Service User and Carer Experiences of Engaging with Early Intervention Services: A Meta-Synthesis Review

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Service User and Carer Experiences of Engaging with Early Intervention Services: A Meta-Synthesis Review

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Service user and carer experiences of engaging with early intervention services: A meta-synthesis review

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Abstract

Aim: The provision and implementation of Early Intervention for psychosis Services (EIS) has received increasing attention over recent years. Maximising engagement with EIS is of clinical and economic importance, and exploring the experiences of those who access EIS is vital. Although research has been conducted exploring the experiences of engaging with EIS from both a service user and carer/family member point of view, these data have not been systematically collated to generate new understanding. The primary aim of this study is to review, critically appraise and synthesise qualitative findings relating to the experiences of service users and/or carers and family members engaging with EIS.

Methods: Four databases were systematically searched. Studies were analysed using an inductive thematic analysis (ITA) approach, within a critical realist epistemological framework. Studies were critically appraised using the Critical Appraisal Skills Programme (CASP) tool.

Results: Fourteen papers were identified for inclusion. Three main themes were identified: the importance of a personal relationship with an EIS staff member, the impact of this relationship; consideration of life after EIS. The importance of a strong relationship with EIS staff was the most prominent theme throughout papers reviewed.

Conclusions: The quality of the therapeutic relationship with at least one EIS staff member was the single most important factor in determining whether the experience of accessing EIS was a positive or negative one. The majority of the studies reviewed were conducted in the United Kingdom (UK) or Australia. Therefore, more research across countries is needed to understand transferability of findings.

Introduction

Early Intervention Services (EIS) are community based multi-disciplinary services that are offered worldwide to provide treatment and support to individuals experiencing a first episode of psychosis (FEP; Marshall & Rathbone, 2011). Engagement with EIS typically lasts for three years and support is often of a more intensive nature than other secondary care services, taking a more assertive outreach approach, which, if appropriate, can extend to family members and carers (Marshall & Rathbone, 2011). Engaging with EIS results in better clinical outcomes than standard care alone (Bird et al., 2010), including fewer subsequent inpatient admissions (Craig et al., 2004), improved social functioning (Knapp, Patel, Curran et al., 2013) and reduced symptomatology (Revier, Reininghaus, Dutta et al., 2015). When support is extended to family members, relapse rates have been shown to reduce by as much as 40% (Knapp, Andrew, McDaid et al., 2014).

Given the short and long-term benefits of engaging with EIS from both a personal and economic point of view, much research has focussed on routes to accessing services and the experiences of seeking help for early psychosis (Anderson, Fuhrer & Malla, 2013; Bechard-Evans et al., 2007). There has, however, been comparatively less research investigating the subjective experiences of service users and family members experience of services, once they access services. Ongoing engagement and willingness to engage with services has been shown to be a major factor in the recovery process (Lecomte et al., 2008) and sustaining both the personal and economic benefits of EIS involvement. Additionally, the benefits of exploring the experiences of those who access mental health services to aid evaluation and further development, as opposed to looking at them from a purely economic or academic viewpoint, are numerous. In broad terms, the process of exploring individuals’ experiences via qualitative research provides rich, meaningful data, which can be interpreted in further detail and incorporated with existing or emerging theory (Seidman, 2006). With regards to

mental health services, the practice of involving service user and carers' views in the provision and assessment of services provides the opportunity to learn from 'experts by experience' (Law & Morisson, 2014), thereby potentially reducing marginalisation and systematic disempowerment for those involved (Ennis & Wykes, 2013). Although there have been some qualitative studies exploring the experiences of service users and carers engaging with EIS, there are no published papers that have collated these findings into a single review, evaluated the relative strength of papers, and distilled the key clinical findings within each paper. This meta-synthesis was conducted to address this need. The aims of this meta-synthesis were to: (1) review and synthesise qualitative findings relating to the experiences of service users and/or carers/family members engaging with EIS; and (2) highlight the implications of findings for applied practice.

Method

Meta-synthesis is an interpretative approach to collating and synthesising existing qualitative data, with the aim of establishing a coherent new interpretation of the findings (Paterson & Canam, 2001; Zimmer et al, 2006). An explicit systematic approach of identifying and assessing the quality of potential papers, followed by analysis of the data and synthesis, was employed with the aim of gaining an understanding of the experiences of service users and/or their family members in accessing Early Intervention Services for psychosis.

