential in maintaining recovery momentum for this age group and preventing the long-term impact of mental health difficulty and associated stigma and discrimination.

Rationale

As NHS trusts become more recovery focused and incorporate specific recovery tools and ideas into policy and operation, it is increasingly important to understand factors implicated in personal recovery (Shepherd et al., 2008). Alongside this, ideas of what represents recovery have shifted in recent years with greater focus being placed upon functional and personally meaningful outcomes as opposed to focus on alleviation of symptoms (Hodgekins & Fowler, 2010).

With the significance of hope prevalent within the recovery literature (Esteves et al., 2013; Leamy, et al. 2011; Slade, 2010) it is important to clarify how this is experienced and engendered in young people experiencing psychosis. This understanding can inform development of accessible and meaningful interventions. Esteves et al. (2013) suggested that qualitative studies are needed to aid understanding of hope during adolescence, and Landeen et al. (2000) cited the need to listen to individual experiences in order to understand meaning on an individual level. Additionally, Slade (2010) proposed that a central challenge for mental health services is to support 're-engagement', which involves personally relevant goal-setting. In light of the findings by Berry and Greenwood (2015) that hope may mediate this, it seems timely to gain further understanding of the impact of an experience of psychosis and its treatment on a young person's sense of self and hope. Understanding how young people conceptualise their mental health within the recovery journey may also provide useful information as to the timing of particular intervention.

Narrative research allows for rich and detailed exploration within individual accounts in order to gain an understanding of individuals' experiences of hope. By listening to individual experiences as proposed by Landeen et al. (2000), further understanding of how hope might rise and fall over time can be gained. By using whole stories it would be possible to gain understanding of the person within their unique context and over time. As Gorski (2013) suggested when writing about critical realism, interpretative work involves a degree of 'contextualization'.

Research aims

The aim of this research was to expand understanding of how young people with psychosis experience hope. Within this, the following questions were considered:

a. What stories do young people experiencing psychosis tell about their experiences of hope?
b. How do young people experience hope in specific domains, especially work, education or friendship?
c. To what factors do young people attribute changes in their hopefulness?

Method

Design

The study employed a qualitative non-experimental design, using a semi-structured interview schedule developed in accordance with narrative methodology (Riessman, 1993; 2008). Narrative methodology is particularly suited to exploring stories as a whole and would allow insight into how young people view the experience of psychosis. Gathering narratives, rather than more quantitative methodology, would allow for exploration of a young person's self-perceived role within their story as well as greater clarification of temporal aspects such as how experiences of psychosis or hope changed over time (May, 2002). Waters, Holttum and Perrin (2013) suggested that gaining a contextualised and holistic understanding of an individual's recovery journey may challenge popular discourse and in doing so enable generation of new hypotheses. This understanding may help in designing personally meaningful interventions for young people.

Epistemological position

A critical realist position is adopted within this research: rather than creating a reality, the narratives capture a 'reflection' of reality (May, 2002; Sullivan, 2010). Within mental health, structures and power relationships exist amidst people's changing experiences of them, and narrative methodology is well placed to explore such experiences and beliefs within this

existing context including exploration of the relationship between the context and the individual (Gorski, 2013).

Participants

Inclusion criteria

Young people aged 16 – 26 years who had experienced an episode of psychosis within the last year were eligible for inclusion in the study. Anyone who was unable to provide informed consent or unable to speak English was excluded from the study.

Participant characteristics

Ten young people consented to take part in this research. All young people identified as white British with further demographic details presented in Table 4. Participants were recruited from four early intervention in psychosis services (EIP), and two Recovery College campuses. Twenty two young people were invited to participate overall.

All participants were in the 'critical period' of 3 - 5 years following a first episode of psychosis (McGorry, Killackey, & Yung, 2008) and eight participants were currently receiving medication to help manage symptoms. One participant had a diagnosis of Todd's syndrome (also referred to as Alice in Wonderland syndrome) which is characterised by visual hallucinations and distorted time, space and body perception (George & Bernard, 2013).

Table 4. Participant demographics

Participant number & pseudonym	Gender	Age (year: months)	Length of time since FEP (self-report)	Understanding of experience
1 - Sophie	Female	26:00	18 months	Acute psychosis
2 - Tim	Male	23:05	12 months	First Episode Psychosis
3 - Mark	Male	18:10	24 months	Psychosis
4 - Ben	Male	22:07	8 months	First Episode Psychosis
5- Gary	Male	22:10	3 months	First Episode Psychosis
6- Luke	Male	23:09	6 months	Psychosis
7- Seb	Male	24:02	7 months	First Episode Psychosis
8 - Sam	Male	22:10	36 months	Bipolar Disorder
9 - James	Male	20:11	15 months	Bipolar Disorder
10 - Tina	Female	20:01	48 months	Todd's Syndrome

Procedure

Ethical considerations

Ethical approval for the research was granted by an NHS Research and Ethics Committee (Appendix D). Additional approval for the study was granted by the local NHS research and governance panel as well as the EIP research and audit governance group. The British Psychological Society 's (BPS) Code of Ethics and Conduct (2009) was followed throughout the research.

Informed consent

Participants recruited from the EIP services were identified by the care coordinators who considered the young person's current well-being and capacity to provide informed

consent before approaching them with details of the research. Current mental health was considered so as to ensure that participation would not add further distress. After discussion about the research with the care co-ordinator, the young person gave permission for their details to be passed to the chief investigator for inclusion in the study (n = 9). Participants from the Recovery College (n = 1) were invited to participate if they had earlier given consent to be contacted for research purposes and had applied for a psychosis course. Initial contact was made by a member of RC staff followed by a letter from the chief investigator if consent given (Appendix E).

All the young people who participated in the study reviewed the participant information sheet (Appendix F) at least 48 hours before meeting with the researcher, were given the opportunity to bring a relative or friend to the interview, and were involved in a full discussion about the purpose and nature of the study. Following this, all participants gave informed written consent (Appendix G), which included consent to be interviewed, audio-recorded, and for the use of anonymised quotes to be used within this body of work and future publications.

Interviews

A semi-structured interview schedule was developed in consultation with supervisors and with consideration of the existing literature (Appendix H). In accordance with narrative methodology, the questions were designed to elicit detailed accounts of experience rather than brief answers (Riessman, 2008). However, due to the nature of psychosis, which may include difficulties linking events to the self (Allé, Potheegadoo, Köber, & Schneider, 2015) and poorer insight about their internal world (Lysaker et al., 2013), some specific prompts about the interaction between hope and events or context were included. Each participant took part in a

face-to-face interview at a location convenient to them lasting between 40 - 120 minutes. Interviews took place either in young people's homes or nearest service base.

Each young person was told that the purpose of the interview was to gather stories of their experiences. Participants were told that they could talk for as long as they felt comfortable about any area within the interview. Each interview started with a question regarding the young person's conceptualisation of hope. Table 5 provides examples from the interview schedule. Participants also answered a short demographic questionnaire (Appendix I).

Table 5. Example questions and prompts from interview schedule

1. Can you remember back to the earliest time you felt hope?
2. Can you tell me how your hopefulness has gone up or down since then?
3. Can you tell me a bit more about that?
4. What was that like?
5. Have there been any times when that was not the case?

Data analysis

McAdam (1996) wrote that 'human events are often ambiguous and resistant to paradigmatic efforts to understand them' whereas the 'narrative mode of thought [is] concerned with human wants, needs and goals' (p.29, McAdams, 1996). The data collected for this research were analysed according to narrative techniques in order to gain understanding of those 'human wants'.

The data set consisted of ten verbatim interview transcripts (see Appendix J for an example). Mishler (1995) described a 'multiplicity and diversity of approaches' within narrative research and Reissman (2008) suggested that narrative analysis is a complex process without a step-by-step guide. However, as narrative research expands, narrative frameworks are becoming established within the literature and commonalities of the analytic process were followed within this research. These included a thorough reading and re-reading of each interview, consideration of the whole story and context, roles within the main story and central themes, tones and imagery evident within and between narratives (Crossley, 2007; McAdams, 1996; Murray, 2015). The focus of analysis in the current study was the conceptualisation of hope told by each participant and the role of the narrator (main protagonist) within that.

McCormack (2004) suggested a process of 'immersement' whilst reading transcripts using active listening in order to 'interrogate' the narrative. This involved asking the questions described in Table 6, to ensure full engagement with each interview and to consider the co-construction between listener and narrator.

Table 6. Questions for active listening (McCormack, 2004).

Who are the characters in this conversation?
What are the main events? Where/When do they occur?
As researcher, how am I positioned in relation to the participant?
How am I responding emotionally and intellectually to this participant?

Each story was then re-organised according to a temporal sequence so that attention could be given to 'sequencing and [any] progression of themes' within the interviews (Squire, 2013). Mishler (1995) refers to this as 'reconstructing the told from the telling'. Following the

framework described by Adame and Hornstein (2006), questions (Table 7) were asked of each transcript and recorded with supporting quotes (Appendix K). Questions were discussed with the main supervisor and those thought best to answer the research questions whilst also accessing the richness of a narrative approach were included. In this way, the initial questions (Table 6) were used to consider the researcher's connection with each interview, whereas the following questions (Table 7) were used to address the research questions and create participant profiles (Appendix L).

Table 7. Questions asked of the interviews.

Are metaphors and / or symbols used in the narrative or to describe the narrator's conceptualisation of hope?
Are there salient themes or tones throughout the narrative?
Is one dimension of hope more salient than another - what type of language is used to describe hope?
Is hope conceptualised with a sense of agency?
What roles are featured within the narrative that possibly promoted or hindered hope?
What domains are emphasised within the narrative e.g. work, study, friendships?
Is there a clear distinction between the narrator's distressed self and the non-distressed self?
Is there a turning point in the narrative which clarified the temporal sequence of the narratives from pre psychosis experience to post?
How does the participants' narrative relate to the literature on hope within recovery?
Other aspects of the story relevant to the research questions, or giving rise to further questions?

Through this process and discussion with the supervision team and reflection, four over-arching strands were identified across the narratives and were considered representative of the dominant stories told by the young people (Figure 2). These were:

1. The experience of hope

2. A sense of belonging and social networks

3. Information

4. Planning, work and occupation.

Within each of these strands were features of a young person's story which challenged, contrasted or supported shared experience with other young people. Whilst the experience of hope is a strand in its own right, it also weaves within the other strands in different ways with different impact and so this is included throughout for consideration. The main strands evident across the narratives are presented in detail with particular attention to turning points, agency, roles and concept of hope (line numbers are given in parentheses). All identifying information has been removed from any quotes and pseudonyms have been used throughout.

Quality assurance

Quality guidelines were considered throughout to ensure rigour (Mays & Pope, 2000; Yardley, 2000). Three main strategies were utilised:

First, a bracketing interview was undertaken with the lead supervisor as an exploration of any personal experience which may encroach on the analysis process and in order to 'mitigate preconceptions' (Tufford & Newman, 2010). This enabled personal opinions on the role of medication and diagnosis to be made transparent which was useful when analysing the

transcripts. Being aware of existing preconceptions enabled ongoing awareness of the researchers 'voice' within each stage of the research which helped prevent over-interpretation of the interviews (Dowling, 2006).

Secondly, a reflective journal was kept throughout to aide reflexive thinking (Appendix M). This detailed the researcher's awareness, and development, of concepts throughout the research. For example, making explicit an awareness of a personal 'resilience' narrative of hope as always available, but not necessarily accessible. If the researcher had not brought this into conscious awareness the analysis of the narratives may have ignored moments of low hope, or mis-interpreted indicators of hope. Being aware of personal influences on the analytic process enabled a more reflective stance.

Thirdly, independent validation occurred throughout the study which involved the researcher, three supervisors and an 'expert by experience' in order to gain several perspectives. The supervisors had a combination of research, clinical and / or lived experience. Including expert by experience commentary within this process enabled greater consideration of the relevance and applicability of the research question and findings as well as ensuring wider perspectives of key concepts such as 'recovery' and 'hope' (Gould, 2012). The questions and profiles were cross-checked across n= 4 interviews by two supervisors and then all interviews, profiles and strands were discussed by the full supervision team on two occasions. This ensured an iterative process through multiple positions with reflexivity at each stage of the research (Dowling, 2006).

Hope	Hospital	diagnosis	Medication	Relapse	Friends	Family	Professionals	Work	Education	Lived experience	Occupation	Stigma	language
Strand 1: HOPE													
Common Elements Future-oriented Goals and pathways Agency Hope as physically embodied Hope as mood or heavily linked to mood, Reciprocal- activity ←→Hope Easier for people to talk about mood rather than the more abstract hope													

Strand 2: Sense of belonging and social relationships	**Strand 3: Information**	**Strand 4: Planning / Occupation**
Common Elements Friendships Family Professionals Recovery college Importance of nature Creativity Self-identity stigma	Common Elements Diagnosis - helpful / unhelpful Hospital - confusion, not knowing Different ways of knowing e.g professionals 'know' if actually ill knowing yourself vs being known by others internet search information as enabling, being able to understand experience, research on internet, find other people internalised psychologist – talking about gradual exposure, facing anxiety, sense of understanding and coping – knowing 'the nature of the beast'	Common Elements Small steps Goals Value of work Productivity, sense of being valued, of days having value Small steps- the reciprocal benefits and hope-inspiring effects of making small gains

Turning points
The role of information The impact of psychosis

Figure 2: The development of common elements from the interviews

Respondent validation

Two young people, Tina and Sam, provided comments on their profiles. Both had consented to be contacted by the researcher for additional comments. They were asked to comment on how representative of their experience the profile was and consequently whether they would like to add or remove any detail. Tina described the profile as fully representative and Sam provided further clarification : his profile has been annotated to include his clarifications (Appendix L).

Results

Adame and Hornstein's framework (2006) has been used to draw out key elements from the interviews in answer to the research questions: Further information can be found in Appendix N. The following Table 8 provides summary information regarding each participant in order to orient the reader.

Table 8. Summary information of each participant

	Sophie Interview 1	**Tim Interview 2**	**Mark Interview 3**	**Ben Interview 4**	**Gary Interview 5**	**Luke Interview 6**	**Seb Interview 7**	**Sam Interview 8**	**James Interview 9**	**Tina Interview 10**
Narrative tone	Initially energetic, then slowed down, 'matter of fact'	Positive, with stress placed upon his goals and dreams. Proud	Tentative, but light hearted in places. Growing positivity when talking about goals	Positive tone, building momentum as Ben describes how he has become stronger through adversity	Very flat, slow tone. Hesitant with many pauses. Tired.	Hesitant initially then gained momentum matching story. Most positive when talking about recent gains	Very 'matter of fact' tone	A very thoughtful but energetic tone, some sense of Sam delivering a lecture on a favoured subject	Flat with little cadence	Positive and warm with energy throughout
Before	Happy Hopeful Energetic Competitive 'pushing hope'	Difficult Bleak No hope	Angry or annoyed Difficult time Drug use - legal highs	Rough early life Successful mid - adolescence Followed by job loss / drugs	'Quite bad depression' University Sense of competitiveness	'little shit' Drinking / drug taking Period of homelessness 'wanted to get high all the time'	Artistic 'good working background'	Energetic Hazy, disconnected from this? Dyspraxia	Academically able, not really connecting with other parts of self, hazy	Struggling Not understanding School unhelpful Seeking help / understanding 'stuck'
After	Slow Plodding low	Strong sense of movement Goal setting Hopes and dreams New family	New friends College / work aspirations Feeling cared for	Recovery gathering momentum Psychosis as part of identity New way of living	'in limbo' Being referred, little sense of agency Being adrift	Hopeful Sense of belonging Focused on achieving - education / job	Returning to art Experience as a scar but returning to 'old self'	Psychosis as a 'death of me' Achieving, moving forwards	Slowed sense of one day at a time using creativity little sense of agency	Motivated Positive and optimistic Growing independence

	Sophie Interview 1	Tim Interview 2	Mark Interview 3	Ben Interview 4	Gary Interview 5	Luke Interview 6	Seb Interview 7	Sam Interview 8	James Interview 9	Tina Interview 10
Stories	'not failing' Spirituality Then / now happiness related to 'medical problem'	Movement - improvement Aiming high	Drugs Belonging - new friends	Momentum Healthier life style Beating anxiety Overcoming adversity	Isolation 'different from peers'	Being inspired by others Improvement People caring anxiety	Getting old self back Hospital Growing independence	Research of self / meaning Spirituality and discovery / intensity / cycle of emotions	Isolation Creativity Depression / passivity	Creativity Overcoming adversity Becoming independent Belonging
Turning points	Medication - used to be happy - now low, 'plodding along'	News of baby	Medication - started to feel better psychosis as turning point / people caring	Medication - getting it right, mood / anxiety lifting 'something lifted inside me'	After diagnosis When functionality started to improve 'came to terms with it'	Psychosis as a turning point	Leaving hospital Sense of freedom	Sense that Sam is still 'turning' Knowledge and research leading to better understanding	None identified	Diagnosis Gaining university place

Following temporal sequencing of the stories, it was possible to discern a common narrative structure and content for each interview (Murray, 2015), which helps address research question A, what stories do young people experiencing psychosis tell about their experiences of hope (Table 9)

Table 9. Common narrative structure and content

Beginning:	Each young person identified a time prior to their experience of psychosis, either immediately before or further back in their childhood. Some young people identified difficult early experiences meaning that their life before psychosis indicated a 'distressed self' rather than this characterising the experience of psychosis itself. Different aspects of adolescence were identified – school, friendships, drinking or drug taking.
Middle:	The middle part of the stories focused on the experience of psychosis, periods of hospitalisation, medication and the role of family or professionals at this time. Confusion in remembering was evident during this part of each story reflective of the experience of psychosis. Some young people were able to identify the experience of psychosis as a turning point from their previously distressed self to a position of hope. The absence or change of friendships was prevalent as was the importance of different types of information.
End:	The young people looked back and identified moments of hope which arose during their experience of psychosis but also looked forwards to what they might now be capable of. Some young people seemed to be focusing on one day at a time whilst others were looking further ahead with hopes for careers and continued education. There were very few stories about 'returning to an old self' in terms of activity. The importance of planning and occupation was noticeable as was the value of stories of lived experience, either through personal research or via courses at the Recovery College.

