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Title:
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Date:
2018-10-01

Citation:
Tindall, R. M., Simmons, M. B., Allott, K. & Hamilton, B. E. (2018). Essential ingredients of engagement when working alongside people after their first episode of psychosis: A qualitative meta-synthesis. Early Intervention in Psychiatry, 12 (5), pp.784-795. https://doi.org/10.1111/eip.12566.

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Essential ingredients of engagement when working alongside people after their first episode of psychosis: A qualitative meta-synthesis

(Resubmission: EIP-2017-076)

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Acknowledgements:
This project was supported by the Australian Government Research Training Program Scholarship, HOSPIRA and the Windermere Foundation Doctoral Scholarship in Health (Nursing) Program. We also thank Jason Wasiak for his support with the method for the systematic search.

Word Count:
Abstract: 232 words
Paper: 5593 words (including citations)

ABSTRACT

Aim: Early intervention services for first episode psychosis have been established

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/eip.12566

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internationally, however service disengagement is a recurrent concern resulting in unplanned treatment cessation. The implications of this are far-reaching due to the financial and personal costs associated with untreated symptoms. The aim of this meta-synthesis was to collect, interpret and synthesize qualitative research about how engagement is experienced within early intervention services for first episode psychosis.

Methods: A systematic search was conducted in PsycINFO, Ovid MEDLINE and Ovid Emcare from date of conception to November 2016. Following initial screening, 91 abstracts and 13 full texts were reviewed for eligibility. Nine studies were then critically appraised using the CASP tool for qualitative studies, data were systematically extracted and results were synthesized using constant comparison and reciprocal translational analysis.

Results: Nine qualitative studies explored engagement with early intervention services, from the perspectives of service users and their caregivers. No studies were found from the perspectives of clinicians or services. All nine studies employed an inductive methodology, within an interpretivist epistemology. Five main themes were identified: experiences of finding help; factors promoting engagement; the therapeutic relationship; the role of caregivers in supporting engagement; and factors impacting ongoing engagement.

Conclusions: There is a critical need to stimulate discussion around this multifaceted phenomenon, including a continued focus on the roles of key stakeholders and clinical models that may further facilitate collaboration in treatment plans and recovery.

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KEYWORDS

Community mental health services; first episode psychosis; qualitative research; service engagement; therapeutic relationship

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INTRODUCTION

Mental health service engagement is a multi-faceted and complex phenomenon that moves beyond the concept of attendance at appointments, and encompasses both the relationship between clinician and service user, and the potential partnership when working towards shared goals (Kreyenbuhl, Nossel, & Dixon, 2009; Littell, Alexander, & Reynolds, 2001; O'Brien, Fahmy, & Singh, 2009). Disengagement ranges on a scale from active avoidance of services, to attending but not participating in session content (Littell et al., 2001). The complexities of defining engagement within mental health services, and conceptualizing how it relates to service providers and users, have been addressed in recent reviews (Bright, Kayes, Worrall, & McPherson, 2015). Of note, people experiencing a first episode psychosis (FEP) have been identified as a particularly 'difficult to engage' population (Dixon, Holoshitz, & Nossel, 2016). Comprehensive intervention following a FEP has direct correlation with longitudinal prognosis. Therefore, understanding how to better engage people with a FEP in treatment is a research area that requires ongoing attention (Doyle et al., 2014; Lal & Malla, 2015).

Early intervention services (EISs) for FEP have been established internationally, and have the core aims to reduce symptoms and risks, and enhance global functioning. However, treatment can only be effective if people engage with it. In EISs, multi-disciplinary teams provide flexible bio-psycho-social treatments. These typically involve antipsychotic treatment, psychosocial support and therapy. Internationally, EISs vary in terms of age groups (ranging from 15 to 65 years) and available treatment length (on average, treatment

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is provided over two to five years) (Hughes et al., 2014). Best practice guidelines, such as the International Clinical Practice Guidelines for Early Psychosis (International Early Psychosis Association Writing Group, 2005) and the Australian Clinical Guidelines for Early Psychosis (Early Psychosis Guidelines Working Group, 2016) provide guidance around what an EIS should incorporate in their core philosophy and treatment approaches, however due to differences in international funding models and healthcare systems, EISs vary in terms of their values and treatment paradigms.

Despite the potential differences in service structure, a driving philosophy of all EISs is to engage people experiencing FEP in treatment. However, disengagement rates parallel those of traditional mental health services. In the systematic review by Doyle et al. (2014) disengagement from EISs, when defined as 'no contact', was found to occur at rates of approximately thirty percent. Consistent nonattendance at any healthcare appointment may lead to untreated symptoms, and this can impact a person's ability to participate socially and remain in education or employment. People who disengage from services also experience higher rates of suicide; violence to others; relapse; involuntary admissions to acute mental health services; problematic substance use; and forensic activity (O'Brien et al., 2009; Stowkowy, Addington, Liu, Hollowell, & Addington, 2012).

Consequently, there has been an increasing research focus on what influences engagement with EISs. This is of particular importance given that EISs are designed to be an appealing treatment option for people experiencing FEP, however with disengagement rates so high, it can be argued that the model may not be meeting this populations' needs.

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Reasons for disengagement have been explored in the quantitative literature on service disengagement, and includes the study of factors such as socioeconomic disadvantage, ethnic minority status and substance use. This body of research has been summarized in reviews such as Doyle et al. (2014) and Lal and Malla (2015). However, the results of qualitative studies, which aim to explore the meaning, context and processes of engagement, have not been synthesized (Walsh & Downe, 2005). The aim of this meta-synthesis was to collect, interpret and synthesize qualitative research about how engagement is experienced within early intervention services for first episode psychosis.

