**Title:** Early Intervention in Psychosis Services:  A systematic review and narrative synthesis of the barriers and facilitators to seeking access

Short title: Barriers and facilitators to accessing EIP

Jacqui Tillera\*, Tess Maguirea&b and Katherine Newman-Taylora&b

aPsychology Department, University of Southampton, Southampton, UK

bPsychology Department, Southern Health NHS Foundation Trust, Southampton, UK

\*Corresponding author: Psychology Department, University of Southampton, Building 44, Highfield Campus, Southampton, SO17 1BJ, UK

Jacqui Tiller email: [J.L.Tiller@soton.ac.uk](mailto:J.L.Tiller@soton.ac.uk); ORCID ID:0000-0002-5929-7756

Tess Maguire email: [T.L.Maguire@soton.ac.uk](mailto:T.L.Maguire@soton.ac.uk); ORCID ID: 0000-0002-9355-6985

Katherine Newman-Taylor email: [knt@soton.ac.uk](mailto:knt@soton.ac.uk); ORCID ID: 0000-0003-1579-7959

**CRediT author contribution statement:** Jacqui Tiller – conceptualization, methodology, data curation, investigation, formal analysis, writing (original draft preparation, review and editing). Tess Maguire and Katherine Newman Taylor – conceptualization, methodology, supervision, writing (review and editing).

**Data availability statement:** Not applicable.

**Ethical statement:** This work has been carried out in accordance with the Declaration of Helsinki. Privacy rights were observed throughout.

**Declaration of interest:** None.

**Early Intervention in Psychosis Services: A systematic review and narrative synthesis of barriers and facilitators to seeking access**

**Abstract**

**Background:** Duration of untreated psychosis continues to be a global priority. Early intervention services were established to reduce treatment delays but have had limited impact. This systematic review examines barriers and facilitators to seeking access to these services, to identify targets for service level change.

**Methods:** We conducted a systematic review of relevant databases (PsychINFO, MEDLINE, CINAHL and PsychARTICLES) using pre-defined search terms for *psychosis, early intervention* and *barriers and facilitators*. Given a majority of qualitative studies, a thematic synthesis rather than meta-analysis was indicated.

**Results**: The search yielded 10 studies. Mental health stigma and discrimination predict duration of untreated psychosis, compounded by structural barriers which limit the impact of early intervention services on timely access to recommended treatments. Synthesis of the qualitative studies generated three themes: *knowledge, relationships* and *stigma*. Lack of knowledge, absence of supportive relationships (social and professional), and self-stigma constitute significant barriers to seeking access to early intervention services.

**Conclusions**: This is the first review of the barriers and facilitators to seeking access to early intervention services. The findings highlight public health and secondary care service targets to expedite access to recommended treatments and thereby reduce duration of untreated psychosis.

**Key words:** Early intervention, psychosis, barriers, facilitators, duration of untreated psychosis, systematic review, qualitative synthesis

**1. Introduction**

*Duration of untreated psychosis* (DUP) describes the period between initial psychotic symptoms and engagement in recommended treatments, and typically lasts 1-2 years [1, 2]. Delayed access to treatment predicts poorer clinical and social outcomes up to eight years later [3-6]. This comes at considerable personal and healthcare costs [7-9], leading the World Health Organisation [10] to identify DUP as an international healthcare target.

Specialist early intervention services have been established in Australia, New Zealand and the UK, and more recently in North America, Asia, Scandinavia and other European countries, with the aim of identifying and treating early symptoms of psychosis over the initial *critical period* [11-13]. These services have been well received by young people with psychosis [14], with some evidence of improved outcomes [15]. Disappointingly, however, the expectation that this step change in service delivery would lead to overall reductions in DUP is not (yet) supported by the literature [16], leading to calls to identify and target barriers and facilitators to accessing these services [17].

A recent systematic review of the barriers and facilitators to successful *implementation* of early intervention services highlighted systemic (e.g., funding and organisational structures), service (e.g., coherence of provision) and staff (e.g., knowledge and attitudes) factors [18]. A linked but distinct question concerns the factors affecting the likelihood that people will *seek access* to early intervention services. To our knowledge, this is the first review of barriers and facilitators to seeking access to early intervention for psychosis services.[[1]](#footnote-1)

**2. Methods**

Broad methodological alignment with O’Connell et al. [18] allows comparison across these two complementary reviews.

**2.1. Pre-registration and search procedure**

The review was pre-registered on PROSPERO (ID: omitted for blind review) and follows the preferred reporting guidelines for systematic reviews [PRISMA; 21]. We searched four electronic databases on 18.09.23 (PsychINFO, MEDLINE, CINAHL and PsychARTICLES) using free text and subject headings (where applicable) to improve search accuracy (see Table 1). Additionally, we searched ProQuest, Ethos and British Library databases for grey literature to ensure a comprehensive search and reduce risk of publication bias [22].

**Table 1:** *Free text and subject headings*

|  |  |  |  |
| --- | --- | --- | --- |
|  | Psychosis | Early intervention | Barriers and facilitators |
| Free Text | Schizo\* OR Psychotic\* OR Psychosis\* OR “Schizophren\* spectrum\*" OR “Acute psychosis” | "Early onset" OR "First onset" OR "First episode" | Barrier\* OR Challenge\* OR Obstacle\* OR Access\* OR Facilita\* OR Enabl\* OR Disengag\* OR Engag\* |
| PsychINFO  subject headings | “Schizophrenia” OR “Psychosis” | “Early intervention” OR “First episode (disorders)” | No relevant terms available |
| MEDLINE subject headings | MM “Schizophrenia” OR MM “Psychotic disorders” | No relevant terms available | No relevant terms available |
| CINAHL subject headings | “Schizophrenia” OR “Psychotic disorders” | “Early intervention” | No relevant terms available |
| PsychARTICLES subject headings | “Schizophrenia” OR “Psychosis” | “Early intervention” OR “First episode (Disorders)” | No relevant terms available |

**2.2. Inclusion and exclusion criteria**

Table 2 outlines study eligibility criteria, following Butler et al. [23]. The search was not limited by publication date or status, to ensure a balanced summary of the evidence and reduce impact of publication bias [24].