'Light at the end of the tunnel' - the experience of hope

Although participants experienced different levels of hope throughout their individual stories, there was a coherent sense between stories that hope was conceptualised as future-oriented with an idea that life would improve.

Hope was described as:

> ...a feeling that everything is going to be completely fine...at some point. ... Everything will probably change..at some point..for the better. (Tina, 1[2])

> Hope is .. looking towards your future and .. seeing some sort of positive outcome in your future I think. (Luke, 1)

Some participants recognised hope by its absence:

> when I think about hope it signifies that there is something in the immediate now that is not okay. (Sam, 2)

Hope was also associated with motivation and some participants found it easier to talk about hope in other guises such as enabling and motivation rather than the more abstract concept of hope. It was interesting to note the sense of agency connected with hope and how, for many participants, agency could be more easily articulated in relation to activities, but less so in relation to mood. Both Tim and Luke talked about just waking in a particular mood:

[2] Numbers are line numbers in transcript

> ...It's a totally random thing, some days I just wake up in a bad mood.
>
> (Tim, 47)

At different times within their stories, participants talked with a sense of agency about activities they had chosen in order to alleviate their low mood which gave a sense of purpose and decision-making. Hope was therefore conceptualised as goal-oriented with many of the goals articulated relating to a work domain and future careers.

Those stories particularly which seemed to indicate a change for the better were characterised by agentic thinking with identified goals and pathways and the rise and fall of hope could be seen throughout their story (Table 10):

Table 10. Tim's story of hope (line numbers in parenthesis)

(22)Pretty tricky for me then, my mum and dad split up when I was about 12 and I had been through a really rocky patch with him [dad] then I was kind of getting things back on track with him, but then I started to go off the rails as well. As teenagers do, rebellious streak and that's when I was experimenting with drink and marijuana that kind of stuff, never led to anything serious but around 15, 16 I was just off the rails just doing my own thing...
(23)I didn't have any hope. Was just living in the here and now, not thinking about the future. There was nothing to hope for
(9)... that was my biggest hope when I first got diagnosed that I got to a point when I could ignore them [voices] and carry on
(25) I woke up one morning and realised there was no point to my life. I wasn't getting anywhere, I wasn't accomplishing anything and

that's when I started thinking maybe if I do this I'll get to this place and maybe if I do that I'll get to there

(20) ...I'm not going to say I'm in the best position in the world, I could do with more money with more this that and the other, but I'm always thinking that one day I'll get to the point that I want to be at. I want to be at a point where I earn more money. I want to be at a point where I own my own house and that's all hope

(36) ...we're [self, partner and their baby] going to go down the road of going to the council, try and get a place...and then we'll progress on from there, it's all a step forwards, a step on from there. I'm hopeful for what that is going to bring

Those stories which conceptualised hope as more domain-specific, for example focused on a specific goal such as work, education or family (such as the above), rather than global, also appeared to be moving forwards with positivity.

'No one told me that' - The role of information and explanation

The role of information was an important element within many stories and this was featured in a variety of guises, both as a lack of, exacerbating periods of confusion, and as a factor contributing to a change in hopefulness. A lack of information appeared to exacerbate uncertainty about the future, which was associated with increased feelings of low mood and confusion. Receiving information appeared to have an enabling role throughout the narratives. This was presented as information given by professionals, for example regarding diagnosis or medication, self-research through books or the internet for

further explanation of an experience or through meeting other people with lived-experience. Although meeting other people with lived experience related to a sense of belonging, it also fulfilled an important informative role beyond that of diagnosis, or other medical-related explanations. This seemed particularly relevant during periods of low hope such as being in hospital.

Seb talked about the impact of hospitalisation. His tone during this was hesitant as he tried to articulate the fear he felt through 'not knowing' and the sense of being locked up. Seb initially thought that he would be in hospital forever. Receiving information, an explanation for his experience, from professionals enabled Seb to see a way forwards (Table 11):

Table 11. Seb's story of hospital

(11) There was not much hope in the hospitals
(12) Because being like not only locked up, but there's a door and there's.. I did not know what the medication did and I did not know what psychosis is, I didn't know what I was going through since I had the breakdown at my [relative's] house.
(16) I was told about psychosis in [second hospital] they explained it more clearly, they explained a bit more about [medication] the drug and they explained a bit more about what was going on and all that and they explained about the incident, what happened at my [relative]'s house
(17)..it did affect some beliefs I think there was hope, there was more knowing in that time

(62) seeing that I'm not alone really, trapped in the hospital forever and you know and not knowing that there is other people with problems

(63) [seeing others]... made me see a little bit different about the future a little bit...

(64)...I think knowing that someone has been discharged before me and discharged after me and thinking you know and I might get discharged

Luke's story was similar and for him meeting people with similar experiences who were moving forwards was a powerful instigator for hopeful thinking. Professionals at this time featured less in his story, indeed lack of explanation increased feelings of low hope for Luke. Hope and information came from examples of lived experience which enabled Luke to see a different future for himself from that which he had imagined. Luke's enthusiasm for his new future was almost tangible as he talked about the time period following hospital (Table 12).

Table 12. The role of information in Luke's story of hope

(3) no one really told me that I might get better and be able to work. They just stuck me in ...I don't know..it's like...just mental health, there isn't any future,

(8)... I went to [name] hospital then in March and when I was in there, I had no hope

(9)People in there would tell me they'd been in there 6 months, 8 months, some bloke told me he'd been in there a year. I just

thought that would be it, I'd just be in hospitals. That's when I really had no hope...I just thought I was stuck in this mental health cycle and I'd never get out of it. By meeting people who were suffering from mental health, but were also there in recovery...that's when hope builds back up, when you realise that there are people out there willing to help you and that... there's no time period on recovery... I mean you can still have a normal life with mental health and that ...meeting people that were in education and planning for the future...that really got my hope back up.

(24) It's [hope] not gone up and down, it's just gone up ...because I thought I'd be in hospital for ever and then when I was in a place called [name of community mental health facility] I started ....what did I do....Oh yeah, I got into Recovery College and I was coming here to see a psychologist

(2) ... and there was a lady there [at the Recovery College] who taught there and she'd been through the mental health system and managed to get a degree and stuff it's when you hear stories like that, you start to get hope. Hope for me is, it's like having belief, it's not the end, mental health is not the end.

(27) I just kept finding out about more things, when I was living there we have to cook for everyone in the house and that's how I learnt and I thought of a career and I sort of have my future planned....this place where I'm getting my course they take

> volunteers and I can get work experience. They give out contracts, help you find a job. Right now my hope is the best it's ever been

The Recovery College had a big impact on Luke's hopeful thinking and his vision of the future. This led to some concrete goals and a sense of agency.

For some young people, receiving information about their diagnosis acted as a turning point and gave them a focus to move forwards:

> I think it was the day that I got diagnosed; I can still remember how happy I was that day, how hopeful I was for the future. You know, I finally had a clear diagnosis and understanding of what's happened to me (Tina, 2).

James described his diagnosis as 'reassuring' and this information gave James a sense of hope and impetus to find out more;

> (17) ...so when I got a diagnosis it was reassuring
> (18) ..it made me sort of realise that it was going to go up and down...it gave me a little bit of solace when I was depressed that it would come back up
> (21)... feel a bit more hopeful because I mean nothing had really changed obviously, I didn't become bi polar when I was diagnosed with it . ..it helped me put a label on the things I was experiencing

> erm..and I knew there would be a lot of help, like online and I could read up about it and things like that

However, although James found his diagnosis reassuring and a means of gathering further information, it was noticeable that James also felt a lack of agency in relation to his mood. Having bipolar disorder meant that his mood would go up and down, rather than James having a role in influencing this.

> Researcher - what was that shift that got you from that very low point to where you are now?
>
> Erm..I don't think it was anything really in the environment, I think it was probably more likely some sort of biological change because nothing was really very different, (James, 13)

However, acknowledging the rise and fall inspired James to find out more information and promoted a more hopeful outlook.

Sam spoke eloquently about his experience of information from professionals versus his own research raising interesting questions regarding the nature of information (Table 13).

Table 13. Sam's story of his search for meaning

(20) I don't know what I've been through I'm not even in a position to make sense of it and no one is going to understand it and it's all my fault because it's from within

(29) Hope maybe came into play for me in the psychosis period where you've got you know...the first time prominently when I was reading up about it afterwards or being told information about messianic figures

(45)... when I'm interacting with NHS services therapeutic encounters in some form or another, why there is no explanation given to you in the framework of spirituality or spiritual commonality between cases of psychosis. Like surely, if a common feature of manic episodes is that messianic complexes are developed how is that not fed back to the patient in terms of some kind of form of explanation or food for thought

(46)... I would have found a lot of strength in that. It's something I had to question myself to my own devices... Then it becomes...medically based as opposed to not holistic but what about your experience?

Sam appeared to be seeking a more collaborative explanation of his experience which incorporated more explicitly his own understandings. Other young people needed similar understanding and explanations. Sophie's narrative started with a very strong message from her grandmother, and she described herself as an energetic, optimistic young woman, 'pushing hope'. However, the information she received was that the message from her grandmother was part of her psychosis: This, combined with her medication, seemed to reduce her sense of hope and motivation. She associated her energetic, hopeful feelings with being medically unwell which reduced her sense of agency (Table 14).

Table 14. Reduced hope in Sophie's story

(72) Hope never ends. That was the message I got from my grandmother ...I was really upset when I was told it was a mental health problem, that really upset me it was such a strong message (10) ... looking back now, I see it as a medical problem, but I believed it 100%, I believed everything I was trying to convince everyone else. (18)... I've changed quite a lot since my episodes, recently I'm not so hopeful, I'm more sort of...I'll do that because I have to, that sort of attitude these days . (20)...now I'm on medication, it has bought me to the middle... I don't have that burst of energy, I'm sort of plodding along. It does change everything it changes the way I think as well, I think much slower now

Stories within the narratives which incorporated forms of information giving or receiving also identified differences between care received from professionals and care received from families. Professionals were viewed as providing practical care, activities, groups, diagnostic information and medication whereas families were supportive on an emotional level. This seemed to have been characterised by different types of 'knowing', for example, whilst his family was viewed as supportive, Luke viewed professionals as having a different type of knowledge about him which evoked his trust, increased his hope and provided reassurance (Table 15).

Table 15. Different types of knowing (Luke)

(94) I guess they know if you're becoming ill, whereas your family is more of a supportive role. When I tell a professional they can...I don't know, tell whether you are really becoming ill or whether it is just a phase like one episode

(95) ...I worry when I'm depressed if I like am going back into a breakdown but having a professional there they know and they can tell by your behaviour if you're becoming ill again and I guess its confidence, it's like...reassurance. You might think you're really ill, but they know

(96) Yes they [family] can really only support you and sort ... just let you know someone is there, they can't diagnose you, you need a professional.

(97) ... it's being able to know it's not as bad as you think, I mean obviously you are going to think the worst

(98) ... it's so new for me, I don't really understand it completely so having a professional right there I know someone can explain everything.

Different types of knowing were also exemplified by Sam when he was discussing the reaction of friends and family to changes in his expressed mood and his knowing of himself being different from that of others (Table 16). This juxtaposition of knowing appeared to increase Sam's self-exploration and seemed to create a self-reliance in his research of self and recovery.

Table 16. Sam's experience of knowing

(50)... I'm coming to the table with my set of experiences and we're making sense of them. Sometimes I'm coming, not only with the experiences, with my own analysis of my own experiences which then makes the job a little bit harder to deal with the therapist perspective...

(54) Going to therapy was like, I knew who I was before I walked into the room and then I had no idea who I was when I walked out, and then a good day was I had no idea who I was when I walked into the room and I knew totally who I was walking out and that fluctuated a lot and I was most frustrated when I went to therapy and erm.....I didn't have any problems and then I came out and I had more problems...eventually I had to take a break because I felt gridlocked in the therapeutic encounter, it felt like I wasn't actually...helping my situation...maybe the ways in which the therapeutic encounter was meant to help were not the ways I wanted to receive help

(60) I think I've become very aware through therapy that it's very important to question the ways in which I tell my own narratives ... I think every time I've said my stories do I say them consistently? Why did I miss that piece of information out?

(76) My support network...freaked out when I started to get um slightly more animated because I had a slightly larger concentration span.

(77) I think I had a personal trainer as well, but I felt like I was, I was er, a refurbished engine ...

(79)...now looking back on it because they were freaking out that I was going into another manic episode essentially

'*Someone actually cares' - A sense of belonging*

Information throughout the experience of psychosis was also linked with a sense of belonging. Mark talked about making a plan with his care coordinator which provided both motivation and a sense of belonging. There was a sense that collaborative planning with someone was new and welcome;

(72) [care coordinator] makes like a plan for a year or something of what I'm going to do and what we're going to have to do to do that, stuff

(73) Feels good - someone actually cares

(74) We make it together, we made it together, it's my ideas as well as hers and we put it together and that makes the plan

For some young people, this sense of belonging and of being supported was new and characterised a change in their life story from distress before psychosis to a more hopeful future. The experience of psychosis itself represented a turning point for Mark and he identified a clear role for friends and his care coordinator which increased his sense of belonging and feeling cared for (Table 17). Mark's story described the change for him from life before psychosis to his current self.

Table 17. Mark's story of belonging

(70) When I was younger I was just really angry little kid... When I wasn't angry I was just annoyed

(8) [life was] very difficult, I didn't really understand a lot, my head was all over the place,

(29) I used to have different friends they weren't so good for me, I used to do drugs and stuff, so I became ill, so when I went into hospital I lost all my friends, I hoped to get new friends to get better, to get new friends and stuff

(42)Yeah, like when we're at a festival or something and there'll be loads of drugs around and my friends will just say don't go near them cos they're doing drugs and stuff, they are helping me

(43)Makes me feel quite good actually makes me feel like I can actually have friends

(72)[care coordinator] makes like a plan for a year or something of what I'm going to do and what we're going to have to do to do that.

(73)Feels good, someone actually cares

Friendships were interesting throughout these narratives, either because of their absence which was unexpected for this age group, or because of the purposeful move from old friends to new. Some participants commented on a sense of isolation from peers, of being 'left behind', whilst for others peers were absent from their narratives altogether. The transition between friendship groups was through recognition of needing change in order to move forwards in a hopeful and new way, as in Mark and Luke's stories of a move away from drugs. Ben highlighted a change in friendship group which he had experienced as rejection and as a lack of understanding about his mental health. His relationship with his mum took precedence both during and following his experience. Both Gary and Mark referenced peers being ahead of them in terms of education or jobs, of being 'behind' or

'missing out'. Seb and Tina discovered a new sense of belonging when they joined some Recovery College art courses stemming from a love of creativity but also the knowledge of shared experience which previously differentiated them from their peers.

> (30) I didn't really feel like I fit in at school
>
> (31)...the reason I went there [Recovery College] was because I needed some time in my week to do some art so I found all the art courses you know ... they are really nice and they are just a lovely bunch of people... It's where I feel most normal
>
> (32) ... meeting other people who are just as crazy as I am, or crazier! In a good way, in a good way ... just kind of makes me feel like ... ok with being a little bit different I guess... (Tina)

In this way, the Recovery College, specifically other people with lived experience achieving, both engendered a sense of belonging and provided young people with a frame of reference for their experiences thus providing some hope that positive change was possible for them.

'*One step at a time*' - *the importance of planning and occupation*

Evident throughout these narratives were the reciprocal benefits and hope-inspiring effects of making small gains. These were supported both from sources of information and from a sense of belonging. There were elements of the importance of productivity which instigated a sense of being valued and of the days having value and signified a move forwards from 'being in limbo' (Gary) or 'wasting days on the computer' (Luke). Several of the young people had domain-specific hopes of either gaining employment (Luke, Mark, Ben, Gary) or maintaining the jobs they had (Tim, Sophie). For some of the young people this appeared to encourage some pathway thinking, how they might achieve this, as well as

a sense of agency in managing the small steps towards employment. Mark talked about going to college and 'getting something out of it' in order to gain employment. Within this story was also a sense of his having missed out within his peer group:

(19) I'm hoping to get a job, I'm handing my CV in after this

(53) I'm hoping to get qualifications and I'm hoping to get an apprenticeship

(54) In bricklaying

(55) A lot of my friends have already been at college, so I've missed like two years of my life (Mark)

Sophie's narrative tone was slow and measured, representative of her feelings of being 'slowed down' by medication and her concept of hope was of big, global change rather than small concrete goals. However, within this, Sophie recognised the benefits of small steps and described the importance of even managing small tasks and maintaining her work (Table 18).