METHODS

Design

Using the Walsh and Downe (2005) approach to meta-synthesis, the aim was to identify key elements of engagement that are relevant to both service-level and individual-level decisions that effectively engage people in treatment. Qualitative meta-synthesis is an amalgamation of studies by different investigators in a related field, and involves summarizing, interpreting and representing data in a collective form. The meta-synthesis methodology goes through a number of stages including searching the literature, appraising the studies and synthesizing the results. Synthesizing the results, in this qualitative context, means to interpret the information provided rather than aggregate results, as is seen in its quantitative counterpart.

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Literature search

A systematic literature search was performed in PsycINFO (1806 to November 2016), Ovid MEDLINE (1946 to November 2016), and Ovid Emcare (1995 to November 2016) using Medical Subject Heading (MeSH) and free-text words related to engagement or disengagement, first episode psychosis and qualitative research. The thesaurus vocabulary of each database was used to adapt the search terms. In addition, one author (XX) searched the reference lists of included studies. Search terms are outlined in Figure one.

Inclusion/exclusion criteria

Inclusion criteria were: empirical qualitative data about engagement in an EIS for FEP; published in English; and published in a peer-reviewed journal. Exclusion criteria were: experiences of contact with services prior to treatment in an EIS. Two authors (XX, XX) independently screened and reviewed the titles and abstracts against the inclusion criteria. Full-text articles were retrieved and reviewed independently in duplicate by two authors (XX, XX, XX or XX) for potential eligible studies. Discrepancies were resolved by discussion and consultation with the authorship team.

Data extraction

One author (XX) independently extracted study characteristics and demographics using an author-devised data extraction sheet, including: first author surname, year,

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country, study aim/objective, sample and methodology (instrument/s used, analysis).

Assessment of methodological quality

The included studies were appraised using the 10 questions for appraisal of qualitative research developed by Critical Appraisal Skills Programme (CASP) (2013). Two authors (XX, XX, XX or XX) appraised each study independently, and disagreements were resolved through third author re-rating and discussion. Consensus was reached for all studies. Appraising the studies using CASP facilitated evaluation of each in a systematic manner. The CASP tool was chosen as it has been widely used in previous syntheses of qualitative research and no tool has been shown to be superior (Dixon-Woods et al., 2007).

Data synthesis and analysis

One author (XX) read the articles multiple times, whereas two authors (XX, XX, XX or XX) read the articles twice. The initial readings were undertaken to determine how the included studies were related to each other and how they contributed to the broader understanding of engagement with an EIS. Subsequent readings focused on identifying patterns of meaning within and across studies. Study results were juxtaposed, cross-compared, and integrated, so that key concepts and themes were identified. Data analysis methods included coding units of meaning from each study and organizing these codes into themes, so patterns of meaning could be identified. These derived analytic themes were

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organized, shared, and discussed using reciprocal translational analysis until two authors (XX, XX) arrived at a consensus regarding the final synthesis of themes. One author (XX) maintained an audit trail throughout the coding process. In addition, one author (XX) an expert in qualitative methodologies assisted with study design, and offered extensive reflective consultation during analysis.

RESULTS

Search results

The initial search strategy of medical databases identified 91 studies, whilst hand searching captured an additional two studies to give a total of 93 studies for potential inclusion. Independent scrutiny of the titles and abstracts identified 13 potentially relevant articles. Of those, four studies failed to meet the inclusion criteria. A total of nine studies were included in this review (see Figure two).

Description of included studies

The general study characteristics are described in Table one. Most papers were published within the last four years, with the earliest publication in 2004. Study locations only included: United States, United Kingdom and Australia. The total sample consisted of 192 service user participants (mean 24, SD 18.1) and 43 caregiver participants (mean 14.3, SD 4.7), and the study samples ranged from seven to sixty-three participants. Detailed

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demographic data of participants, such as ethnicity, race and other potential areas of socioeconomic differences, were provided in five papers, but this was not brought further into the study results or discussions. All studies collected data through semi-structured interviews apart from O'Toole, Ohlsen, Taylor, Walters, and Pilowsky (2004), who conducted focus groups. Types of analysis included: thematic analysis (n=5), interpretive phenomenological analysis (n=2) and grounded theory (n=2). These analyses all employ an inductive methodology, within an interpretivist epistemology. All studies were cross-sectional apart from one (Lester et al., 2011), which used a longitudinal approach with interviews at six and twelve months after entry to an EIS. The critical appraisals highlighted several methodological flaws across studies, such as lack of reflexivity that decreases overall rigour; however, due to the paucity of qualitative research in this area, all studies were included in the review (see Table two).

Integrated findings

The five main themes identified in this meta-synthesis were: (a) experiences of finding help; (b) factors promoting engagement; (c) the therapeutic relationship; (d) the role of caregivers in supporting engagement; and (e) factors impacting ongoing engagement (see Table three).

Experiences of finding help

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Five papers provided substantial analysis of initial experiences of seeking help and engaging with an EIS (Allard, Lancaster, Clayton, Amos, & Birchwood, 2016; Lucksted et al., 2015; Lucksted et al., 2016; Stewart, 2013; Tanskanen et al., 2011; Tindall, Francey, & Hamilton, 2015), whilst remaining reports discussed this phase in other aspects of their analysis. Allard et al. (2016), Lucksted et al. (2015) and Lester et al. (2011) purposefully interviewed participants in the initial six months of treatment to ensure that participant reflections on initial experiences of engagement were recent at the time of interviews.

Individuals were often referred to mental health services through family or friends. The overarching experience of caregivers prior to referral was one of profound confusion and distress (Allard et al., 2016; Lucksted et al., 2016; Tanskanen et al., 2011; van Schalkwyk, Davidson, & Srihari, 2015). Delays between onset of symptoms and treatment were confounded by both the individual's uncertainty about their psychotic experience and the hope that symptoms would go away without intervention (Tanskanen et al., 2011; van Schalkwyk et al., 2015). Individuals sometimes described actively disguising psychotic symptoms from others due to a strong desire to preserve their self-image and appear 'normal' to those around them (Tanskanen et al., 2011). Symptoms and social difficulties (for example, breakdown of relationships and difficulties with school or work) often reached a crisis point before any mental health treatment was sought (Stewart, 2013; Tanskanen et al., 2011; Tindall et al., 2015).