**Table 2:** *Inclusion and exclusion criteria*

|  |  |  |
| --- | --- | --- |
|  | Inclusion | Exclusion |
| Population | Participants ≥ 14 years old  Psychosis or psychosis-type experiences (e.g., schizophrenia, schizoaffective disorder, first episode psychosis, drug induced psychosis) | Participants < 14 years old  Participants identified as experiencing:   * at risk mental states, * prodromal experiences of psychosis * prolonged psychosis * co-morbid mental health condition in addition to psychosis   Carers or family members as participants  Staff as participants  Service provider views/accounts |
| Phenomena of interest | Views/perspectives on barriers and/or facilitators to accessing early intervention for psychosis services | No consideration of individuals’ experiences relevant to initial access to early intervention services (e.g., help-seeking once contact made) |
| Context | Early intervention for psychosis services  Early access to care for psychosis | Community mental health teams  Inpatient treatment settings |
| Study design | Quantitative or qualitative research – published or unpublished | Books, chapters, book reviews, commentaries |
| Other | Available in English | Not written in English |

The perspectives of carers, family members and staff are also important in understanding access to services. However, these may diverge in important ways from the views of service users themselves, and so we focus on people with psychosis in the current review.

**2.3. Study selection, data extraction and analysis plan**

We used Rayyan reference management software [25] to collate search results. The search yielded 582 articles, 421 after duplicates were removed. An independent reviewer second rated 10% of abstracts (*n*=38) with good agreement (84.2%)[[2]](#footnote-2) [26]. Full-text screening and hand searching of selected papers resulted in identification of 10 papers which described three quantitative [17, 27, 28] and seven qualitative studies [29-35] (see Figure 1).

**Figure 1:** *PRISMA diagram for paper selection*

Additional studies identified through hand searching (*n*=1)

Additional records identified through other sources  
(*n*=6) (Proquest=6)

(

Records identified through database searching  
(*n*=576)

(PsychINFO=298, Medline=176, CINAHL=98, APA PsycArticles=4)

Studies included in quantitative synthesis  
(*n*=3)

Studies included in qualitative synthesis  
(*n*=7)

N=10

Full-text articles excluded

(*n*=45)

Barriers/facilitators to accessing EIP not reported=19

Participants not individuals with FEP/early psychosis=20

Not conducted in EIP context=3

Poster abstract=1

Systematic review=2

Full-text articles assessed for eligibility  
(*n*=54)

Records excluded  
(*n*=367)

Records screened  
(*n*=421)

Records after duplicates removed  
(*n*=421)

## Identification

## Eligibility

## Included

## Screening

With just three quantitative studies measuring differing primary outcomes, a narrative summary of the characteristics and key results was indicated rather than a meta-analysis. In line with Cochrane recommendations for synthesising qualitative research, we undertook a thematic synthesis of the qualitative studies [36-38]. This approach is positioned between integrative and interpretative approaches and includes: (1) *line by line coding* of individual study results (for which we used NVIVO, [39], (2) generating *descriptive themes*, and then (3) generating *analytical themes* which interpret qualitative data across primary studies[[3]](#footnote-3) [40].

**2.4. Quality assessment and risk of bias**

The Study Quality Assessment Tool (SQAT) [41] for observational studies, and the Critical Appraisal Skills Programme (CASP) [42] checklist for qualitative studies include 14 and 10 items respectively to assess methodological, analysis and interpretation bias. In line with previous reviews, we totalled the number of ‘Yes’ responses [cf. 43]. Quantitative studies scored 7/10 relevant domains (see Table 3) and qualitative studies scored at least 7/10 (see Table 4). The key limitation of the quantitative studies was the reliance on cross-sectional data which precludes causal inferences. Though strong in most domains, the majority of qualitative studies failed to address researcher reflexivity and the impact of researcher/participant interactions, which are key to rigorous qualitative designs [44, 45].

**Table 3:** *Quality assessment – quantitative studies*

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| First author | Was the research question or objective in this paper clearly stated? | Was the study population clearly specified and defined? | Was the participation rate of eligible persons at least 50%? | Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants? | | Was a sample size justification, power description, or variance and effect estimates provided? | For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured? | Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed? | For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)? | Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants? | Was the exposure(s) assessed more than once over time? | Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants? | Were the outcome assessors blinded to the exposure status of participants? | Was loss to follow-up after baseline 20% or less? | Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)? | Total (/number of relevant domains) |
| Archie | Y | Y | Y | | Y | N | N | N | NA | Y | NA | Y | NA | NA | Y | 7/10 |
| Birchwood | Y | Y | Y | | Y | N | N | N | NA | Y | NA | Y | NA | NA | Y | 7/10 |
| Kular | Y | Y | Y | | Y | N | N | N | NA | Y | NA | Y | NA | NA | Y | 7/10 |

*Note.* Y=yes; N=no; CD=cannot determine; NA=not applicable; NR=not reported

Quality assessments were completed by two raters independently with excellent agreement (100% SQAT; 95.71% CASP). Initial discrepancies with the CASP were resolved through discussion with the supervisory team. The quality assessment was not used to exclude studies (following Noyes et al. [46] who note that domains are not equally weighted and so cut-off scores are arbitrary).

