#### **REVIEW PAPER**



# A qualitative systematic review of Early Intervention in Psychosis service user perspectives regarding valued aspects of treatment with a focus on cognitive behavioural therapy

Lauren Cox1\* o and Colette Miller2

(Received 20 October 2020; revised 25 June 2021; accepted 8 August 2021)

#### Abstract

**Background:** Despite the increasing evidence base and focus given to Early Intervention in Psychosis (EIP) services, qualitative literature remains sparse, particularly in relation to the 'At Risk Mental State' (ARMS) group. Although research has looked to service user experience within EIP, data have not been collated to understand valued aspects of treatment across both EIP groups: first episode psychosis (FEP) and ARMS, particularly regarding cognitive behavioural therapy (CBT).

**Aims:** To conduct a systematic review of qualitative literature to examine service user perspectives on support provided in EIP treatment with a focus on CBT.

**Method:** This was a thematic synthesis of qualitative studies. Nine studies were included in the analysis identified through a systematic database search and citation tracking. Studies were critically appraised using the critical appraisal skills programme tool.

**Results:** Nine studies were identified for inclusion. Six analytical themes and 20 descriptive categories were identified.

Conclusions: User perspectives confirm previous findings highlighting importance of therapeutic relationships for treatment success. Normalisation, learning and understanding were valued across both groups, which increased coping, and can be facilitated throughout the EIP journey. Harnessing the support of those involved in users' care and understanding these relationships further enhances interventions utilised. Understanding the stage the individual is at regarding their experiences is essential in relation to targeting support. Transdiagnostic aspects of CBT were valued across both groups. ARMS referred to more specific strategies and there were some differences regarding coping styles and flexibility preferences; however, this may be due to group differences in problem trajectory and care provision.

Keywords: at risk mental state; CBT; early intervention; first episode psychosis

#### Introduction

Early intervention in psychosis (EIP) services provide care and treatment for people experiencing first episode psychosis (FEP) and more recently those who are deemed at risk of developing psychosis (At Risk Mental State, ARMS) (NICE and NHSE, 2016). Healthcare professionals (HCPs) provide evidence-based care appropriate to the biopsychosocial needs of the individual whilst also supporting family and carers (NICE, 2014). A symptom led approach allows for treatment as early as possible before a diagnosis is made (McGorry *et al.*, 2008).

© The Author(s), 2021. Published by Cambridge University Press on behalf of the British Association for Behavioural and Cognitive Psychotherapies

<sup>&</sup>lt;sup>1</sup>Halton & Warrington Early Intervention in Psychosis Team, Merseycare NHS Foundation Trust, Liverpool, UK and

<sup>&</sup>lt;sup>2</sup>Faculty of Health and Care, University of Central Lancashire, Preston, UK

<sup>\*</sup>Corresponding author. Email: loz-cox@hotmail.co.uk

Literature has indicated the value of Early Intervention Teams in: reducing chronicity amongst the population; increasing control and autonomy; and reducing associated long-term costs of mental health care provision (Royal College of Psychiatrists, 2016).

Treatment guidelines (NICE, 2014) advocate the application of cognitive behavioural therapy (CBT) for both FEP and ARMS service users due to its positive outcomes. It is also considered a less restrictive measure to implement with a younger population, who are widely represented within these services, compared with the traditional uses of psychotropic medication previously utilised with psychosis spectrum conditions (Wood *et al.*, 2015). Despite the endorsement of CBT for both groups, in practice this can prove challenging particularly within the ARMS group where high levels of co-morbidity and complexity are displayed (Addington *et al.*, 2011a).

Within the qualitative literature, reviews of the application of CBT to people with psychosis outline the importance of the therapeutic alliance, facilitating change through interventions (assessment, formulation, normalisation, psychoeducation) and the challenges of applying CBT which are often associated with emotional difficulties, readiness to engage in the process, difficulties with self-concept and motivation issues (Berry and Hayward, 2011; Wood *et al.*, 2015).

Comparatively little is known about the lived experience of engaging in CBT within the setting of early intervention services, particularly in the field of ARMS. Most of the research into CBT within EIP groups has focused on empirical data, i.e. keen focus given to CBT effects on transition to psychosis and symptom severity across the ARMS group (Hutton and Taylor, 2014; Stafford *et al.*, 2013). Findings indicate reduced subthreshold symptoms for ARMS users at some points (12 months) but not others (6, 18 and 24 months, respectively) (Hutton and Taylor, 2014), and moderate effects on reducing transition (Stafford *et al.*, 2013). Similarly, within FEP groups data has given focus to effects on positive symptoms and psychopathology, indicating superiority to treatment as usual (Mehl *et al.*, 2015). These findings, although important, do not indicate the broader experiences of receiving CBT from users' perspectives, and fail to capture effects beyond symptom reduction.

Previous quantitative CBT ARMS studies, although based on the same treatment approach (French and Morrison, 2004), utilised different variables, i.e. number of sessions offered (Addington *et al.*, 2011b; Morrison *et al.*, 2012) or this being enriched with adjunct exercises and specific psychoeducational materials (van der Gaag *et al.*, 2012), which makes generalisations difficult. A systematic review and meta-analysis of CBT for psychosis prevention (Hutton and Taylor, 2014) found the risk of developing psychosis was reduced by more than 50% for those receiving CBT at 6, 12, 18 and 24 months; however, no effects on functioning, symptom-related distress or quality of life were observed, which are important factors to consider from users' perspectives.

CBT is one form of support offered by EIP teams and is a mainstay of treatment. However, it is unclear which aspects of EIP input are helpful from a subjective perspective, therefore we are also interested in the experiences of broader support provided to both FEP and ARMS populations and whether services meet their psychological needs. It is also important to understand service users' experiences as therapeutic change (i.e. reduction in symptoms, improvements in quality of life), and preferences concerning treatment and support may differ across groups.

The aims of the review were to:

- (1) Explore the views of EIP service users on support received within early intervention, to establish valued components.
- (2) Explore user experiences of CBT within EIP.
- (3) Establish practice points for consideration and possible areas for future research to enhance user experiences of EIP support.

## Method

# Refining the research question

Initially a summative approach was adopted whereby the research question was established a priori, and the focus of the review was planned to explore perspectives of the ARMS population on their experiences of CBT. Progressive evaluation indicated a paucity of relevant qualitative literature (Bettany-Saltikov, 2012). Therefore a broader research focus was adopted and the research question was re-defined to incorporate both FEP and ARMS users, as both are supported through the majority of EIP services in the UK (NICE, 2014), and to incorporate broader support (inclusive of CBT provision). The review was undertaken to illuminate key aspects of support across both groups to enhance intervention delivery, as it was deemed important that qualitative findings were synthesised to develop a deeper understanding of the needs of the early intervention population.

# Design

A systematic review of qualitative literature was conducted using thematic synthesis (Thomas and Harden, 2008). It aimed to bring together findings to make connections between existing studies and compare main concepts with the purpose of re-interpreting findings and generating new insights (Dixon-Woods *et al.*, 2006; Major and Savin-Baden, 2010).

# Search strategy

Patient exposure outcome (PEO) delineated key search components (Hewitt-Taylor, 2017). Database thesaurus of AMED, MEDLINE and PsycInfo were consulted to identify both Medical Subject Headings and keyword terms (Moule *et al.*, 2016), which were subsequently grouped into three key concepts to locate relevant literature (Polit and Beck, 2009). NHS Evidence, grey literature searches and regular online searches for policy pertaining to early intervention were also conducted. Forwards and backwards citation tracking was performed on all full-text screened articles (Aromataris and Riitano, 2014). Due to time delays in developing this review for publication, the original search strategy was repeated in October 2019. This identified two additional relevant papers for inclusion (Harris *et al.*, 2012; Uttinger *et al.*, 2018).

## Inclusion and exclusion criteria

Articles were eligible for inclusion if they met the following criteria:

**Population:** Service users receiving treatment from EIP services, ARMS or FEP, aged between 14 and 35 years (in line with national EIP guidelines).

**Exposure:** Being provided with care and/or CBT from EIP services.

**Outcomes:** (i) Lived experiences of ARMS/FEP in relation to provision of care from EIP services; (ii) views and beliefs regarding CBT: preferences, valued tenets of therapy.

**Eligible study designs included:** Qualitative studies; mixed method studies that reported some qualitative data relating to the outcomes of interest.

**Articles were excluded if they were:** purely quantitative; not concerned with service user views; not in English; not a journal article in a peer reviewed journal; non-EIP studies where the clinical population was not ARMS/FEP.