Initial help-seeking was described both as a support and impediment to engagement. When individuals and their caregivers presented to primary care or

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community services, identification of symptoms and referrals to specialist support seemed to depend on the level of clinicians' knowledge and attitudes towards psychosis. Tanskanen et al. (2011) provides contrasting examples of participants reporting symptoms were either unnoticed and not acted upon, or noticed with appropriate and timely referrals made. Tindall et al. (2015) provides an example of a doctor stigmatizing mental illness ("I had a doctor ask me - do you go crazy?"), which impacted on the young person's willingness to engage with mental health services. Pathways into care also frequently involved participants contact with emergency services and followed by acute psychiatric inpatient admissions. Stewart (2013) described the participant's difficulties with being treated in 'adult-orientated environments' that increased levels of distress, and van Schalkwyk et al. (2015) stated that these initial contacts increased the risk of participants not engaging in ongoing treatment at all.

Overall, referral to a specialized EIS was met with a sense of relief for young people and their family members/caregivers (Allard et al., 2016; Lucksted et al., 2016; Stewart, 2013). Stewart (2013) and Allard et al. (2016) described this relief as immediate, however for the caregivers interviewed in Lucksted et al. (2016), the relief was mixed with uncertainty whilst they negotiated their level of involvement in the person's care. Timely referral was seen to be associated with positive engagement in the studies conducted by both Stewart (2013) and Tindall et al. (2015).

Factors promoting engagement

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Entry into an EIS occurred in three main ways: involuntarily, ambivalently, or enthusiastically. Accordingly, young people reported that their clinicians used specific engagement strategies. One prominent strategy is discussed as a separate theme ("the therapeutic relationship"). Other reported strategies included: meeting the person's perceived needs; building a shared explanatory model of psychosis; and using outreach in lieu of clinic-based appointments.

Young people often accepted that they had a problem, but had different perceptions of what that problem was. For example, they may have first noticed difficulties functioning at school or work, and this may not have been linked to mental state at first contact with a service (van Schalkwyk et al., 2015). To initiate engagement, it was important to ensure that treatment met the current needs of the person as perceived by the person. This often took the form of practical support (Lucksted et al., 2015; Tindall et al., 2015; van Schalkwyk et al., 2015). For example, a young person in the study by Tindall et al. (2015) was close to disengaging from the EIS on initial referral, but the case-manager worked with them on completing an appeal application for school. This case-manager was perceived as useful and the young person subsequently engaged with the EIS.

Some participants described a strong personal motivation to get better and avoid relapse. This was notably to avoid associated consequences, such as readmission to hospital (Lucksted et al., 2015; Stewart, 2013; Tindall et al., 2015). When clinicians supported people to build an understanding of their experiences, this fear lessened and individuals subsequently felt empowered and more able to engage in treatment (Allard et al., 2016;

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O'Toole et al., 2004; Tindall et al., 2015; van Schalkwyk et al., 2015). Lester et al. (2011) and O'Toole et al. (2004) expanded further on this, discussing that building an identity post psychosis was also an ongoing motivator for some people to engage with the service. As young people and caregivers noticed improvements in mental state, and found the practical support they received to be effective, engaging with the EIS was valued more.

The use of outreach in lieu of clinic appointments was discussed in four studies. Three studies mentioned outreach as a core part of engaging people, particularly when this resulted in consistent contact from their case-manager and demonstrated a more intensive level of care for the individual (Lester et al., 2011; Lucksted et al., 2015; Tindall et al., 2015). However, attending appointments at a clinic also helped some participants to build a routine. For some people, immediately post a psychotic episode, social contact was often very limited, so the opportunity to be around others was appreciated (O'Toole et al., 2004; Tindall et al., 2015). Opportunities for peer support, such as through specific peer-led groups, was valued by both caregivers (Lucksted et al., 2016) and young people (Lester et al., 2011; Stewart, 2013).

Several service-level factors also had a role in supporting ongoing engagement. These included service location, access to public transport, 24-hour support, free services, and the availability of multiple services on site (Lucksted et al., 2015; O'Toole et al., 2004). Organizational characteristics such as professionalism (Lucksted et al., 2015; Lucksted et al., 2016) and flexibility were valued (Lester et al., 2011; Lucksted et al., 2015; Lucksted et al., 2016; O'Toole et al., 2004; Stewart, 2013; Tindall et al., 2015). Lester et al. (2011) was the

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only study to clearly identify a youth friendly environment as positively impacting engagement, although Lucksted et al. (2015) identified that the more 'hospital-like' the environment appeared to participants, the less appealing it was to attend.

The therapeutic relationship

The therapeutic relationship was found to be a significant factor for enabling service engagement in all studies except Tanskanen et al. (2011), possibly because this study focused on help-seeking and initial referral to an EIS. The longitudinal study by Lester et al. (2011) described the therapeutic relationship as pivotal at both time points (six and twelve months after entry to the EIS). One of the most vital qualities of the therapeutic relationship was the dedication of time for talking, and the sense of being heard (Allard et al., 2016; Lester et al., 2011; O'Toole et al., 2004; Stewart, 2013; Tindall et al., 2015; van Schalkwyk et al., 2015). Therapeutic dialogue not only gave the young person an opportunity to make sense of their situation, but to also discover their own solutions to problems. As being understood was so pivotal in building a therapeutic relationship, it is therefore no surprise that continuity in case-manager was also valued (Tindall et al., 2015).