**Table 4:** *Quality assessment – qualitative studies*

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| First author | Was there a clear statement of the aims of research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collection in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Total |
| Bay | Y | Y | Y | Y | Y | CT | Y | Y | Y | Y | 9 |
| Cowan | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| Harris | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| Islam | Y | Y | Y | Y | Y | CT | CT | Y | Y | Y | 8 |
| Jansen (2015) | Y | Y | Y | Y | Y | CT | Y | Y | Y | Y | 9 |
| Jansen (2018) | Y | Y | Y | Y | Y | CT | Y | Y | Y | Y | 9 |
| Lee | Y | Y | Y | Y | Y | CT | N | CT | Y | Y | 7 |

*Note.* Y=yes; N=no; CT=can’t tell

**2.5. Researcher reflexivity**

Reflexivity is key element of qualitative research and requires researchers to consider their own role in the study and how this may influence findings [45]. This study was completed as part of the first author’s doctoral research. The second and third authors are experienced clinicians and researchers in the field. All three are healthcare professionals with experience of collecting data in early intervention services. We reflected on our roles, experiences and assumptions during the thematic synthesis process to reduce risk of bias [47].

**3. Results[[4]](#footnote-4)**

**3.1. Study characteristics**

All three quantitative studies and six of the seven qualitative studies were published, with one unpublished qualitative thesis. All were conducted in the northern hemisphere, though one explored experiences of international students studying abroad and receiving support for first episode psychosis [35]. The quantitative studies recruited 78-200 majority male participants to observational cohort designs. The qualitative studies recruited 5-24 participants, with a broadly even male:female reported gender mix (though Cowan et al. [30] recruited more men). The majority utilised semi-structured interviews (*n*=5) and thematic analyses (*n*=4).

**Table 5:** *Study characteristics*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Author (year)  Country | | Title | Aims | Participants  Age range (*Mean*)  Gender | Data collection method | Design and analyses |
| Quantitative studies | | | | | | |
| Archie et al. (2010)  Canada | | Ethnic diversity and pathways to care for a first episode of psychosis in Ontario | To investigate pathways to care for different ethnic groups accessing early intervention services in Ontario | *N*=200  16-50  (White *M*=24.1; Black *M*=24.2; Asian *M*=26.8; Other *M*=22.6)  78% male |  | Cross-sectional (secondary analysis)  Chi-square; regression |
| Birchwood et al. (2013)  UK | | Reducing duration of untreated psychosis: care pathways to early intervention in psychosis services | To identify components in pathways to care during untreated psychosis and contribution to delays in accessing early intervention services  To model impact of targeted changes in care pathways to reduce DUP | *N*=348[[5]](#footnote-5)  14-35 (*M*=21.6 at illness onset)  73% male | Questionnaires | Cross sectional  ANOVA; sensitivity analysis |
| Kular et al. (2018)  UK | | Stigma and access to care in first-episode psychosis | To investigate associations between mental health stigma and access to care for people with first episode psychosis | *N*=89[[6]](#footnote-6)  14-37 (*M*= 23.2)  72% male | Questionnaires | Cross sectional  Regression |
| Qualitative studies | | | | | | |
| Bay et al. (2016)  Norway | Obstacles to care in first-episode psychosis patients with a long duration of untreated psychosis | | To investigate factors preventing or delaying people with long DUP from accessing services | *N*=8  17-44 (*M*=not stated)  4 male, 4 female | Semi-structured interviews | Interpretative phenomenological approach |
| Cowan et al. (2020)  Canada | Engagement in specialised early intervention services for psychosis as an interplay between personal agency and critical structures: A qualitative study | | To investigate factors influencing people’s choices to access, remain involved with, and leave early intervention services | *N*=24  17-34 (*M*=22.67)  16 male, 6 female, 2 transgender | Semi-structured interviews | Thematic analysis |
| Harris (2016)  UK | Exploring young people’s constructions of a first episode of psychosis | | To investigate culture narratives held by young people regarding access to and impact of early intervention services | *N=*5  22-35 (*M*=28)  2 male, 3 female | Semi-structured interviews | Narrative analysis |
| Islam et al. (2015)  UK | Black and minority ethnic groups’ perception and experience of early intervention in psychosis services in the United Kingdom | | To investigate barriers to early intervention services for Black and minority ethnic groups, linked to cultural appropriateness, accessibility and acceptability | *N=*22  18-35 (*M*=22)  11 male, 11 female | Focus groups | Thematic analysis |
| Jansen et al. (2015)  Denmark | Service user perspectives on the experience of illness and pathway to care in first-episode psychosis: A qualitative study within the TOP project | | To investigate perspectives on helpful and unhelpful pathways to care for people with first episode psychosis, and barriers to early detection and treatment | *N=*11  15-24 (*Median*=20)  6 male, 5 female | Semi-structured interviews | Thematic analysis |
| Jansen et al. (2018)  Denmark | Important first encounter: Service user experience of pathways to care and early detection in first-episode psychosis | | To investigate people’s experiences of early detection and transition to psychosis services, including pathways to care, illness understanding and barriers to adequate care | *N=*10  18-27 (*Median*=21)  5 male, 5 female | Semi-structured interviews | Thematic analysis |
| Lee et al. (2015)  Canada | Challenges in and recommendations for working with international students with first-episode psychosis: Descriptive case series | | To identify and describe challenges for international students with first episode psychosis accessing early intervention services | *N=*7  14-35 (*M*=not stated)  4 male, 3 females | Chart reviews | Descriptive case series |

**3.2. Key findings**

The three quantitative studies examined care pathways to early intervention services to determine barriers to access, the role of stigma specifically, and potential differences with ethnicity (see Tables 5 and 6). Mental health stigma was identified a key barrier to seeking access to services and predicted DUP [28]. Structural barriers within broader mental health services then delayed access to early intervention teams, thereby limiting the impact of these services on reducing DUP [17]. Perhaps unexpectedly, there were no differences in DUP or who initiated help-seeking (the person themselves, family/friends or police) between ethnic groups, though Asian and other minoritised ethnic groups were more likely than White (x4) and Black (x3) participants to access early intervention via emergency services [27].