Table 18: The importance of small steps (Sophie)

(35) ... a lot of my family have been there supporting me and helping me with housework and just with things I felt I couldn't do, but with that support I feel like I'm still succeeding
(36) I mean, if I can allocate people jobs and things like that just to help me then I don't feel like I'm failing at life
(38) I just work in [place] nothing fantastic, but its easy work, I've always found it really easy and enjoy being quick and things like that but now I'm struggling a little bit, but my family will take me into work

so that I'm definitely going and still pushing myself so I'm not losing that completely, I just need that get out and do something

(43) Well, if I feel as if I can't do something I feel quite low and if someone comes and does it for me I feel that the pressure has lifted and that I can still do little things, instead of just having that one thing sort of playing on my mind, so it does help with my hope it brings me back to life as such ...

(44)... the washing up or something stupid, once that's done, I can think, now that's out the way ... I can think ok that's done what else can I do?

The role of professionals, particularly collaborating with care coordinators, was prevalent as young people discussed their activities. As in Sophie's story, small steps represented movement and productivity which had a reciprocal role with hope.

The smaller goals are good because they are easier to get to and now and then I do hit the small goals ... it is fantastic to know that I have reached that point ... it gives me something to go towards the next one, ... I know I've reached this one, so I know I can reach that one

(Tim, 69)

Often when young people had expressed little or no sense of agency over their mood, they identified some occupation which inspired hopeful thinking which in turn was associated with improved mood. Small steps were also associated with overcoming additional mental health difficulties such as anxiety (Ben, Mark and Luke). Some of the small steps seemed to act as scaffolding towards (re) integrating with society in the form of

football or walking groups and were supported by professionals rather than a young person's social context.

For Ben small steps also helped him manage his anxiety about a relapse. His narrative had a strong sense of positive forward movement and a story of overcoming adversity which moves full circle to hopeful thinking about the future (Table 19).

Table 19: Ben's story of small steps

(25)…it's like running before you can walk, like a couple of months ago, I couldn't walk I could crawl, but now I'm thinking I can walk a lot faster now... I take each day as it comes and if I feel good in the morning....I will sort of...get through this, but it seems a lot more hopeful and...
(26) I'll learn to live with it, but lead a better life than I did before,
(27) Sometimes, well a few times I've thought will I relapse? Will I end up going back to hospital but now that's something that I put to the back of my mind. I think I won't need to go back to the hospital, I'll deal with it in a different way...
(28) What doesn't kill you makes you stronger. I believe if I can get through that I can get through most things. A lot of my

friends won't suffer a nervous breakdown like I did. I always think there's a light at the end of the tunnel

Ben was able to think of his small steps as a positive achievement compared to friends who have not experienced a period of acute mental health problems. By taking some small steps and recognising these, Ben was also able to recognise factors which kept him healthy which in turn enabled him to reassure himself about coping and the possibility of a relapse. His experience had led to a stronger self-identity of someone who can cope with adversity and a sense of a brighter future - 'light at the end of the tunnel'.

Research questions

The four strands presented here address the research questions in the following ways: The stories young people told about their experiences of hope (question A) had a common structure (Table 6) with hope conceptualised as future-oriented. Barriers to hopeful thinking seemed to be uncertainty regarding future prospects, low mood and different types of information and explanation which could both reduce and engender hope. Barriers and facilitators for hopeful thinking were evident throughout the four strands. Some young people experienced psychosis-related symptoms as a turning point towards hope and it was possible to follow the rise of hope within their stories as they discovered new possibilities and made choices over ways of living their lives. For other young people, hopeful thinking did not appear so salient (Gary, James) and the tone of the stories appeared slowed down with hope as a more global concept and a reduced sense of agency.

In relation to research question (B), how do young people experience hope in specific domains, there was a predominant focus on working life across these narratives

more so than other domains of friendship, leisure, education or family life. However, within some individual narratives there were stories of creativity and enjoying nature which appeared to embody some characteristics of hope. For example, both Tina and Seb found creativity both enhancing of their sense of self as well as representing the small steps towards a bigger goal. For Tina, creativity represented a pathway towards making sense of her experiences which appeared to increase her sense of hope of completing her university degree and gaining employment. Although only two participants were actively working at the time of these interviews, it was a goal for all of them to progress towards employment either as a long-term more global goal or one with specific pathway thinking. Luke identified help from an employment support worker with his curriculum vitae and also identified ways to gain work experience. Those narratives which seemed particularly hopeful towards work were characterised by some pathways thinking. For example, Tim identified that a time frame, a plan and some training would promote hopeful thinking for him. Ben identified managing his anxiety as part of the pathway towards actualising his work goal. Having experienced success with small steps Ben appeared able to hold work as a realistic future goal.

Friendships were less prevalent within these interviews; some young people had made decisions to lose contact with previous friendships, or to have a much reduced friendship circle. For other young people there was mention of being 'left behind' and a sense of psychosis as an interruption to typical developmental tasks of individuation from parents.

Young people attributed changes in their hopefulness to several factors (question C). Stories which showed a rise in hopeful thinking included receiving information which challenged some negative beliefs about future possibility, for example from people with

lived experience as in Luke's story. Equally, a reduction in hope was related to uncertainty. Some young people who had received medical explanations for their experiences and were invested in the use of medication as the 'only' way of managing their symptoms appeared less hopeful with a reduced sense of agency towards their own role in recovery.

Care co-ordinators, family members and other people with similar experiences all contributed to hopeful thinking and led to the achievement of small steps. Some of this was through collaborative planning and promoting specific activity, as in the case of professionals, whereas for some it was a sense of being cared for which led to hopeful thinking. The idea of small steps increasing hope was a common element throughout the narratives.

Discussion

This research used narrative methodology to explore how a sample of young people with psychosis experienced hope. This included consideration of the stories young people told about their hope, how hope was experienced in specific domains such as work or friendship and to what factors young people attributed changes in their hopefulness. Four dominant strands were identified within each narrative: 1. Hope, 2. a sense of belonging and the importance of social networks, 3. the importance of information and explanation and 4. the significance of planning and work / occupation. The experience of hope threaded throughout each of these. Using narrative methodology enabled the rise and fall of hope to be tracked and acknowledged within the context of each young person. Additionally, exploring stories, rather than themes or structure kept as close as possible to the young person's account of their experience.

Collaboration between the young person and professional was a salient feature of many of the narratives and this is consistent with a literature review conducted by Schrank et al. (2012) which suggested collaborative strategies for recovery as a potentially successful intervention to engender hope. This is also consistent with advice given in the BPS (2014) guide to understanding psychosis and schizophrenia. Concordant with Snyder's (2002) Hope Theory, having a plan (goal) and a structure (pathway) appeared to promote hopeful thinking with domain-specific hope being particularly related to work and careers. This enables certain developmental tasks or stages to be met successfully, such as seeking identity and generativity (Erikson, 1968). However, in a time period of development typically characterised as one of growing independence, the relative lack of, or change in, friendships stands out within these narratives. It seems as if these typical developmental tasks were disrupted or delayed as people reduced their friendship circle, or experienced 'being left behind'. Instead, for some of the young people, in terms of social inclusion, professionals filled the gap typically occupied by friends. Meeting peers with lived experience and finding these helpful, and hopeful, suggested the importance for young people of having a peer group with which they could relate.

An emphasis on work-related domain-specific hope is consistent with an NHS patient mental health survey (NHS, 2015) in which people say that they want more help to get work. The statistics indicated that only 25% people get help with work from mental health professionals whereas 45% of respondents said they wanted it but did not receive it. Only 14% of the demographic for this survey were between 18 years and 35 years and it would be interesting to focus more specifically on this age group.

By focusing on this period of adolescence, this research adds to the literature in further understanding the role of professionals and information in engendering hope in

young people. Care following the initial medical input, for example hospital, seemed to be more practical and focused on motivating young people towards activity and inclusion. These results support findings of Berry and Greenwood (2015) in which professionals hold a key position in relation to promoting social inclusion for young people via occupation, as seen within this cohort as walking groups, football, employment and promoting Recovery College courses. Those participants with a sense of isolation perhaps needed greater input, in the form of structure and planning, to engender hopeful thinking and prevent further social withdrawal. If hope is a belief in positive change in the future as suggested within these narratives, and consistently within the extant literature, being able to plan and set small goals implies possibility and consequently promotes hopeful thinking (Dufault & Martocchio, 1985; Snyder, 2002).

Young people expressed less agency regarding their mood or state-hope, but were able to identify activities which provided motivation and in turn improved their mood. Additionally, information and explanations offered, or with-held, about their experiences impacted on hope expressed by the young people. Although information regarding a specific diagnosis was perceived as reassuring for some (e.g. James), there was a sense of an illness as agent. For example a diagnosis of bipolar disorder meaning that the young person would experience consistent periods of elevated or low mood which could be moderated by taking medication. This explanation appeared to reduce personal agency for the future and in a similar way, some participants' reliance on professionals to confirm the extent and veracity of 'actually' being ill removed personal agency to some extent. For some young people, the explanations they were given did not account for difficult pre-psychosis experiences such as family life or drug use, although the young person acknowledged the experience of psychosis almost as a positive turning point. In this way, talking with people with lived

experience inspired and motivated the young people towards a different future to one which they had previously imagined.

Limitations

Although qualitative research is a growing trend within the recovery literature, using narrative methodology with young people who may have experienced a loss of coherence has its limitations. Participants had all experienced periods of confusion from which they were unable to recall details. Additionally, the sample of young people was small, and the narratives analysed within this paper are particular to a specific time in their recovery journey. All participants were white - British and thus we may not have a sense of the rise and fall of hopefulness in the context of cultural differences, where psychosis itself may attract different explanations and meanings.

Squire (2013) commented, 'narratives cannot be repeated exactly…stories are performed differently in different social contexts' (p.51, Squire 2013). Therefore the context of the interviews, the researcher and the point of the young person's journey as well as many other external factors all have a bearing on the way each story was told. However, the quality checks integrated within this research aimed to ensure a fair representation of each young person and their story.

Clinical implications

This research supports the importance of a collaborative relationship between professionals and young people to enable a sense of agency in moving forwards and scaffolding social inclusion and hopeful thinking. Additionally, the importance of support from people with lived experience as engendering hopeful thinking was prevalent.

Including peer support and peer trainers within mental health services can provide additional impetus to move forwards.

For some young people, a lack of information about their experience, their medication or the process of hospitalisation left them feeling scared and hopeless. It is important to consider information from different sources e.g. psychiatrists, EIS and lived experience, and the impact each may have on a young person's recovery. Working with diagnostic uncertainty, as do EIPs, may be useful in terms of thinking beyond diagnosis, but it seems that professionals must balance this with providing information about the impact an experience may have on a young person, length of hospital stay (i.e. not forever), recovery and role of other professionals. Recovery Colleges, whereby education is offered with a combination of expertise by training and by lived experience, may be especially valuable. There was little mention of explanations from psychological interventions within the narratives, which was surprising given the role of psychologists in providing formulations in collaboration with clients and these formulations typically being to make sense of experiences. This may be because psychologists creatively encourage a focus on social inclusion and functional recovery rather than meaning-making, or because they are working with the young people in areas not seen as directly related to psychosis. This may include anxiety-reduction or working indirectly by supporting care coordinators. Additionally, access to a psychologist is limited and may not have been experienced by all the young people interviewed.

The importance to young people of information, belonging and social networks and the role of small steps has implications for the way in which clinicians work with young people. It is possible that professionals fulfil a gap typically filled by friendship groups and in doing so have an opportunity to support young people to move forwards which may

facilitate developmental progression. The value, for the young people within this research, of lived experience promoted a sense of belonging within a peer network as well as hopeful thinking about future possibilities. Recognising the impact of different explanations on a young person's sense of personal agency and hopeful thinking needs to be considered.

Research implications

Future research should explore changes in hope in a more longitudinal study to further understand the impact of experiences of psychosis as well as the benefits of particular interventions. More research is needed into the role of different components of treatment. For example, psychological formulations could potentially help increase agency and hope by incorporating biological, social and psychological factors thus rendering events more explicable. Formulation could additionally support understanding of the young person's experiences within the context of the life narrative, for example linking to life before psychosis, in order to gain a greater understanding of the impact of psychosis. Further research could look more closely at ways in which personal sense of agency could be fostered and how this is enabled, for example, an Open Dialogue approach in which the 'explanation' as well as ways to support the person are co-constructed (Seikkula, Alakare, & Aaltonen, 2011). Within this approach young people are considered able to remain within their social context, for example friendship groups, family and employment, and supported as such with shared decision-making (Seikkula et al., 2011).

Conclusion

This research explored how young people experience hope following an experience of psychosis. The findings highlight that psychosis and recovery is a complex journey and that hopeful thinking and social inclusion is engendered by collaboration, positive examples

of lived experience and achieving small steps. For some young people, psychosis acts as a turning point towards positive life changes whilst for others it represents an interruption to typical developmental tasks such as individuation and development of peer relationships.

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Major research Project

Section C: Appendices and Supporting Material

Appendices

Appendix A- Quality assessment guidelines

Qualitative research review guidelines – RATS (Clark, 2003)

ASK THIS OF THE MANUSCRIPT	THIS SHOULD BE INCLUDED IN THE MANUSCRIPT
R Relevance of study question	
1. Is the research question interesting? 2. Is the research question relevant to clinical practice, public health, or policy?	Research question explicitly stated Research question justified and linked to the existing knowledge base (empirical research, theory, policy)
A Appropriateness of qualitative method	
3. Is qualitative methodology the best approach for the study aims? • *Interviews:* experience, perceptions, behaviour, practice, process • *Focus groups:* group dynamics, convenience, non-sensitive topics • *Ethnography:* culture, organizational behaviour, interaction • *Textual analysis:* documents, art, representations, conversations	Study design described and justified i.e., why was a particular method (e.g., interviews) chosen?
T Transparency of procedures	
Sampling	
4. Are the participants selected the most appropriate to provide access to the type of knowledge sought by the study? 5. Is the sampling strategy appropriate?	Criteria for selecting the study sample justified and explained • *theoretical:* based on preconceived or emergent theory • *purposive:* diversity of opinion

ASK THIS OF THE MANUSCRIPT	THIS SHOULD BE INCLUDED IN THE MANUSCRIPT
	• *volunteer:* feasibility, hard-to-reach groups
Recruitment	
6. Was recruitment conducted using appropriate methods?	Details of how recruitment was conducted and by whom
7. Could there be selection bias?	Details of who chose not to participate and why
Data collection	
8. Was collection of data systematic and comprehensive?	Method(s) outlined and examples given (e.g., interview questions)
9. Are characteristics of the study group and setting clear?	Study group and setting clearly described
10. Why and when was data collection stopped, and is this reasonable?	End of data collection justified and described
Role of researchers	
11. Is the researcher(s) appropriate? How might they bias (good and bad) the conduct of the study and results?	Do the researchers occupy dual roles (clinician and researcher)? Are the ethics of this discussed? Do the researcher(s) critically examine their own influence on the formulation of the research question, data collection, and interpretation?

ASK THIS OF THE MANUSCRIPT	THIS SHOULD BE INCLUDED IN THE MANUSCRIPT
Ethics	
12. Was informed consent sought and granted?	Informed consent process explicitly and clearly detailed
13. Were participants' anonymity and confidentiality ensured?	Anonymity and confidentiality discussed
14. Was approval from an appropriate ethics committee received?	Ethics approval cited
S Soundness of interpretive approach	
Analysis	
15. Is the type of analysis appropriate for the type of study? • *thematic:* exploratory, descriptive, hypothesis generating • *framework:* e.g., policy • *constant comparison/grounded theory:* theory generating, analytical •	Analytic approach described in depth and justified *Indicators of quality:* Description of how themes were derived from the data (inductive or deductive) Evidence of alternative explanations being sought Analysis and presentation of negative or deviant cases
16. Are the interpretations clearly presented and adequately supported by the evidence?	
17. Are quotes used and are these appropriate and effective?	Description of the basis on which quotes were chosen Semi-quantification when appropriate Illumination of context and/or meaning, richly detailed

ASK THIS OF THE MANUSCRIPT	THIS SHOULD BE INCLUDED IN THE MANUSCRIPT
18. Was trustworthiness/reliability of the data and interpretations checked?	Method of reliability check described and justified e.g., was an audit trail, triangulation, or member checking employed? Did an independent analyst review data and contest themes? How were disagreements resolved?
Discussion and presentation	
19. Are findings sufficiently grounded in a theoretical or conceptual framework? 20. Is adequate account taken of previous knowledge and how the findings add?	Findings presented with reference to existing theoretical and empirical literature, and how they contribute
21. Are the limitations thoughtfully considered?	Strengths and limitations explicitly described and discussed
22. Is the manuscript well written and accessible?	Evidence of following guidelines (format, word count) Detail of methods or additional quotes contained in appendix Written for a health sciences audience
23. Are red flags present? These are common features of ill-conceived or poorly executed qualitative studies, are a cause for concern, and must be viewed critically. They might be fatal flaws, or they may result from lack of detail or clarity.	*Grounded theory:* not a simple content analysis but a complex, sociological, theory generating approach *Jargon:* descriptions that are trite, pat or jargon filled should be viewed sceptically *Over interpretation:* interpretation must be grounded in "accounts" and

ASK THIS OF THE MANUSCRIPT	THIS SHOULD BE INCLUDED IN THE MANUSCRIPT
	semi-quantified if possible or appropriate *Seems anecdotal, self evident:* may be a superficial analysis, not rooted in conceptual framework or linked to previous knowledge, and lacking depth *Consent process thinly discussed:* may not have met ethics requirements *Doctor-researcher:* consider the ethical implications for patients and the bias in data collection and interpretation

