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An exploration of young people's narratives of hope following experience of psychosis

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Abstract

Purpose: To expand understandings of how young people with psychosis experience hope. This included to which factors young people attributed changes in their hopefulness and the role played by professionals and others with lived experience.

Materials and Method: Ten young people recovering from an experience of psychosis were interviewed using narrative methodology.

Results: The experience of hope as an overarching strand throughout the narratives had three common elements; sense of belonging, which included social inclusion, the importance of information and the significance of planning and occupation. Professionals played an important role in facilitating small steps forwards.

Conclusions: The findings suggest the importance to young people of a sense of belonging and achieving small goals to facilitate hopeful thinking and for clinicians the value of supporting new peer relationships and meaningful occupation.

Declaration of interest: None

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Keywords: Hope, psychosis, qualitative research, social inclusion, lived-experience

Introduction

Focus on recovery from mental health difficulties has shifted from service-led priorities to service-user goals. Within this, experiencing hope has been identified as an important element in moving forwards (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Snyder, Feldman, Shorey, and Rand (2002) conceptualised hope as a cognitive process consisting of agency, motivational belief in one's ability to begin and continue moving towards goal achievement, and pathways; cognitions regarding specific routes or means for reaching goals (Snyder et al., 2002). As a cognitive process, hope has no emotional component per se, yet the achievement (or non-achievement) of goals influences emotions thus creating a feedback loop for hopeful thinking. Hope, and goal-setting, fluctuate across

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different domains, such as friendship, work or family (Snyder, 2002). In this way, hope is future-oriented, domain-specific and a way of thinking of future possibilities. This is consistent with the wider recovery literature in which hope is seen as essential to and a 'foundation' of recovery (Allott, Loganathan, & Fulford, 2002; Repper & Perkins, 2003) and a 'turning point' towards a sense of agency (Deegan, 1988). For adolescents, hope is associated with treatment engagement, improved self-care and sense of purpose (Burrow, O'Dell, & Hill, 2010; Esteves, et al., 2013; Kylmä, et al., 2006; Perry, Taylor, & Shaw, 2007). Additionally, sequelae of mental health difficulties, such as self-stigma, may impact on recovery through a reduction in hopefulness (e.g. Berry & Greenwood, 2017; Corrigan, Larson, & Rüsçh, 2009).

Whilst it is widely acknowledged that hope is important, little is documented of its conceptualisation by adolescents following an episode of psychosis or how hope can be supported by practitioners (Sælør, Ness and Semb, 2015). A first episode of psychosis is usually experienced by young people between the ages of 15 and 30 years. Early intervention services (EIS) have been established to try to mitigate potential disruption through timely detection and targeted treatment (Csillag et al., 2015). EIS treatment may include pharmaceutical intervention but has a broader remit promoting social inclusion, addressing educational or vocational concerns and encouraging functional recovery within the changing landscape of mental health difficulties (Fowler et al., 2009). The National Social Inclusion Programme described social 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 (1999) 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.

Incorporating targeted services with a growing emphasis on personal recovery requires close attention to domain-specific hope and goals. In a study investigating the therapeutic

relationship, Berry & Greenwood (2015) found that greater domain-specific hope predicted social inclusion in psychosis; with greater hopefulness experienced in the context of a positive therapeutic relationship in EIS, reduced self-stigma and some form of vocational activity (Berry & Greenwood, 2015; Berry & Greenwood, 2017).

With a growing awareness of the need for developmentally appropriate mental health services, it is important to clarify how hope is experienced and engendered in young people experiencing psychosis. Waters, Holttum, and Perrin (2013) suggested that gaining a contextualised and holistic understanding of an individual's recovery journey may challenge popular discourse and enable generation of new hypotheses; helping inform the development of targeted support. In light of findings that hope may play a mechanistic role in social inclusion in psychosis (Berry & Greenwood, 2015; Hodgekins & Fowler, 2010), it seems timely to gain further understanding of the impact of psychosis on a young person's 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

Participants

A convenience sample of young people aged 16 - 26 years who had experienced an episode of psychosis were recruited from four EIS services and two Recovery College campuses in South East England. The research was presented to the respective teams, with a request to offer participation to clients on their lists who fulfilled the age and diagnosis inclusion criteria. Twenty-two young people were invited to participate overall with ten young people

giving written consent to take part (Table 1). Participants were informed that the purpose of the research was to increase understandings about hopefulness for young people who had experience psychosis. Participants were also informed that the study was being conducted as part of the first author's doctoral qualification.