Thematic analysis of the qualitative data [36-38] yielded three descriptive themes associated with barriers and facilitators to accessing early intervention for psychosis services: *knowledge*, *stigma* and *relationships* (see Table 6 and supplementary material).

*Knowledge* describes individuals' experiences in which information (or absence of information) known to the person and their support system (including families and mental health professionals) had a critical impact on whether and when they were able to access early intervention services. All studies identified limited knowledge – whether regarding psychosis symptomology, possible trajectories, and treatment options – as a significant barrier to help-seeking. For example, misattribution of symptoms to depression, drug use, or normal experiences of adolescence [33], believing that symptoms did not warrant treatment [29, 31, 33], and being unaware of services available [29, 32], all delayed help-seeking and therefore access to recommended treatments. When people did seek help, this lack of knowledge could be compounded by that of primary care clinicians (e.g., General Practitioners in the UK) who also misattributed symptoms to anxiety or depression [29, 32], and other relevant professionals (e.g., immigration officials for international students) [35].

By contrast, four studies highlighted the impact of accurate information about psychosis and mental health services, for example from ongoing public health campaigns, on facilitating access [29-31, 33], and that actively seeking additional information helped people develop an understanding of their experiences which in turn prompted help-seeking [31, 33].

*Stigma* of mental health problems was identified in all qualitative studies as a key barrier to seeking access to early intervention services. Participants’ stigmatised beliefs about mental illness, and fears about others’ responses, in line with dominant societal discourses, affected likelihood of disclosure and help-seeking [29-31, 33-35]. Two studies found that specific fears about being returned to hospital stopped people seeking help [31, 34]. Socio-cultural factors affected stigma and therefore help-seeking and access to services. For example, where dominant narratives were highly stigmatising of mental illness (and psychosis specifically) people were less likely to seek help from early intervention services [e.g., 31, 32].

**Table 6:** *Key findings of the original studies*

| Author (year) | Participant and service characteristics | Key findings reported | Limitations |
| --- | --- | --- | --- |
| Quantitative studies | | | |
| Archie et al. (2010) | Schizophrenia spectrum conditions  Early intervention services | No differences between ethnic groups for DUP (median=22 weeks) or initiation of help seeking by family/friends (53%), self (33%) or police (15%)  More similarities than differences in pathways to care across ethnic groups  Asian and other minority ethnic groups more likely than White (x4) or Black (x3) participants to use emergency services as first point of contact | Cross-sectional design  Retrospective reporting of DUP  Inter-rater reliability not established  Exclusion of non-English speaking participants |
| Birchwood et al. (2013) | Schizophrenia spectrum conditions  Early intervention service | Delays in accessing early interventions services strongly correlated with DUP  DUP *prolonged* once people entered mental health services  Structural barriers likely to negatively affect impact of early intervention services on reducing DUP | Cross-sectional design  Retrospective reporting of DUP  30% of original sample not consented |
| Kular et al. (2018) | First episode psychosis  Early intervention services | Associations between total stigma and DUP (*r*=0.276, *p<*0.01), discrimination and DUP (*r*=0.272, *p*=0.01), and disclosure and DUP *(r*=0.253, *p<*0.05)  General mental health stigma and perceived discrimination significant predictors of DUP | Cross-sectional design  Retrospective reporting of DUP  Other facets of stigma not measured |
| Qualitative studies | | | |
| Bay et al. (2016) | Schizophrenia spectrum conditions  Wider research sub-sample | Five themes generated: (i) participants’ failure to recognize symptoms of psychosis; (ii) difficulties expressing their experiences; (iii) concerns about stigma; (iv) poor psychosis detection skills among health-care professionals; and (v) participants’ lack of awareness or understanding of informational campaigns | Retrospective accounts  Ethnicity not reported  Negative symptoms may have affected recall for some participants  Service user accounts may not reflect others who are not service users |
| Cowan et al. (2020) | First episode psychosis  Early intervention service | Three themes generated: (i) fluidity and temporality of engagement and disengagement; (ii) engagement as an ongoing negotiation; and (3) critical structures and agency  As people’s needs changed, they sought to renegotiate service input but this was constrained by service and societal structures | Retrospective accounts  Service user accounts may not reflect others who are not service users |
| Harris (2016) | First episode psychosis  Early intervention service | Young Black people’s narratives of their unusual experiences changed over time and linked to dominant social discourses  Dominant medical discourses may tacitly reinforce stigmatised identities; biopsychosocial explanations more helpful to some | Retrospective accounts  Service user accounts may not reflect others who are not service users |
| Islam et al. (2015) | Diagnoses not specified  Early intervention service | Five themes generated: (i) help-seeking; (ii) culture and beliefs; (iii) social stigma and shame; (iv) experience of early intervention services; and (v) improving BME access and experiences of services  Initial help sought from faith/spiritual healers for many with diverse ethnicities  Limited collaboration between mental health services and charity/voluntary organisations to meet individuals’ cultural and spiritual needs. | Retrospective accounts  Service user accounts may not reflect others who are not service users |
| Jansen et al. (2015) | Schizophrenia spectrum conditions  Early intervention service | Four themes generated: (i) support from significant others; (ii) use of internet as a source of information about psychosis and treatment; (iii) lack of knowledge of symptoms or normalisation of psychotic symptoms, and (iv) fear of stigmatisation and embarrassment following symptom disclosure | Retrospective accounts  Service user accounts may not reflect others who are not service users |
| Jansen et al. (2018) | First episode psychosis  Early detection service | Five themes generated: (i) stigma and fear of the psychiatric system; (ii) impact of traumatic experiences; (iii) importance of significant others in finding the right treatment and supporting help seeking; (iv) experience of safety and trust within the early detection team; and (v) relief at receiving a diagnosis  ‘Anti-stigmatised space’ within early detection team key to accessing support | Retrospective accounts  Service user accounts may not reflect others who are not service users  First study of early detection service – requires replication |
| Lee et al. (2015) | First episode psychosis  Early intervention service | Four themes generated (barriers to access for FEP international students): (i) difficulty maintaining student visa status; (ii) limited social and family support; (iii) financial and health insurance issues; and (iv) service disengagement  Unique challenges for international students require specific support | Retrospective accounts  Service user accounts may not reflect others who are not service users |