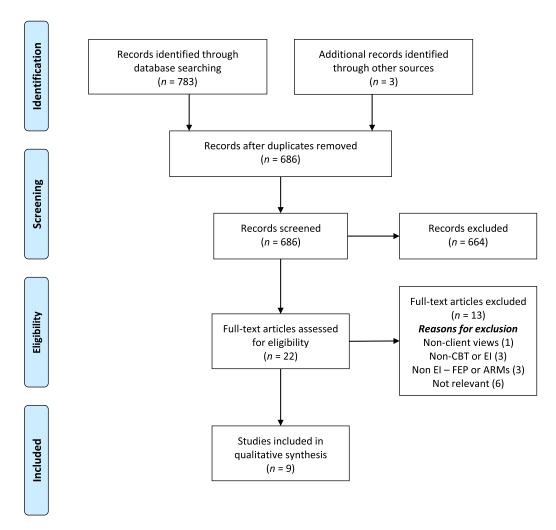


Figure 1. PRISMA 2009 flow diagram.

## Data screening and selection

The process of selecting studies for inclusion consisted of sifting through titles and abstracts of all articles retrieved, screening systematically and selecting those that met the pre-determined inclusion criteria (Bettany-Saltikov, 2012). If neither the title nor abstract contained sufficient information to be judged as either relevant or irrelevant, the full text was accessed, and the same criteria used to make the final decision and duplicate studies were removed. After two rounds of screening, nine eligible studies were included. The selection process, including search results and reasons for exclusion at each stage of screening are represented in a PRISMA flow diagram (Fig. 1).

## Data extraction and synthesis

Data were extracted using a bespoke data extraction form to ensure consistency. Information extracted from primary studies included: bibliographic information; setting and location; population; research question(s) and aim(s); data collection methods; data analysis methods; and primary or secondary data relating to the outcomes of interest.

The quality of included studies was appraised using the Critical Skills Appraisal Programme (CASP, 2017) appraisal tool for qualitative studies, which includes assessments of rigour, credibility, relevance and appropriateness of methodology. Each item was assigned a score, with '3' indicating yes, '2' meaning can't tell and '1' not addressed. A modified approach using the ConQual method to grade synthesised findings on aggregate level of quality gave an overall ranking which was considered a rating of confidence (Munn *et al.*, 2014).

Credibility was further supported through second coder review of research themes and codes, and consensus was reached on the selection of illustrative quotes, which enhanced data quality (Finlay, 2006) and demonstrated congruency between author interpretation and supporting data (Munn *et al.*, 2014).

Dependability was supported through following PRISMA guidelines to report the review to ensure findings were consistent and could be repeated, which demonstrated congruity between methodology and aims, data collection, representation and analysis (Munn *et al.*, 2014).

The author engaged in critical reflection of how their position could influence the data as they are a clinician based in EIP services (McCabe and Holmes, 2009). Potential bias was mitigated through the process of reformulation of the intended initial research aims to reflect the evidence base, and during data collection and analysis which required regular reflection on the review aims, use of supervision and peer review.

Data were analysed using thematic synthesis (Thomas and Harden, 2008) conducted in three stages, with the aim to generate themes regarding service users' experiences of treatment and support through EIP. Codes identified as exemplifying similar constructs were merged into descriptive categories, and subsequent analytical themes.

It was originally planned to synthesise data according to the review's aims regarding valued aspects of EIP support with a focus on CBT; however, few study findings addressed this wholly and directly. In order to avoid imposing an *a priori* framework without allowing for the possibility that a modified framework may be more appropriate, study findings themselves formed the basis of the analysis (Thomas and Harden, 2008).

Identified studies were coded line by line inductively to capture meaning, resulting in descriptive categories (Thomas and Harden, 2008), which reflected the findings of the primary studies. The use of line-by-line coding enabled translation of concepts from one study to another (Britten *et al.*, 2002). Codes were reviewed across studies, similarities and differences were identified, and grouped into a hierarchical structure; new codes were created to capture meaning of groups of initial codes which were then collapsed into analytical themes.

Further consideration led to removal of analytical themes that did not meet the review aims and the generation of additional descriptive categories (Britten *et al.*, 2002). An iterative reflective process resulted in revisions to analytical themes until these were sufficient to inform descriptive categories. The resulting thematic structure organised a total of 20 descriptive categories into six analytical themes.

## Results

The PRISMA flowchart (Fig. 1) illustrates the flow of studies through the synthesis. Table 1 summarises the characteristics of included studies.

Although aspects of EIP support are documented in line with the over-arching aims of the review, much of the focus in studies was on factors that may be deemed non-intervention specific. However, these factors had an impact on EIP support experiences and are important when considering how attention to these may enhance service delivery and experiences. This will be expanded upon in the Discussion.

Cognitive behavioural therapy studies									
Author (year), country	Participants	Age (mean and range)	Participants (% female)	Ethnicity	Setting	Aim	Data collection method	Data analysis	Quality appraisa (out of 30)
Byrne and Morrison (2014), UK	Help-seeking, at high or ultra- high risk of psychosis	28 14–35	10 (40%)	9 WB; 1 BB	One EIS in Manchester	To explore participants' experiences of 'enhanced monitoring' and cognitive behaviour therapy (CBT) within a randomised controlled trial evaluating early detection and prevention of psychosis	Semi-structured interview	Thematic analysis	26
Welfare-Wilson and Jones (2015), UK	First Episode Psychosis Service users having difficulties with anxiety	28 16-63	12 (33%)	8 WB; 3 A; 1 WE	One EIS in Kent	To explore participants' thoughts and feelings about a 1-day CBT skills and anxiety management workshop	Questionnaire	Framework approach	24
Early intervention	on studies								
Author (year), country	Participants	Age (mean and range)	Participants (% female)	Ethnicity	Setting		Data collection method	Data analysis	Quality appraisa (out of 30)
	Service users in	22	20 (250/)	NR					
Barr <i>et al</i> . (2015), UK	third year of input from EIS	22 17–33	20 (25%)	INK	Four local EIS in the Northeast	To explore with service users what elements they found the most valuable during their EIP experience	Exploratory interview	Q-methodology	26

(Continued)

Table 1. (Continued)

Author (year), country	Participants	Age (mean and range)	Participants (% female)	Ethnicity	Setting	Aim	Data collection method	Data analysis	Quality appraisa (out of 30)
Hardy et al. (2009), UK	Help-seeking service users, assessed by CAARMS, of EIS	22 16-30	10 (60%)	9 WB; 1 BA	One EIS site (location not stated)	To explore how people who have been assessed as being at risk of developing psychosis make sense of and understand their experiences	Semi-structured interview	Grounded theory	28
Harris <i>et al</i> . (2012), UK	Service users with over 2 years experience of EIS	29 21–37	8 (38%)	5 WB; 2 W&A 1 W&BC	One EIS (location not stated)	To explore what is it like from a service user's perspective to be in contact with an EIP service	Semi-structured interview	Interpretative phenomenological analysis	28
Lester <i>et al.</i> (2011), UK	Service users recruited to National EDEN study	NR 14–35	34 (28%)	25 WB; 3 PA; 2 IN; 1 BC; 1 IR; 1 MR; 1 WO	Five EIS in geographically diverse locations	To explore in depth the value of EIS over time from the perspective of service users	Semi-structured interview	Grounded theory	28
Uttinger <i>et al.</i> (2018), Switzerland	Service users either receiving clinical treatment or follow-up at one EIS	27 NR	11 (36%)	NR	One EIS (location not stated)	To assess whether ARMS individuals experience stigmatisation and to what extent being informed about the ARMS is experienced as helpful or harmful	Semi-structured interview	Interpretative phenomenological analysis	28
Welsh and Tiffin (2011), UK	Service users recruited to another research study	NR 13-18	6 (50%)	NR	Not stated	To explore the understanding and experiences of adolescents categorised as having an ARMS	Semi-structured interview	Interpretative phenomenological analysis	21

A, Asian; BA, Black African; BC, Black Caribbean; BB, Black British; IN, Indian; IR, Irish; MR, mixed race; PA, Pakistani; WB, White British; WE, White European; WO, White other; W&A, White and Asian; W&BC, White and Black Caribbean; NR, Not Recorded.

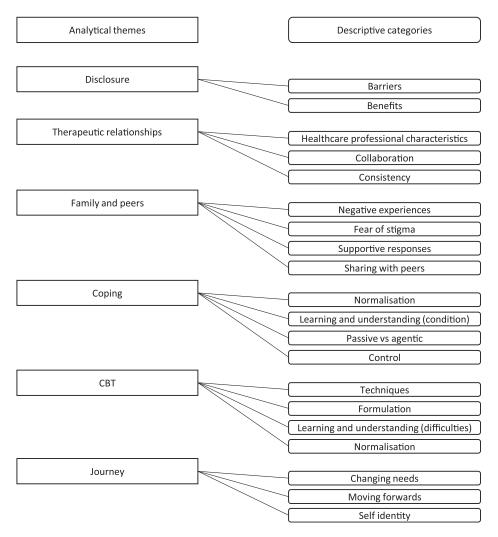


Figure 2. Thematic analysis.