Appendix B - example of quality assessment

Example of scoring using the RATs to review a high and the low scoring article

Grealish, A., Tai, S., Hunter, A. and Morrison, A.P. (2013) Qualitative exploration of empowerment from the perspective of young people with psychosis. *Clinical Psychology and Psychotherapy,* 20, 136 - 148.	**Justification**	**Score (0 or 1)**
1. Is the research question interesting?	Yes, and clearly stated	1
2. Is the research question relevant to clinical practice, public health, or policy?	Yes, links to recovery, adolescence and psychosis clearly stated. Relevance to policy and mental health services explicit.	1
3. Is qualitative methodology the best approach for the study aims?	Yes, explanation as to why chosen	1
4. Are the participants selected the most appropriate to provide access to the type of knowledge sought by the study?	Yes, young people with an experience of psychosis	1
5. Is the sampling strategy appropriate?	Yes, based on IPA recommendations	1
6. Was recruitment conducted using appropriate methods?	Yes, recruitment explained	1
7. Could there be selection bias?	Yes, participants were identified by one consultant psychiatrist so may have missed some participants who would have wanted to take part, but not seen by that particular psychiatrist	0
8. Was collection of data systematic and comprehensive?	Yes, outline in procedure with example interview questions given	1
9. Are characteristics of the study group and setting clear?	Yes, in text	1
10. Why and when was data collection stopped, and is this reasonable?	Yes, explained in accordance with IPA	1
11. Is the researcher(s) appropriate? How might they bias (good and bad) the conduct of the study and results?	Yes, considered in text. Professional roles and experience of researchers noted	1
12. Was informed consent sought and granted?	Yes, stated in text	1
13. Were participants' anonymity and confidentiality ensured?	Yes, stated in text	1
14. Was approval from an appropriate ethics committee received?	Yes, stated in text	1
15. Is the type of analysis appropriate for the type of study?	Yes, explained in the text	1
16. Are the interpretations clearly presented and adequately supported by the evidence?	Yes, presented coherently under sub headings	1
17. Are quotes used and are these appropriate and effective?	Yes, included throughout to support the interpretations	1

18. Was trustworthiness/reliability of the data and interpretations checked?	Yes, explained clearly	1
19. Are findings sufficiently grounded in a theoretical or conceptual framework?	Yes, conceptualisation of empowerment and relationship with the findings explained	1
20. Is adequate account taken of previous knowledge and how the findings add?	Yes, considered throughout the discussion section	1
21. Are the limitations thoughtfully considered?	Yes	1
22. Is the manuscript well written and accessible?	Yes, clear sections and correct format	1
23. Are red flags present? These are common features of ill-conceived or poorly executed qualitative studies, are a cause for concern, and must be viewed critically. They might be fatal flaws, or they may result from lack of detail or clarity.	No, the article is well written, and the results clearly considered	1
Total score out of a possible 23		**22**
Lam, M. M. L., Pearson, V., Ng, R. . K., Chiu, C. P. Y., Law, C. W., & Chen, E. Y. H. (2010). What does recovery from psychosis mean? Perceptions of young first-episode patients. International Journal of Social Psychiatry, 57, 580 - 587.	**Justification**	**Score (0 or 1)**
1. Is the research question interesting?	Yes, the aims of the study are clearly stated and are interesting	1
2. Is the research question relevant to clinical practice, public health, or policy?	Yes, relevance to clinical practice is explicit within the introduction	1
3. Is qualitative methodology the best approach for the study aims?	Yes, although not described and justified	0
4. Are the participants selected the most appropriate to provide access to the type of knowledge sought by the study?	Yes, young people with an experience of psychosis	1
5. Is the sampling strategy appropriate?	No, a very small window for inclusion was used and strategy not explained clearly	0
6. Was recruitment conducted using appropriate methods?	Not enough detail given	0
7. Could there be selection bias?	Yes, a very small time frame for selection was used (two weeks) of 35 young people invited only 6 agreed which may have resulted in a very biased sample	0
8. Was collection of data systematic and comprehensive?	Yes, a clear table given with discussion guidelines	1
9. Are characteristics of the study group and setting clear?	Yes, presented in a clear table	1
10. Why and when was data collection stopped, and is this reasonable?	No justification given for only one focus group with small sample	1

11. Is the researcher(s) appropriate? How might they bias (good and bad) the conduct of the study and results?	Yes, multiple researchers and experience of researchers explained in the text	1
12. Was informed consent sought and granted?	Yes, clearly stated	1
13. Were participants' anonymity and confidentiality ensured?	Not discussed	0
14. Was approval from an appropriate ethics committee received?	Not discussed	0
15. Is the type of analysis appropriate for the type of study?	Yes, content analysis	1
16. Are the interpretations clearly presented and adequately supported by the evidence?	Yes, clearly presented with sub headings	1
17. Are quotes used and are these appropriate and effective?	Yes	1
18. Was trustworthiness/reliability of the data and interpretations checked?	Yes, three researchers, notes during the focus group taken and consensus reached	1
19. Are findings sufficiently grounded in a theoretical or conceptual framework?	Not explicit within the discussion section	0
20. Is adequate account taken of previous knowledge and how the findings add?	References are given but the discussion does not explicitly link the current findings with previous / existing knowledge	0
21. Are the limitations thoughtfully considered?	Several limitations are considered	1
22. Is the manuscript well written and accessible?	The manuscript is clearly written	1
23. Are red flags present? These are common features of ill-conceived or poorly executed qualitative studies, are a cause for concern, and must be viewed critically. They might be fatal flaws, or they may result from lack of detail or clarity.	This is a very small sample with some methodological limitations. Greater clarity is needed as to recruitment and choice of analysis. The authors needed to be more explicit about how the findings add to the existing literature. However the result section is clear with some interesting quotes and as such can be included in the review	0
Total score out of a possible 23		**14**

Appendix C: Recovery elements within each paper

Elements of recovery explicit within paper	Paper Title
Loss of self	**Recovery from first episode psychosis: A dialogical perspective**
Strengthening of self	
Who they were prior to illness	
Lives interrupted	**Reshaping an enduring sense of self: the process of recovery from a first episode of schizophrenia**
Encountering the illness	
Engaging in services and supports	
Re engaging in life	
Envisioning the future	
Re-shaping an enduring sense of self	
Symptom recognition	**Changing perceptions of illness in the early course of psychosis: psychological pathways to self-determination and self-management of treatment**
Awareness of change	
Negative appraisals	
Positive appraisals	
Treatment self-management	
Engaging in highly valued activities	**Well-being and engagement in valued activities: Experiences of young people with psychosis**
Making meaning	
Expressing thoughts and emotions	
Changing physical, emotional and cognitive states	
Cultivating skills, strengths and virtues	
Connecting and belonging	
Making a contribution	
Social support	**A qualitative analysis of influences on recovery following FEP**
Medication	
Meaningful activities	
Lifestyle modification	
Unhelpful - stigma, substance abuse, medication side effects	
Being listened to	**Qualitative exploration of empowerment from the perspective of young people with psychosis**
Being understood	
Taking control	
Making decisions for self	

Adjusting to distress of past experiences	**Distress trauma and recovery: Adjustment to FEP**
Uncertainty	
Challenged identity	
Being in a psychiatric system	
Reaction of others	
Social disadvantage	
Meaning of psychosis and psychotic experiences	**What does recovery from psychosis mean? Perceptions of young FEP**
The meaning of recovery	
Stigma	
optimistic view of recovery	
Experiences of self-estrangement	**Recovery from FEP and recovering self: A qualitative study**
Self-consolidation	
Loss of control	**The responses of young people to their experiences of first-episode psychosis: Harnessing resilience**
Harnessing resilience	
Experience of psychosis	**Experience of recovery from a first-episode psychosis**
Elements contributing to recovery	
Perception of recovery	
Positive adjustments and successful individuation	**Recovering and emerging self: Exploring reflective function in recovery from adolescent - onset psychosis**
Unresolved adaptation and blocked individuation	

Appendix D: Ethical Approval

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Appendix E: Initial Letter to Recovery College Students

Canterbury Christ Church University
Salomons Centre for Applied Psychology

Sussex Partnership NHS
NHS Foundation Trust

Dear Recovery College Student

We are writing to you because you have previously indicated to the Recovery College that you are interested in taking part in research projects. We are running a new project about hopefulness and are seeking individuals who are 16 - 26 years old and have had an experience of psychosis.

The research will involve being available for an interview at a location convenient to you. This interview will last approximately one hour. During this interview we will ask you some questions and ask you to tell your story about moments of hope. All information will be treated in confidence.

If you are interested to hear more about this research project, please text or email me and I will contact you with additional information. If you are not interested, you need do nothing further and we will not contact you again regarding this project.

Email: v.bonnett134@canterbury.ac.uk
Mobile: 07468 88 98 34

Yours sincerely

Victoria Bonnett
Trainee Clinical Psychologist and Chief Investigator

Version 3 13.07.15

Appendix F: Participant information sheet

Canterbury Christ Church University

Sussex Partnership NHS
NHS Foundation Trust

Salomons Centre for Applied Psychology

Participant information sheet

Research Title: Hopeful and included: An exploration of domain-specific hope and social inclusion
Researcher name and title: Victoria Bonnett, trainee clinical psychologist.

We would like to invite you to be involved in our research study. Before you decide, it is important that you understand the purpose of our study and what you will need to do. We would like you to read the following information. It is important that you read this sheet carefully and note any questions you may have (if any). It may be helpful to talk to others who know you if you want to, it may help you decide whether it is a good idea to take part. Please ask us if there is anything that is unclear or if you have any further questions.

Thank you for reading this.

Part 1: The purpose of our study and what will happen to you if you choose to take part.
What is the purpose of the study?
We are interested in how people experience hope, when you feel most hopeful and whether there are areas of your life which feel more hopeful than others? This will then help professionals understand and plan better treatment.

Why have I been chosen?
We are inviting people to take part if they are receiving a service from a Sussex Early Intervention in Psychosis service. We are also asking people attending a Sussex Recovery College to take part, if they have experienced an episode of psychosis within the last year or have a current diagnosis of psychosis. We are only inviting people aged 16 to 26 years to take part.

You have been invited to take part because you have previously indicated that you are happy to be contacted about research opportunities.

Do I have to take part?
You do not have to take part. It is important that you read this information and consider whether you wish to share your story and experience. This is your decision. You may wish to talk with people who know you before deciding. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?
If you decide that you would like to share your story and experiences with me (Victoria), we will arrange a time that suits you in which to meet me somewhere convenient to you. We will go through the research information again and you can ask me questions. I will then ask you to sign a consent form. This will ask if you have read and understood information about this study. I will ask a few background information questions such as your age and gender.

What do I have to do?
I will ask you to tell your story. I will ask a few questions about your story as you are telling it. We will have a private space in which you can tell your story. I will only need to meet with you once. This might take between one and two hours. However, if you are interested in what I have found out, you can speak with me on the phone at a later time. I can also send you a summary to read.

Where will we meet?
We will meet somewhere convenient to you. This might be your home or it might be a research base such as a clinic near you. We can refund your travel costs up to £10.00 and I will ask you to sign a form for these.

Is there anyone who should NOT take part?
Unfortunately, we cannot invite you to participate if you cannot take part in an interview or give informed consent in English.

What are the possible disadvantages and risks of taking part?
Although this research is focusing on positive experiences of hope, it is possible that discussing difficult experiences may raise uncomfortable emotions or remind you of an unhappy time. It is important that you consider this before agreeing to take part. The interview will go at your pace and you can ask for a pause or to stop entirely at any time without having to give a reason. The interviewer (Victoria) will also ask to pause the interview if it appears to be causing distress for you. You do not have to answer any questions or speak about any experience you do not want to. There will be time for you to ask questions both before and after the interview. We will ask you for a contact number of someone who supports you. We will ask you if we can contact this person on your behalf should you appear distressed at any point during our meeting.

What are the possible benefits of taking part?
We cannot promise that the study will help you but the information we get from this study may help us to improve our understanding of hope, young people and psychosis. This may help us improve treatments.

What do I do now?
I will contact you to ask whether you agree to take part and you can ask further questions about the research if you need to. If you would like, I can also speak with someone who knows you well to answer any questions. If you say yes, you would like to take part, then we will arrange a time for the interview, we will meet and I will give you a consent form to sign and then we will have the interview. If you say no I will not contact you again.

Part 2 has further information for you to read if you would like to take part in this research.

Part 2: More detailed information regarding results, consent and funding.

What will happen to my story?
We will voice record your story whilst you tell it. This recording will then be kept on an encrypted and password protected memory stick. Any information from your interview will be anonymised before it is used. We will follow ethical guidelines and keep ALL your information securely by separating your contact details from your interview. No one else will have access to your identifying information.

Further information from you
Following your interview we will ask you if you would like to complete an online diary once a week. This will be for a total of four weeks (four diary entries). Each week we will send you a link to the diary. This means that we would need an email address that we could send a link to. The same rules of confidentiality will apply both to your email address and to your diary information. You may wish to discuss this part of the study with someone who knows you well before deciding. This is an additional part of the research. You may choose to take part in just the interview, it will be your choice.

Confidentiality
We will ask your permission at the start of the study to let your GP or care team know that you are taking part in this study. We will let them know the date of our interview. We will not share your story with your GP or care team.

Your story, diary entry (should you choose to complete this) and information will remain anonymous and confidential unless you tell me, Victoria Bonnett, something during your interview, or diary, that suggests that you or another person is currently at risk of harm. I would need to pass this on to my supervisor and to your care team. I would discuss this with you.

You will be given a code which links you to your story. This means that we do not store your name with your data.

The audio-recording will be stored after the study has finished on a password protected CD along with the anonymous written record of the interview. This will be kept in a locked filing cabinet in a specified office in Canterbury Christ Church University. This will be kept for 10 years.

The data may be used at the University of Sussex. This means that further analysis will be conducted to study the data in more depth. The same rules of confidentiality will apply. The University of Sussex will be given your code against each story but will not have a list of names or addresses. They will not be able to identify you from this data.

What will happen if I don't want to carry on with the study?
If you decide to withdraw from any part of the study, we will ask you if we can still use your interview or diary entries to that point. If you say no, we will delete all records of the data you have given us using the unique code we gave you. This will not affect any future care you may need or, if relevant, enrollment on Recovery College courses. It is your choice to take part or not to take part.

What if there is a problem?

We do not expect problems to arise, but should they, you would be able to make a complaint to the Research Director (details at the end of this information). If you have a concern about any aspect of the study, you should ask to speak to me in the first instance, and I will do my best to address the issue to your satisfaction. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Paul Camic, Research Director, Christ Church Canterbury University, Broomhill Road, Tunbridge Wells, TN3 0TF. Telephone: 03330 117 114.

You can also contact the Patient Liaison Service complaints@sussexpartnership.nhs.uk or telephone - 01903 843049. Details can be found here
http://www.sussexpartnership.nhs.uk/patient-advice-and-liason-service-pals

Additionally, although we do not expect anything to go wrong, in the event that something does go wrong and you are harmed during the research and this is due to someone's negligence than you may have grounds for a legal action for compensation against Canterbury Christ Church University or Sussex Partnership NHS Foundation Trust, but you may have to pay your legal costs. The normal National Health Serve complaints mechanisms will be open to you. In addition, both the university and the researchers associated with this project have indemnity insurance.

What will happen to the results of the study?
It will not be possible to identify you in the results or in the report. The results will be used to form part of a doctoral thesis for a doctorate in Clinical Psychology at Christ Church Canterbury University. A report about the study will also be submitted to a journal that publishes research into mental health. All data will be anonymized so that no one person can be identified. If you wish, when the project has finished we will send you a letter describing the major findings and letting you know if the findings will be published.

Who is sponsoring the Research?
The study is being organized and funded as part of a doctorate at Canterbury Christ Church University.

Who has reviewed the study?
Before any research goes ahead it has to be checked by a Research Ethics Committee to make sure that it is fair. Your project has been checked by the NHS Ethics Committee, by SPFT research and development board, Canterbury Christ Church university research panel and the Early Intervention Service research and audit governance group.

What If I Have Questions about the Project?

Please contact Victoria by email at v.bonnett134@canterbury.ac.uk
By post at
Salomons Centre for Applied Psychology
Canterbury Christ Church University
Runcie Court
Broomhill Road
Tunbridge Wells
TN3 0TF
Or by telephone message - 07468 889834

You can also speak with your care team or contact SURF for advice. SURF is a service user research forum.

http://www.sussex.ac.uk/spriglab/people/surf

Appendix G: Consent form

Canterbury Christ Church University

Sussex Partnership NHS
NHS Foundation Trust

Patient Identification Number:

CONSENT FORM

Title of Project: Hopeful and included: An exploration of domain-specific hope and social inclusion

Name of Researcher: **Victoria Bonnett**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated **13.07.15** (version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to the use of audio-taping, with possible use of anonymised verbatim quotation which may be used in a doctoral thesis or within published research. ☐

4. I agree to my care team/ consultant psychiatrist /GP being informed of my participation in the study. ☐

5. I agree to take part in the above study. ☐

Preferred Contact (e.g. telephone number or email) _____

Support contact details _____

Name of Participant	Date	Signature
Name of Person taking consent.	Date	Signature

Consent form date of issue: **13.07.15**
Consent form version number: **version 4**

Appendix H : Interview schedule

Interview schedule

For all interviews:

As we go through life there are times when we feel more, or less, hopeful. I'm interested in what you think hope is and how you think of it?

Can you remember back to the earliest time you felt hope?

Prompts such as:

What was that hope like?

What did you see for yourself in that hope?

Going on from there, when was the next high point?

And what happened next?

Can you tell me a bit more about that?

Can you remember anything that happened in between?

When you look back on that now, what do you think?

Can you tell me how your hopefulness has gone up or down since then?