The third descriptive theme describes the impact of quality of *relationships* on likelihood of accessing early intervention services. Consistent emotional and practical support to disclose and manage psychotic experiences day-to-day increased access to services across six studies [30-35], and a lack of supportive familial relationships and friendships was identified as a barrier [31, 35]. Similarly, collaborative relationships with interpersonally effective professionals that support autonomy and shared decision making, and flexible service systems (e.g., regarding pace of engagement), facilitated help-seeking and maintenance of early engagement with services [30-32; 34]. Given the typical age of onset for psychosis, parental relationships were both a key facilitator and barrier [33, 34].

The iterative process of thematic analysis, and discussion within the research team, highlighted links between the three themes, and how *knowledge*, *stigma* and *relationships* often intersect to facilitate or create barriers to accessing early intervention services. Interpreting the qualitative data across the primary studies yielded an overarching analytic theme of *intersectional knowledge and beliefs about self and others,* which represents the three overlapping themes and highlights the inherently interpersonal nature of stigma and relationships (see Figure 2, below).

**Figure 2:** *Intersectional knowledge and beliefs about self and others*

Knowledge and likelihood of accessing further information are affected by stigmatised beliefs about psychosis, mental health care, and oneself as a person who may have psychosis and need to access services. Generalised and self-stigma beliefs are by definition dependent on dominant socio-cultural discourses (e.g., psychosis as shameful) as well as personal and professional relationships. These generalised and specific social relationships in turn influence the knowledge we access and privilege when making healthcare decisions. The intersectionality of *knowledge*, *stigma* and *relationship* beliefs about self and others suggests that public health and healthcare initiatives that target these in combination are likely to be more effective than strategies that focus on any one area in isolation.

**4. Discussion**

This is the first systematic review of the barriers and facilitators to accessing early intervention for psychosis services. A comprehensive search of the published and unpublished literature (with no date limits) yielded 10 papers, the majority of which were qualitative.

A recent review by O’Connell et al. [18] highlights factors likely to improve *implementation* of early intervention services. Our review complements this by identifying factors which influence whether people *seek access to* these services. Mental health stigma is a key barrier and predicts DUP. Structural service barriers then further delay access to specialist services, despite the introduction of access and waiting times standards [48]. A synthesis of the qualitative studies generated three themes which both hinder and facilitate access to services: *knowledge, stigma,* and *relationships*, and an overarching analytic theme of *intersectional knowledge and beliefs about self and others.*

These findings align with and extend the wider literature which suggests that limited knowledge about mental health delays access to services for people with psychosis [49, 50], and that mental health literacy alongside supportive social and professional relationships increases help seeking, which may in turn reduce DUP and improve outcomes [51]. Like McGonagle et al. [52], we found that stigma plays a key role in whether people disclose early psychosis and seek access to services, and that this is affected by dominant socio-cultural expectations [53]. Our review suggests that public health and service level initiatives should target these factors in integrated approaches that acknowledge the links between knowledge, stigma and relationships.

**4.1. Public health, service and research implications**

Mental health literacy campaigns (targeting *knowledge*) delivered in cultural context (to address culturally shaped *stigma*) and targeting local communities as a whole (to influence *social and professional relationships*) may be particularly effective. For example, healthcare in-reach to schools might strengthen the impact of accurate information about psychosis and treatment options by drawing on young people’s often strong and collective sense of social justice to challenge the shame that drives stigmatising beliefs about psychosis [cf. 54], and engaging well-regarded people in the local community to speak about their experiences of psychosis and accessing services – parent, child and clinician triads might be particularly compelling.

Targeted training on the early signs of psychosis, how to access information and services, and how to be interpersonally effective in these interactions, should be delivered to professional groups who may come into contact with young people experiencing early signs of psychosis. Given the barriers identified in the current study, this should include primary care clinicians, emergency services, and education/immigration officials working with international students.

Secondary care services are likely to be more effective when clinicians are able to prioritise the development of supportive and trusting relationships with young people, shared decision making, and flexible service delivery. These are of course built into service models for early intervention services, but are at risk when caseloads increase beyond recommended levels. The growing inclusion of peer support workers and befriending schemes in these teams is particularly welcome given the likely impact on knowledge, stigma and relationships [55-57]. Routine clinical practice within these services should be extended to include culturally sensitive exploration of self-stigmatising beliefs, and modelling of alternative ways of understanding and responding to psychosis, as a means of securing tentative engagement with young people.

In terms of research, we now need longitudinal quantitative and qualitative studies of young people’s decision making and behaviours from first signs of at risk mental states, in order to examine the role of candidate individual, interpersonal and service-related factors that affect likelihood of seeking access to specialist services, and how these change and can be targeted over time.