Search Strategy

As outlined in figure 1, in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009), the initial search for published papers utilised four databases: PsycInfo, Cinahl, Embase and Medline. All papers were required to be qualitative studies published in English. There were no restrictions on

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publication year. Search terms were: (Early Intervention Service*) OR (First episode*)) AND ((Psychotic) OR (Psychosis) OR (Schizophren*) OR (Bipolar)) AND ((Satisfaction*) OR (Opinion*) OR (Attitude*) OR (View*) OR (Experience*) OR (Perception*) OR (Evaluati*) OR (Value*) OR (Perspective*). Reference lists of retrieved papers were also searched. Papers were initially reviewed by title, abstract and then full article and were eligible if they met the following criteria: i) examined service user and/or family member opinions on the experience of being registered with an EIS; ii) qualitative method design; iii) separated out the views and experiences of service users and family members; and iv) published in English language. This led to a final sample of 14 studies.

Quality appraisal

Study quality was assessed using the Critical Appraisal Skills Programme (CASP, 2013), which comprises 10 items assessing the relevance and credibility of papers. Adopting the principle suggested by Duggleby et al. (2010), each item was assigned a score, with ‘3’ indicating fully addressed, ‘2’ denoting partially addressed and ‘1’ barely addressed. Scoring was completed by the first author and cross-referenced with the other authors to reach a consensus, enabling discussion regarding difference in opinions.

Data extraction and synthesis

The selected papers were read, re-read and key information from the studies was recorded (see Table 1). In accordance with the principles of meta-synthesis and in line with previous examples of meta-synthesis of qualitative studies (Bayliss et al, 2014), data were extracted from each paper from the original authors’ analysis of their primary qualitative data (first order constructs). Using a thematic approach (Braun and Clarke, 2013) from a critical realist perspective (Fletcher, 2016), MM then grouped these constructs into core themes. Following

discussion of these within the research team, including consideration of how each paper identified contributed to each core theme, an iterative process of further analysis was undertaken. The aim of this process was to develop a cohesive, synthesised understanding of the data, going beyond the reported findings in each individual paper (Malpass et al., 2009) and led to themes being further grouped into final higher-order themes. These final themes were again reviewed and agreed by the research team. These final themes are considered second order constructs and allow for further reflection on how these synthesised findings sit within the wider literature and might extend beyond the original papers. Following this, MM returned to the data and checked that themes identified sufficiently reflected the data and that other themes had not been overlooked, ensuring findings were data-driven and substantiated.

Results

Summary of papers

Fourteen papers were deemed eligible for inclusion in the review. Nine studies were conducted in the UK, three in Australia, one in Denmark and one USA. Six utilised Interpretive Phenomenological Analysis (IPA), five used thematic analysis, and three used a grounded theory approach. Participant numbers ranged from 7-80 (mean=24). Eight papers interviewed service users only; five interviewed carers/family members and one interviewed both. It has been argued that synthesising research holding different epistemological viewpoints is problematic, due to the inherent differing concepts and underlying principles (Sandelowski, Docherty & Emden, 1997). In contrast, Finfgeld (2003) contend that synthesising multiple approaches can be a productive process, leading to a richer, 'truer' understanding. Papers were not excluded on the basis of their epistemological viewpoints in this review.

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Findings

Analysis of the data revealed three main themes, which are summarised in Figure 2: the importance of a personal relationship with an EIS staff member, the impact of this relationship and the consideration of life after EIS.