Table 1. 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

Eight participants were currently taking medication. One participant had been given a diagnosis of Todd's syndrome; characterised by visual hallucinations and distorted time, space and body perception (George & Bernard, 2013).

Ethical approval was provided by the NRES Committee London - Bromley (Reference: 15/LO/0899). The British Psychological Society (BPS) Code of Ethics and Conduct (2009) was followed throughout the research.

Data collection

The first author (female trainee Clinical Psychologist) conducted interviews of between 40 to 120 minutes at various venues convenient to the participants, including NHS services and participants' own homes. Interviews were audio-recorded and transcribed verbatim with all identifying information removed.

Interview schedule

A semi-structured interview schedule was developed in consultation between the authors and with consideration of existing literature. In accordance with narrative methodology, the questions were designed to elicit detailed accounts of experience (Riessman, 2008). However, it was noted that psychosis may include difficulties linking events to the self (Allé, Potheegadoo, Köber, & Schneider, 2015) and difficulty reflecting on one's internal world (Lysaker et al., 2013). Therefore, each young person was encouraged to talk freely about their understanding and experience of hope, but with specific prompts provided to encourage further narrative, for example: *Are there areas of your life which feel more hopeful than others? Can you tell me how your hopefulness has gone up or down? We also used more general prompts, for example, And what happened next? Can you tell me a bit more about that? Can you remember anything that happened in between?*

Analysis

The data were analysed using narrative techniques to follow the rise and fall of hope throughout stories. Narrative methodology was chosen to access rich stories of participants' experiences and enable clarification of the meaning of psychosis within an individual's life. Narrative methodology is particularly suited to exploring stories as a whole. Qualitative methodology allows 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). Although Reissman (2008) suggested that narrative analysis is a complex process without a step-by-step guide, commonalities of the analytic process do exist and were utilised; 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). An inductive approach to analysis was taken, with no a priori identification of themes, commonalities or strands. The focus of analysis in the current study was the conceptualisation of hope described by each participant and the role of the narrator (main protagonist) within that.

Three methods were used to sustain focus on quality assurance throughout the analysis (Mays and Pope 2000; Yardley, 2000). First, a bracketing interview was undertaken to ‘mitigate preconceptions’ and explore personal experience which may bias the analysis process (Tufford & Newman, 2010). Secondly, the first author maintained a reflective journal throughout to aid reflective thinking around her awareness and development of concepts. Thirdly, independent validation occurred throughout the study which involved multiple coding and discussion amongst the four authors and an ‘expert by experience’, thus representing a combination of research, clinical and lived experience. All interviews, profiles and narrative strands were discussed by all authors on at least two occasions.

Additionally, two young people provided comments on their profiles. In response to being asked about how representative of their experience the profile was, one young person described the profile as fully representative and the other provided further clarification on three points. These methods ensured an iterative process through multiple positions with reflexivity at each stage of the research (Dowling, 2006).

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 services, 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).

Results

Commonalities within and between the narratives were identified, for example of, diagnosis, professionals, medication and occupation (see Figure 1). These were used to create four over-arching strands across the narratives and were considered representative of the dominant stories told by the young people (Figure 1). Particular turning points from one understanding to another were also noted within the stories (final row Figure 1).

These were:

1. The experience of hope
2. The role of information and explanation
3. A sense of belonging
4. The importance of planning, progress 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 narrative strand in its own right, it also weaves throughout all strands and is included as such. The main strands are presented with attention to turning points, agency, roles and concept of hope. Pseudonyms are used throughout.