**4.2. Conclusion**

This review identifies key barriers and facilitators to *seeking access* to early intervention for psychosis services, and complements a recent review of the barriers and facilitators to *implementation* of these services [18]. Together, these reviews highlight public health, systemic, service and staff factors that may be targeted to facilitate access to early intervention services, with the aim of reducing DUP and improving outcomes for people with psychosis.

**Conflicts of interest:** All authors declare none.

**Financial support:** This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

**Supplementary material:** For supplementary material accompanying this paper, visit cambridge.org/EPA.

**References**

[1] McGlashan TH. Duration of untreated psychosis in first-episode schizophrenia: marker or determinant of course? Biological Psychiatry. 1999 Oct 1;46(7):899-907.

[2] Barnes TR, Hutton SB, Chapman MJ, Mutsatsa S, Puri BK, Joyce EM. West London first-episode study of schizophrenia: clinical correlates of duration of untreated psychosis. The British Journal of Psychiatry. 2000 Sep;177(3):207-11.

[3] Crumlish N, Whitty P, Clarke M, Browne S, Kamali M, Gervin M et al., Beyond the critical period: longitudinal study of 8-year outcome in first-episode non-affective psychosis. The British Journal of Psychiatry. 2009 Jan;194(1):18-24.

[4] Marshall M, Lewis S, Lockwood A, Drake R, Jones P, Croudace T. Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: a systematic review. Archives of General Psychiatry. 2005 Sep 1;62(9):975-83.

[5] Perkins DO, Gu H, Boteva K, Lieberman JA. Relationship between duration of untreated psychosis and outcome in first-episode schizophrenia: a critical review and meta-analysis. American Journal of Psychiatry. 2005 Oct 1;162(10):1785-804.

[6] Sullivan SA, Carroll R, Peters TJ, Amos T, Jones PB, Marshall M et al. Duration of untreated psychosis and clinical outcomes of first episode psychosis: An observational and an instrumental variables analysis. Early Intervention in Psychiatry. 2019 Aug;13(4):841-7.

[7] Boonstra N, Klaassen R, Sytema S, Marshall M, De Haan L, Wunderink L et al. Duration of untreated psychosis and negative symptoms—a systematic review and meta-analysis of individual patient data. Schizophrenia Research. 2012 Dec 1;142(1-3):12-9.

[8] Salomon, JA, Vos, T, Hogan, DR, Gagnon, M, Naghavi, M, Mokdad, A, et al. Common values in assessing health outcomes from disease and injury: disability weights measurement study for the Global Burden of Disease Study 2010. Lancet. 2012;380(9859):2129–43.

[9] Valmaggia LR, McCrone P, Knapp M, Woolley JB, Broome MR, Tabraham P et al. Economic impact of early intervention in people at high risk of psychosis. Psychological Medicine. 2009 Oct;39(10):1617-26.

[10] World Health Organization. Mental and neurological disorders. Fact Sheet: The World Health Report 2001. NMH Communications, Geneva, Switzerland. 2001.

[11] McGorry PD, Killackey EJ. Early intervention in psychosis: a new evidence based paradigm. Epidemiology and Psychiatric Sciences. 2002 Dec;11(4):237-47.

[12] McGorry PD, Killackey E, Yung A. Early intervention in psychosis: concepts, evidence and future directions. World Psychiatry. 2008 Oct;7(3):148.

[13] Maric NP, Petrovic SA, Raballo A, Rojnic‐Kuzman M, Klosterkötter J, Riecher‐Rössler A. Survey of the European Psychiatric Association on the European status and perspectives in early detection and intervention in at‐risk mental state and first‐episode psychosis. Early Intervention in Psychiatry. 2018 Aug;13(4):853-8.

[14] Lester H, Marshall M, Jones P, Fowler D, Amos T, Khan N et al. Views of young people in early intervention services for first-episode psychosis in England. Psychiatric Services. 2011 Aug;62(8):882-7.

[15] Larsen TK, Melle I, Auestad B, Haahr U, Joa I, Johannessen JO et al. Early detection of psychosis: positive effects on 5-year outcome. Psychological Medicine. 2011 Jul;41(7):1461-9.

[16] Singh SP. Early intervention in psychosis. The British Journal of Psychiatry. 2010 May;196(5):343-5.

[17] Birchwood M, Connor C, Lester H, Patterson P, Freemantle N, Marshall M et al. Reducing duration of untreated psychosis: care pathways to early intervention in psychosis services. The British Journal of Psychiatry. 2013 Jul;203(1):58-64.

[18] O’Connell N, O’Connor K, McGrath D, Vagge L, Mockler D, Jennings R et al. Early Intervention in Psychosis services: A systematic review and narrative synthesis of the barriers and facilitators to implementation. European Psychiatry. 2022;65(1):e2.

[19] Friskney R, Branney P, Iqbal S, Edwards L, Wem L. Cultural inequalities in access to Early Intervention for Psychosis services in the United Kingdom. Unpublished doctoral thesis.

[20] Loughlin M, Bucci S, Brooks J, Berry K. Service users’ and carers’ experiences of engaging with early intervention services: A meta‐synthesis review. Early Intervention in Psychiatry. 2020 Feb;14(1):26-36.

[21] Moher D, Liberati A, Tetzlaff J, Altman DG, Prisma Group. Reprint—preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Physical Therapy. 2009 Sep 1;89(9):873-80.

[22] Boland A, Dickson R, Cherry G. Doing a systematic review: A student's guide. Doing a Systematic Review. 2017:1-304.

[23] Butler A, Hall H, Copnell B. A guide to writing a qualitative systematic review protocol to enhance evidence‐based practice in nursing and health care. Worldviews on Evidence‐Based Nursing. 2016 Jun;13(3):241-9.