### Themes identified

Analysis of the data revealed six analytical themes and 20 descriptive categories, which are summarised in Fig. 2. A narrative discussion of each theme is provided below, and exemplar quotes for each theme are given in Table 2.

# Disclosure

Disclosing first experiences was highlighted across studies as often difficult but important in facilitating support. Fear of judgement and negative responses often had an impact on both groups' willingness to talk about their experiences, which could be a barrier to accessing services (Byrne and Morrison, 2010; Byrne and Morrison, 2014; Harris *et al.*, 2012; Uttinger *et al.*, 2018).

For the FEP group, perceived seriousness of the psychosis label served as a barrier; however, when this was overcome early contacts provided relief and optimism (Harris *et al.*, 2012). Similarly, ARMS users expressed a fear of 'going mad' which led to delayed help-seeking and

disclosure due to fear of negative reactions or lack of relevant support (Byrne and Morrison, 2010; Byrne and Morrison, 2014; Harris et al., 2012; Uttinger et al., 2018). Many chose not to disclose the ARMS label or if they did, 'watered down' their experiences (Uttinger et al., 2018). Some ARMS users advised of a 'breaking point' due to intensification of experiences which meant they felt they needed to talk to someone (Hardy et al., 2009). After overcoming fear associated with not knowing what to expect (Uttinger et al., 2018), having a chance to talk was valued, providing relief (Byrne and Morrison, 2014; Welsh and Tiffin, 2012), realisation that help was forthcoming (Uttinger et al., 2018; Welsh and Tiffin, 2012) and validation that their experiences had been named as a condition (Uttinger et al., 2018). Simply sharing problems safely without upsetting those close to users reduced stress (Byrne and Morrison, 2014) and was viewed as a form of treatment (Welsh and Tiffin, 2012). Fears could continue after receipt of the ARMS label and disclosing this to others (Welsh and Tiffin, 2012); some reported negative reactions from those around them (Hardy et al., 2009; Harris et al., 2012; Welsh and Tiffin, 2012), but these were often offset by acceptance and supportive experiences (Byrne and Morrison, 2010; Uttinger et al., 2018; Welsh and Tiffin, 2012) leading to reductions in anxiety, improvements in emotional well-being and increased access to psychological help (Byrne and Morrison, 2010; Hardy et al., 2009).

## Therapeutic relationships

The therapeutic relationship was the most commonly endorsed theme across studies. Specific qualities were outlined as important in the development of positive working relationships and was highlighted across eight studies.

Both groups placed high value on therapeutic relationships with EIP staff, strengthened by their specific qualities and approaches, i.e. youth-friendliness, informality, genuineness, and flexibility tailored to individual needs which facilitated engagement (Byrne and Morrison, 2014; Barr *et al.*, 2015; Lester *et al.*, 2011; Uttinger *et al.*, 2018); when opening-up, being listened to and receiving empathic non-judgemental responses (Byrne and Morrison, 2014; Barr *et al.*, 2015; Uttinger *et al.*, 2018). Users valued working collaboratively with HCPs (Byrne and Morrison, 2010; Harris *et al.*, 2012) and consistency in seeing the same person regularly, having HCPs sticking with them when things were difficult (Barr *et al.*, 2015) and building a long-term relationship with one person with whom they could talk freely, and feel understood, which facilitated engagement (Byrne and Morrison, 2014; Lester *et al.*, 2011). When this was compromised, users reported disruption in having to repeat things to various HCPs, which affected the ability to build trust (Lester *et al.*, 2011; Uttinger *et al.*, 2018).

For the FEP group, experiencing a strong working alliance, often with care coordinators, was instrumental for recovery (Barr *et al.*, 2015; Harris *et al.*, 2012). This relationship allowed for therapeutic support and facilitated access to other interventions, i.e. psychosocial intervention (Barr *et al.*, 2015; Lester *et al.*, 2011) and further engagement with others (i.e. HCPs, agencies and peers) (Barr *et al.*, 2015; Harris *et al.*, 2012; Lester *et al.*, 2011). How users were treated, being taken seriously, provided with validation and valued beyond their illness was often endorsed over specific intervention factors (Barr *et al.*, 2015).

# Family and peers

Service users described the importance of the role of peers and family in seven of the studies in the review.

Some users from both groups opted to rely on professional support due to a lack of closeness or understanding and fears regarding possibly stigmatising responses within their relationships (Byrne and Morrison, 2010) and previous negative experiences within the family (i.e. feeling misunderstood and judged) (Harris *et al.*, 2012).

Across the ARMS population there was evidence of poor or lost social and family relationships often due to trauma and ARMS experiences which negatively affected users' mental health and well-being (Byrne and Morrison, 2010).

Both groups worried about responses from peers and family when sharing their experiences openly. Some FEP users experienced shame or fear of worrying those close to them (Lester et al., 2011). Some ARMS users feared discrimination, stigma or not being taken seriously; some instances of stigma were noted within the workplace and from friends and family (Uttinger et al., 2018). However, many reported receiving sympathy and understanding (Lester et al., 2011; Uttinger et al., 2018; Welsh and Tiffin, 2012); support with referral into services and others around them opening up regarding their own mental health difficulties (Uttinger et al., 2018).

The FEP group often benefited from emotional and practical support from family and friends (i.e. financial support, accommodation, shopping) (Lester *et al.*, 2011), and social and family support was often viewed as important as other interventions (i.e. CBT, medication) (Lester *et al.*, 2011). Relationships across user, family and care coordinators was highly influential in recovery (Barr *et al.*, 2015), with some users feeling that support and closeness with families and carers had increased due to EIP services facilitating family and carer understanding and engagement so that they were better equipped to support the user. This allowed families/carers to better advocate for treatment (Barr *et al.*, 2015; Lester *et al.*, 2011) and engage in intervention work, i.e. relapse plans (Lester *et al.*, 2011).

The positive role of sharing experiences with peers was highlighted across both groups, with many users expressing a keen interest in sharing with others who were affected similarly through group therapy (Uttinger *et al.*, 2018; Welsh and Tiffin, 2012). For the FEP group peer support reduced social isolation, helping users to feel understood and creating a sense of belonging which reduced shame, increased confidence and provided opportunities to help others, thus increasing agency (Harris *et al.*, 2012). Group CBT also facilitated learning from others, instilling hope and reducing anxiety and stress levels, with participants expressing a preference to work alongside peers of a similar age (Welfare-Wilson and Jones, 2015).

#### Coping

This theme related to users managing and coping with their experiences and was explored in all of the studies reviewed.

ARMS users often presented as active in their attempts to cope with experiences across the trajectory of their involvement with EIP, often demonstrating a keenness for involvement and understanding (Uttinger et al., 2018) and through use of personal coping mechanisms, i.e. family support, spirituality and inner strength (Hardy et al., 2009). Psychological input increased ARMS users' coping repertoires (Uttinger et al., 2018), with therapy sessions often cited as informal which was normalising, giving users the space to talk things through (Byrne and Morrison, 2014; Welsh and Tiffin, 2012). For ARMS users, non-intervention specific aspects of coping were related to a sense of safety and security in knowing that everyday support was available through EIP (Uttinger et al., 2018), and through monitoring assessments which augmented perceived coping ability, mood and optimism via engagement, informality, normalisation and practical support (Byrne and Morrison, 2014).

A key factor in managing and coping with experiences was normalisation facilitated through involvement with EIP. This generated relief through knowing others had similar experiences (often valued above interventions) (Welfare-Wilson and Jones, 2015; Harris *et al.*, 2012; Lester *et al.*, 2011; Uttinger *et al.*, 2018; Welsh and Tiffin, 2012) and that everyone is susceptible and it is possible to get through such experiences (Barr *et al.*, 2015; Harris *et al.*, 2012). Normalisation fostered hope for the future in reducing fears that users were not 'going mad' or were 'abnormal' (Barr *et al.*, 2015), and was facilitated through reassurance, empathic

responses (Byrne and Morrison, 2014) and an informal approach to language (Byrne and Morrison, 2010; Byrne and Morrison, 2014).

Another coping factor was learning and understanding; for ARMS users this increased a sense of agency through being actively involved and learning about the condition; however, some users reported that knowing about the condition did not change anything and they were determined to carry on as before (Uttinger *et al.*, 2018). The FEP group also wanted to understand their illness: why they had become unwell and learning about early warning signs and triggers was important (Lester *et al.*, 2011), alongside acquiring coping skills in helping to manage stress and increase confidence (Barr *et al.*, 2015).

Participants in both groups could be observed to move from passive to agentic stances in dealing with experiences (this appears to be related to impacts on self-identity in their 'personal journey'); for the ARMS users this was seen in early stages where individuals either attempted to actively help themselves or waited for symptoms to disappear; the latter often failed (Uttinger et al., 2018). The FEP group's progress also appeared to correspond with the way in which individuals accepted and integrated their experiences but this happened often later during their involvement with EIP. FEP users usually moved from avoidance of psychosis experiences to acceptance and control, which positively correlated with recovery (Harris et al., 2012).