Did the experience of psychosis challenge hope in any way? In a particular area of life?

That time must have been a lot of different things for you, confusing or with elevated or low mood - what was that like for hope?

[If not already covered] I would like us to think now about hope which might motivate you towards a particular goal. We may feel hopeful in one area, or two, but not necessarily all areas of life. Or, we may feel hopeful in different areas at different times, for different reasons. I am interested in how and when you experience hope and whether this has gone up or down for you.

Are there areas of your life which feel more hopeful than others?

Prompts such as:

Do you have an idea why this might be?

Are there times that this might change?

Focusing on particular goals and life areas mentioned:

How did/does your hopefulness relate to this life area/goal?

How did/does your hopefulness relate to your activities or how you spend your time [i.e. social life, work/study, hobbies and leisure]?

***Probe associations mentioned as appropriate*: How do you think your hopefulness has influenced your activities/achievements? How do you think your activities/achievements have influenced your hopefulness?**

***Prompt to explore exceptions*: Have there been any situations where this has not been the case?**

Additional questions

You've told me about a few times when you have felt hopeful. I wonder if you could tell me if you remember a role other people might have played at those times. It is quite possible no one did, but if they did I am interested what role they played.

Possible prompts if the role of others mentioned:

Who are these other people?

How have they been involved?

How did these people influence your hopefulness?

***Prompt to explore exceptions*: Have there been any times when this has not been the case?**

If difficult - what do you think of other people with similar experiences? Who is more / less hopeful than you?

How do you view hope in your day to day life?

Is this different to when you were younger (before your diagnosis?) (orient to a particular time)

What is different about your day to day life when you're feeling more hopeful?

Version 2 4.4.2015

Appendix I: Demographic questionnaire

The information reported on these pages will be confidential and will be kept separate from your interview. These details will not be made available to anyone other than the chief investigator Victoria Bonnett. Any data reported will be anonymised.

Full Name	
Date of Birth	
Preferred method of contact **(please tick)**	Post ☐ Telephone ☐ Email ☐
I would like to be sent an over view of the results of this study at the end of the project.	Yes ☐ No ☐
Gender	
Course enrolled on (or completed) at the Recovery College (if applicable)	Date of course (month / year)

ABOUT YOU			
Do you use any services or see anyone from Sussex Partnership or have you in the past six months?		YES	NO
Please give details of service (if known)		Length of time with service? .....years / months	
Do you see anyone or use any other service related to mental health and recovery e.g. Southdown, Together, Mind, Alzheimer's Society?		YES	NO
Please give details of service (if known)		Length of time with service?.....years / months	
Are you a carer, relative or friend of someone who uses mental health and recovery services?		YES	NO
Do you have a mental health diagnosis? (please give details if you are able) Prefer not to say_____		YES	NO
Are you currently on medication to support you with this? Prefer not to say_____		YES	NO

Ethnic Origin *(tick one box)*			
White	**Mixed**	**Asian or Asian British**	**Black or Black British**
☐ British ☐ Irish	☐ Asian and Black Caribbean ☐ Asian and African	☐ Indian ☐ Pakistani	☐ Caribbean ☐ African

☐ Gypsy ☐ Irish Traveller ☐ Polish ☐ Other European *(please specify)* ..... ☐ Any other White background *(please specify)*	☐ Asian and White ☐ White and Black Caribbean ☐ White and Black African ☐ Other mixed background *(please specify)*	☐ Bangladeshi ☐ Chinese ☐ Japanese ☐ Thai ☐ Other Asian background *(please specify)*	☐ Sudanese ☐ Any Other Black background *(please specify)* ..... **Other ethnic group** ☐ Arab ☐ Turkish
	☐ **Any Other Ethnic Group** *(please specify)*		☐ **Prefer not to say**

Religion *(tick one box)*		
☐ No particular religion	☐ Christian	☐ Pagan
☐ Agnostic	☐ Hindu	☐ Rastafarian
☐ Atheist	☐ Humanist	☐ Sikh
☐ Baha'i	☐ Jain	☐ Spiritualist
☐ Buddhist	☐ Japanese (Shinto)	☐ Prefer not to say
☐ Catholic	☐ Jewish	☐ Other *(please specify)* .....
☐ Chinese (Taoist)	☐ Muslim	

Appendix J: An example of an interview transcript

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Appendix K - An example of the questions asked of the narratives: **Sam- Interview 8**

Are metaphors and / or symbols used in the narrative or to describe the narrator's conceptualisation of hope?

- mental illness as being underwater, life as a festival, 'It's almost like a lot of the experience was a video game'

Are there salient themes or tones throughout the narrative?

- Theme of researching the self
- third person narrative

  Sam had an intellectual and interested tone throughout with a sense that he had really considered the topic and what it meant to him. At times I felt as if Sam was delivering a lecture to an interested student and was slightly removed from his own experience.

  5 -*'it's interesting because it's the language which traps us with buying into the language we're also buying in to how it associates it's meaning as opposed to independently creating meaning for ourselves'*
- A story of spirituality and discovery

  68 -' *You see when I think about hope I think about its associations to spirituality and religiosity'*
- not knowing and confusion leading to loss of hope (period of hospitalisation)

Is one dimension of hope more salient than another - what type of language is used to describe hope?

- 'a private as well as collective affair'
- a shift from 'not okay'

---

2 -'*what I think about when I think about hope signifies that there is something in the immediate now that is not ok. So it's a kind of emotional state, gripping to alter the state of affairs that is now*'

- enablement linked with well-being and functionality

Is hope conceptualised with a sense of agency?

- Different explanations led to different feelings of agency with a biomedical explanation meaning for Sam that he had little control over his experiences which was disempowering

  107 -*'... if I buy into it being a psyc...biochemical thing as opposed to a social cultural and psychological thing predominantly..that's got major implications. That's got major implications. The minute I say, I believe it's a chemical thing it means I've got no control over it.'*

  108 -'*Well, If I said it was a psychological thing, we could think about how we would think about our position differently....er...you can think your way out of this essentially.'*

  109 -*'... if you start to call it a biochemical thing you are disempowering yourself. ..*'

  110 -' *Hope, hope is for the chemicals to be ok'[if that is the explanation = disempowering]*

- hope is tied in which different internal states

  31 -'...*Hope didn't really play out because so much is spontaneous, your flight of ideas so they say and a kind of symptom of it, you're actually.....I wouldn't describe it personally as a flight of ideas but you're creatively gauging and enacting and acting upon things that are occurring in your consciousness ...It's actually multi layered, it's hope and despair and desire and excitement and fear and loss, all happening themes*'

What roles are featured within the narrative that possibly promoted or hindered hope?

- therapeutic encounter seen as enabling hope if supportive, encouraging towards functioning capacity

  48 -'*but the whole experience was unsettling, disruptive and traumatic to be honest compared to an actual therapeutic encounter I would say that would be more*

encouraging, nourishing and supportive to getting you to a state where you could function. If hope comes into play in a therapeutic encounter in terms of beginning your functioning capability, as that's as neutral a term as possible without making it seem like you need to correct a patient's behaviour'

54 -'eventually I had to take a break because I felt gridlocked in the therapeutic encounter, it felt like I wasn't actually.....helping my situation, felt like maybe I wasn't there for the right reasons, or maybe the ways in which the therapeutic encounter was meant to help were not the ways I wanted to receive help'

- Sam seemed to have a strong sense of agency in making choices to manage and direct his recovery and making his own sense of his experiences

  57 -' *So, like doing stuff on my own away from any subjective contamination other people involved in my process'*

What domains are emphasised within the narrative e.g. work, study, friendships?

- study and research

Is there a clear distinction between the narrator's distressed self and the non-distressed self?

- Sam describes the experience of psychosis as a change from one life, one person to being another with new experiences making up that person

  13 -*'I feel like the psychosis that I've gone through, the periods of psychosis kind of ended a death.. of a part of me...'*

- the experience of hospital was distressing

  22 -'*Because there was no diagnosis. Everyone is entitled to one case of psychosis..you know psychotic of psychosis period um..it was so extravagant and such beauty fused with such a lot of..towards the end part of the experience such a lot of psychotic mess I guess if I'm buying into that meant you know there was a lot of info...a lot of stuff to reflect upon but I wasn't in a position to. In a way, the traumatic side of the experience was more so in the actual um ward experience than the actual experience itself'*

23 -'*Because you don't know who's who in the zoo. Everyone got their own little thing going on but you don't necessarily know. I'm quite an outgoing person, I like speaking to people, being with people. I get a natural buzz from that and getting to know people. So when you've got a character like that in a circus of people who want to just be on their own, and also who switch between being on their own and also wanting to be as extroverted as hell ...and you've got eating disordered and you've got ..there..there...there..and so forth, the dynamic becomes, it almost lends itself naturally to being quite paranoid because you don't* if *someone is out to get you'*

Reading and researching has helped Sam

100 -' *that's my kind of personal journey, really distinguishing between challenging something intellectually and embracing something practically to help, enable, the ...just your way of being'*

Is there a turning point in the narrative which clarified the temporal sequence of the narratives from pre psychosis experience to post?

- hope came via knowledge after the experience of psychosis when Sam was able to read up about his experiences
- There is a sense that Sam is still 'turning'

How does the participants' narrative relate to the literature on hope within recovery?

- Sam is conceptualising hope as enabling -with agency, goals and pathway

70 -'*...well-being, terms like this as being aims as opposed to hope which lends itself to the delusional capacities to which you first started your manic episode. Hope is very much for me, like in an expectation arena, if you're in an expectation arena then you've got the capacity to go off in delusional tendrils and beyond essentially, does that make sense'*

71 -*'well health and well-being, so if I've reconfigured hope to be more enabling, and well-being as a desire to be...to function and to be, then you're talking about very er.....very concrete and practical things. You're talking about walking, you're talking about meditating...'*

Are there other aspects of the story which are relevant to the research questions, or give rise to further questions?

- the way psychosis is explained, not necessarily concordant with young person's own interpretation of psychosis

  45 -'*when I'm interacting with NHS services therapeutic encounters in some form or another, why there is no explanation given to you in the framework of spirituality or spiritual commonality between cases of psychosis. Like surely, if a common feature of manic episodes is that messianic complexes are developed how is that not fed back to the patient in terms of some kind of form of explanation or food for thought*'

  103 -'I think it was the gap in which people didn't offer me in which I expected a lot of that to actually...it sounds like a lot to expect right? And it sounds a bit outrageous but I think that knowing about, very simply how other people in the world deal with mental health is actually something that should be incorporated into the account that you have'
- experience of hospital being more distressing than the experience of psychosis
- feeling of shame

  20 -'*the shame cycle is really prevalent, it was for me the first psychosis..it was like fuck, I've just been through something, I don't know what I've been through I'm not even in a position to make sense of it and no one is going to understand it and it's all my fault because it's from within*'

Appendix L – Participant profiles

NB: All names of people and places have been replaced by pseudonyms to protect confidentiality

Sophie – Interview 1

Summary:

Sophie was a 26 year old single woman. She was living in her own home with her two young children. It had been 18 months since her first episode of psychosis. Prior to her psychosis, Sophie described herself as very giving and optimistic and seemed quite independent in relation to her mood and sense of hope. Sophie was influenced by her grandmother, 'pushing hope' and this message formed part of her experience of psychosis. Sophie talked about other people helping her following her experience of psychosis with less ability of her own to inspire herself with a sense of hope. In this way Sophie's hope did not originate from her own concrete goals, but from other people who helped her with small tasks and motivated Sophie. This increased her sense of hope in being able to achieve other activities. There is a sense of slowing down in Sophie's story and reduced sense of agency: she starts off as a vital, energetic force promoting hope followed by a slowed down, one step, one day at a time approach. Sophie talked about hope as a force – 'pushed hope' and as a feeling - a belief in change for the better. The language Sophie chose to talk about her message of hope was interesting; 'inflicting' and 'pushing'.

Beginning:

Sophie described being a very spiritual and hopeful person prior to her experience of psychosis, with a sense of spirits around her. This may have stemmed from her relationship with her grandmother who Sophie recalled as 'pushing hope'. Sophie also described herself as quite competitive, with a motivation to achieve more than others and be the best. Sophie talked about hopeful thinking having a role in her life at this time and as something she wanted to share with others. Hope was talked about as a force, something to 'lift', to grow 'plant a seed' and share and this seemed to be something which had always been a part of her identity. Sophie talked about herself as giving out hope but not really experiencing it back from other people other than her grandmother. Her grandmother always said "Hope never ends".

Middle:

Sophie experienced an episode of psychosis and talked about this developing from her desire to spread the message about hope to try to encourage people to believe as strongly as she did and described herself as 'pushing hope' which she recognised was uncomfortable for other people. Sophie described her experience in hospital as being still focused on others when she would try to play games with people to help them out of a low mood. The experience of psychosis seemed to have challenged Sophie's identity and her sense that she can succeed.

End:

Sophie talked about her current mood, a loss of motivation and hopeful thinking and noted this as a change from her previous energy levels and motivation.

As she talked, Sophie ascribed this mood change to her medication which had levelled her mood to the extent that she no longer experienced low mood, but also no longer experienced a burst of energy or joy.

Sophie talked about her current mood as being temporary with implicit recognition of change over time and she had some hope of achieving previous energy levels in time.

Sophie also described the role of other people in her life and how other people are helping her reconnect with her hopefulness. Being able to accomplish small steps gave Sophie a sense of hope that she could continue and feeling hopeful had an impact on what Sophie could achieve. Sophie appeared to have no sense of agency over her mood and relied on others supporting her to help her achieve those first steps, once she had achieved, Sophie described how she could then feel able to achieve further.

Sophie finished our interview with a reflection on the permanent and inclusive sense of hope

'I don't think hope is ever just in yourself, I think other people can inflict that on you, it never ends, it's like time really, everyone has their own time, but time never ends'.

Tim – Interview 2

Tim was a 23 year old man living with his girlfriend and new baby. It had been 12 months since his first episode of psychosis. Following a distressful early adolescence, Tim had experienced voice hearing. Expecting a new baby gave hope and motivation to change his life for the better. There is a sense of continuity in Tim's story as he moves from distress to hope and concrete, long-term goals. Throughout Tim's narrative there is a sense that having a defined role, such as a parent or a youth leader, motivated him and gave him hope for the future. Tim talked about hope as a future-oriented destination, '*light at the end of the tunnel*' which motivated him towards concrete goals for work and family. Tim's sense of agency seemed to be promoted through his goals and 'doing' and he described less autonomy over his moods. Tim talked about achieving small goals inspiring him towards trying for larger goals. Tim's narrative had a strong theme of achieving and improving over time.

Beginning:

Tim talked about his early life as being difficult, with his parents divorcing which created difficulties between Tim and his dad. Tim described his teens as 'rebellious' and experimenting with drink and drugs

This difficult time seemed to have a direct effect on Tim's sense of hope, *'I didn't have any hope. Was just living in the here and now, not thinking about the future. There was nothing to hope for'.* Tim talked about life being very bleak

Middle:

Tim's episode of psychosis led to some feelings of hopelessness, which seemed to have been extenuated by confusion. Tim's uncertainty about his experience meant he was confused about what he could do; this confusion negatively impacted on his sense of hope. Tim described this time as feeling alone, unsure and not able to see a way forward. It seemed as if Tim hit 'rock bottom' before trying to change things, and he described this as a realisation that he had hit rock bottom followed by a desire to make positive changes.

The news of a new baby seemed to lead to a turning point in which Tim considered his current position and re-evaluated his life and goals and Tim described how even on bad days he wanted to 'fight' because he had his baby to consider as added motivation.

Other people played a role for Tim at this time, and Tim described how listening to other people helped him calm and feel supported.

End:

Tim described his hopes of achieving specific goals in his life very focused around his family and the future, money and housing.

Tim connected his future hopes to his past experiences and used an example of his dad overcoming adversity as contributing to a sense of hope. Tim was able to reconnect with things he had been good at as a younger boy and also things his dad had shown him. These in turn gave him hope, that he could pass skills on and that he could overcome adversity.

The language Tim used when talking about moving forwards sounded very disciplined with a strong sense of agency; *'Forcing myself to go about my daily life and not letting anything get me down, making sure I was continuing on and not letting myself sit and wallow in whatever was going on.'* However, this sense of agency appeared related to achieving concrete goals *despite* low mood rather than autonomy in lifting low mood, *'It's a totally random thing, some days I just wake up in a bad mood.'*

Goal setting and the support of others continues to feature in Tim's recovery journey and hope. Tim talked about feeling involved in his recovery and he welcomed the way his care coordinator kept him informed. Being honest with Tim about his recovery was important for Tim. Tim valued knowing the 'good and the bad' and information gave Tim hope that he would be able to cope. This seemed to resonate with Tim's earlier experience of confusion and uncertainty when Tim had no hope

Mark – Interview 3

Mark was an 18 year old man living in his family home. He had experienced his first episode of psychosis 24 months ago. Mark described himself as an angry adolescent, taking drugs and legal highs. Mark's experience of psychosis acted as a pause in a chaotic life and resulted in a change of direction. There is a tentative tone in Mark's narrative and uncertainty, but a theme of life improving, with psychosis acting as a catalyst for change. Mark's hope was focused on college and a concrete goal of gaining an apprenticeship. There was a sense that he was trying to 'catch up' with peers who had already finished college. Mark seemed to transition through his narrative from feeling isolated to knowing that 'someone cares'. Mark described hope as being both goal-oriented and as a feeling; '*It's like, you hope for something and there is hope that's just a feeling'.* Mark attributed a happier mood to feeling hopeful.