Collaboration was a core feature of the therapeutic relationship, and this involved identifying and working towards shared goals (Allard et al., 2016; Lester et al., 2011; Lucksted et al., 2015; O'Toole et al., 2004; Stewart, 2013; Tindall et al., 2015; van Schalkwyk et al., 2015). Individuals sometimes described feeling initially skeptical about building a relationship with a clinician, but when the clinician invested time in them, this mistrust

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often gave way to relief, easing of defensiveness and building of trust. Working together to complete practical tasks, or personalized goals, not only demonstrated trustworthiness and reliability of the clinician, but also allowed opportunities for young people and clinicians to get to know each other. Throughout all interactions, opportunities arose to instill hope and optimism in recovery, which further facilitated engagement.

The role of caregivers in supporting engagement

As individuals were often referred to mental health services through family or friends, building a relationship with caregivers was vital to the work of establishing and maintaining engagement (Lester et al., 2011; Lucksted et al., 2015; Lucksted et al., 2016; O'Toole et al., 2004). When caregivers were included in discussions to build a shared understanding about mental health and were supported to avoid relationship breakdowns with the young person, then family significantly facilitated the acceptance of illness and treatment. Caregivers had both a practical role in supporting engagement (for example, taking the person to appointments) and a relational role (for example, encouraging attendance) (Allard et al., 2016; Lester et al., 2011; Lucksted et al., 2015; Lucksted et al., 2016).

Caregivers were overall the primary people identified to provide ongoing emotional support throughout the peaks and troughs of recovery from the FEP. A complicating aspect of this caregiver role was consideration of the person’s increasing autonomy, especially as symptoms improved and independence was regained (Lester et al., 2011; Lucksted et al.,

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2016). There was a paucity of discussion on the experiences of people who had minimal caregiver involvement due to caregiver overburden or due to alternative caregiver systems being in place. One study identified a person who was in foster care arrangements (Stewart, 2013) and one study identified four people who lived in "other" circumstances than their parental home (Lester et al., 2011), but what this meant for their engagement journey was not discussed or elaborated upon.

Factors impacting ongoing engagement

Initial contacts with mental health services could greatly influence ongoing engagement, especially as hospital admissions and crisis contact/s could be experienced as both distressing and paternalistic. Most commonly, this pathway into care heightened internal stigma, as most young people preferred to think of themselves as a regular person with a slight condition. A first contact that contradicted this was keenly felt, and could precipitate reluctance to engage (Tanskanen et al., 2011; Tindall et al., 2015; van Schalkwyk et al., 2015). This was not true for all individuals; two studies identified that this difficult pathway into care motivated some people to actively engage with EISs (Stewart, 2013; Tindall et al., 2015).

The initial stages of engagement often continued to be distressing and confusing for people, especially if they remained unclear about why they were being advised to engage in treatment. Psychiatric treatment was often prescribed before the person identified symptoms as a concern, highlighting the disparities in perceived needs and treatment

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priorities (van Schalkwyk et al., 2015). At times, ongoing symptoms could impact a person's desire to engage (Allard et al., 2016; Lucksted et al., 2015). People often hoped that symptoms would not need intervention, and at times there was a strong desire to solve their own problems (Lucksted et al., 2015; Tanskanen et al., 2011). Alongside this distress, confusion and avoidance of help, some people described difficulties opening up about their experiences, which could impact the ability of the service to treat symptoms or assist with needs (Tindall et al., 2015).

When symptoms and circumstances were improved, the expectation of continued appointments could act as reminder to the individual that they were still a 'patient', and had not yet reached their desired recovery (Lester et al., 2011). The longitudinal study by Lester et al. (2011) also considers the length and intensity of treatment, with one-third of individuals describing that three-years of continued treatment was more than they desired, although it should be noted that this appeared to correlate with high turnover of clinicians. As described in Tindall et al. (2015), most people were striving towards a "normal life", and the constant reminder of illness could undermine this. As situations improved, other appointments (for example, with job services) took priority, and the intensity of engagement with the EIS lessened (Lucksted et al., 2015; Lucksted et al., 2016; Tindall et al., 2015).

DISCUSSION

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The aim of this meta-synthesis was to identify, interpret and synthesise qualitative research about how engagement is experienced within EISs for FEP. Qualitative studies from the perspectives of service users and their caregivers were identified and included in this study; no studies were found that represented the viewpoints of clinicians. The present review analysed nine studies conducted across three countries. A key strength of this meta-synthesis is that it allowed for increased insight into the different elements of engagement from the perspectives of both service users and their caregivers. However, there are also limitations that must be considered.

Limitations

Since we did not have access to the original data, any bias introduced into the original papers, for example lack of reflexivity, may continue in this meta-synthesis (Walsh & Downe, 2005). The critical appraisals of each study highlighted these potential methodological flaws, but due to the paucity of qualitative research in this area, all studies were included in the review. An example of this, which warrants future consideration, is that despite five of the studies providing detailed demographic data on participants, there is limited discussion of the role of structural, socioeconomic disadvantage, or ethnic/racial minority status on the experience of engagement. As discussed in O'Brien et al. (2009), these factors place people at substantially higher risk of disengaging from services, but as this was not brought forward into results of discussions of the papers, it cannot be commented on within this review.

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All the studies except Lester et al. (2011) used a cross-sectional approach to understanding engagement. It should also be noted that in the final sample of papers, data was collected from individuals who were well engaged with the service. As engagement is understood as a dynamic and evolving process, this methodology may impact the level of understanding around this process (Tindall et al., 2015). This sampling limits opportunity for understanding the experiences of individuals and caregivers who have disengaged from EISs. As disengagement sits on a spectrum, it is likely that many people experienced varying levels of disengagement during their time in the EIS. This issue warrants considerable future research.

Variability in settings should be also considered. Despite the review focussing on EISs, fidelity to the ideal early intervention model, as discussed in Hughes et al. (2014), can vary according to resources and service structure. This makes it difficult to generalise statements about the experiences of service engagement. Additionally, each person did not necessarily experience every theme, and sample sizes were varied. Instead, the list of themes identified from this synthesis should create awareness regarding potential factors that may be experienced when a person engages with an EIS. The paucity of data around lack of caregiver involvement and the impact this may have on service engagement was also highlighted in this study, limiting new understanding of the role of caregivers in engagement.