THE IMPORTANCE OF A PERSONAL RELATIONSHIP WITH AN EIS STAFF MEMBER

The vast majority of studies explicitly described the nature of the relationship that both service users and carers formed with EIS staff. In most studies, this was narrowed down to the relationship with a specific member of staff, typically a key-worker. The value of a ‘real’ relationship with at least one EIS staff member was evident throughout most studies and underpinned most accounts of engaging with EIS. A ‘real’ relationship was described as one in which service users and carers felt staff members took a genuine, person-centred interest in their holistic well-being, ultimately seeing them as more than ‘just a patient’ or ‘just a carer’. More specifically, across the papers, several factors were identified as necessary in ensuring this relationship was experienced as ‘real’. These included EIS staff adopting a calm, warm and approachable style of interaction (McCann et al., 2011; Lester et al., 2012; Jansen et al., 2015), using ‘plain’ language so as to avoid a sense of hierarchy (Lavis et al., 2015; McCann et al., 2011;), ensuring the service user and/or carer felt listened to and taken seriously by adopting a non-judgemental stance (O’Toole et al., 2004; McCann et al., 2011; McCann et al., 2011a; Stewart, 2012; Tindell et al., 2015; Jansen et al., 2015; Van Schalkwyk et al., 2015) and not dismissing or overlooking any concerns (Jansen et al., 2015; Van Schalkwyk et al., 2015). Additionally, where staff were perceived as being prepared to work flexibly both in terms of the immediate practicalities of working together (e.g. discussing location and

frequency of meetings) and more longitudinally (such as negotiating medication changes or psychosocial interventions), this was seen as beneficial in helping to create an equal, two-way relationship (O'Toole et al., 2004; Stewart, 2012; Tindell et al., 2015).

The combination of these identified factors appeared to aid both parties in experiencing the relationship as a genuine, 'human' one, free of typical clinical boundaries. This 'human' element was something that Stewart (2012) and Jansen et al. (2015) expanded upon and described as the main impetus for continued engagement with the service, in part due to the difference of this relationship when compared to other mental health staff and services, which were often seen as more distant and removed:

... [EIS staff member], *she's very human, you know. She didn't put up a wall between what's professional and private, so she's herself, whereas often with [previous] psychiatrists and nurses, it's like hitting your head against a brick wall...* (Participant in Stewart, 2012).

Furthermore, an individualised, human relationship with EIS staff was identified by service users and authors as an integral component of recovery, underpinning the prime importance of the establishment and maintenance of this unique therapeutic bond, more so than any specific psychosocial or pharmaceutical intervention:

I see her every two weeks. I don't know what I would do without her...

(Participant in Lester et al., 2011).

Their [service users'] naming of particular nurses as their key point of contact was also symbolic of the treatment as being primarily relationship-based and highly individualized... (O'Toole et al., 2004).

Support for the importance of this genuine two-way relationship was found in papers that reported the impact of changes or disruptions in care on service users, which included feeling

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3 engagement with EIS was over-bearing (Lester et al., 2011) and increased reluctance and
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5 scepticism in opening up to new members of staff (Tindell et al., 2015), suggesting that a
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7 constant, caring relationship would prevent such feelings and promote meaningful,
8
9 continuing engagement. Additionally, even if the relationship was constant, findings reported
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11 in McCann et al. (2011) suggest that experiencing staff who adopt a superior, stigmatising
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13 approach led to participants feeling excluded, isolated, and ultimately, more reluctant to
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15 engage with EIS. This further supports the importance of a genuine, two-way, human
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17 relationship.
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25 **THE IMPACT OF THE RELATIONSHIP WITH AN EIS STAFF MEMBER**
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28 As outlined in Theme 1, a stable, genuine relationship with EIS staff appeared to be the
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30 cornerstone on which future progress under EIS was built upon. Exploring this further and
31
32 examining the direct impact of this relationship on recovery yielded three sub-themes: an
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34 increased sense of agency; improved quality of interactions with others; and an improved
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36 sense of identity.
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40 *Sense of agency*
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43 A positive working relationship with EIS appeared to have a direct impact on the reported
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45 level of agency individuals felt they had with regards to their mental health difficulties.
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47 Agency here refers to the degree to which individuals felt they had ‘control’ over their
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49 problems, or ability to deal with related issues. Harris et al. (2011) explicitly link the
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51 development of a good rapport with EIS with an increased sense of mastery and control over
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53 the symptoms and impact of psychosis, while O’Toole et al (2004), Jansen et al. (2015) and
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55 Tindell et al. (2015) discussed the empowering nature of gaining a sense of control over one’s
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57 psychosis as a result of engaging with EIS and building therapeutic relationships. This
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increased sense of agency was viewed as a highly valued by-product of engagement for many service users:

...even if I do hear voices, I know that it's not actually people talking, I know it's actually just going off in my own brain... I'm able to think, I can challenge it myself... Jane (EIS Psychologist) helped with that... when I do hear the voices, I go straight to my list that I got off Jane and it works... (Participant in Harris et al, 2011).