Beginning:

Mark had experienced a difficult time during his younger adolescence and described himself as either angry or annoyed. Mark described how his circle of friends at this time weren't good for him and were people he drank and took drugs with. Looking back during his narrative Mark evaluated his friends as not being good for him and as part of his motivation to take drugs.

Middle:

Mark experienced drug induced psychosis and this period of his life sounded lonely and confusing without any particular hope. Mark described a period of loneliness when he went into hospital. He said that he lost all his friends at this time and couldn't talk to anyone.

Mark's first hope following his experience of psychosis was for a change in his friendships and this appeared to be a recognition of needing support to change his life, old friends would lead to old habits. Mark attributed this first feeling of hopefulness to receiving medication, which he said helped lift his low mood.

End:

Mark talked about planning as important and sense of someone caring, for example, friends to keep away from drugs, mum to get to college, care coordinator. Other people providing motivation to move forwards; Mark mentioned feeling more hopeful at college which suggested a spatial-relational environmental effect on his sense of hope.

Mark expressed warmth towards his friends helping him stay off drugs and a sense of feeling good and that friendship was something possible for him. This sense of feeling cared for was also repeated when talking about his care coordinator and Mark talked about how they made a plan for the year and Mark was involved and included.

Ben - Interview 4

Ben was a 22 year old man living at home with his mum. He had experienced his first episode of psychosis eight months ago. Before he became unwell Ben described himself as confident and outgoing, he talked about having a lot of energy. During his narrative, Ben's mum made links between taking drugs and Ben's experience of psychosis and Ben's narrative became a re-evaluation of his early life with themes of improvement, determination and 'starting over'; making changes rather than returning to his previous lifestyle. Ben talked about hope as '*a light at the end of the tunnel'* and a helpful belief, a sense that life will improve; *'I believe it is good to believe in hope it just lifts you that little bit more.'* Some interesting imagery arose throughout Ben's narrative of movement, a journey of recovery, *'… I can get through it and come out the other side'.* Ben seemed to have reached an acceptance of his experience and incorporated this into his self-identity; '*What doesn't kill you makes you stronger. I believe if I can get through that I can get through most things. A lot of my friends won't suffer a nervous breakdown like I did I always think there's a light at the end of the tunnel'.* Ben was currently experiencing high levels of anxiety but was taking positive steps to try to overcome this.

Beginning:

Ben described his early life as '*rough*', his dad had died when he was little, but he talked about 'getting on with it' which was a reoccurring theme of resilience and determination throughout his narrative. Ben talked about a successful mid-adolescence and then recounted how he started taking drugs following a job loss when everything seemed to get worse for him.

Middle:

Ben's experience of psychosis started with depression, drug use and then a nervous breakdown which resulted in a period of hospitalisation. This was a period of confusion for Ben in which he couldn't remember much other than a 'racing mind' and a nervous breakdown.

Looking back on the role of other people at this time, Ben had found his family supportive as well as professionals. Ben valued his family visiting him in hospital and felt that they cared for him and his recovery. Ben also talked about the nurses and it seemed as if he perceived a high level of personal care from them which made him feel supported.

The support of his family and professionals appeared to have provided balance to a possible sense of abandonment from friends. Ben described how some friends have distanced themselves and struggled with his mental health difficulties.

End:

Ben's experience seemed to have added to his sense of self and his narrative elicited images of a journey with movement expressed in the language he used, *'what doesn't kill*

you makes you stronger' and he was reflective about his experiences, talking about his recovery as gathering momentum, *'like running before you can walk, like a couple of months ago, I couldn't walk I could crawl, but now I'm thinking I can walk a lot faster now'.* Ben's trajectory since leaving hospital appeared to have been one of re-evaluation and moving forwards.

Ben had recently experienced a shift in his well-being moving from a position of anxiety to one in which he felt more hopeful. He attributed some of this to medication, but had also been active in making changes to his life style such as avoiding environments which might remind him or earlier bad times such as clubbing. Ben was also making a conscious effort to eat more healthily and go to the gym.

Ben expressed additional hope and motivation to move forwards and make changes in order to avoid a relapse. It seemed that Ben had a new awareness of his capabilities of coping. Ben's talked about his sense of hope as a reflection on his experiences which also gave him hope for the future and getting back to work as a hope, *'I'm always hopeful because I've come such a long way, so I believe it is good to believe in hope it just lifts you that little bit more'...*

Gary - Interview 5

Gary was a young man of 22 years who had experienced his first episode of psychosis 3 months previously. Gary lived in his family home with his parents. The tone of this narrative felt very slow and static with themes of isolation and low mood and images of being 'adrift'. Gary seemed competitive and high achieving referring often to school, university and a career. Hope was conceptualised as a change in the future, in quite big global terms. Gary had a concrete goal of a successful career but seemed disconnected from hopeful thinking and a sense of agency at the time of his interview. Gary did not yet seem able to articulate a way forwards beyond the immediate present. Gary also appeared disconnected from his peers which was perhaps reflective of how recent his FEP was.

Beginning:

Gary described himself as competitive and being able to compare himself to others as motivating. Gary had gone to university, but struggled a little which precipitated depression and subsequently his episode of psychosis. A lack of a plan seemed to have led to low mood and Gary described a loss in motivation following university exacerbated by not being able to find work. The lack of structure appeared demotivating and Gary described himself as drifting.

Middle:

The combination of a difficult time at university and being unable to find work appeared to have led to low mood, followed by an episode of psychosis. Gary described feeling hopeless

and expressed his difficulty in working with services at this time. This seemed exacerbated by seeing several different people and repeating the same information each time.

Gary's experience also distanced him from his peers, and there seemed a sense of loss for Gary at his friends all being still at university. Gary's need for a comparative frame of reference was evident at several points throughout his narrative and at this time, the lack of this appeared to contribute / maintain[?] his low mood. However, Gary did identify a turning point from feeling in despair to starting to recognise that he could move forwards, after he had 'got his head' around his diagnosis.

End:

It seemed that Gary had been having an uphill struggle with his low mood with my sense being that he was not quite at the point of recognising positive change. It seemed important for Gary to have some plan in place and the support he identified was around making such a structure, without goals it was difficult for Gary to get a sense of how he was doing and this appeared to be a clash between competitiveness and resilience in the face of challenge, *'… I think it's important for everyone to have goals otherwise there is no real measure of how you are doing, does that make sense?'* [reminded me of my previous thesis into achievement goal orientation and how performance-oriented children cope very well until faced with unexpected challenge and then they lose their frame of reference for measuring their success which leads them to think they aren't succeeding - not sure if I'm being objective here]

Luke - Interview 6

Luke was a young man of 23 years living in his family home. Luke had experienced his first episode of psychosis 6 months previously. Luke described his late adolescence as one in which he had no clear aim or structure, taking legal highs which led to an addiction. Consequently, Luke's experience of psychosis acted as a turning point in his life story and one in which he re-evaluated the direction he was taking and his choices. There were themes of improvement and collaboration with services throughout his narrative and a sense of moving forwards one step at a time. There was an important theme of 'being normal' aided by 'people who understand' and a valuing of role models. Luke's concept of 'normal' appeared to be in the sense of someone who has never experienced mental health difficulties. The tone of Luke's narrative was optimistic with a sense that Luke was trying to keep momentum in moving forwards in order to prevent a relapse. Luke experienced hope as a belief but he also talked about it as motivating, as a 'lift'. Luke appeared to experience a sense of agency in engaging in activities which in turn engendered a feeling of hope, but that sense of agency was missing when Luke was talking about his mood. Luke was currently experiencing high levels of anxiety, but was working hard to take positive steps to overcome this. The value of being with people with similar experiences was a strong feature throughout Luke's story as both promoting initial hope and as a maintenance factor.

Beginning:

Luke described his young self as *'a little shit',* with himself being *'the naughty one'* in comparison to his brother. His adolescence seemed to be dominated by drinking and drug taking and a lack of direction, playing computer games and not really working. The theme of not doing anything came up again as he relayed his early twenties, when he was addicted to legal highs and working odd jobs to pay for his habit.

Middle:

Luke's addiction led to low mood, loss of hope and a period of homelessness which then became a vicious circle as legal highs became a coping strategy.

Luke experienced a 'breakdown' and remembered this time as confusing with low hope. This seems to have been a time when Luke needed reassurance and when this didn't happen (or he didn't recognise it) this affected his hope and belief that things would turn out alright. Luke's description of his time in hospital seemed particularly bleak and he considered he had no future and would just be in hospital. Not understanding what was happening to him added to his sense of hopelessness.

End:

Luke talked about feeling hopeful and recognised his experience of psychosis as a turning point, which helped him beat his addiction. Luke's turning point during his psychosis seemed to come when he met other people who had recovered or were recovering from similar experiences. Luke described how he now wanted to learn which was something he had not previously experienced. That feeling of wanting to learn, coupled with hearing from other people who had succeeded, gave Luke hope and indicated to him that a different future was a possibility.

His experience of enrolling at a Recovery College appeared to have had a significant impact on his motivation and hope, particularly his tutor who had mental health difficulties but also a degree and a career. This seemed at odds with Luke's previous understanding of mental health difficulties and gave him hope plus a sense of belonging. People 'understanding' him is reflected at different points throughout his narrative and is expressed at one point as a worry about stigma, although Luke expressed choice about whether he chose to tell people about his experience or not. This was a challenging and interesting tension in Luke's narrative between disclosing his mental health difficulties in order for people to know and understand him but also then having the bear the risk of being rejected.

Luke also expressed autonomy over his recovery choices, between 'dwelling' and 'getting on with it'.

Luke described how achieving one small thing increased his hope and helped him feel able to achieve further. Achieving small targets inspired Luke to continue and achieve more.

Luke discussed his choices about his recovery and he expressed a sense of agency about activities, which in turn improved his mood. Luke appeared not to feel a sense of agency over his mood and experienced this as beyond his control. Luke linked feeling happy to having hope.

Luke was reflective of his past experiences, expressed envy of his peers who had moved on with jobs and talked about changes he wished to make.

Seb - Interview 7

Seb was a young man of 24 years living in sheltered accommodation. Seb had experienced his first episode of psychosis 7 months previously and was currently being assessed for a possible diagnosis of autism. A search for, or a return to, freedom and autonomy were important themes running throughout Seb's narrative. Seb had experienced his psychosis as a period of confusion and there was a theme throughout his narrative of returning to his '*old self*' with some strong imagery of his experiences representing a *'locked door'* and a scar which would take time to heal. Seb's narrative tone was matter of fact. Seb conceptualised hope as a belief in positive change, *'... hope is a belief, if you can find something, hope is...where you keep up your spirits and you really want to see something happen'* and this was related to other people / shared experience. Freedom represented renewed hope for Seb, but he found it difficult to identify anything he could do to promote hope. Creativity was important to Seb and something within which he experienced joy. There was a sense that art making gave Seb a sense of mastery which in itself was empowering.

Beginning:

Seb described himself as coming from a '*good working background*' and having been through school and college knowing nothing about '*mental health'*. He enjoyed art and had been planning to get a job and a flat before his experience of psychosis.

Middle:

Seb narrated his experience of psychosis followed by being 'locked up' in hospital, *'I thought there was no future'*, and portrayed his confusion at this time in a way that made it feel like it was a very recent, accessible memory. This was a period of confusion and uncertainty for Seb with the experience of being locked up and the lack of understanding contributing to a lack of hope.

Being given some more information increased Seb's sense of hope and this appeared related to not being 'locked up' forever which enabled him to hope that things would improve, he would get his 'old self back'.

End:

In his narrative, Seb's distress at his experience was related to being hospitalised and once he was discharged his hope increased / returned *'being discharged my hope was better, the*

sense of that freedom, going out from the door'. Seb reflected that his experience of being in hospital, rather than psychosis per se, had changed him. Being able to walk about, eat what he liked and choose activities all appeared to be contributing to Seb's sense of recovery and enabled him to look ahead. Seb appeared very mindful that recovery would take some time and referred to his experience as a 'scar'. Seb's experience of psychosis was represented as an interruption within his life, but one he could incorporate into his identity and then continue as before, as his 'old self'.

Sam - Interview 8

Sam was a young man of 22 years. He had experienced his first episode of psychosis 36 months previously and at the time of this interview had a diagnosis of bi polar. Sam was living in student accommodation and currently completing a degree. There was a theme throughout Sam's narrative of a research of self and the tone was a mix of an intellectual third person narrative and a strong spiritual awareness[3]. The imagery was vibrant throughout with a mix of spiritual symbols and life metaphors, mental illness as being underwater[4], life as a festival, 'It's almost like a lot of the experience was a video game'. Sam described hope as starting from a place of despair and recognition that another emotional state is possible even if not explicitly hopeful. Sam differentiated between an inherent state versus an external situation, for example being in despair versus being in a difficult situation.

Sam also described how hope seemed more of a religious term and he preferred enabling as more neutral. For Sam it seemed that hope represented a sense of enablement that shifted him from not okay to okay. Sam described hope as 'a private as well as collective affair' which was also reflected in the activities which he considered helpful to his recovery. These were solitary activities in which he would encounter people, but then separate with no emphasis on further engagement or dependency. In this way Sam seemed to have a strong sense of agency in making choices to manage and direct his recovery. Sam also described his sense of hope within therapeutic encounters and personal wondering about the way in which professionals explained psychosis. It seemed as if professionals needed to meet Sam where he was at and explore the type of help relevant to Sam, when this did not happen, Sam took a break from therapy. Sam was very thoughtful about the language used within mental health and how it can be difficult to work out the individual meaning of something as terms and labels can be so laden and consequently disempowering.

[3] I think that what was evident was my problematising of the word and concept of hope -due to its disregard for the state of difficulty that I was in as i was in it, aiming for a reformation of self as opposed to an investigation and dialog into the complexities of self in a time of difficulty which I consider to be a prerequisite to any other plan of action / hope. And the religious connotations of hope further difficult as it was the over abundance of spiritual symbolism apparent in my psychosis that scarred me towards spirituality period.

[4] the underwater metaphor was only to encapsulate the period of recovery after hospitalization - how distant reality was . -- not during psychosis - psychosis was a hyper reality

Beginning:

Sam described his life prior to his experience of psychosis as hazy. He had a diagnosis of dyspraxia which he described as making his life far more difficult than the experience of psychosis, partly because it had affected him for longer.

Sam had been planning on organising a music festival before his first episode of psychosis

Middle:

Sam's experience of psychosis had begun at the end of a music festival. People were packing up their tents and to Sam it felt like they were dismantling his life. Psychosis was for Sam being at rock bottom, but also a quick succession of thoughts, feelings and colour. Sam described this experience as chaotic but also exciting, almost as if he had abandoned himself to just 'feel' and embrace different experiences and people.

Hope at this time was described by Sam as being in despair and reaching out for change. Sam likened this time to being underwater and looking up, reality was hazy. Sam also described his physical state at this time as being constantly tired, eating too much and a time when he took up smoking. Sam also described a 'shame cycle' of not understanding or being able to explain his experience and a sense that as it came from within himself then he must be to 'blame' for it. Sam described the 'traumatic' aspect of the experience as that of being hospitalised rather than the psychosis per se and this appeared to be related to uncertainty, not knowing who was in the ward with him, or what was happening to him personally.

End:

Sam described his experience of psychosis very eloquently and said that experience had ended the previous version of himself. This gave the impression of Sam being on an onward journey of growth, development and incorporating new learning into his self-identity. Sam spoke with energy and enthusiasm about his experiences and thoughts. Sam described how he first experienced a sense of hope following his first episode when he started to read up on what might have happened to him and then began able to process the experience and recognise certain traits in the literature. Sam's experience was explained to him by professionals in medical terms and Sam questioned why no spiritual explanation was given[5]. Sam compared his experience to those of other countries and the disparity of explanations for what seemed like similar experiences. Sam's ability to read about experiences in other countries / cultures seemed to fulfil a gap left by professional explanations. Different

[5]Questioning why no other explanation was given that addressed the similarity of testimonials/ symptoms of psychosis outside of the medical understanding - not necessarily a spiritual one - however cross-cultural psychiatry informed me as to one such approach to redefining the experience.

explanations also led to different feelings of agency for Sam with a biomedical explanation meaning for Sam that he had little control over his experiences which was disempowering for Sam.

Sam described solitary activities as helpful to his sense of recovery, connecting with nature by taking walks and talking to people, but then being able to separate from them with no further obligation. Sam also talked about changes in the way he thought about himself, some mental health 'safety checks' which helped him monitor his well-being and alerted him if he was becoming unwell, for example asking himself what was bothering him, why did he feel uneasy. Sam seemed extremely self-aware and as if he is on a continual journey of discovery.

Sam talked about other people's reactions to his mood and it seemed difficult for Sam to express heightened emotion such as joy, playfulness or excitement without other people feeling concerned that he was entering a manic state.

James - Interview 9

James was a young man of 20 years living at home with his parents. James had experienced his first episode of psychosis 15 months previously and at the time of this interview had a diagnosis of bi polar. James attributed his change in mood, both positive and negative, to biological change which seemed to reduce James' sense of agency. However, receiving a diagnosis seemed more positive for James and enabled him to look up further information which James found helpful. There was a theme of isolation running through James' narrative with James' mood linked to his sense of productivity. The tone throughout was quite flat. James' concept of hope was goal directed and focused on career and James associated hope with a naturally occurring good feeling like any other which again suggested little sense of agency. There was a sense in James' narrative that he was maintaining a state of status quo rather than progression. Creativity was a strong feature of James' narrative and this seemed to give James a sense of mastery through other people recognising his achievements.