The final limitation was the challenge of synthesising data grounded in somewhat different methods of analysis. This is a common issue in qualitative meta-syntheses, and we

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were guided by Walsh and Downe (2005) who identify that it is legitimate to include a variety of methodological processes as long as each approach is acknowledged. This was done throughout the analysis process.

Substantive findings and reflections on the roles within engagement

This review confirms that engagement is a complex phenomenon. Despite this, the key facilitators to engaging people with FEP in treatment are the therapeutic relationship and therapeutic dialogue. This is consistent with engagement experiences across other mental health services, such as assertive community teams for concurrent mental illness and substance abuse in adult populations (Pettersen, Ruud, Ravndal, Havnes, & Landheim, 2014) and general youth mental health populations (Watsford, Rickwood, & Vanags, 2013). Especially important for the FEP population is the experience of working collaboratively with a trusted clinician (Allard et al., 2016; Tindall et al., 2015; van Schalkwyk et al., 2015). Pathways into care and experiences of finding help also greatly impact initial engagement with an EIS. The factors that promote or negatively impact engagement are dependent on time in service, individual needs and service structure.

Alongside this, there are three active agents in the engagement process: the individual, their caregiver/s and the clinician/s. Engagement can have a different meaning to each. The literature and clinical practice guidelines predominantly focuses on skills that the clinician can bring to engage a person in treatment. Clinician experiences of adhering to these guidelines and of engaging people and their caregivers is currently lacking. The most

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recent clinical practice guidelines, published in Australia (Early Psychosis Guidelines Working Group, 2016) provide strategies to support clinicians in facilitating engagement, for example, "communicate to people that they are being listened to and treated seriously" and "offer practical help" (p.76). These core principles are aligned with what individuals and their caregivers valued about engagement and are therefore important. However, evidence regarding strategies to re-engage people who have disengaged or are poorly engaged are lacking.

The role of individuals themselves in engaging with the EIS is a particularly important enquiry, in light of current understandings of recovery as a process centred in autonomy and agency. The recovery framework is a core component of mental health treatment internationally, with the direction for recovery determined and led by the individual (Clarke, Oades, & Crowe, 2012). In the engagement process, this applies to both the individual's motivation to connect with service providers and to pursue goals. Throughout the qualitative literature, people described an overwhelming sense of confusion associated with the experience of a FEP and the relationship between symptoms and behaviours. Successful engagement was often seen when a collaborative approach to treatment was used to communicate understanding of symptoms and behaviour, and when identifying mutual goals (Allard et al., 2016; Lester et al., 2011; Lucksted et al., 2016; O'Toole et al., 2004; Stewart, 2013).

However, the overwhelming experience of confusion also appeared to encourage the individual to seek guidance and direction from the clinician, especially in the early stages

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of engagement (Tindall et al., 2015). Reflecting on the use of a recovery framework in the engagement process also raises questions around capacity and reliance on involuntary treatment, especially when clinicians and services feel a weight of responsibility should an adverse event occur (Davidson, O'Connell, Tondora, Styron, & Kangas, 2006; Le Boutillier et al., 2015). EISs often operate on a basis of assertive treatment, as effective treatment of FEP correlates with longitudinal outcomes (Doyle et al., 2014).

Clinical practice guidelines currently emphasise the importance of viewing individuals and their caregivers as partners in treatment, and advocate for a shared decision making (SDM) model (Hughes et al., 2014; International Early Psychosis Association Writing Group, 2005). For example, the National Institute for Health and Care Excellence (2013) (NICE) guidelines for treating psychosis and schizophrenia in children and young people recommend that clinicians “undertake shared decision-making routinely with children or young people in hospital who are of an appropriate developmental level, emotional maturity and cognitive capacity, including, whenever possible, those who are subject to the [relevant Mental Health Act]” (p.25-26).

SDM is a collaborative approach to making decisions that involves the sharing of information between clinician and individual (and caregiver where appropriate) (Elwyn et al., 2012), in line with the fact that developing a shared understanding and knowledge promoted engagement. In the SDM model, clinicians are encouraged to be transparent about all relevant treatment options and the potential risks and harms of these. Individuals and their caregivers are encouraged to convey their preferences and values about potential

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outcomes. A model such as this could address the stigma and lack of knowledge experienced by some people, and the uncertainty caregivers felt when negotiating involvement in care. The value SDM places on input from all parties could also ensure that individuals and their caregivers felt they had dedicated time for talking and a sense of being heard, which was important for the therapeutic relationship.

Although SDM is traditionally used when considering specific healthcare decisions, adopting the principles for broader use has the potential to increase engagement. SDM about care overall may address factors that this review highlighted as promoting engagement, such as: treatment meeting individual needs, which may be more practical than treatment related; preferences around location of appointments (e.g., outreach); and length of treatment. One such adaptation of SDM has been evaluated in a youth mental health service, which also involved the promotion of SDM by a peer workforce, something that was also valued in this review (Simmons, Batchelor, Dimopoulos-Bick, & Howe, 2017). SDM is shown to be feasible for adult inpatients diagnosed with schizophrenia (Hamann et al., 2006) as well as in EISs (Dixon et al., 2014). However, the few studies that have investigated current rates of SDM suggest that it is unlikely that it is routinely undertaken, and there are a lack of training and tools available to facilitate it (Goossensen, Zijlstra, & Koopmanschap, 2007; Goss et al., 2007; Loh et al., 2006).

What SDM will not address fully is the inherent power imbalance in the relationship between clinician and service user. This is likely to be amplified in the context of hospitalisation and/or involuntary treatment. To address legal barriers to individuals

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expressing autonomy in making decisions about their own care, a model such as supported decision making may be necessary. Although there are similarities between the two models (e.g., emphasis on service user involvement), differences also exist (Simmons & Gooding, 2017) and supported decision making provides a mechanism for individuals to have their preferences considered during times of involuntary treatment.