This suggests that the presence of a wiser other figure that service users trusted allowed for the gradual internalisation of the methods and techniques EIS staff employed to help manage their difficulties, meaning they were gradually able to utilise such techniques without the help of EIS.

Engagement with EIS also had an impact upon the extent to which carers felt they themselves had agency, or at least some degree of control, over their responses to their loved ones' difficulties. For many, the experience of having a positive relationship with staff and subsequently receiving psychoeducation enabled many carers to feel better able to support their family member and respond accordingly to acute episodes (McCann et al., 2011; Sin et al., 2012; Lavis et al., 2015):

They've all been fantastic [clinicians] in including us when they could, in treating... [son's name] and explaining everything to us. There's some very good information and fact sheets put out [by clinicians] and that's all very supportive of us and enables us to provide that information to friends of...[son], to let them understand what's going on...

(Participant in McCann et al., 2011).

This process appears to be less dependent on internalising information, as in service users' experiences, and rather more based on the acquisition and subsequent application of practical

advice and information, on a much more pragmatic basis. This arguably reflects the different needs of service users and carers, with the former requiring a deeper sense of agency in order to cope with the phenomenological experience of psychosis, and the latter needing a sense of mastery over the everyday, practical impact of psychosis.

Interactions with others

As with the process of internalising a sense of agency, many papers note that through forming a secure, stable bond with EIS staff, service users gained a framework of a positive relationship that they could take forward into other relationships, such as with family members (Lester et al., 2011; Allard et al., 2016) or future mental health services (Harris et al., 2011; Stewart 2012). Such findings would suggest that the introduction of a positive relationship in the safe, managed environment of EIS provided service users with the confidence to explore similar experiences in other areas of their lives:

...I'm more willing to say, 'This is what I'm experiencing,' without feeling ashamed or seeing it as a weakness. I was scared about her [mother] getting worried and things like that. But she's been great (Participant in Lester et al., 2011).

It also seemed that their [service users'] positive relationships with [EIS] staff prevented negative beliefs about initial treatment from generalizing across all staff relationships and defining future treatment experiences... (Stewart, 2012).

Similar experiences were reported by carers and/or family members, who reported seeing the benefits of the client-staff relationship:

He [participant's son] seems happier since he's been seeing someone on a regular basis and he seems more able to talk to us now. He's opening up and talking about

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3 *things, you know, like how he feels, what's happening in his life. I think that the EIS*
4 *have made him feel that it's okay to talk and to say how you feel about things, you*
5 *know...* (Participant in Allard et al. (2016)).
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10 This was also noted in Penny, Newton & Larkin (2009), in which, although many family
11 members felt there were aspects of the service they were dissatisfied with, the value of their
12 loved one having a genuine relationship with a key-worker was held in high esteem. It can
13 therefore be postulated that the formation of a trusting connection with an external party
14 (EIS) provided a much-needed 'breathing space' for both sides of the service user-carer
15 relationship. With this breathing space, both were able to gradually work on establishing
16 positive bonds with each other again, with the burden of managing the difficulties associated
17 with psychosis eased by the introduction of another source of support that was involved
18 enough to have a positive impact, but removed enough so as not to interfere with the
19 dynamics of the familial relationship.
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37 ***Improved sense of identity***