Perceived level of control affected coping; FEP users expressed a sense of hopelessness when control was taken away (which relates to views on intensive sustained engagement indicated in 'the journey'), and being resigned to a life with psychosis, whereas others expressed feeling as if level involvement was their choice (Harris *et al.*, 2012). In contrast, some FEP users emphasised the value of help during a crisis (Barr *et al.*, 2015), and ARMS users could fear withdrawal of support in case of problems returning (Hardy *et al.*, 2009), indicating an acceptance and knowledge of the need for support when problems held the risk of intensifying.

Taking active control helped to address and challenge experiences for both groups; for FEP user's social (Barr et al., 2015) and family support (Lester et al., 2011) and partnership working (Harris et al., 2012) helped individuals cope; and for ARMS users the use of personal coping strategies and self-efficacy was important (Uttinger et al., 2018). Both groups valued psychological support which engendered a sense of control and security (Harris et al., 2012; Uttinger et al., 2018). Whilst many users attributed aspects of progress to involvement with EIP, they recognised a need for taking personal responsibility for the future (Hardy et al., 2009; Harris et al., 2012).

## Cognitive behavioural therapy

CBT techniques were instrumental in increasing resilience, often through increased understanding around experiences, learning and normalisation (Barr *et al.*, 2015; Byrne and Morrison, 2010; Byrne and Morison, 2014; Uttinger *et al.*, 2018; Welfare-Wilson and Jones, 2015). Benefits of CBT approaches were highlighted in eight studies.

Despite the key role of an informal approach adopted within sessions for ARMS users, specific CBT techniques were endorsed, i.e. agenda setting, evidence-gathering and reappraisal of distressing experiences (Byrne and Morrison, 2014), and the group valued the collaborative nature of the intervention (Byrne and Morrison, 2010). Disclosure in therapy regarding talking about symptoms or previous life experiences and engaging in homework were cited as difficult, as it encouraged further self-examination; however, users recognised the need for this in order for therapy to be effective (this also spans across disclosure and associated benefits) (Byrne and Morrison, 2014).

For ARMS users the formulation process (maintenance and longitudinal) helped to normalise their experiences and facilitated understanding around symptoms in the context of life experiences (Byrne and Morrison, 2014), leading to discoveries about what could be worked

Table 2. Exemplar quotes for each theme

Cabaaaa.	Cook the auto	Formulas acceta	Ct., d.,
Category	Sub-theme	Exemplar quote	Study
Talking and disclosure	Barriers	I thought if I went to a doctor I always thought it was like what you saw on EastEnders and that I was going to get arrested and put in a padded cell and I am never going to see my family and friends again	Byrne and Morrison (2014)
		If I told someone, 'I have a risk of developing psychosis', he would be disturbed and treat me differently	Uttinger et al. (2018)
	Benefits	It is better to say it; I knew somebody else had already noticed, then I could work with that with the At-Risk Mental State kind of label it was helpful 'cos then I could read up and I knew how it was going to be dealt with	Welsh and Tiffin (2012)
		I'll talk to [neighbour] because she seems more understanding and more concerned it's good to speak to somebody face to face	Byrne and Morrison (2010)
Relationships with healthcare professionals	Positive aspects Informality Flexibility	It was like you was sitting in your living room having a conversation with a friend I belonged to somewhere	Byrne and Morrison (2014)
	Consistency Care co-ordinator facilitating engagement	If I feel particularly upbeat she might say shall we leave it 3 weeks? But then if she thinks that maybe I need a bit extra she says, okay well I'll come and see you in the week	Lester <i>et al</i> . (2011)
	with others	Dealing with the same person over the 3 years With the help of [care co-ordinator] I keep in contact with friends and go round and see them and ask them to come around and see me	Barr et al. (2015) Harris et al. (2012)
Relationships with family and peers	Negative aspects	I don't bother trying to explain to family or friends, I just keep it to myself you feel a bit like, they're gonna think you're going mad	Byrne and Morrison (2010)
		There are doctors in my family who know the mental health system my parents said 'you are not going there'	Uttinger et al. (2018)
	Positive aspects	I kept a diary one of my closest friends snatched it off me It made me a bit more happier that she didn't exactly think I was completely crazy	Welsh and Tiffin (2012)
		I only told my mum about how I've been feeling a few months ago, so it's just really changed since she's known. She was really supportive and could understand it's an illness	Lester et al. (2011)
	Peer support	People tell you what their illness is then you try to come up with something that will help them, and they do it vice versa to you	Welsh and Tiffin (2012)
		You can't help but think they don't really get what you are going through it would be useful to talk to someone who has either been through a similar situation or has the same thing as you	Harris et al. (2012)
Theme 2: Psycholog	gical factors		
Category	Sub-theme	Exemplar quote	Study
Agency and coping	ARMS factors	It was mainly about working week by week [they] would ask if anything had stressed me out they would say, 'how could you cope with that better? Could it have been	Welsh and Tiffin (2012)

Table 2. (Continued)

Category	Sub-theme	Exemplar quote	Study
	Normalisation	They just told me there are other people like you and you can get better from it It felt more of a relief to sort of know you	Harris <i>et al.</i> (2012)  Welsh and Tiffin
	Understanding	weren't alone you feel a lot more sort of comfortable knowing that you are not a freak	(2012)
	Understanding	I talk and he sort of goes through it all – so he explains it all to me and my family. Now I know it's more to do with me trying to learn to cope with my anxieties	Lester et al. (2011)
	Accepting and integrating experience	Sort of living with my symptoms and dealing with it, accepting it	Harris <i>et al.</i> (2012)
	Control	My own decisions and strategies were required and helpful	Uttinger et al. (2018
		Jane [EIP psychologist] helped with that as well when I do hear the voices, I go straight to my list I got off Jane and it works	Harris <i>et al.</i> (2012)
	Personal responsibility	They've offered me support in every area there is no one who can actually provide the solution, other than yourself	Harris <i>et al.</i> (2012)
		I brought [son] into the life so I've got to see it through	Hardy et al. (2009)
Cognitive behavioural	Collaboration	It's a team and I'm part of that team I'm just as important, I'm making decisions	Byrne and Morrison (2010)
therapy	Difficulties	and then there was like homework I struggled with that because I was having to look at myself	Byrne and Morrison (2014)
	Reappraisal and formulation	I was able to start looking at myself people were not necessarily thinking what I thought they was thinking there could be a million and one other answers that is what [therapist] helped me to deal with	Byrne and Morrison (2014)
		Through counselling I learned my symptoms were related to my cannabis consumption I could get better by stopping it	Uttinger <i>et al</i> . (2018
		I've been able to understand what is happening and why I've now got a list of things that I need to work on to minimise them, increase them or just to accept there's nothing I can do about them	Byrne and Morrison (2010)
	Specific interventions	Would do behavioural experiments with my care co-ordinator	Welfare-Wilson and Jones (2015)
	Learning	Understanding my symptoms and experiences better using CBT	Barr et al. (2015)
heme 3: Persona	al factors		
Category	Sub-theme	Exemplar quote	Study
The journey	Changing needs	I knew there was obviously something wrong and the fact that somebody acknowledged that and I kind of had something to go away with I knew how it was going to be dealt with	Welsh and Tiffin (2012)
		and then it all came to a halt and then went back I was doing good then obviously this all happened, and it just stopped	Hardy et al. (2009)
		What is valuable at the end of EIP is not the	Barr et al. (2015)

(Continued)

Table 2. (Continued)

Theme 3: Personal factors				
Category	Sub-theme	Exemplar quote	Study	
	Orientation to future/moving on	I think if I do have these problems again I am fairly sure I'll be able to deal with them I've got the tools to fix the problems in future	Byrne and Morrison (2014)	
		I'd just like me own place all I know is once I've got somewhere, I can start doing things	Hardy <i>et al.</i> (2009)	
		I needed practical strategies for everyday life I would have liked to have delved deeper into this subject but there was little time to do so	Uttinger et al. (2018)	
		As I've got better it's not nice having somebody come in all the time constantly reminds me that you're suffering from an illness	Lester <i>et al.</i> (2011)	
	Changing self- identity	I used to be a normal person you feel so alone, and you feel jealous of normal people	Lester et al. (2011)	
	ŕ	All the psychotic people are operating on the same frequency and all the people outside of that are operating on another frequency	Harris et al. (2012)	

on and how (Bryne and Morrison, 2010; Uttinger *et al.*, 2018). This provided a route to rethink and reappraise unhelpful thoughts, beliefs and behaviours (Byrne and Morrison, 2014) through learning about the links with symptoms (Uttinger *et al.*, 2018). Users cited improved social functioning as a valued outcome of CBT, i.e. they spent more time with others and in previously avoided places as a result of applying techniques in feared situations, e.g. using rationalisation when feeling paranoid (Byrne and Morrison, 2014).