Implications

This review highlights the unique experiences each person and their caregiver has with an EIS. A model to further facilitate collaboration between the individual, clinician/s and caregiver/s is the shared-decision model as described by Hoffmann et al. (2014). At times of impaired capacity, such as during the acute phase of illness, alternatives such as supported decision making could be utilised to enhance collaboration between the individual, caregiver and clinician (Pathare & Shields, 2012). Ultimately, successful engagement begins with the clinician, service user and caregiver/s understanding the individual's view about what brings them to the service at that time. This allows the individual to raise their concerns, which may have a more social focus rather than a symptomatic or psychological focus (van Schalkwyk et al., 2015). Caregivers and clinicians can then also raise their key concerns for the individual. As the clinician begins to work with the individual on addressing their goals, they can continue to draw awareness to symptoms, the impact of these symptoms on individual goals, and potential treatments for these

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symptoms, thereby assertively treating FEP. This allows all agents to feel that their priorities and needs are being met.

The present results also highlight the need for further research into engagement, both for the FEP population and all people accessing mental health services. There does not currently exist a meta-synthesis of broader experiences of mental health (dis)engagement beyond EISs. Also, despite the fact that this review provides considerable insight into different factors about engagement with an EIS, it remains unclear exactly how socioeconomic factors impact the experience of engagement or disengagement from the perspective of individuals, caregivers of clinicians. It also remains unclear how the engagement process develops over time. The longitudinal study by Lester et al. (2011) begins to explore the issue, but only at two time points, and this study only includes the perspectives of service users. Further longitudinal qualitative research, following people through their entire journey of engagement with a mental health service, from entry to discharge, would provide much needed information about the experience of engagement, encompassing how the engagement process and therapeutic relationship develops and changes over time. This would also allow for more targeted research on the experiences of those who disengage from services, and their reasons for doing this.

It would also be pertinent to include all relevant agents in future research on the engagement process. Specific data from individuals who do not have caregiver involvement, and how this impacts on their experiences of engagement with an EIS would be greatly beneficial. This would enable a more comprehensive examination of the different needs,

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roles and responsibilities of each person, allowing for informed discussions on models such as shared decision making and support decision making, that can be further incorporated into the engagement process. Research that incorporates lived experience into the research process (including individuals and their caregivers), may yield more credible and relevant research to greatly enhance this current literature base.

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Table one: Summary of included studies

Author, Year, Country	Aim / Objective	Sample Summary	Participant Demographics	Methodology
Lucksted et al. (2016), United States of America (USA)	To understand caregivers' experiences of engaging with early intervention services (EISs) and their roles in client engagement with services	Caregivers (n=18) 9 family members of well-engaged clients and 9 family members of clients not well-engaged in an EIS.	Caregiver demographics: • 25 years old + • 12 females / 6 males • 11 mothers / 5 fathers / 1 sibling / 1 cousin • 8 African American / 4 Asian, Pacific Islander / 6 White, Caucasian / 1 Other • 4 non-college qualifications / 14 college qualifications or higher	• Semi-structured interviews • Inductive thematic analysis
Allard et al. (2016), United Kingdom (UK)	To explore caregivers' and clients' experiences of UK EISs following referral for first episode psychosis	Caregivers (n=18) Clients (n=16) Current clients within first 6 months of treatment in an EIS and current participants in a larger National EDEN multi-site research study. Clients nominated caregiver(s) to participate.	Client demographics: • 18-33 years old • 5 females / 11 males • Diagnosis of FEP Caregiver demographics: • 34-81 years old • 12 mothers / 1 stepmother / 2 fathers / 1 partner / 2 grandparents	• Semi-structured interviews • Thematic analysis

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Lucksted et al. (2015), USA	To assess factors that facilitated or impeded clients' engagement in an EIS	Current clients (n=32) Clients treated in an EIS and identified as well engaged with services (n=18) or not-well engaged with services (n=14).	Client demographics: • Up to 34 years old • 11 females / 21 males • Diagnosis of FEP • 16 African American / 1 Asian, Pacific Islander / 10 White, Caucasian / 5 Other • 24 non-college qualifications / 8 college qualifications or higher	• Semi-structured interviews • Thematic analysis
Van Schalkwyk et al. (2015), USA	To explore why engaging young people in EISs is challenging	Current clients (n=11) Clients treated in an EIS.	Client demographics: • 20-35 years old • 1 female / 10 males • Diagnosis of FEP	• Semi-structured interviews • Inductive thematic analysis
Tindall et al. (2015), Australia	To explore young people's experiences of engaging with a case-manager in an EIS	Current clients (n=7) Clients treated in an EIS.	Client demographics: • 15-25 years old • 5 females / 2 males • Diagnosis of FEP	• Semi-structured interviews • Interpretive phenomenological analysis
Stewart (2013), Australia	To understand the experiences of young people who are well engaged with an EIS, including how they successfully engage and what enables the process of engagement	Current clients (n=30) Clients treated in an EIS and identified as well engaged.	Client demographics: • 18-20 years old • 15 females / 15 males • Diagnosis of FEP • 4 born overseas (Hong Kong, Greece, Spain, Fiji) / 21 first-generation Australian (parents from Italy / Turkey / Scotland / Philippines / Serbia / Germany / Malta / India) / 5 second generation Australians +	• Semi-structured interviews • Grounded theory analysis