Beginning:

James described how he had taken his GCSEs and how at this time he was feeling relaxed, unpressured and hopeful. He had a place at sixth form and was confident of gaining good grades. James then went on to complete his A levels and begin a university course.

Middle:

James described his experience of psychosis as a time of wild plans followed by being unrealistically pessimistic.

James experienced a time in hospital and commented that he was given medication which slowed him down to an extent he was uncomfortable with. James declined to talk further about this experience, but no longer took medication.

James talked about his experience of receiving a diagnosis and how this gave him a sense of something he could understand and research in order to find out more. James commented that he did not become bi polar when he received his diagnosis but that it enabled him to find out more. Receiving a diagnosis therefore seemed to increase James' sense of agency in some respects. There was a sense that the diagnosis gave James more control over how he felt about his mood states and that even when very low he could know that it would change due to his understanding of his diagnosis. In this way, James also found reading of other people's experiences to be hope inspiring.

End:

James found being creative helped as a coping strategy which took the focus off his mood. James also linked productivity to feeling hope and prevented feelings of hopelessness and this was expressed by James as a reciprocal relationship between hope and productivity. Other people commenting positively on his achievements enabled James to feel able to continue. The more James achieved, the more he felt able to.

Regarding the role of professionals, James reported mixed thoughts - seeing different professionals and answering the same questions was unhelpful and effortful for James, but at times he also appreciated having someone to talk to and someone who showed an interest in him.

Tina - Interview 10

Tina was a young woman of 20 years who lived in student accommodation. At the time of this interview she was mid-way through a degree. Tina had received a diagnosis of Todd's syndrome 48 months earlier. Tina was an immensely hopeful, engaging, warm and optimistic young person. There was a theme of creativity and busyness running through her narrative with a positive, energetic tone. Tina's concept of hope was of positive change, that everything would turn out better. For Tina this feeling of hope was also a feeling of anticipation which Tina described as akin to a feeling of reminiscence. Tina also differentiated between low mood, as a transient feeling which she knew she could just sit with and would shift, and hopelessness as unhelpful thoughts which require her to take some action to change.

Beginning:

Tina talked about the time before her psychosis as not fitting in. She moved about a lot during her childhood and experienced an unhappy time at school during her A Levels which culminated in Tina failing her exams.

Middle:

Tina's experience was slightly different from other interviewees as she had had an awareness of having unusual experiences from a young age. Tina also experienced several moments throughout her adolescence of feeling unusual, for example not been able to differentiate items by touch, having unusual spatial experiences which Tina described as 'blocky'. Tina found her school were unsupportive which increased her feeling of isolation at this time. Her turning point came when she received her diagnosis after her mum discovered an artist with similar symptoms. This enabled Tina to research more about her symptoms, read about other people with a similar diagnosis and Tina described this time as one of hope which has only improved since.

Tina's experience of professionals at this time was unhelpful and found a lack of knowledge of her diagnosis and subsequently being offered epilepsy medication strange and unhelpful. Tina would have found a support group more useful than medication at this time. Tina's narrative at this time had a theme of being alone and unsupported by professionals. Tina commented that following this appointment to confirm her diagnosis she had no further appointments with professionals and it seemed to her as if the diagnosis was the only requirement of the professional. Tina appeared to draw upon a personal resilience narrative at this time and went online to find support and information.

End:

Tina moved from a position which sounded fairly 'stuck' in which she felt her peers were moving ahead of her in ways which would not be possible for her due to her failed A Levels to a position of hope and possibility when she gained a place at university and moved away from home. Having a plan was hopeful and reassuring for Tina and it seemed that the move from uncertainty to a plan was also an ignition of hope. Tina seemed very self-sufficient with a strong sense of agency when it came to moving forwards by researching about her diagnosis on line. This is concordant with her experience of professionals not really understanding her diagnosis or offering support. Tina talked about other people with lived experience of psychosis or mental health difficulties as being supportive of her and it seemed that Tina felt a sense of belonging with these people that she had never felt at school and perhaps didn't quite feel at university despite similar levels of creativity. Tina also talked about her parents as role models and as inspiring her to achieve. Creativity was a theme throughout Tina's narrative which acted to both inspire her forwards, but also as a coping strategy. Tina appeared to be incorporating her mental health needs into her self-identity and making life adjustments as she went in order to achieve a life she was happy with. Being productive maintained a sense of hope for Tina and creativity was a big part of this.

Appendix M: Reflective journal (abridged)

02.07.14 - So, rethinking my proposal. I am quite excited about being more recovery oriented and positive. I'm still struggling with my feelings re time and am reflecting on my background where I had days and days to think, read, think some more and not try and cram it into cancelled appointment slots, evenings around the children etc.

04.07.14 - my personal 'resilience narrative' is that there must always be hope. Sometimes you have to seek it out, but there is always something to hold in mind. Tomorrow will be different.

[Supervisor] shared some of her personal story in relation to my new suggested question. I found this moving and enabled me to start thinking about containing my own emotion around difficult or hopeful stories. I was aware of wanting to know more.

11.09.14 - been awhile since I've given thought to this, other work has taken priority and life. I'm still excited about the idea of recovery and resilience and have reframed my research into a much more positive question which I think fits much better with me. I'm feeling my way around some of the literature, signed up for alerts from the recovery network, which has already yielded some interesting papers, so I'm feeling positive. I do notice that I move quite easily between confidence and panic. Definitely striving for a more even line!

16.01.15 - Well, feeling despondent. Despite a year of work, three re-writes and back and forth to supervisors my research idea has failed to get to ethics. So...starting from scratch. Trying to distance myself from the emotion and reflect on what this says about me and my perceptions of myself and my ability. My self-esteem is extremely low. Flitting between 'I will not be beaten' to 'I can't do this' not sure which will win at the moment. Wondering how this resembles a recovery journey....

06.02.15 - We're back in business! Gosh what a roller coaster of emotion. My supervisor has been working extremely hard on my behalf to sort out a research project and engineered a joint meeting with [trust R and D] research. I was so interested to read back over my reflective log and note my earlier entry about hope - 'my personal 'resilience narrative' is that there must always be hope. Sometimes you have to seek it out, but there is always something to hold in mind. Tomorrow will be different.' - my new project is about hope and at [University] where I worked for ten years and have been the happiest I have ever been - once again feeling hopeful.....

20.02.15 - thinking of ways to make this research resonate with me and trying to read a lot about psychosis. I am interested in the importance of peer support. I have noticed this quite strongly on this course, the strength drawn both from 'we're all in this together' as well as the promise of hope from the year above, that promise that 'this gets better'. I imagine within mental health this must also be important. I remember a client telling me about a book - 'shoot the damn dog' which she said gave her so much hope. 'She got through it so can I'

08.04.15 - I have to keep telling myself this will happen. This ethics form feels like my personal Moby Dick. Reminding me a lot of my MPhil research. I know I like to

consider myself mastery oriented, and I definitely use myself as a benchmark, however I have noticed that external reassurance reduces my anxiety markedly. Feeling 'uncontained' and I am beginning to recognise the roots of this which is helping me regulate myself a little better. It seems as if within my family difficult situations escalate quickly to drama, everyone mobilises, talks to everyone, then things reduce in fact without much else changing. Trying to take a step back and not escalate to drama so quickly!

02.05.15 - thinking a lot about the way I work and recognising a lack of confidence in my own decision making process. Finally booked my ethics panel, so relieved to get a step further along.

08.05.15 -Spent a lot of today's reflective group discussing hope - resonated with me as feel personally a hopeful person as well as MRP thesis based on hope. Discussed whether it has to be a position of hopeful OR hopeless or whether it is possible to hold both positions this is interesting as I am not sure hopelessness is the polar opposite of hopeful. Also raises questions about links with low mood. Discussed choosing a hopeful position as hopeless can be really difficult to sit with.

20.08.15 - the role of the Dictaphone is interesting in my interviews. For some young people, the most interesting comments have arisen once this has been switched off and I've asked permission to also write down what has been said. Also thinking about my position with hope - for some young people early life has lacked hope. Being mindful that my view on hope is not everyone's view. Undoubtedly important to hold hope, yet not always possible.

11.10.15 - Feeling quite emotional after transcribing - some of these young people have had an immensely tough time, yet are still hopeful and are using this time as a catalyst for changing their lives. Some of the confusion of psychosis is evident and yet some of my pre conceptions about medication are absent. My developmental background coming into focus for me and thinking a lot about developmental stages and tasks and what kind of interruption psychosis may represent

15.10.15 - Very long interview, a very articulate young man. I was aware of feeling an enormous amount of warmth towards him during the interview and feeling on a journey as he was articulating his experiences. I notice however as I am transcribing that I have fleeting feelings of irritation as if he is side stepping my questions, or lecturing me. This didn't come across at the time. This for me I think is the tension between being generally interested in a young person, but also having an external motive of achieving a piece of coursework and I think this is where the irritation is coming into play as I am not sure how his answers fit. This is a tension for me that has come up with each case study we have had to write on the course as a whole and being able to hold those two motives as separate constructs.

30.10.15 - Got hung up in this interview on medication and choice. Not really sure where I was going with my questions. I'm not sure if this was influenced by the bracketing interview or whether I noticed more because of the interview, either way I was aware of my supervisor's views on medication and my views on the importance of choice and how I feel disempowered if I don't have choice. Holding medication as necessary seems

to have removed some choice, or some agency. Holding my frustration separate (trying) as I think what this young person is saying and how any hope they hold is conceptualised.

11.12.15 - Reading and re reading the interviews today and wondered about differences between these and the wider recovery literature. Seem to be some interesting concepts within the stories which although quite tentative in my mind, keep popping back up; Other people - giving hope / not alone, Differentiated role of family vs professionals, Hope as a feeling / belief / something which 'lifts', Agency with 'doing' but not with 'feeling'. Also discovered Mishler's (1986) narrative analytic method which seems to resonate with how I wish to view these stories, rather than dissecting them piece by piece: 'This approach identifies the "core narrative." A core narrative is the global theme—an interpretive summary, stripped of all details—drawn inferentially from an examination of full texts (Mishler, 1986)'.

18.12.15 - Participant 5 reminded me of my previous thesis into achievement goal orientation and how performance-oriented children cope very well until faced with unexpected challenge and then they lose their frame of reference for measuring their success which leads them to think they aren't succeeding - not sure if I'm being objective here though. Feel really despondent reading this account and a bit hopeless, I remember on the day how the low mood really impacted me and the sense of feeling really quite hopeless without any clear direction. I wonder how this would relate to clinical implications at this stage? Mindful that sometimes I am absurdly hopeful / positive and I don't want this to get in the way of noticing stories with less hope.

04.01.16 - Worried about my write up and the multiple viewpoints on narrative analysis, I seem to be picking bits I like from various papers rather than one coherent framework. This is a point which comes up time and again in the narrative reading I have done. I think I need a firmer grasp of my framework before I progress with my analysis

04.02.16 - Thinking how to present my results is taking up a lot of thinking time. I am still undecided whether to use categories, such as the Adame and Hornstein (Or Gergen and Gergen stable / progressive / regressive). Makes me reflect on difficulties within my life and how I would categorise the stories I might tell about that time. For me, these are just part of one much bigger, broader and ongoing story, so feels more meaningful to think about the main issues raised at a particular time. I have gone back to the audio today and re-listened to each participant. Hearing the interviews one after the other has helped me identify similar issues between the stories.

10.03.16. Trying to synthesise comments from my supervisors has given me pause for thought. Three very different comments and opinions. After finding myself taking out sentences, changing phrases and then putting back in phrases I have taken a step back to think about my own voice and what it is I feel is important to say. I have been focusing on maintaining the voices of the young people as honestly as I can and have forgotten my own to some extent. Part of this is tied in, I think, with having to produce a piece of work which 'passes' and that ongoing conflict of meeting my needs to pass the course. Maybe trusting my supervisors more than I trust my own opinion, so academic confidence I guess.

15.03.16. Been really beneficial to have different opinions on this and has broadened my thinking about some of these narratives.

Appendix N: Identification of common elements across interviews

	Sophie - Interview 1	**Tim - Interview 2**	**Mark - Interview 3**	**Ben - Interview 4**	**Gary - Interview 5**	**Luke - Interview 6**	**Seb - Interview 7**	**Sam - Interview 8**	**James - Interview 9**	**Tina - Interview 10**
Hope	Depends on mood Never - ending, enduring Hope to 'do well' Global concept Low activity = low hope Low hope / low motivation linked Little sense of agency, other people 'pushing' / 'inflicting' Planting the seed for others	'light at the end of the tunnel' - something to work towards, future-oriented Motivated by a goal Agency over doing - if I feel myself slipping I do things to pick myself up vs moods being random Can think about other pathways to elevate low mood 'not get there, but ... we might go there instead'	Enduring 'there is always hope' Both a feeling and a goal Links hope with mood (happiness) Little sense of agency over hope Dependent on Teachers / friends /CC	'light at the end of the tunnel' future-oriented 'lifts you' Enduring 'there is always hope' Hope to return to old self in terms of confidence / energy 'take each day as it comes, if I feel good...' low sense of agency 'what doesn't kill you makes you stronger'	Looking towards the future Seeing positive outcome Change from one state to another Described in global terms Low mood = loss of hope 'return to normal life' Passive Little sense of agency	Future-oriented 'it's not the end' Change towards improvement Happy linked to hope Low mood = give up A 'lift' Less agency over mood 'I'm not really in control'	A belief Keeping up your spirits, you want to see something happen Future-oriented	Enabling 'private as well as collective affair' A shift from 'not okay' Hope through understanding / information Hope tied in with different internal states Strong sense of agency in making choices / making sense Well-being less threatening than hope	Future-oriented Hope about the future Hope associated with mood Depression = hopelessness / despair 'a naturally good feeling' Reciprocal nature of hope - as I become more productive, I become more hopeful and vice versa	Positive change, things will improve Future-oriented Hope linked to activity and thoughts as separate from mood

Hospital	Helping others			Saw a reverend that gave me hope Can't really remember all a bit blurred		No / Low hope - thought I'd be in hospital forever 'not knowing' Confusion 'they just stuck me in...'	Hopeless - linked with 'not knowing' Confusion Scared 'locked up' Isolation / separation = frightening more so than psychosis itself	Not knowing and confusion = loss of hope More traumatic than experience of psychosis	Not wanting to talk about this time	
Diagnosis	Disappointment - not grandmother, but medical 'problem'. sense of grief / loss	'Didn't know which way to turn' Not really a prominent feature of narrative			Was annoyed with it followed by 'coming to terms' - moving on	Not knowing 'no one told me'	Not knowing - reduced hope 'more knowing in that time' - hope slowly rising	Not concordant with sense of experience Too medicalised Resistant to 'label' then moving to enabling, giving framework to experience - 'sense making' draws the line between past and future 'within' person = low hope 'it's my fault' Language gives meaning rather than	Reassurring - led to seeking information, more manageable, sense of certainty 'didn't become bipolar when diagnosed with it' but meant there would be help / support = hopeful moving from alone to supported Also passivity - mood =	A turning point, a sense of understanding and sense-making

								creating own meaning	biochemical so can't do anything to alter this	
Medication	Flat mood, emotional stabilisers, struggling, slowed down		First hope - started to get better	Now medication is 'right' starting to feel better. Medication has 'lifted spirits' Part of keeping well		'Medication doesn't really play a part in anything'	Confusion, not knowing Didn't really like the medication / side effects	Severely tired 'a necessary evil but more evil than necessary'	Chosen not to take / not helpful	Chosen not to take - living a healthy life
Relapse				worried about relapse ending up back in hospital - but worry is a motivator to change life style		'scared I'm going to have another breakdown' 'I hold on to things I've done, that gives me hope' Making definite choice not to 'dwell' fear of breakdown is motivating being productive will make mind stronger being positive = helpful	Fear of going back to hospital more than fear of psychosis itself	Fear of going back into a state of uncontrol		

Friends	In the abstract, not specific - 'they are good to me, I'm lucky'	'less important' Few very close friends	Change within friendship groups - 'different friends' 'not good for me' 'get new friends to get better' Friends give a sense of being cared for, hope that friends will help stay away from drugs. more important within narrative than family	Not central - change of friends, loss of old friendships (ignorance / stigma) Few close friends text / facebook support rather than face to face sense of someone caring	Isolated from peers Still at university - 'on my own a bit' One friend, supportive 'fixed thing in my schedule' as helpful One friend with depression ' lowering the mood' - bad for the atmosphere (increases isolation? self - imposed? won't want to be round me if I'm like that? sense of not that much insight) Friends important for competiveness = motivating Isolation = reduced competition = reduced motivation	Changing of friendships - leaving behind those linked with drugs Not central to narrative 'focusing more on a career than friends'	Not central to narrative	Sense of purposeful isolation Not central to narrative	Absent from narrative	Friendships are not a large feature of Tina's narrative, sense of feeling left behind from friends and then the happiness and hope associated with going to university and having concordant experiences Being accepted