For the FEP group CBT was often valued later in the treatment pathway (after building therapeutic relationships, understanding the label and receiving medical care) (Barr et al., 2015). Some users expressed initial avoidance and anxiety prior to engaging in CBT work; however, when this was overcome, they were willing to utilise skills upon completion, especially coping strategies (also behavioural experiments, diary work) with others involved in their care (i.e. care co-ordinators), and they also valued the CBT model (Welfare-Wilson and Jones, 2015). Although indicated by only one participant, it is noteworthy that CBT was cited as less helpful when on a high dose of medication or not being in the right frame of mind (in line with 'the journey' and psychological input being valued at different time points) (Barr et al., 2015).

Both groups highlighted CBT as instrumental in increasing their coping repertoire through learning; upon completion of CBT, ARMS users reported an increased psychosocial understanding of difficulties, and use of adaptive strategies when faced with these (Byrne and Morrison, 2010; Byrne and Morrison, 2014; Uttinger *et al.*, 2018). FEP users reported increased learning and understanding of the links between experiences, symptoms, and impact upon mood, through both individual and group CBT formats (Barr *et al.*, 2015; Welfare-Wilson and Jones, 2015).

# The journey

This theme highlights a common journey when moving through EIP services, which referred to experiences preceding service involvement, accessing help, understanding and prioritising needs and consideration of moving on, as endorsed by seven studies in the review.

For the ARMS group, the beginning of the journey often consisted of identification of the need for help due to the knowledge something was wrong (Uttinger *et al.*, 2018; Welsh and Tiffin, 2012), with users outlining either gradual build-up of symptoms, others with sudden changes

in perception/thinking (Uttinger et al., 2018), and some when at breaking point (Hardy et al., 2009). Triggers were often related to stress at work, illness, or drug use (Uttinger et al., 2018).

Both groups valued mental health support at inception of problems; for the ARMS group this meant knowing something was wrong so that it could be dealt with (Uttinger *et al.*, 2018; Welsh and Tiffin, 2012); for the FEP group this often meant recognising and managing early symptoms, i.e. being given a diagnosis to explain their illness, understanding this and learning about triggers in order to manage them. These mechanisms were often prioritised above learning different skills to stay well or the use of psychological interventions in the earlier stages of problems. However, later, orientation towards recovery was aligned with being supported to consider and reach other goals (Barr *et al.*, 2015).

Both groups valued psychological input later in their recovery journey after perceived hierarchical needs had been met, outlining the need for different interventions and support at different time points (Barr *et al.*, 2015). This was often due to progression and regression (Hardy *et al.*, 2009) and in line with the stage the user was at in relation to confronting and managing their experiences (Harris *et al.*, 2012). Both groups referred to prioritising and reaching goals distinct from symptom reduction (i.e. addressing housing issues) (Hardy *et al.*, 2009; Harris *et al.*, 2012).

For the ARMS group moving forwards was associated with post-therapy changes through understanding difficulties, learning to cope long-term using relevant tools, and through improved social functioning (Byrne and Morrison, 2014; Hardy *et al.*, 2009). However, some users feared having no support if problems resurfaced (Hardy *et al.*, 2009) and would have appreciated further practical support (Uttinger *et al.*, 2018). In contrast, FEP users appreciated flexibility and negotiation regarding service provision, often viewing three years sustained engagement as too intensive (Lester *et al.*, 2011), despite recognising that regular contact with EIP was necessary to understand their experiences and move forwards (Harris *et al.*, 2012).

Some ARMS users were aware of negative stereotypes about psychosis (Uttinger et al., 2012); however, positive responses from others and support received appeared to mediate these experiences (see talking and disclosure, relationships with family and peers). However, FEP users often described changes in self-identity due to their experiences (i.e. loss of normality, changes in appearance) and service involvement, leading to fear of stigma and self-stigma (Harris et al., 2012; Lester et al., 2011). The way EIP was viewed could affect this, i.e. if it was viewed as different from mainstream services this could induce shame and separation, but if viewed as helping to reduce stigma this could positively affect involvement (Harris et al., 2012).

Some FEP users discovered a more positive self-concept following EIP involvement due to their experiences being noticed, allowing users to face things and re-establish aspects of life that had been lost (Harris *et al.*, 2012) enhancing their coping strategies and ability to meet and share experiences (Lester *et al.*, 2011). Conversely, some described an ongoing sense of detachment from their world and others, and a lack of understanding of a new self (Harris *et al.*, 2012; Lester *et al.*, 2012).

#### Discussion

The aims of this qualitative synthesis were to explore views on EIP provisions, namely CBT, and what was valued in order to make inferences regarding enhancing support. Findings outlined factors which were not always intervention specific; however, these impacted on the users' experiences of support, are in line with aims of the review and have important implications for provision. An example is the role of disclosure; whilst inclinations to initially disclose experiences come prior to service engagement, this was noted to be further facilitated through various aspects of EIP support (i.e. CBT, indicated as providing a safe context for disclosure; Byrne and Morrison, 2010; Byrne and Morrison, 2014; Uttinger *et al.*, 2018; Welfare-Wilson

and Jones, 2015). Disclosure experiences are also closely linked with the beginning of 'the journey'; indicated in the review as an imperative time frame, with both groups valuing support at inception of their problems. Thus, it is important for practitioners and policy makers to consider the experiences of those accessing support, and initial engagement. Fears about accessing support have been noted elsewhere (i.e. ARMS users' concern regarding others' attitudes), and calls have been made for services to address health beliefs and consider access issues related to stigma and difficult emotions (Ben-David et al., 2019). Wider issues regarding difficulties associated with accessing services may also affect disclosure and initial experiences, with calls made for more targeted and streamlined pathways into services (Allan et al., 2020). Policy supports a public health approach to identification of early psychosis which may facilitate earlier disclosure and more timely access. Within EIP, attention to beliefs about accessing and engaging with services, supporting other services in their referral systems (NICE, 2020) and stigma challenging initiatives may help to address these issues, i.e. liaison with employers (Izon et al., 2020). Research into the value of specific up and running programmes within EIP, i.e. individual placement support (IPS) and its effects may clarify the effectiveness of these programmes on stigma across individual networks. However, the evidence base regarding effectiveness of IPS generally within the UK is small (Heffernan and Pilkington 2011), with limited recent updates.

High value was placed on the therapeutic relationship, which echoes previous literature (Boydell et al., 2010), where positive qualities of HCPs, and the way individuals are treated, influences levels of engagement. The importance of building therapeutic relationships is widely cited as holding potential to enhance interventions and affect willingness to continue (Gee et al., 2018; Morrison and Barratt, 2010; Wood et al., 2015) and is a catalyst for enhancing other valued aspects of support. The instrumental role of wider relationships in augmenting support was outlined across both groups, but particularly with the FEP group in enhancing a sense of control. The literature recommends provision of family intervention (FI) across both groups (NICE, 2014); however, uptake across the country is low for the FEP group (Royal College of Psychiatrists, 2020), and ARMS is research still in its relative infancy (Izon et al., 2020; Law et al., 2019). Where provision of traditional FI is not possible, a less intensive approach may be of benefit, i.e. use of guided family self-help resources during clinical contact, psychoeducation and early support which may help improve carers' quality of life, benefiting the user (Izon et al., 2020). Guidance outlines a minimum expectation that carer focused education support programmes are offered to all FEP carers (NICE, 2014). This may consist of stand-alone interventions where FI is not possible, i.e. general emotional support, provision of signposting to relevant resources and networks, psychoeducational interventions, carer groups, relapse prevention work (Onwumere, 2018). Inclusion of carers in therapy sessions or associated homework tasks in CBT can further encourage a holistic approach to care. Where family histories may be traumatic there is a role for HCPs to explore this (with consent) due to correlations between trauma and psychosis symptoms and recommendations to formulate these experiences to guide treatment planning (Mayo et al., 2017).

Both groups expressed an enthusiasm to share their experiences with peers. Research has suggested the value of peer support in developing individuals' confidence, engaging in more relationships, work and education and feeling more hopeful about themselves and the future (Repper and Carter, 2010). Guidance advises that EIP services should provide encouragement to access peer support organisations, offering the opportunity to meet and engage with other service users (Royal College of Psychiatrists and Early Intervention in Psychosis Network, 2018). However, research into peer support initiatives remains limited. The existing evidence base looks to established populations with serious mental illness (Davidson *et al.* 2012), and is lacking where organisational and team benefits are concerned (White *et al.*, 2017).