[24] Paez A. Gray literature: An important resource in systematic reviews. Journal of Evidence‐Based Medicine. 2017 Aug;10(3):233-40.

[25] Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. Systematic Reviews. 2016 Dec;5:1-0.

[26] Fleiss JL, Levin B, Paik MC. Statistical methods for rates and proportions. John Wiley & Sons; 2013 Jun 12.

[27] Archie S, Akhtar-Danesh N, Norman R, Malla A, Roy P, Zipursky RB. Ethnic diversity and pathways to care for a first episode of psychosis in Ontario. Schizophrenia Bulletin. 2010 Jul 1;36(4):688-701.

[28] Kular A, Perry BI, Brown L, Gajwani R, Jasini R, Islam Z et al. Stigma and access to care in first‐episode psychosis. Early intervention in Psychiatry. 2019 Oct;13(5):1208-13.

[29] Bay N, Bjørnestad J, Johannessen JO, Larsen TK, Joa I. Obstacles to care in first‐episode psychosis patients with a long duration of untreated psychosis. Early Intervention in Psychiatry. 2016 Feb;10(1):71-6.

[30] Cowan T, Pope MA, MacDonald K, Malla A, Ferrari M, Iyer SN. Engagement in specialized early intervention services for psychosis as an interplay between personal agency and critical structures: A qualitative study. International Journal of Nursing Studies. 2020 Aug 1;108:103583.

[31] Harris S. Exploring Young People's Constructions of a First Episode of Psychosis. Unpublished doctoral dissertation.

[32] Islam Z, Rabiee F, Singh SP. Black and minority ethnic groups’ perception and experience of early intervention in psychosis services in the United Kingdom. Journal of Cross-Cultural Psychology. 2015 Jun;46(5):737-53.

[33] Jansen JE, Wøldike PM, Haahr UH, Simonsen E. Service user perspectives on the experience of illness and pathway to care in first-episode psychosis: a qualitative study within the TOP project. Psychiatric Quarterly. 2015 Mar;86:83-94.

[34] Jansen JE, Pedersen MB, Hastrup LH, Haahr UH, Simonsen E. Important first encounter: Service user experience of pathways to care and early detection in first‐episode psychosis. Early Intervention in Psychiatry. 2018 Apr;12(2):169-76.

[35] Lee C, Marandola G, Malla A, Iyer S. Challenges in and recommendations for working with international students with first-episode psychosis: A descriptive case series. International Journal of Migration, Health and Social Care. 2015 Sep 12;12(3):185-93.

[36] Booth A, Noyes J, Flemming K, Gerhardus A, Wahlster P, Van Der Wilt GJ et al. Guidance on choosing qualitative evidence synthesis methods for use in health technology assessments of complex interventions. Bremen (DE): Integrate-HTA. 2016 Feb 1.

[37] Flemming K, Noyes J. Qualitative evidence synthesis: where are we at?. International Journal of Qualitative Methods. 2021 Feb 19;20:1609406921993276.

[38] Noyes J, Booth A, Cargo M, Flemming K, Harden A, Harris J et al. Chapter 21: Qualitative evidence. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA (editors). Cochrane Handbook for Systematic Reviews of Interventions version 6.3 (updated February 2022). Cochrane, 2022

[39] NVivo Q. NVivo qualitative data analysis software. Version 10: QSR international Pty ltd. 2020.

[40] Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Medical Research Methodology. 2008 Dec;8(1):1-0.

[41] National Heart Lung and Blood Institute. (2014). Quality assessment tool for observational cohort and cross-sectional studies. Available online: http://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort (accessed on 15 June 2023).

[42] Long HA, French DP, Brooks JM. Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. Research Methods in Medicine & Health Sciences. 2020 Sep;1(1):31-42.

[43] Al-Dirini RM, Thewlis D, Paul G. A comprehensive literature review of the pelvis and the lower extremity FE human models under quasi-static conditions. Work. 2012 Jan 1;41(Supplement 1):4218-29.

[44] Teh YY, Lek E. Culture and reflexivity: Systemic journeys with a British Chinese family. Journal of Family Therapy. 2018 Nov;40(4):520-36.

[45] Dodgson JE. Reflexivity in qualitative research. Journal of Human Lactation. 2019 May;35(2):220-2.

[46] Noyes J, Booth A, Flemming K, Garside R, Harden A, Lewin S et al. Cochrane Qualitative and Implementation Methods Group guidance series—paper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. Journal of Clinical Epidemiology. 2018 May 1;97:49-58.

[47] McCabe JL, Holmes D. Reflexivity, critical qualitative research and emancipation: A Foucauldian perspective. Journal of Advanced Nursing. 2009 Jul;65(7):1518-26.

[48] Kreutzberg A, Jacobs R. Improving access to services for psychotic patients: does implementing a waiting time target make a difference. The European Journal of Health Economics. 2020 Jul;21:703-16.

[49] Anderson KK, Fuhrer R, Malla AK. “There are too many steps before you get to where you need to be”: help-seeking by patients with first-episode psychosis. Journal of Mental Health. 2013 Aug 1;22(4):384-95.

[50] Lal S, Dell'Elce J, Tucci N, Fuhrer R, Tamblyn R, Malla A. Preferences of young adults with first-episode psychosis for receiving specialized mental health services using technology: a survey study. JMIR Mental Health. 2015 May 20;2(2):e4400.

[51] Upthegrove R, Atulomah O, Brunet K, Chawla R. Cultural and social influences of negative illness appraisals in first‐episode psychosis. Early Intervention in Psychiatry. 2013 Nov;7(4):399-406.

[52] McGonagle G, Bucci S, Varese F, Raphael J, Berry K. Is adult attachment associated with engagement with services? A systematic literature review. Journal of Mental Health. 2021 Sep 3;30(5):607-18.