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			• 20 participants raised by 2 parents / 9 raised by 1 parent / 1 raised in foster care	
Tanskanen et al. (2011), UK	To understand service users' and carers' experiences of the onset of psychosis and help-seeking	Current clients (n=21) Caregivers (not matched to client group) (n=9) Clients and caregivers treated in an EIS.	Client demographics: • 18-35 years old • 6 females / 15 males • Diagnosis of FEP • 3 White British / 4 White Other / 3 Black African / 5 Black Caribbean / 4 Asian Bangladeshi / 2 Mixed Race Caregiver demographics: • 26-68 years old • 8 females / 1 male • 6 mothers / 1 sister / 1 partner / 1 mother-in-law • 5 White British / 2 White Other / 1 Black Caribbean / 1 Mixed Race	• Semi-structured interviews • Thematic analysis
Lester et al. (2011), UK	To described the views over time of young people referred to EISs, particularly as they relate to the importance of relationships	Current clients (n=63 interviewed at 6 months; n=36 were interviewed again at 12 months) Clients within first 6 months of treatment in an EIS.	Client demographics (12-month sample): • 14-35 years old • 10 females / 24 males • Diagnosis of FEP • 25 White British / 1 White Other / 1 Irish / 3 Pakistani / 2 Indian / 1 Black Caribbean / 1 Mixed Race • 23 school qualifications / 5	• Semi-structured interviews • Grounded theory analysis

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			university qualifications / 5 no qualifications • 5 employed / 21 unemployed / 7 voluntary work or student • 25 living with parents / 3 living alone / 1 in hospital / 1 living with partner / 4 other	
O'Toole et al. (2004), UK	To explore clients' experiences of a first episode intervention designed along evidence-based 'best practice' guidelines and to establish specific elements seen as effective to help inform future service planning and provision	Current clients (n=12) Clients treated in an EIS.	Client demographics: • 17-35 years old • Diagnosis of schizophrenia or schizoaffective disorder	• Focus groups • Interpretative phenomenological analysis

Table two: Critical appraisal of studies

	Clear research aims?	Qualitative methodology appropriate?	Research design appropriate?	Recruitment strategy appropriate?	Data collection appropriate?	Participant – researcher relationship considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Clear statement of findings?	How valuable is the research?

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Lucksted et al., 2016	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Very
Allard et al., 2016	Yes	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Yes	Yes	Very
Lucksted et al., 2015	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Very
Van Schalkwyk et al., 2015	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Very
Tindall et al., 2015	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Very
Stewart, 2013	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Moderate (limited discussion)
Tanskanen et al., 2011	Yes	Yes	Yes	Unclear	Yes	Unclear	Unclear	Unclear	Yes	Very
Lester et al., 2011	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Very
O’Toole et al., 2004	Unclear	Yes	Yes	Unclear	Yes	Unclear	Unclear	Unclear	Yes	Moderate (limited discussion)

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Table three: Summary of themes

		Lucksted et al., 2016	Allard et al., 2016		Lucksted et al., 2015	van Schalkwyk et al., 2015	Tindall et al., 2015	Stewart, 2012	Tanskanen et al., 2011		Lester et al., 2011	O'Toole et al., 2004	Total
Experiences of seeking help	Family distress and confusion	X		X		X				X			N=4
	Lack of knowledge about psychosis					X			X	X			N=3
	Actively disguising symptoms from others								X	X			N=2
	Initial help-seeking supporting engagement								X	X			N=2
	Initial help-seeking impeding engagement					X	X	X	X	X		X	N=6

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	Initial crisis pushing towards seeking help						X	X		X			N=3
	Relief on meeting EIS staff	X	X	X				X					N=4
	Timely referral supporting engagement						X	X					N=2
Factors promoting engagement	Practical support				X	X	X						N=3
	Needing help to get better and avoid relapse				X		X	X					N=3
	Understanding and normalizing FEP		X			X	X					X	N=4
	Finding an identity post psychosis										X	X	N=2
	Treatment effectiveness	X			X							X	N=3
	Outreach				X		X				X		N=3

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	Attending appointments giving sense of purpose						X					X	N=2
	Family / client peer support	X						X			X		N=3
	Service-level factors (e.g. opening times, 24-hours access)	X			X		X	X			X	X	N=6
Therapeutic relationship	Formation of a therapeutic relationship	X	X	X	X	X	X	X			X	X	N=9
	The process of talking and being heard		X	X		X	X	X			X	X	N=7
	Collaboration		X	X	X	X	X	X			X	X	N=8
	Individualized care	X			X							X	N=3
	Instilling hope and optimism supporting engagement			X				X			X	X	N=4

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Role of caregivers	Active involvement in treatment and engagement	X			X						X	X	N=4
	Practical support	X			X						X		N=3
	Emotional support	X	X		X						X		N=4
	Balancing young person’s autonomy	X									X		N=2
Factors negatively impacting ongoing engagement	Previous negative experiences of treatment					X	X		X	X			N=4
	Ongoing distress and confusion		X		X								N=2
	Desire to solve own problems				X	X			X	X			N=4
	Not wanting to open up about experiences						X						N=1

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	Engaging being a reminder that still a patient									X			N=1
	Competing priorities	X			X		X						N=3
	Service–level factors (e.g. location, opening hours)	X			X		X			X			N=4

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Figure legends

Figure one: Search terms

Figure two: Search strategy

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PsycINFO <1806 to November Week 4 2016>

(engage* or disengage*) or exp Treatment Dropouts/ or exp Treatment Compliance/ or (drop-out* or drop out* or non-adher* or nonadher* or complian* or comply or non-complian* or noncompli* or participat* or non-participat* or nonparticipat*)
and
((first-episode or 1st episode) adj5 psycho* or recent-onset psycho*, early-onset psycho*, early psycho*, first-episode schizophrenia, recent-onset schizophrenia)
and
exp Qualitative Research or qualitative or exp INTERVIEWS/ or interview* or mixed method or (survey* or questionnair* or focus group*)
and
exp Early Intervention or early intervention or exp Mental Health Services/ or (program* or service* or case manage*) or exp Case Management/