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40 Another benefit of service users establishing a positive bond with at least one EIS staff
41 member was that for many, it appeared to aid in reframing their sense of identity, from
42 feeling essentially flawed or damaged, to being increasingly accepting and compassionate
43 towards their difficulties (Harris et al., 2011; Lester et al., 2012; Stewart, 2012). This
44 suggests that for many, the space to talk freely about their problems with someone they could
45 trust and receive useful information from helped service users, in essence, to rewrite their
46 personal narrative, thereby no longer seeing themselves as fundamentally 'broken', but rather
47 a multi-faceted individual who happened to be dealing with mental health difficulties:
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3 *I know my [EIS staff member] wants us to believe that we can get through this... I*
4 *quickly got from that I'm not the problem, the problem is the problem... (Participant*
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6 *in Stewart, 2012).*
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11 Of the papers, only O'Toole et al. (2004) explored this development further, postulating that
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13 although receiving practical help such as psychoeducation is important, a much more latent
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15 process may be involved in this internalisation, with service users strongly identifying with
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17 services and their ethos, integrating it into their newly formed, post-psychosis, identity:
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21 *"The main observation is that participants strongly identified with the team, its*
22 *philosophy and goals... participants seemed to have taken on the identity of the team*
23 *as their own..."*
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27 (O'Toole et al, 2004).
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31 This was not universally reported, however, as for a smaller number of service users, this
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33 reframing, and indeed involvement with EIS in general, was not such a positive experience
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35 and only served to reinforce their perception of themselves as different from others:
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38 *I used to be a normal person you know... you feel so alone, and you feel jealous of*
39 *normal people (Participant in Lester et al., 2011).*
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44 Engagement with EIS also appeared to have a positive impact on many service users' sense
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46 of identity within the context of wider society. Many studies refer to the social isolation
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48 experienced by service users prior to involvement with EIS; subsequently, a number also
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50 report that through engaging with EIS, individuals were increasingly able to integrate
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52 themselves back into society and view themselves as a member of a wider community,
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54 whether this was amongst peers (Stewart, 2012; van Schalkwyk et al., 2015) or within society
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56 in a broader sense (O'Toole et al., 2004; Lester et al., 2012; Tindell et al. 2015). EIS
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58 facilitated peer groups were identified as helpful in achieving this, serving to further reduce
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3 social isolation and providing opportunities to disprove negative beliefs about the self, such
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5 as being alone in their difficulties (Harris et al., 2011; Stewart, 2012; Lester et al., 2012). In
6
7 addition to this, the practical support offered by EIS in gaining life skills and helping with
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9 issues such as employment was also seen as important in helping service users feel a sense of
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11 identity within wider society, again suggesting that the gradual internalisation of the help and
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13 support provided by a ‘wiser other’ enabled lasting change that could be taken beyond EIS
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15 involvement (Tindell et al., 2015; van Schalkwyk et al., 2015).
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23 **LIFE AFTER EIS**

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26 Building upon the process of taking the support and advice beyond engagement with EIS, a
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28 third overarching theme emerged from the data around consideration of life after EIS. This
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30 included two sub-themes: the hope of living a ‘normal’ life, and hopes and fears post-
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32 discharge.
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36 ***Living a ‘normal’ life***

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39 A common goal for recovery identified by service users was the hope of achieving some
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41 degree of ‘normality’ in life, which could be sustained after leaving services. This goal was
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43 highly valued and was seen as more important than specific, more measurable goals, such as
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45 symptom reduction (Harris et al., 2011; Tindell et al., 2015; Lester et al., 2012; O’Toole et
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47 al., 2004). Although this sense of normality is highly subjective and overlaps with the sub-
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49 themes of improved agency and identity, it particularly highlights the acquisition of very
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51 practical ‘skills’ that can be applied to everyday situations into the ongoing recovery process,
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53 again something that cannot be easily operationalised or quantified:
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3 *The first clinician... he was cool. He really knew what I was going through when I*
4 *was trying to find work, the struggle about it. Getting up, getting your clothes on,*
5 *going to interviews, coming back home, doing follow-ups... He really sounded like he*
6 *could actually relate to what it was I was going through. And he gave me advice on*
7 *how to talk to girls, how to fix a car, simple things* (Participant in van Schalkwyk et
8 al., 2015).
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18 That is not to say symptom reduction and continued stability was not seen as important to
19 service users, and many did state this to be a positive experience of recovery (O'Toole et al.,
20 2004; Lester et al., 2011; Harris et al., 2011; van Schalkwyk et al., 2015). However, in the
21 main, the reintegration into society and increased efficacy in dealing with 'everyday'
22 difficulties was valued as more important. Many carers also reported similar findings. When
23 discussing the recovery process, many carers saw the process of their loved one gaining
24 confidence and increased engagement with wider communities as a priority, more so than
25 symptom reduction or medication management (Penny et al., 2009; Allard et al., 2016):
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37 *I want him to have good company, because that's like medication* (Participant in
38 Penny et al., 2009).
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45 ***Hopes and fears for the future***