[53] Chatmon BN. Males and mental health stigma. American Journal of Men's Health. 2020 Aug;14(4):1557988320949322.

[54] Svensson B, Hansson L. How mental health literacy and experience of mental illness relate to stigmatizing attitudes and social distance towards people with depression or psychosis: A cross-sectional study. Nordic Journal of Psychiatry. 2016 May 18;70(4):309-13.

[55] Repper J, Aldridge B, Gilfoyle S, Gillard S, Perkins R, Rennison J. Peer support workers: Theory and practice. London: Centre for Mental Health; 2013 Jun 5.

[56] Proctor K, Wood R, Newman-Taylor K. Welcoming peer workers in NHS settings: facilitating readiness with an Early Intervention in Psychosis team. Mental Health and Social Inclusion. 2019 Feb 11;23(1):30-5.

[57] Hansen L, Bayford E, Wood R, Proctor K, Jansen R, Newman‐Taylor K. Lessons from an aborted controlled trial on the impact of befriending in an early intervention in psychosis population. Early Intervention in Psychiatry. 2022 Apr;16(4):453-5.

**Supplementary material:** *Code book of* *descriptive themes and illustrative quotes (from primary qualitative studies)*

|  |  |  |
| --- | --- | --- |
| Themes | Papers evidencing themes | Quotes from papers |
| Knowledge | 1, 2, 3, 4, 5, 6, 7 | *6. “I thought it was only a sad period, ‘just let things pass as they normally do’, until I’d gotten my head under control again.”*  *5. “I think I kept it to myself because I thought it was normal.”*  *1. “Others did not consider themselves as belonging to the TIPS target group mainly due to feeling insufﬁciently unwell (i.e. not sick enough) for TIPS.” (A)*  *1. “At times, they received treatment from GPs, psychologists, psychiatrists and school nurses for symptoms of anxiety and depression, but health-care professionals failed to correctly detect and diagnose psychosis.”* (A)  *3. “Joseph emphasised his open-mindedness to multiple explanations of his experiences… However, it is possible that Joseph was not entirely satisfied with the range of explanations provided, since he described seeking sources of additional information in his search for meaning.” (A)*  *3. “Joseph explained how the support provided by the EIP service and his personal research had facilitated self-reflection and knowledge.” (A)* |
| Stigma | 1, 2, 3, 4, 5, 6, 7 | *5. “Six participants discussed that shame and fear of stigma in relation to mental illness and how this made them less inclined to disclose symptoms and seek appropriate treatment.” (A)*  *6. “What I was most nervous about . . . to be labelled as crazy, afraid of being locked up, and not being let out again. It took a lot of courage to tell my general practitioner.”*  7*. “She presented with a long history of untreated psychosis and reported not seeking help earlier as mental illness was considered a taboo back home.” (A)*  *6. “I still ﬁnd it difﬁcult to accept that I have it, more because I’m worried that when I tell people about it, they label me crazy.”*  *5. “… so you’re just kind of afraid of being stigmatised by other people … you just know there are prejudices about all these things.”*  *3. “Frank talked about accessing the EIP service in a way that suggested this posed a threat to his previous sense of self, one strongly associated with dominant narratives of masculinity and the non-expression of emotion.” (A)*  4. “*I think for Asian people it’s quite difficult having a mental health problem . . . Asian people aren’t as accepting if you have a mental health problem and treat you very differently.”* |
| Relationships | 2, 3, 4, 5, 6, 7 | *3. “…facing numerous barriers to receiving support as she was dismissed by health care professionals and her family.” (A)*  3*. [216-219] “But the more time that they don’t give up on you (1) if that makes any sense, the more times that they stay there and when you do your stupidness they kind of don’t react to it, it kind of makes you realise that you do need a service.”*  *2.* ***“****Even when I haven’t come for like months on end, they always end up taking me back, when I feel like they’re going to think I’m using them but they’re always like, ‘This is what we’re here for’, so I really appreciate that. And they’re –they’re good, they’re ﬂexible and they’re understanding.”*  *3... “I told my family members (1) my sister but they, they didn’t believe me at first, they said it might be nothing.”*  *5. “Parents also assisted in ﬁnding, motivating for and visiting appropriate services.” (A)*  *7. “Despite reporting loneliness, she had one supportive friend in Montreal (also from her country) whom she considered to be like a sister. This friend occasionally accompanied her to appointments. Ms E was involved in a church that offered her emotional and instrumental (e.g. clothing) support.” (A)* |

*Note.* 1=Bay et al. (2016); 2=Cowan et al. (2020); 3=Harris (2016); 4=Islam et al. (2015); 5=Jansen et al. (2015); 6=Jansen et al. (2018); 7=Lee et al. (2016); (A)=Author quotes

1. Friskney et al. [19] examine barriers and facilitators to access for people from South Asian heritage specifically, and Loughlin et al. [20] review ongoing engagement once people have accessed early intervention services. [↑](#footnote-ref-1)
2. The second rater reviewed 10% of the initial 375 articles identified. Further studies were identified when the search was checked and updated following a request from a reviewer. [↑](#footnote-ref-2)
3. Thomas and Harden [40] report considerable variation in reporting of qualitative syntheses in systematic reviews of qualitative studies, particularly in the extent of data and results presented. We follow these authors’ recommendation that all text recorded in the primary study ‘Results’ be identified as data for potential coding. [↑](#footnote-ref-3)
4. Full coding manual available on reasonable request. [↑](#footnote-ref-4)
5. Five participants excluded from analyses due to insufficient information to calculate DUP. [↑](#footnote-ref-5)
6. N denotes a subset of the 132 participants in a wider study; demographic details describe the full sample. [↑](#footnote-ref-6)