Following temporal sequencing of the stories, a common narrative structure and content for each interview was discerned (Murray, 2015), which helps address the first research question; what stories do young people experiencing psychosis tell about their experiences of hope? (Table 2).

Figure 1: The development of common elements from the interviews

Hope	Hospital	diagnosis	Medication	Relapse	Friends	Family	Professionals	Work	Education	Lived experience	Occupation	Stigma	language
Strand 1: HOPE													
<u>Common Elements</u> 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: Information and explanation					Strand 3: Sense of belonging					Strand 4: Planning, progress and Occupation			
<u>Common Elements</u> 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'					<u>Common Elements</u> Friendships Family Professionals Recovery college Importance of nature Creativity Self-identity stigma					<u>Common Elements</u> 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													

Table 2: Common narrative structure and content

Beginning	<p>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.</p>	‘
Middle:	<p>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.</p>	L i g h t a
End:	<p>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.</p>	t t h e e n

d of the tunnel’ - the experience of hope

Although participants experienced different individual levels of hope, there was a coherent sense between individuals that hope was conceptualised as a future-oriented expectation of life improving:

... everything is going to be completely fine...at some point. ... Everything will probably change...for the better. (Tina, 1⁴)

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 associated with motivation and some participants found it easier to talk about hope in other guises such as ‘enabling’ and ‘motivation’ rather than the potentially abstract concept of hope. It was interesting to note the sense of agency connected with hope and how, for many participants, agency could be articulated in relation to activities, but less so in relation to mood.

...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 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 narratives that particularly indicated 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:

(23) I didn't have any hope. Was just living in the here and now.... There was nothing to hope for

⁴ Numbers are line numbers in transcript

(25) I woke up ... and realised there was no point to my life. I wasn't getting anywhere, ... 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 want to be at a point where I earn more money...where I own my own house and that's all hope

(36) we're going to ... try and get a place... we'll progress from there, it's all a step forwards... I'm hopeful for what that is going to bring... (Tim)

Hope appeared predominantly in the domains of work and education with less focus on friendships, leisure or family. Stories were typically future-oriented rather than seeking to re-claim a previous life-style. Stories with a less clearly defined concept of hope appeared to have less forward momentum.

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

The role of information was an important element within many stories and represented a turning point towards, or away, from hopefulness. A lack of information appeared to exacerbate uncertainty about the future, which was associated with reduced hopefulness, and increased low mood. Receiving information appeared to have an enabling role throughout the narratives. Information was conceptualised as that given by professionals, for example regarding diagnosis or medication, self-research for further explanation or through meeting people with lived-experience. Information seemed particularly relevant during periods of low hope such as being in hospital. Luke gave a powerful account of how a lack of information reduced his hopefulness, but fellow patients enabled him to see a way forward.

(3) no one told me that I might get better ... be able to work. They just stuck me in [hospital]

(9) I thought that would be it, I'd just be in hospitals. That's when I really had no hope... By meeting people who ... were also in recovery...that's when hope builds back up... meeting people ... in education and planning for the future....

Rather than desiring information about symptoms or diagnosis, Luke wanted to know that 'mental health was not the end' and forming relationships with others enabled him to gain this information through example. Luke also talked about meeting people with lived experience outside of hospital and receiving practical information related to education and work possibilities, which increased his hope significantly.

... there was a lady...and she'd been through the mental health system ... managed to get a degree ... it's when you hear stories like that, you start to get hope. Hope for me is, it's like having belief, mental health is not the end... I can get work experience. Right now my hope is the best it's ever been (Luke, 2;27)

Some young people welcomed specific information regarding a diagnosis, which in turn enabled exploration online and further information. For others, it seemed as if receiving a diagnosis diminished a sense of agency; mood would go up and down without external input,

(18) ...it made me realise that it was going to go up and down, if it was up, it was going ... if I was high, ... that I was going, at some point, dive straight down again...