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48 Although some papers report initial scepticism from service users during the early stages of
49 engagement (Stanbridge et al., 2003), once a good relationship was established (as in Theme
50 1), many report a subsequent sense of relief and optimism for the future (Stewart et al., 2012;
51 Lester et al., 2012; Jansen et al., 2015):
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3 *They encourage me to be interested in things and to think that I have a future. I*
4 *thought my life was coming to an end and they kind of encourage me to see that there*
5 *is life after psychosis...* (Participant in Lester et al., 2012).
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11 This was also reported in carers' recollections of EIS involvement. Allard et al. (2016) report
12 that many carers felt an immediate sense of relief once they felt services were able to offer
13 support and share the burden of care, something also reported in McCann et al. (2011) and
14 Lavis et al. (2015):
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20 *...when they rang and said that they were going to take her (carer's daughter) on and,*
21 *you know, I can't remember what happened after that, it was just such a relief...*
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25 (Participant in Allard et al., 2016).
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28 In several instances, however, the optimism carers experienced gradually wore off and one
29 paper reported carers expressing their concerns that EIS may have been overly optimistic in
30 their initial appraisals and plans for engagement (Penny et al., 2009). Additionally, Lavis et
31 al. (2015) reported that although carers saw the recovery of their loved one as more important
32 than their own needs, over time, some frustrations grew that their own emotional needs were
33 not considered by EIS. This was echoed in McCann et al. (2011) and also in Sin et al. (2012),
34 which explored the views of siblings of individuals accessing EIS. These authors found that,
35 like a significant minority of carers reported in other papers, though they self-identified as a
36 cog within the mechanism of recovery alongside EIS, they felt there were insufficient
37 resources to cope with both the enduring practical implications of caring for a loved one
38 experiencing psychosis, and their own emotional responses. This suggests that although
39 initial relief and optimism instilled by EIS involvement may be a highly valued component of
40 services, the lack of continued emotional and practical support for carers or family members
41 result in reduced optimism for their own futures, post-EIS, even if the service users
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themselves still hold an optimistic view of their chances of being able to lead a sustained 'normal' life.

Discussion

The importance of a strong relationship with EIS staff was the most prominent theme throughout the papers reviewed and permeated subsequent themes. The quality of this relationship appeared to be the single most important factor in determining whether the experience of accessing EIS was a positive or negative one, for both service users and carers. This is in line with existing research that has highlighted the similarities between the nature of relationships built with mental health services and attachment bonds (Bucci et al., 2014), in that inconsistent or sub-optimal relationships are often associated with increased scepticism and reluctance to engage with mental health services (Catty et al., 2012), while a strong therapeutic bond can be linked to increased positive outcomes in service users (Lambert & Barley, 2001). More specifically, such findings have been reported when investigating relationships with EIS, in that forming an avoidant or insecure attachment with staff predicted reduced engagement with EIS (Gumley et al., 2014), whereas a secure, trusting bond was linked with increased trust and engagement (Mallinckrodt, 2010; Laugharne, Priebe & McCabe, 2011).

When considering this relational bond, many of the findings in this review suggest that through interacting with a trusted member of staff, who was perceived as knowledgeable and emotionally available, service users were able to learn and gradually internalise received advice and support, to the extent that they were eventually able to manage their difficulties independently. This is akin to the concept of 'scaffolding' (Fernandez, Wegerif, Mercer & Drummond, 2002), a process at the core of the Zone of Proximal Development (ZPD) theory.

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2
3 ZPD can be applied to learning in an educational sense (Hedegaard, 2005), but also with
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5 regards to emotional and cognitive development (Ryle & Kerr, 2003) and postulates that an
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7 individual learns how to complete a task (such as how to cope with auditory hallucinations in
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9 this instance) through interaction and increased co-facilitation with a trusted, more proficient
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11 other, until they eventually become independently skilful (Kozulin, 2003). This is important
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13 when considering that in the papers reviewed, many service users identified their primary
14
15 goals as ones that would require such a process of internalising received wisdom, including
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17 learning ways to cope with distressing aspects of psychosis. Importantly, and in line with
18
19 ZPD, these are achievements that would hopefully continue post-discharge when the EIS
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21 worker was no longer available to help. As this is a relational process, building a strong,
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23 genuine rapport is essential.
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29 That carers also reported finding support in the relationships they themselves formed with
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31 EIS demonstrates the importance of developing a good rapport beyond the service user-staff
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33 dynamic. Previous literature has outlined the impact caring for a loved one experiencing
34
35 psychosis can have on carers or family members, including increased isolation, stress, decline
36
37 in social functioning and increased economic difficulties (Awad & Voruganti, 2012). Once
38
39 carers and wider family networks have engaged with services, however, research has
40
41 indicated this can have a significant impact on their confidence in being able to offer help to
42
43 their loved one and reduce the burden of care they had experienced prior to engagement
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45 (Awad & Voruganti, 2012), both of which were reported in the findings of this review.
46
47 Although carers and family members valued EIS intervention, especially at first point of
48
49 contact, a number often felt that as engagement progressed, their emotional well-being was
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51 not sufficiently considered. This concurs with findings that family interventions may help the
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53 support systems around an individual experiencing psychosis with regards to practical
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matters, yet may not necessarily reduce caregiving distress (Szmuckler, Kuipers, Joyce, et al., 2003).