Coping and attempts to manage experiences spanned across all studies. There appeared to be an inverse experience of coping across groups, whereby ARMS users often presented with high motivations to cope early in their experiences (corroborated elsewhere, i.e. Gee et al., 2018), through learning about these and later expressing some concern regarding withdrawal of support. FEP users often accepted and confronted experience later, appreciating flexibility around service involvement. These differences may require similar proactive efforts to augment coping in both groups at initial involvement in order to address any avoidance or passivity (it is noted elsewhere that ARMS users may rely on passive rather than active coping styles thus increasing stress) (Kang et al., 2018), encourage early acceptance and integration for FEP users, negate risks of fearing being resigned to a life with psychosis, and capitalising on ARMS users' motivation to increase self-efficacy and reduce anxiety around discharge. Both groups had positive outcomes when taking active control to cope with experiences which may be fostered by drawing on existing coping mechanisms and supporting their use, i.e. family support in helping to explore more adaptive coping strategies (Izon et al., 2020). Moving from a passive to an agentic stance has been correlated with an increase in power and coping, particularly as a process of CBT for those with psychosis (Berry and Hayward, 2011). We can view interventions which seek to augment involvement as important, i.e. sharing control through collaborative working in CBTp and targeting cognitive appraisals which may be determinants of coping styles within ARMS groups (Kang et al., 2018).

Normalisation, learning and understanding – features of many aspects of support found in the review – increased coping and are intrinsically interlinked. Normalisation can be supported throughout all stages of EIP involvement, correlated with review findings, i.e. normalising responses during initial involvement may facilitate disclosure and engagement, and the opportunity to share with peers can reduce distress. Learning and understanding regarding ARMS and FEP labels positively affected coping and understanding experiences. Use of psychosocial intervention (PSI), i.e. coping strategy enhancement, self-monitoring, motivational techniques and problem solving, have been found to improve overall quality of life for those with psychosis and have been recommended for FEP users (Ruggeri *et al.*, 2015). Specifically, use of psychoeducational materials as early as possible may serve to increase coping through increased understanding and normalisation (Favrod *et al.*, 2011), and can be actively utilised within therapeutic relationships. These strategies may be used prior to, or when CBT is not prioritised, which was also found to increase coping through its focus on learning and normalising approach.

There were some differences across CBT findings, i.e. ARMS users reported more intervention specific components as useful, and FEP users valued this later, with the input of key worker help in practising skills. Variations are not surprising given both differences in the trajectory of problems and EIP input (early use of CBT as an often stand-alone 6-month treatment offer for ARMS in comparison with a 3-year multidisciplinary intensive approach for FEP users) (NICE and NHSE, 2016). Both groups highlighted the value of understanding experiences, their impacts and learning strategies to manage these through CBT, which is corroborated by existing literature which espouses the value of normalisation, psychoeducation and formulation, linking these with increased understanding, acceptance, social and functional ability, for those with psychosis (Berry and Hayward, 2011; Kilbride et al., 2013; Morrison and Barratt, 2010). Importantly, these transdiagnostic features of CBT may be modelled in routine practice and can be supported by trained therapists; evidence has suggested that delivery of CBT interventions by staff with non-specific training can be highly effective (Ekers et al., 2011; Waller et al., 2014). Encouragement of basic formulation development may aid initial understanding and normalisation, socialising users to the CBT model and can be facilitated in routine clinical practice by HCPs (Cox, 2021).

Both groups indicated a hierarchy of needs related to support, i.e. valuing practical support earlier and psychological input later which makes sense given wider motivational theory (McLeod, 2007) and specific psychosis literature (French and Morrison, 2004). This may have implications for ARMS users (due to a short CBT focused treatment window) who were also

found to value a flexible and informal approach, and especially younger ARMS users who have been found to have lower attendance rates and may be less receptive to CBT (Stain *et al.*, 2016). The FEP group also appreciated flexibility regarding psychological input. This is important given evidence suggesting that engagement in CBT can be hard work despite it being acknowledged as beneficial in similar populations (Gee *et al.*, 2018; Kilbride *et al.*, 2013; Valmaggia *et al.*, 2008). Awareness of the stage the person is at in their personal journey offers insights as to where and how support should be targeted, which may negate risks of offering this early and potentially causing iatrogenic harm.

Less structured interventions have been advocated across both groups where flexibility is required; i.e. non-directive listening and active engagement has been suggested with ARMS users (Stain *et al.*, 2016) in line with a stepped care approach often advocated with this group (McGorry *et al.*, 2008). For the FEP group interventions other than formal CBT or FI may be of value and preferable to users at the beginning of their journey, which may also be less stigmatising (Bird *et al.*, 2010; Marshall and Rathbone, 2011). This approach may reduce the risks of experiencing detachment and negative changes in self-identity found in the review. Later consideration of CBT may positively affect self-image, acceptance and self-esteem through normalisation, understanding and coping (Morrison and Barratt, 2010). These are important considerations given that achievement of identity has been prioritised within this group (Boydell *et al.*, 2010). Sensitively staging support may foster disclosure, therapeutic relationship building and lay foundations for psychological input and use of more complex interventions.

The strengths of this review are that focus was given solely to service user led papers, thus attempting to provide a rich narrative from a users' perspective. The fact that the previous CBT reviews discussed have included only one at risk study (Wood *et al.*, 2015) indicates that this review is important in synthesising the perspectives of this group which needs to be built upon.

#### Limitations and future research

The nine eligible studies consisted of five ARMS and four FEP studies. Two were CBT studies (Byrne and Morrison, 2014; Welfare-Wilson and Jones, 2015), three made reference to CBT (Barr et al., 2015; Byrne and Morrison, 2010; Uttinger et al., 2018) and the remainder refer to psychological intervention (Hardy et al., 2009; Harris et al., 2012; Lester et al., 2011; Welsh and Tiffin, 2012). We might assume psychological intervention pertained to use of CBT, especially given national guidelines (NICE and NHSE, 2016); however, we cannot draw firm conclusions around this, making generalisations difficult.

One study utilised mixed methods, the qualitative component using a framework which generated a coding matrix of themes and categories (Welfare-Wilson and Jones, 2015). Another condensed data using qualitative content analysis (Uttinger *et al.*, 2018). Another utilised Q-methodology, which may be critiqued as it forces respondents to offer opinions based on pre-determined items (Barr *et al.*, 2015). These studies, although arguably not fully meeting criteria against PEO, were deemed useful regarding conclusions as they identified the views of patients and all made direct reference to CBT, giving insights across all categories.

Only three studies reported Patient, Carer and Public Involvement (PCPI) activity; a service user researcher conducting interviews and contributing to analysis of results (Byrne and Morrison, 2010; Byrne and Morrison, 2014) and involving a service user in refining data (Barr *et al.*, 2015). The majority of studies were not ethnically diverse (three failed to record ethnicity), reducing generalisability and an understanding of how culture may shape opinions of mental health services. Age of participants in the studies also indicates a limited voice for those who are over 35, despite increased age range provision outlined in recent guidelines (NICE and NHSE, 2016).

This review revealed an absence of research conducted with the EIP population concerning their psychological and treatment preferences, which has been outlined elsewhere (Boydell *et al.*, 2010). Issues regarding ARMS service variation and patchy provision (Stain *et al.*, 2019)

may explain limited literature regarding service users' experiences. The focus of the included studies may explain the identified themes highlighting relationships and personal factors rather than intervention specific themes. Further research should explore the impacts of EIP commissioned interventions from service users' perspectives to further elucidate valued aspects of support. More CBT studies are required to clarify specific valued mechanisms and interventions (i.e. exactly how psychological support serves to affect sense of security, control and resultant coping). Both groups expressed an enthusiasm for group support, which may benefit from further exploration, i.e. research into use of peer networks and group CBT undertaken within EIP services. Such research has the potential to inform effective and holistic care and influence psychological therapy delivery.

#### **Conclusion**

Despite the limitations of the evidence base in this area, the review confirms the importance of relationships in facilitating disclosure and engagement. Therapeutic relationships are best cultivated through efforts to work collaboratively and consistently with individuals, understanding the stage of their personal journey which is key regarding targeting support at the relevant level. Developing coping skills is also important, which may be encouraged through learning, understanding and normalisation, enhanced through the principles of, and transdiagnostic interventions of, CBT.

This is a sound starting point for EIP care delivery, although further research into specific interventions and mechanisms of support is required for individual groups who are at different points in their journey and receive different levels of care. This is also indicated by group differences regarding experiences of CBT, coping responses and service flexibility preferences.

#### **Key practice points**

- (1) Normalising responses to experiences throughout involvement, especially early on, is key in fostering disclosure and engagement and may address fears of stigma.
- (2) A keen focus to building early coping skills may instil hope, reduce potential avoidance and increase ability to engage in targeted interventions, i.e. CBT. Understanding individual coping skills and building on these enhances individuals' sense of control regarding their experiences.
- (3) Consideration should be given to the role of families and peers in the therapeutic journey for both groups, and how this could augment interventions, i.e. through targeted family intervention, guided carer self-help resources, care and relapse prevention planning.
- (4) Encouraging involvement in CBT activity from HCPs and carers/family, i.e. with homework tasks, engaging with the therapy blueprint will support ongoing progress and maximise use of skills outside and beyond sessions.
- (5) Learning and understanding are imperative in cultivating coping and can be supported through provision of psychoeducational materials and facilitated through use of individual formulation.
- (6) Understanding the stage of the person's individual journey will help target support (i.e. whether basic needs require addressing prior to psychological input).