(19)...so I don't really have any long term.... coping strategies... (James)

or gave an impression of a long-term difficulty and reliance on others, thus reducing hope for recovery:

(67) *...it's not a hopeful thing the ability to have a label. It actually implies chronicness (sic) to a condition. A chronicness to dependency ... (Sam).*

'Someone actually cares' - A sense of belonging

Meeting people with lived experience, and being supported by professionals, was also linked with a sense of belonging, which promoted social inclusion and indicated a relational aspect to hope. Mark talked about how collaborative planning provided hope for change, motivation and a sense of belonging.

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

(73) *Feels good - someone actually cares*

(74) *We make it together... we put it together and that makes the plan*

For some young people, this novel sense of belonging and support with the impact of psychosis characterised as a turning point in their life story from distress before psychosis to a more hopeful future. Discussion of friendships were interesting throughout these narratives, either because of their unexpected absence for the sample 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.

Attending a Recovery College featured in several stories and appeared to fulfil a need for a peer group with shared experiences: *'It's where I feel most normal... just kind of makes me feel ... ok with being a little bit different...'* (Tina,32). Recovery Colleges, specifically sharing the achievements of people with lived experience, both engendered a sense of belonging and provided young people with a frame of reference for their experiences and

hope for positive change. By establishing a therapeutic rapport or discovering a peer group, young people started to think about setting goals.

‘One step at a time’ - the importance of planning, progress and occupation

Evident throughout these narratives was the hope-inspiring effect of making small gains. These were supported both from sources of information and from a sense of belonging. The role of professionals was prevalent as young people discussed activities. Achieving small goals represented movement and productivity, which reciprocally raised hopefulness.

... smaller goals are good because they are easier to get to ... now and then I do hit the small goals ... it is fantastic to know that I have reached that point ... I know I’ve reached this one, so I know I can reach that one (Tim, 69)

For some, goals included maintaining household tasks such as the washing up, for others it was securing work experience or a college place. Small steps within the broader sense of occupation, such as football or walking groups, seemed to act as scaffolding towards (re) integrating with society and were supported by professionals rather than a young person’s social network.

Discussion

The narratives had a common structure and a shared conceptualisation of hopefulness as a future-oriented idea of improvement; ‘light at the end of the tunnel’. Themes across the stories included the importance of a sense of belonging, the provision of information, and of planning, progress and occupation. Reduced or absent hopefulness appeared related to uncertainty, low mood or isolation. The availability of information could both reduce and engender hope. For some, psychosis-related difficulties were experienced as a turning point

towards hope; with hope rising as they discovered new possibilities. As such, these discoveries promoted resilience and supported the ability to ‘bounce back’ (Walsh, 2008). This is consistent with a review by Stuart, Tansey, and Quayle (2016) which suggested that hope is possibly an ‘escape from something undesirable’ as well as goal-setting. Hope seemed especially domain-specific and linked to concrete goals and dreams within these stories.

Our results indicate an important relational aspect interwoven within the narrative strands: a) others providing clear, optimistic and hopeful communication and information, b) others modelling hope and recovery and normalising psychosis, c) collaboration with others, and d) feeling cared about. This aspect is important for professionals to consider when planning intervention; friendships were less prevalent across these interviews and family dynamics were at times strained, meaning that the availability of a wider support system was at times lacking.

A key point for practitioners is that stories which showed a rise in hopeful thinking included receiving information and finding a relatable peer group. Due to the developmental stage of individuation, when young people typically move away from close family relationships towards friends, supporting young people to find a relatable peer group is an important consideration for practitioners. Additionally, challenging negative beliefs and modelling hope, increased hope and supported a move from a deficit model of psychosis. Equally, a reduction in hope was related to uncertainty, specifically a lack of information but also possibly a lack of inspiring or motivating relationships. A recent review of mental health diagnosis communication reported significant benefits to sharing information with clients with no ‘evidence of negative outcomes’ (Milton & Mullan, 2016). It worth considering that some young people within the present study who had received predominantly medical explanations for their experiences and were invested in the use of medication as the ‘only’

way of managing their symptoms appeared to feel a reduced sense of agency in their recovery.