Clinical Implications

Findings suggest that one of the most valued aspects of engaging with EIS is the development and maintenance of a positive therapeutic bond with at least one member of staff. This is of clinical significance when placed alongside findings that difficulties in trusting others and forming new relationships are common in the experience of psychosis (Berry & Drake, 2010) and is of further importance when considering that the benefits of this can extend to service users’ support networks and families. The focus of EIS initially should be directed towards initial engagement once an individual is referred to EIS, with effort placed on creating a genuine, two-way relationship to devise an individualised care plan that places at the heart of it the service users’ hopes for recovery. Once achieved, the maintenance of this bond is integral in enabling continued engagement and extending this to wider support networks.

Limitations and Future Research

As meta-synthesis is still an emerging practice, there is not yet an established gold standard for the searching and synthesising of qualitative findings (Thomas & Harden, 2008); it is possible that a number of eligible papers were not included. Papers that were included, however, were thoroughly read and references were hand-checked, thereby minimising the likelihood of this and reducing the chance potentially important findings or themes were missed. As other’s findings are being synthesised in meta-synthesis, it is possible that data omitted by the authors of the papers reviewed may have altered the findings of this review. However, similar findings across papers reduces this likelihood. The majority of studies reviewed were conducted in UK or Australia; only one study examined experiences of an

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2
3 ethnic minority sample (Penny et al., 2009). Transferability of findings is therefore reduced,
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5 particularly considering the varying structures of many nations' healthcare systems. Future
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7 research could consider exploring views and experiences of important but currently
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9 underrepresented groups so that their viewpoints are also heard.
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Figure 1: The screening process for studies to be included in the review

Figure 2. Schematic of themes

Table 1: Summary of the papers included in the review

Study	Participant s	Aim	Data analysis	Setting	Results and themes	Quality Appraisal Score (out of 30)
O'Toole et al. (2004) (UK)	3 focus groups, made up of FEP SU's (n=12)	Explore SUs' experiences of an FEP intervention service	IPA	1 EIS in UK (location not specified)	EIS as a 'very different experience' – importance of 1:1 relationships. Increased engagement with society and motivation. 'Human' approach as a key component of recovery. Flexibility as a positive	21
Penny et al. (2009) (UK)	6 families – no SU involvement in interviews (n=11)	To explore the treatment experiences of families of Pakistani origin accessing an EIS	IPA	1 EIS in UK (location not specified)	Theme of loss – EIS overly optimistic; social aspect of psychosis; carers valuing the relationship between key workers & SUs; diverging understandings of illness and recovery	22
McCann et al. (2011) (Australia)	Primary caregivers of individuals accessing an FEP service (n=20)	Describing primary caregivers' experiences of young adults accessing FEP services	IPA	FEP service, Melbourne, Australia	GP as a source of referral to EIS; barriers encountered when trying to access EIS – thresholds of 'illness', insufficient services; carers' knowledge, experience & assertiveness enhancing access – increased knowledge matching increased confidence	27
McCann et al, (2011a)	Primary caregivers of	Exploring caregivers' satisfaction with	IPA	FEP service, Melbourne,	Clinicians being approachable as strong positive – accessible & supportive, responsive to carers' needs, knowledgeable &	24