Limit to English language n=56

Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>

Patient Dropouts/ or (engage* or disengage*) or exp Patient Compliance/ or (drop-out* or drop out* or non-adher* or nonadher* or complian* or comply or non-complian* or noncompli* or participat* or non-participat* or nonparticipat*)
and
((first-episode or 1st episode) adj5 psycho* or recent-onset psycho*, early-onset psycho*, early psycho*, first-episode schizophrenia, recent-onset schizophrenia)
and
exp qualitative research/ or qualitative or exp Interview, Psychological/ or exp Interview/ or interview* or mixed method* or (survey* or questionnair* or focus group*)
and
exp Early Intervention/ or early intervention* or exp Mental Health Services/ or (program* or service* or case manage*) or exp Case Management/

Limit to English language n=63

Database: Ovid Emcare <1995 to 2016 week 49>

Patient Dropouts/ or (engage* or disengage*) or exp Patient Compliance/ or (drop-out* or drop out* or non-adher* or nonadher* or complian* or comply or non-complian* or noncompli* or participat* or non-participat* or nonparticipat*)
and
((first-episode or 1st episode) adj5 psycho* or recent-onset psycho*, early-onset psycho*, early psycho*, first-episode schizophrenia, recent-onset schizophrenia)
and
exp qualitative research or qualitative or exp Interview, Psychological/ or exp Interview/ or interview* or mixed method* or (survey* or questionnair* or focus group*)
and
exp Early Intervention/ or early intervention* or exp Mental Health Services/ or (program* or service* or case manage*) or exp Case Management

Limit to English language n=53

Figure one: Search terms

Figure One - Search Strategy TIFF.tiff

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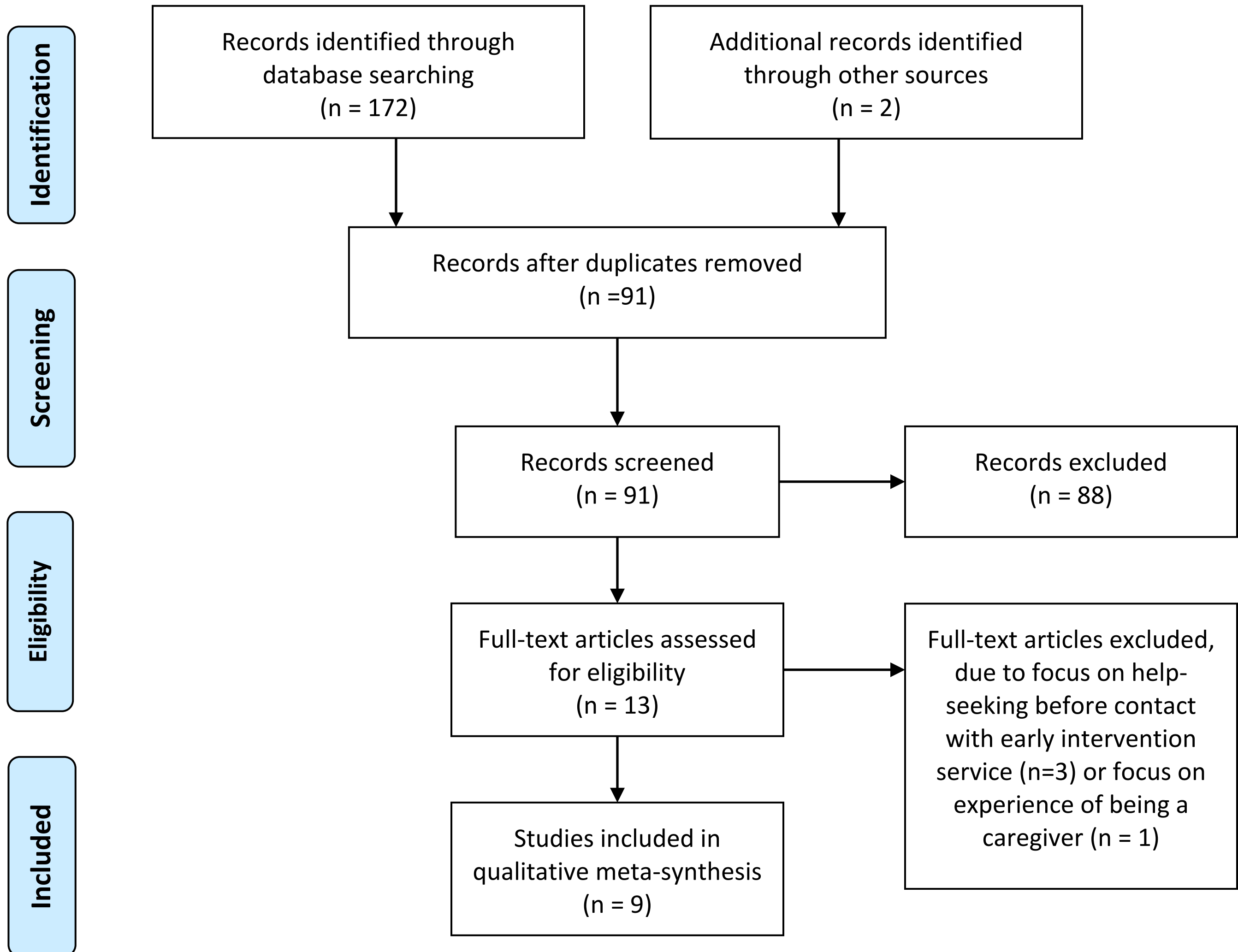
Figure two: Search and study inclusion flow-chart



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Essential ingredients of engagement when working alongside people after their first episode of psychosis: A qualitative meta-synthesis

(Resubmission: EIP-2017-076)

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Acknowledgements:
This project was supported by the Australian Government Research Training Program Scholarship, HOSPIRA and the Windermere Foundation Doctoral Scholarship in Health (Nursing) Program. We also thank Jason Wasiak for his support with the method for the systematic search.

Word Count:
Abstract: 232 words
Paper: 5593 words (including citations)

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