Collaboration between the young person and professional was a salient feature of many narratives, which gave a sense of being cared for, in turn promoting progress. Again, this has implications for the way clinician's work with young people and is consistent with a literature review by Schrank et al., 2012, which suggested collaborative strategies for recovery as a potentially successful intervention to engender hope, and with research which suggested a positive therapeutic relationship in early psychosis predicts greater domain hopefulness (Berry & Greenwood, 2015). This is also consistent with the wider developmental literature, which highlights the necessity of using a developmental lens to consider the importance of a secure attachment. Snyder (2002) suggested that hopeful thinking develops in the context of a secure base. Therefore, working collaboratively with young people, can provide a secure, trusting relationship to then engender hopeful thinking and support goal-setting. The idea of setting small goals suggested the importance of working within a zone of proximal development in which the young person can be gently challenged to move forwards increasing their capability and aspirations (Vygotsky, 1978). This would also present the opportunity to work closely within each young person's developmental phase and scaffold increasing capability and social inclusion.

The present participants commonly reported that achieving small goals increased hope, which then created a positive and motivating feedback loop. These results further support findings of Berry and Greenwood (2015) in which professionals hold a key position in promoting social inclusion for young people specifically via occupation, as seen within this cohort as walking groups, football, employment and Recovery College courses. Students at Recovery Colleges emphasise the value of collaborative relationships with peer trainers, increased social opportunity and acquiring new understanding (Meddings, Guglietti, Lambe,

& Byrne, 2014). This suggests benefits from both provision of information and a sense of belonging, which is consistent with our findings and further supports the relational aspect to recovery.

Domains of hope focused on work and to some extent education, with less focus presently on friendship, leisure, or family life. Although only two participants were actively working, all participants expressed a desire for employment; either as a long-term global goal or one with specific planning to meet goals (pathways thinking). A potential difference between this cohort and an older cohort is the forward-focus of hope; moving out of education into work, as opposed to 'returning to work'. Those narratives which seemed particularly hopeful towards work were characterised by specific planning. These findings fit well within Snyder's conceptualisation of domain-specific rather than global hope as more closely linked to outcomes (Snyder, 2002; Snyder et al., 2002) and cohere with a desire for normative activities, especially paid employment, amongst young people with psychosis (Grealish, Tai, Hunter, & Morrison, 2013; Lal et al., 2013; NHS, 2015).

For some young people, a lack of information about their experience left them feeling hopeless, at a times over-whelmed and isolated from peers. Meeting people with lived experience served the dual purpose of providing clear information and inspiration for hope and recovery. It is important to consider information from different sources e.g. psychiatrists, EIS and people with lived experience, and the impact each may have on a young person's recovery. Working with diagnostic uncertainty, as in EIS, must remain balanced with providing realistic but hopeful and transparent information about the potential impact of psychosis, hospital admission, recovery and professionals' involvement. Recovery Colleges, whereby education is offered with a combination of expertise by training and by lived experience, may be especially valuable. 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.

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. This might have also had an impact on a young person's ability to narrate their experience and would be a useful consideration for future research. Additionally, lapse of time since FEP was varied (range 3 months – 48 months) and this could have impacted on the change in hopefulness as young people adjusted to their diagnosis and understanding of their experience changed. The sample of young people was small, and their narratives are particular to a specific time in their recovery journey. For example, narratives did not capture the impact of treatments offered on the rise, or fall, of hopeful thinking and this is an important consideration. All participants were White British and predominantly male; future research should explore stories of hopefulness in the context of gender and cultural differences, where psychosis itself may attract different explanations and meanings.

Future research should seek to address these limitations and explore longitudinal changes in hope, potentially also capturing quantitative shifts in hope over time, and age, for example with the Hope Scale (Snyder et al., 1991). Additionally, it might be useful to further understand the impact of socioeconomic status and educational attainment on an experience of psychosis. It would also be interesting and worthwhile to explore ways in which personal sense of agency is fostered and 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 friendships, family and employment, and supported with shared decision-making (Seikkula et al., 2011).

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