(Australia)	individuals accessing an FEP service (n=20)	clinicians' response to them as informal carers of YP with FEP		Australia	facilitating; some carers feeling undervalued – not being taken seriously & issues re: confidentiality	
Harris et al. (2012) (UK)	SUs who had been with EI >2 years (n=8)	1. Explore SUs' perspectives of being in contact with and EIS 2. Explore how being in EI has impacted view of psychosis & current life experiences	IPA	1 EIS in UK (location not specified)	Experiences of stigma (self, others & of services); importance of relationships, especially with care co-ordinator, but also, peers; understanding experiences of psychosis necessary to move forward with recovery; sense of agency over psychosis – control vs powerless; impact on sense of self, both individually and within wider world	28
Lester et al. (2011) (UK)	SUs who had left EI (n=21)	Explore SU view on EIS and Primary Care	Constructivist Grounded-Theory	5 geographically diverse sites in UK	EI seen as 'gold standard'; value of good relationship with key workers (trust, good interpersonal skills); barriers and facilitators of transition; underutilisation of primary care	25
Lester et al. (2012) (UK)	SUs – 1 st interview < 6 months of engaging (n=63), 2 nd > 12 months (n=36)	Exploring the views over time of young people referred to EI, especially the importance of relationships	Constructivist Grounded-Theory	As part of wider UK EDEN project	Importance of relationship with key workers – EIS seen as youth friendly and matching needs. Flexible approach helpful; EIS helping with understanding of psychosis; visits too frequent for some, especially when combined with change of workers; some feeling overinvolvement reinforcing illness stigma; value of family support and them gaining an understanding of psychosis; changing self-identity – EIS workers seen as important allies	20
Sin et al.	Siblings of	Understanding the	'Responsive-	2 EIS in	Siblings seeing themselves as important in	19

(2012) (UK)	individuals accessing EIS (n=31)	experiences & service needs of siblings of individuals with FEP	reader and framework methods'	South-East England	liaising with services, despite EIS having limited resources for them; diverse emotional responses; impact of psychosis on relationships; coping strategies & resilience; siblings' needs often overlooked when compared with carers, need for more information and respite	
Stewart (2012) (UK)	Young people engaged with EIS (n=30)	Exploring the factors contributing to engagement with EIS	Grounded Theory	1 EIS in UK (location not specified)	Relationships with key-worker key	26
Van Schalkwyk et al. (2015) (USA)	SUs (n=11)	Exploring participants' narratives of early treatment experience	Inductive Thematic Analysis	STEP (EIS), Connecticu t, USA	Importance of feeling listened to and understood. Understanding of illness as very important factor	18
Jansen et al. (2015) (Denmark)	SUs (n=10)	Examine SU experience of moving between early psychosis detection team (TOP) and a specialised psychosis service (OPUS)	Social constructivist Thematic Analysis	OPUS (EIS) Denmark	Stigma & fear of systems as a barrier to help seeking; impact of trauma on psychosis; importance of significant others; experiencing EIS as safe and trusting the teams, building strong alliances; the relief of receiving a diagnosis and chance to talk about difficulties and gain insight/understanding	28
Lavis et al. (2015)	Carers (n=80)	Exploring the impact of EIS for FEP on carers' experiences	Constructivist thematic Analysis	Part of wider EDEN	EI helping with caring responsibilities, providing information and alleviating distress. Value of plain language; carers feeling	22

(UK)				project	listened to; conflicts with EI re: confidentiality and not feeling taken seriously; some reports of EIS not helping with emotional impact in carers; lack of knowledge re: support for carers	
Tindall et al. (2015) (Australia)	Service users accessing EIS (n=7)	Exploring factors influencing engagement with case managers	IPA	EIS, Australia (not specified)	EIS instilling initial hope for recovery; relationship with keyworker as key facilitator – being knowledgeable re: psychosis, maintaining confidentiality, taking an active interest in SU, warm, sensitive and flexible approach; change in care manager seen as negative – need for consistent relationships	24
Allard et al. (2016) (UK)	Carers (n=16) SUs (n=16)	Exploring service users' and carers' views on EIS	Thematic Analysis, adopting a phenomenological analytical approach	UK. Part of wider EDEN project	Carers: retrospective accounts of desperation, relief at engagement, EIS offering hope & optimism Service Users: relationship with key worker helping with insight, understanding illness more important than long-term goals	22

EIS – Early Intervention Service; SU – Service User; IPA – Interpretive Phenomenological Analysis; FEP – First Episode Psychosis