# Acknowledgements. None.

Financial support. L.C. was partly funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care North West Coast. C.M. is partly funded by the NIHR Applied Research Collaboration North West Coast. The views expressed are those of the authors and not necessarily those of the NIHR, National Health Service or Department of Health and Social Care.

Conflicts of interest. The authors declare that there are no conflicts of interest.

**Ethics statement.** Not applicable due to nature of article.

Data availability statement. The authors confirm that the data supporting the findings of this study are available within the article.

Author contributions. Lauren Cox: conception and design of the paper, data collection, analysis, synthesis and interpretation; writing full first draft, responding to reviewers' comments; handling the revision and re-submission of the revised manuscript up to the acceptance of the manuscripts; final approval of version to be published. Colette Miller: support revising first author drafts; scientific advisor regarding methodology; second draft data collection, ensuring paper adhered to PRISMA guidelines; manuscript correction/proofreading (technical and language editing).

# **Further reading**

- Berry, C., & Hayward, M. (2011). What can qualitative research tell us about service user perspectives of CBT for psychosis? A synthesis of current evidence. Behavioural and Cognitive Psychotherapy, 39, 487–494. doi: 10.1017/S1352465811000154
- Brabban, A., Byrne, R., Longden, E., & Morrison, A. P. (2016). The importance of human relationships, ethics and recoveryorientated values in the delivery of CBT for people with psychosis. *Psychosis: Psychological, Social and Integrative Approaches*, 9, 157–166
- e-Learning for Healthcare (2021). Cognitive Behavioural Therapies for Psychosis. An elearning resource designed to demonstrate different types of therapy techniques. Retrieved from: https://www.e-lfh.org.uk/programmes/cognitive-behavioural-therapies-for-psychosis/ (a certificate is available if self-assessment is passed, and are evidence of learning for CPD purposes. Free access is available for staff working in the NHS).
- Fadden, G., James, C. & Pinfold, V. (2012). Caring for Yourself Self-Help for Families and Friends Supporting People With Mental Health Problems. Rethink Mental Illness and Meriden Family Programme. Birmingham: White Halo Design. Also available as a free online workbook: https://www.meridenfamilyprogramme.com/recovery/what-carers-families-and-friends-can-do-to-help-themselves/caring-for-yourself (exercises support coping skill development, i.e. communication skills, problem solving and goal achievement and relapse management).
- French, P., & Morrison, A. (2004). Early Detection and Cognitive Therapy for People at High Risk of Developing Psychosis A Treatment Manual. Chichester, UK: John Wiley.
- McGowan, J., Lavendar, T., & Garety, P. (2005). Factors in outcome of cognitive-behavioural therapy for psychosis: users' and clinicians' views. *Psychology and Psychotherapy: Theory, Research and Practice*, 78, 513–529. doi: 10.1348/147608305X52559
- Turkington, D., Hagen, R., Berge, T. & Grawe, R.W. (eds) (2013). CBT for Psychosis: A Symptom-Based Approach. London, UK: Routledge.

# References

- Addington, J., Cornblatt, B. A., Cadenhead, K. S., Cannon, T. D., McGlashan, T. H., Perkins, D. O., ... & Woods, S. W. (2011a). At clinical high risk for psychosis: outcome for nonconverters. *American Journal of Psychiatry*, 168, 800–805.
- Addington, J., Epstein, I., Liu, L., French, P., Boydell, K. M., & Zipursky, R. B. (2011b). A randomized controlled trial of cognitive behavioral therapy for individuals at clinical high risk of psychosis. *Schizophrenia Research*, 125, 54–61.
- Allan, S. M., Hodgekins, J., Beazley, P., & Oduola, S. (2020). Pathways to care in at-risk mental states: a systematic review. *Early Intervention in Psychiatry*.
- Aromataris, E., & Riitano, D. (2014). Constructing a search strategy and searching for evidence. American Journal of Nursing, 114, 49–56.
- Barr, K., Ormrod, J., & Dudley, R. (2015). An exploration of what service users value about early intervention in psychosis services. Psychology and Psychotherapy: Theory, Research and Practice, 88, 468–480.
- Ben-David, S., Cole, A., Brucato, G., Girgis, R. R., & Munson, M. R. (2019). Mental health service use decision-making among young adults at clinical high risk for developing psychosis. *Early Intervention in Psychiatry*, 13, 1050–1055.
- Berry, C., & Hayward, M. (2011). What can qualitative research tell us about service user perspectives of CBT for psychosis? A synthesis of current evidence. Behavioural and Cognitive Psychotherapy, 39, 487–494. doi: 10.1017/S1352465811000154
- Bettany-Saltikov, J. (2012). How to do a Systematic Literature Review in Nursing: A Step-by-Step Guide. McGraw-Hill Education, UK.
- Bird, V., Premkumar, P., Kendall, T., Whittington, C., Mitchell, J., & Kuipers, E. (2010). Early intervention services, cognitive-behavioural therapy and family intervention in early psychosis: systematic review. *British Journal of Psychiatry*, 197, 350–356.
- Boydell, K. M., Stasiulis, E., Volpe, T., & Gladstone, B. (2010). A descriptive review of qualitative studies in first episode psychosis. *Early Intervention in Psychiatry*, 4, 7–24.
- Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research & Policy*, 7, 209–215.
- Byrne, R., & Morrison, A. P. (2010). Young people at risk of psychosis: a user-led exploration of interpersonal relationships and communication of psychological difficulties. *Early Intervention in Psychiatry*, 4, 162–168.