Family	Supportive - getting to work, completing small tasks which motivates Sophie - 'not failing'	Emotional support Central to hopes 'gave me a reason to fight everything even stronger' Dad = role model, achieving through adversity, he can do it so can I	Mum 'nagging'	'just being there for me' strong emotional support	Not identified as supportive - very absent from narrative	Supportive on an emotional level More central than friendships 'I've got my mum and my brother, I don't need friendships right now' 'she'll [mum] help me whether Imake friends or not' family = more permanent, friends transient	Supportive / encouraging	Absent from account	Mum = encouraging but family largely absent from narrative	Parents very supportive Role models encouraging
Professionals	CC - helpful giving advice and listening	Practical support. Sense of 'knowing' about progress from unwell - well 'big help' 'tells me exactly what's going on' involved	Practical support but also sense of being cared for 'makes a plan' 'feels good - someone actually cares' Sense of collaboration as important	Nurses at hospital 'fantastic' NHS 'put a lot into me'	'being bounced around' 'lots of different people, different places'	Different level of 'knowing' more 'qualified' to 'know' if becoming ill Employment support worker - practical help CC - is there for me, texts me a lot,	Giving information explaining	Vulnerable Functional support more benefical Sense of more self-reliance, more faith in academic knowledge / personal journey	Seeing lots of different professionals = unhelpful CC seen as supportive - showed an interest Not able to pin point what was helpful someone listening	Much less emphasis More self-motivation

			'we make it together'			can't always talk to family, she listens. trust			improves concept of hope	
Work	'nothing fantastic' - sense of normality	Pathway to goal linked to more money, house, future dreams Motivated by plans / structure	Hoping to get a job	Long term goal	Hope for work - global rather than specific	A future hope, sense of this now being possible	Future hope	No sense of this as a focus	Future hope Beginning to take steps	
Education			Hoping to get qualifications - going to college Friends already been 'missed two years of my life' 'I really want to do it'		Finished university - peers still there, sense of isolation	Desire to learn - new to Luke		Important - academic / research / ongoing sense of continuity in this		
Activities / occupation	'small steps' = sense of achievement / momentum	Achieving small steps motivates to keep going Structure / plan important Having a role = motivating 'something to offer' 'can be of use'		- not clubbing building confidence ' beating anxiety as first step	Regular routine Will feel better for doing activity - future-oriented not yet doing passivity	Sense of agency linked to activities 'Dealing with anxiety' 'At my own pace' 'one step at a time' Walking group	Routine - art course improved confidence	Walking Meditation holds in state of well-being Developing a 'tool-kit' steps to well-being	Having a role is important activities increase sense of value 'days offer more' 'stops me being hopeless' Lists [structure]	Creativity as central Having a plan Being bury, being creative - gives a sense of purpose and control

						Football group Structure / routine provides motivation, sense of achievement = hope Achieve one thing, start to think about other things sense of momentum			as helpful - reassuring as things are ticked off, can do things quicker than I thought	
Lived experience				I would like to meet people going through the same thing - who understand CC recommended courses (Recovery College) Comparison of mental vs physical illness - unseen One friend 'we'll help each other through it'	Hypothetically - Would be helpful - to see people who are further along, who have managed to cope well would be good for hope	Very strong sense of inspiration within narrative - meeting people also with difficulty, realising they were also recovering = hope Recovery College - mental health difficulties AND a degree sense of this as	Hope inspiring 'knowing I'm not the only one' sense of belonging Recovery College - improved confidence	Cross cultural experiences would be helpful	Reassuring that other people are experiencing same thing	Reading stories of hope = positive and hope inspiring Recovery College = inspiring Feeling of being normal not having to explain self just 'be' Sense of difficulties being taken seriously (an experience not encountered at school)

						unexpected challenging pre conceptions Reading stories on internet				Feeling supported and understood
Stigma				Old friends - are scared think I'm a nut		Telling vs not telling fear of rejection		Shame cycle - it's all my 'fault'		
Internalised professional language	'I was very elevated' 'I see it as a medical problem'			'got to put myself in situations that make me feel anxious'		'I fear the fear itself'		'if you're looking at a solution - focused way'		
Before	Happy Hopeful Energetic competitive	Difficult Bleak No hope	Angry or annoyed Difficult time	Rough early life Successful mid - adolescence Followed by job loss / drugs	'Quite bad depression' university	'little shit' Drinking / drug taking Period of homelessness 'wanted to get high all the time'	Artistic 'good working background'	Energetic Hazy, disconnected from this dyspraxia	Academically able, not really connecting with other parts of self, hazy	Struggling Not understanding School unhelpful Seeking help / understanding 'stuck'
After	Slow Plodding low	Strong sense of movement Goal setting Hopes and dreams	New friends College / work aspirations Feeling cared for	Recovery gathering momentum Psychosis incorporated as part of identity New way of living	'in limbo' Being referred, little sense of agency Being adrift 'stuck'	Hopeful Sense of belonging Focused on achieving - education / job	Returning to art Experience as a scar but returning to 'old self'	Psychosis as a 'death of me'	level mood sense of one day at a time using creativity	Motivated Positive and optimistic Growing independence
Stories	'not failing' - competition Spirituality	Movement - improvement Aiming high	Drugs	Momentum Healthier life style	isolation	Being inspired by others	Getting old self back Hospital	Research of self Intellectual	Isolation Creativity	Creativity Overcoming adversity

	Then / now - changed Elevation / happiness related to 'medical problem'			Beating anxiety		Improvement People caring anxiety	Growing independence	Spirituality and discovery Being overwhelmed / intensity / cycle of emotions	Depression / passivity	Becoming independent
Turning points	Medication - used to be happy - now low, 'plodding along'	Pre - post psychosis - rebellious teen News of baby	Medication - started to feel better pre psychosis as distressing, psychosis as turning point / people caring			Psychosis as a turning point		Sense that Sam is still 'turning' Knowledge and research leading to better understanding, greater self-awareness	None identified	Diagnosis Gaining university place

Appendix 0: Author guidelines for Journal of Mental Health

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read them and follow the instructions as closely as possible.

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New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre. Please note that submissions missing reviewer suggestions are likely to be un-submitted and authors asked to add this information before resubmitting. Authors will be asked to add this information in section 4 of the on-line submission process.

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The names of authors should not be displayed on figures, tables or footnotes to facilitate blind reviewing.

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Word Count

The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do not include the abstract, tables and references in this word count. However manuscripts are limited to a maximum of 4 tables and 2 figures.

Manuscript Style

Manuscripts should be typed double-spaced (including references), with margins of at least 2.5cm (1 inch). The cover page (uploaded separately from the main manuscript) should show the full title of the paper, a short title not exceeding 45 characters (to be used as a running title at the head of each page), the full names, the exact word length of the paper and affiliations of authors and the address where the work was carried out. The corresponding author should be identified, giving full postal address, telephone, fax number and email address if available. To expedite blind reviewing, no other pages in the manuscript should identify the authors. All pages should be numbered.

Abstracts: The first page of the main manuscript should also show the title, together with a structured abstract of no more than 200 words, using the following headings: Background, Aims, Method, Results, Conclusions, Declaration of interest. The declaration of interest should acknowledge all financial support and any financial relationship that may pose a conflict of interest. Acknowledgement of individuals should be confined to those who contributed to the article's intellectual or technical content.

Keywords: Authors will be asked to submit key words with their article, one taken from the pick-list provided to specify subject of study, and at least one other of their own choice.

Text: Follow this order when typing manuscripts: Title, Authors, Affiliations, Abstract, Keywords, Main text, Appendix, References, Figures, Tables. Footnotes should be avoided where possible. The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do not include the abstract, tables and references in this word count. Language should be in the style of the APA (see Publication Manual of the American Psychological Association, Fifth Edition, 2001).

Style and References: Manuscripts should be carefully prepared using the aforementioned Publication Manual of the American Psychological Association, and all references listed must be mentioned in the text. Within the text references should be indicated by the author's name and year of publication in parentheses, e.g. (Hodgson, 1992) or (Grey & Mathews 2000), or if there are more than two authors (Wykes et al ., 1997). Where several references are quoted consecutively, or within a single year, the order should be alphabetical within the text, e.g. (Craig, 1999; Mawson, 1992; Parry & Watts, 1989; Rachman, 1998). If more than one paper from the same author(s) a year are listed, the date should be followed by (a), (b), etc., e.g. (Marks, 1991a).

The reference list should begin on a separate page, in alphabetical order by author (showing the names of all authors), in the following standard forms, capitalisation and punctuation: a) For journal articles (titles of journals should not be abbreviated):

Grey, S.J., Price, G. & Mathews, A. (2000). Reduction of anxiety during MR imaging: A controlled trial. Magnetic Resonance Imaging, 18, 351–355. b) For books:

Powell, T.J. & Enright, S.J. (1990) Anxiety and Stress management. London: Routledge

c) For chapters within multi-authored books:

Hodgson, R.J. & Rollnick, S. (1989) More fun less stress: How to survive in research. In

G.Parry & F. Watts (Eds.), A Handbook of Skills and Methods in Mental Health Research (pp. 75–89). London:Lawrence Erlbaum.

Tables and Figures: Tables and figures should not be embedded in the text, but should be included as separate sheets or files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction.

Captions should be typed, double-spaced, on a separate sheet. All original figures should be clearly marked with the number, author's name, and top edge indicated.

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Appendix P: NRES end of study form

DECLARATION OF THE END OF A STUDY

(For all studies except clinical trials of investigational medicinal products)

To be completed in typescript by the Chief Investigator and submitted to the Research Ethics Committee (REC) that gave a favourable opinion of the research within 90 days of the conclusion of the study or within 15 days of early termination.

For questions with Yes/No options please indicate answer in bold type.

1. Details of Chief Investigator

Name:	**Victoria Bonnett**
Address:	**Salomons Centre for Applied Psychology** **Canterbury Christ Church University** **Runcie Court** **David Salomons Estate** **Broomhill Road** **Tunbridge Wells** **TN3 0TF**
Telephone:	**03330117073**
Email:	**v.bonnett134@canterbury.ac.uk**
Fax:	

2. Details of study

Full title of study:	**Hopeful and included:** **A narrative exploration of domain-specific hope and social inclusion**
Research sponsor:	**Canterbury Christ Church University**
Name of REC:	**London-Bromley**
REC reference number:	**15/LO/0899**

3. Study duration

Date study commenced:	**10.06.2015**
Date study ended:	**22.03.2015**
Did this study terminate prematurely?	*No* *If yes, please complete sections 4, 5, 6, & 7.* *If no, please go direct to section 8.*

4. Recruitment

Number of participants recruited	
Proposed number of participants to be recruited at the start of the study	
If different, please state the reason or this	

5. Circumstances of early termination

What is the justification for this early termination?	

6. Temporary halt

Is this a temporary halt to the study?	
If yes, what is the justification for temporarily halting the study? When do you expect the study to re-start?	*e.g. Safety, difficulties recruiting participants, trial has not commenced, other reasons.*

7. Potential implications for research participants

Are there any potential implications for research participants as a result of terminating/halting the study prematurely? Please describe the steps taken to address them.	

8. Final report on the research

Is a summary of the final report on the research enclosed with this form?	*Yes*

9. Declaration

Signature of Chief Investigator:	
Print name:	**VICTORIA BONNETT**

Date of submission:	**23.03.2015**

Appendix Q: Feedback summary for ethics panel and R & D committee

Hopeful and included: A narrative exploration of domain-specific hope and social inclusion.

Summary of research

Aims: The aim of this research was to increase understanding of how young people with psychosis experienced hope. This included how hope was experienced in different life areas, such as work, education or leisure, and which factors contributed to the rise or fall of hopeful thinking.

Method: Ten young people who had experienced psychosis were interviewed. These interviews were audio recorded and typed verbatim. The interviews were then read and re-read several times, with notes made on any elements or stories which occurred within each interview. Interviews were then compared to explore common elements and stories.

Results: As expected, the experience of hope was a common strand throughout all the interviews. There were three further strands; a sense of belonging, the importance of information and the significance of planning and occupation in relation to hope.

Hope

Hope was described as something which could be looked forward to, as a 'light at the end of a tunnel'. This gave the sense that young people were expecting life to change for the better during their recovery. Being unsure about what was happening and feeling low made hopeful thinking difficult. Having a plan, or a structure, and taking small steps supported hopeful thinking. Young people reported a greater sense of agency towards their goals and less so in relation to low mood.

Sense of belonging

Things that contributed to hopefulness and recovery included professionals, such as care co-ordinators, who provided practical support, and meeting other people with similar experience. Working with care coordinators on a plan also gave a sense of being cared for.

Friendships seemed to be less noticeable within the stories young people told about their experiences. Some young people had made a choice to change their friendship groups as part of a life-style change; others had a sense of being left behind as peers went to university or into careers. Those participants with a sense of isolation, or being left behind by their peers, perhaps needed greater input, in the form of structure and planning, to engender hopeful thinking and prevent further social withdrawal.

Several young people had taken part in Recovery College courses and were inspired by the achievements of others who had mental health difficulties. The Recovery College, specifically other people with lived experience achieving, both engendered a sense of belonging and

provided young people with a frame of reference for their experiences thus providing some hope that positive change was possible for them.

Information

For some young people, a lack of information about their experience, their medication or the process of hospitalisation left them feeling scared and hopeless. It seemed important for young people to be told explicitly that being in hospital was temporary and that achieving goals of work and education was still possible.

A medical explanation, such as bipolar disorder, appeared to reduce personal agency and in a similar way, some participants' reliance on professionals to confirm the extent and veracity of 'actually' being ill removed personal agency to some extent.

Some young people found it helpful to look up information on the internet and find out more for themselves. Reading stories of how other people had coped and recovered was hopeful.

Planning and occupation

For some young people, having an experience of psychosis acted as a turning point in their lives and they decided to make life-style changes, for example stop drug use, so they could work towards new goals such as work or college.

Having a plan and a structure seemed important in keeping hope. Work was often a goal, and small steps towards this increased hopeful thinking. Being able to achieve small steps made it seem possible to achieve a bigger long-term goal. Having a goal or activity seemed to give young people a sense that they could have some control over increasing their hope. Young people said that being occupied helped overcome anxiety and reduce low mood and gave the days some value.

Conclusion

This research explored how young people experienced hope following an experience of psychosis. The findings highlight that psychosis and recovery is a complex journey and that hopeful thinking is engendered by collaboration, positive examples of lived experience and achieving small steps. For some young people, psychosis acts as a turning point towards positive life changes whilst for others it represents an interruption to typical developmental tasks such as individuation and development of peer relationships.

Dissemination

This study forms part of a doctoral thesis for a doctorate in clinical psychology. Additionally, there are plans to submit a paper to the Journal of Mental Health in due course. Participants have received a feedback summary and a short summary will appear on the website http://www.sussex.ac.uk/spriglab/ (Sussex Psychosis Research Interest Group).

Victoria Bonnett

Chief Investigator

Trainee Clinical Psychologist

Appendix R: End of study report for participants

Dear

Thank you for taking part in my research - **Hopeful and included: A narrative exploration of domain-specific hope and social inclusion.**

You are receiving this because you requested a copy of the final results. This is a summary of the project which I hope you find interesting. I am very grateful for your time.

Summary of research

Aims: The aim of this research was to increase understanding of how young people with psychosis experienced hope. This included how hope is experienced in different life areas, such as work, education or leisure, and which factors contributed to the rise or fall of hopeful thinking.

Method: I interviewed ten young people who had experienced psychosis. These interviews were audio recorded and typed out. I then read and re-read each interview several times, making notes on any themes or stories which occurred within each interview. I then compared these across all the interviews to explore common themes and stories.

Results: As expected, the experience of hope was a common strand throughout all the interviews. There were three further strands; a sense of belonging, the importance of information and the significance of planning and occupation in relation to hope.

Hope

Hope was described as something which could be looked forward to, as a 'light at the end of a tunnel'. This gave the sense that young people were expecting life to change for the better during their recovery. Being unsure about what was happening and feeling low made hopeful thinking difficult. Having a plan, or a structure, and taking small steps helped hopeful thinking.

Sense of belonging

Things that contributed to hopefulness and recovery included professionals, such as care co-ordinators, who provided practical support, and meeting other people with similar experience. Working with care coordinators on a plan also gave a sense of being cared for.

Friendships seemed to be less noticeable within the stories young people told about their experiences. Young people were either being supported by their families or care coordinators at this time.

Several young people had taken part in Recovery College courses and were inspired by the achievements of others who had mental health difficulties. Being with people who had similar

experiences helped young people feel understood which also helped hopeful thinking for the future.

Information

Being given some information about psychosis was important and especially in relation to hospital stays. For some young people, the experience of being in hospital was more distressing than the experience of psychosis. It seemed important for young people to be told explicitly that being in hospital was temporary and that achieving goals of work and education was still possible.

Some young people found it helpful to look up information on the internet and find out more for themselves. Reading stories of how other people had coped and recovered was hopeful.

Planning and occupation

For some young people, having an experience of psychosis acted as a turning point in their lives and they decided to make life-style changes so they could work towards new goals such as work or college.

Having a plan and a structure seemed important in keeping hope. Work was often a goal, and small steps towards this increased hopeful thinking. Being able to achieve small steps made it seem possible to achieve a bigger long-term goal. Having a goal or activity seemed to give young people a sense that they could have some control over increasing their hope. Young people said that being occupied helped overcome anxiety and reduce low mood and gave the days some value.

Summary

Receiving appropriate information about psychosis, working with care coordinators to establish a plan and achieving small steps towards a bigger goal all contributed to hopeful thinking. Meeting other people with similar mental health experiences was a source of hope and support and helped some young people think about ways in which they could achieve their goals, for example by gaining work experience or taking a college course.

Listening to all the young people tell their stories of hope was interesting and meant that we could understand some of the ways that their hope increased following an experience of psychosis.

If you have any questions about these results, please contact me:

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If you wish to contribute to further research you can contact the service user research forum (SURF) or the research network.

http://www.sussex.ac.uk/spriglab/people/surf

http://www.sussexpartnership.nhs.uk/getting-involved-research-research##

Thank you once again for your time.

Victoria Bonnett

Trainee Clinical Psychologist and Chief Investigator