- Byrne, R. E., & Morrison, A. P. (2014). Young people at risk of psychosis: their subjective experiences of monitoring and cognitive behaviour therapy in the early detection and intervention evaluation 2 trial. *Psychology and Psychotherapy: Theory, Research and Practice*, 87, 357–371.
- CASP (2017). CASP (Qualitative Research) Checklist. Retrieved from: http://docs.wixstatic.com/ugd/dded87\_ 25658615020e427da194a325e7773d42.pdf
- Cox, L. (2021). Use of individual formulation in mental health practice. Mental Health Practice, 24, 33-41.
- Davidson, L., Bellamy, C., Guy, K., & Miller, R. (2012). Peer support among persons with severe mental illnesses: a review of evidence and experience. World Psychiatry, 11, 123–128.
- Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., ... & Smith, L. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. BMC Medical Research Methodology, 6, 1–13.
- Ekers, D., Richards, D., McMillan, D., Bland, J. M., & Gilbody, S. (2011). Behavioural activation delivered by the non-specialist: phase II randomised controlled trial. *British Journal of Psychiatry*, 198, 66–72.
- Favrod, J., Crespi, S., Faust, J. M., Polari, A., Bonsack, C., & Conus, P. (2011). A psychoeducation tool for patients with first-episode psychosis. Acta Neuropsychiatrica, 23, 75–77.
- Finlay, L. (2006). 'Rigour', 'ethical integrity 'or 'artistry'? Reflexively reviewing criteria for evaluating qualitative research. British Journal of Occupational Therapy, 69, 319–326.
- French, P., & Morrison, A. (2004). Early Detection and Cognitive Therapy for People at High Risk of Developing Psychosis A Treatment Manual. Chichester, UK: John Wiley.
- Gee, B., Notley, C., Byrne, R., Clarke, T., Hodgekins, J., French, P., & Fowler, D. (2018). Young people's experiences of Social Recovery Cognitive Behavioural Therapy and treatment as usual in the PRODIGY trial. *Early Intervention in Psychiatry*, 12, 879–885.
- Hardy, K. V., Dickson, J. M., & Morrison, A. P. (2009). Journey into and through an early detection of psychosis service: the subjective experience of persons at risk of developing psychosis. Early Intervention in Psychiatry, 3, 52–57.
- Harris, K., Collinson, C., & das Nair, R. (2012). Service-users' experiences of an early intervention in psychosis service: an interpretative phenomenological analysis. *Psychology and Psychotherapy: Theory, Research and Practice*, 85, 456–469.
- Heffernan, J., & Pilkington, P. (2011). Supported employment for persons with mental illness: systematic review of the effectiveness of individual placement and support in the UK. *Journal of Mental Health*, 20, 368–380.
- Hewitt-Taylor, J. (2017). The Essential Guide to Doing a Health and Social Care Literature Review. Taylor & Francis.
- Hutton, P., & Taylor, P. J. (2014). Cognitive behavioural therapy for psychosis prevention: a systematic review and metaanalysis. Psychological Medicine, 44, 449.
- Izon, E., Au-Yeung, K., & Jones, W. (2020). The challenges of engaging individuals at high-risk of developing psychosis: reflections from research assistants within a randomised control trial. *Psychosis*, 1–9.
- Kang, M., Bang, M., Lee, S. Y., Lee, E., Yoo, S. W., & An, S. K. (2018). Coping styles in individuals at ultra-high risk for psychosis: associations with cognitive appraisals. *Psychiatry Research*, 264, 162–168.
- Kilbride, M., Byrne, R., Price, J., Wood, L., Barratt, S., Welford, M., & Morrison, A. P. (2013). Exploring service users' perceptions of cognitive behavioural therapy for psychosis: a user led study. *Behavioural and Cognitive Psychotherapy*, 41, 89.
- Law, H., Izon, E., Au-Yeung, K., Morrison, A. P., Byrne, R., Notley, C., ... & French, P. (2019). Combined individual and family therapy in comparison to treatment as usual for people at-risk of psychosis: a feasibility study (IF CBT): trial rationale, methodology and baseline characteristics. *Early Intervention in Psychiatry*, 15, 140–148.
- Lester, H., Marshall, M., Jones, P., Fowler, D., Amos, T., Khan, N., & Birchwood, M. (2011). Views of young people in early intervention services for first-episode psychosis in England. Psychiatric Services, 62, 882–887.
- Major, C. H., & Savin-Baden, M. (2010). An Introduction to Qualitative Research Synthesis: Managing the Information Explosion in Social Science Research. Routledge.
- Marshall, M., & Rathbone, J. (2011). Early intervention for psychosis. Cochrane Database of Systematic Reviews, 6.
- Mayo, D., Corey, S., Kelly, L. H., Yohannes, S., Youngquist, A. L., Stuart, B. K., ... & Loewy, R. L. (2017). The role of trauma and stressful life events among individuals at clinical high risk for psychosis: a review. *Frontiers in Psychiatry*, 8, 55.
- McCabe, J. L., & Holmes, D. (2009). Reflexivity, critical qualitative research and emancipation: a Foucauldian perspective. Journal of Advanced Nursing, 65, 1518–1526.
- McGorry, P. D., Killackey, E., & Yung, A. (2008). Early intervention in psychosis: concepts, evidence and future directions. *World Psychiatry*, 7, 148.
- McLeod, S. (2007). Maslow's hierarchy of needs. Simply Psychology, 1, 1-8.
- Mehl, S., Werner, D., & Lincoln, T. M. (2015). Does Cognitive Behavior Therapy for psychosis (CBTp) show a sustainable effect on delusions? A meta-analysis. *Frontiers in Psychology*, 6, 1450.
- Morrison, A. P., & Barratt, S. (2010). What are the components of CBT for psychosis? A Delphi study. *Schizophrenia Bulletin*, 36, 136–142.
- Morrison, A. P., French, P., Stewart, S. L., Birchwood, M., Fowler, D., Gumley, A. I., ... & Murray, G. K. (2012). Early detection and intervention evaluation for people at risk of psychosis: multisite randomised controlled trial. *BMJ*, 344, e2233.
- Moule, P., Aveyard, H., & Goodman, M. (2016). Nursing Research: An Introduction. Sage.

- Munn, Z., Porritt, K., Lockwood, C., Aromataris, E., & Pearson, A. (2014). Establishing confidence in the output of qualitative research synthesis: the ConQual approach. *BMC Medical Research Methodology*, 14, 1–7.
- NICE (2014). Psychosis and Schizophrenia in Adults: Prevention and Management. Clinical Guideline CG178. London, UK: National Institute for Health and Care Excellence.
- NICE (2020). Implementing the Early Intervention in Psychosis Access and Waiting Time Standard: Guidance. London, UK: National Collaborating Centre for Mental Health.
- NICE and NHSE (2016). Implementing the Early intervention in Psychosis Access and Waiting Time Standard: Guidance. National Collaborating Centre for Mental Health.
- Onwumere, J. (2018). Early psychosis services: carer focused psychoeducation and support-brief version. London Early Intervention Clinical Reference Group Report. Retrieved from: https://myhealth.london.nhs.uk/wp-content/uploads/2019/03/Carer-focused-education\_support\_review\_AbbrevVersion\_01\_2019.pdf
- Polit, D. F., & Beck, C. T. (2009). Essentials of Nursing Research: Appraising Evidence for Nursing Practice. Lippincott Williams & Wilkins.
- Repper, J., & Carter, T. (2010). Using personal experience to support others with similar difficulties: a review of the literature on peer support in mental health services. London, UK: Together/University of Nottingham/NSUN.
- Royal College of Psychiatrists (2016). Standards for Early Intervention in Psychosis Services. London, UK: Royal College of Psychiatrists.
- Royal College of Psychiatrists & Early Intervention in Psychosis Network (2018). Standards for Early Intervention in Psychosis Services 1st edn. CCQI285. London, UK: Early Intervention in Psychosis Network, Royal College of Psychiatrists' Centre for Quality Improvement.
- Royal College of Psychiatrists (2020). National Clinical Audit of Psychosis National Report for the Early Intervention in Psychosis Spotlight Audit 2019/2020. London, UK: Healthcare Quality Improvement Partnership.
- Ruggeri, M., Bonetto, C., Lasalvia, A., Fioritti, A., De Girolamo, G., Santonastaso, P., ... & GET UP Group (2015). Feasibility and effectiveness of a multi-element psychosocial intervention for first-episode psychosis: results from the cluster-randomized controlled GET UP PIANO trial in a catchment area of 10 million inhabitants. *Schizophrenia Bulletin*, 41, 1192–1203.
- Stafford, M. R., Jackson, H., Mayo-Wilson, E., Morrison, A. P., & Kendall, T. (2013). Early interventions to prevent psychosis: systematic review and meta-analysis. *British Medical Journal*, 18, f185.
- Stain, H. J., Bucci, S., Baker, A. L., Carr, V., Emsley, R., Halpin, S., ... & Crittenden, K. (2016). A randomised controlled trial of cognitive behaviour therapy versus non-directive reflective listening for young people at ultra high risk of developing psychosis: the detection and evaluation of psychological therapy (DEPTh) trial. *Schizophrenia Research*, 176, 212–219.
- Stain, H. J., Mawn, L., Common, S., Pilton, M., & Thompson, A. (2019). Research and practice for ultra-high risk for psychosis: a national survey of early intervention in psychosis services in England. *Early Intervention in Psychiatry*, 13, 47–52.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Medical Research Methodology, 8, 45.
- Uttinger, M., Koranyi, S., Papmeyer, M., Fend, F., Ittig, S., Studerus, E., Ramyead, A., Simon, A., & Riecher-Rössler, A. (2018). Early detection of psychosis: helpful or stigmatizing experience? A qualitative study. *Early Intervention in Psychiatry*, 12, 66–73.
- Valmaggia, L. R., Tabraham, P., Morris, E., & Bouman, T. K. (2008). Cognitive behavioral therapy across the stages of psychosis: prodromal, first episode, and chronic schizophrenia. Cognitive and Behavioral Practice, 15, 179–193.
- van der Gaag, M., Nieman, D. H., Rietdijk, J., Dragt, S., Ising, H. K., Klaassen, R. M., ... & Linszen, D. H. (2012). Cognitive behavioral therapy for subjects at ultrahigh risk for developing psychosis: a randomized controlled clinical trial. *Schizophrenia Bulletin*, 38, 1180–1188.
- Waller, H., Craig, T., Landau, S., Fornells-Ambrojo, M., Hassanali, N., Iredale, C., ... & Garety, P. (2014). The effects of a brief CBT intervention, delivered by frontline mental health staff, to promote recovery in people with psychosis and comorbid anxiety or depression (the GOALS study): study protocol for a randomized controlled trial. *Trials*, 15, 255.
- Welfare-Wilson, A., & Jones, A. (2015). A CBT-based anxiety management workshop in first-episode psychosis. *British Journal of Nursing*, 24, 378–382.
- Welsh, P., & Tiffin, P. A. (2012). Observations of a small sample of adolescents experiencing an at-risk mental state (ARMS) for psychosis. *Schizophrenia Bulletin*, 38, 215–218.
- White, H., Price, L., & Barker, T. (2017). Exploring the impact of peer support in early intervention in psychosis. *Mental Health and Social Inclusion*, 21, 102–109.
- Wood, L., Burke, E., & Morrison, A. (2015). Individual cognitive behavioural therapy for psychosis (CBTp): a systematic review of qualitative literature. *Behavioural and Cognitive Psychotherapy*, 43, 285–297.
- Cite this article: Cox L and Miller C. A qualitative systematic review of Early Intervention in Psychosis service user perspectives regarding valued aspects of treatment with a focus on cognitive behavioural therapy. *The Cognitive Behaviour Therapist*. https://doi.org/10.1017/S1754470X2100026X