REVIEW ARTICLE

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Psychosis and help-seeking behaviour–A systematic review of the literature

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Abstract

Purpose: Many people with psychosis do not seek help which delays access to recommended treatments. Duration of untreated psychosis is associated with poor healthcare outcomes and increased risk of relapse. The reasons why people delay accessing treatment remain unclear. This is the first systematic review to synthesise the literature examining professional and non-professional help-seeking in psychosis across clinical and subclinical populations.

Methods: We searched four databases (APA PsycINFO, APA PsycArticles, Medline and British Library EThOS) to generate a comprehensive account of the quantitative literature. Heterogeneity of measures precluded a meta-analysis.

Results: We identified 19 articles (including 9686 participants) that met criteria for the review. Help-seeking in psychosis is associated with being female, having a higher level of education, and experiencing more than one symptom. People with psychosis report stigma, poor mental health literacy and lack of family support as key barriers. Clinicians report childhood physical abuse, insecure attachment and severity of psychosis as additional barriers. We also found differences in preferred sources of help across cultures. There is currently no consensus on reliable help-seeking measures.

Conclusions: This is the first systematic review to examine help-seeking behaviour in psychosis. Assertive and culturally sensitive engagement efforts should be targeted towards people with a history of early adversity, poor mental health literacy, limited social support and more severe psychosis.

K E Y W O R D S
adversity, attachment, DUP, help-seeking, literacy, psychosis, public health, schizophrenia, service engagement, stigma, support-seeking

INTRODUCTION

The impact of psychological, pharmacological and social interventions for psychosis depends on people accessing and engaging with services. People with psychosis often delay seeking help which reduces access to recommended interventions and increases duration of untreated psychosis (DUP) – the time between onset of symptoms and start of treatment (Brunet & Birchwood, 2010; Marshall et al., 2005).

DUP is typically 12–24 months (Brunet & Birchwood, 2010; Kane et al., 2016; Riecher-Rossler et al., 2006) and associated with poorer health outcomes, more severe symptoms and increased risk of relapse (Boonstra et al., 2012). This has a detrimental impact on individuals with psychosis, their families and healthcare systems (Groff et al., 2021; Knapp, 1997), leading the WHO (2001) to identify reduction in DUP as an international priority.

Help-seeking includes accessing support from professionals (e.g. general practitioners and mental health teams) and non-professionals (e.g. family and friends). In a recent review of the barriers to seeking access to early intervention services in the United Kingdom, Tiller et al. (2023) identified lack of knowledge, lack of supportive relationships (professional and social) and stigma as significant obstacles, in addition to structural service barriers.

In the healthcare literature, help-seeking from professionals is often defined and assessed under the broader term 'service engagement', which incorporates availability for appointments, collaborative responsibility for management of healthcare needs, direct help-seeking from professionals and adherence to treatment regimens (Tait et al., 2002). Poor service engagement is common in adolescents and young adults, which is particularly concerning as this is the peak time for onset of psychosis, and can result in significant deterioration in the following 2–3 years (Birchwood et al., 1998). Poor service engagement is also reflected in high dropout rates of approximately 25% from mental health services (Kreyenbuhl et al., 2009), which is even higher in first episode psychosis (Doyle et al., 2014) and for psychological therapies in routine practice (e.g. Richardson et al., 2019).

Factors associated with service disengagement include younger age, male gender, minoritised ethnicity, poor social functioning, comorbidity (including substance misuse) and early onset (Kreyenbuhl et al., 2009). In first episode psychosis, severity of symptoms, DUP, substance misuse and lack of family involvement also predict disengagement (Doyle et al., 2014). Additionally, reviews focusing on specific factors have highlighted the impact of attachment style (Berry et al., 2007; Sood et al., 2022) and cultural/religious beliefs (Smolak et al., 2012) on help-seeking in psychosis – people with insecure attachment are less likely to seek help from others, and people with religious beliefs may be cautious of mental health professionals and more inclined to access faith-based support and healers.

Reviews to date have examined pathways into and within mental health services (typically focusing on professional help-seeking), service disengagement (once people have made initial contact) and the impact of specific factors on help-seeking in psychosis (e.g. attachment style and religious beliefs). To our knowledge, this is the first systematic review to examine professional and non-professional help-seeking in psychosis and psychotic-type experience. This is likely to inform efforts to facilitate access to recommended therapies and thereby reduce DUP.

METHODS

The review was registered on PROSPERO (ID: CRD42022342609) and follows the preferred reporting guidelines for systematic reviews (PRISMA, Page et al., 2021).

Search procedure

We searched four databases: APA PsycINFO, APA PsycArticles, Medline and British Library EThOS to generate a comprehensive account of the published and unpublished quantitative literature. Databases

were searched from inception to 15.01.2023 using search strings: psychos?s OR psychotic OR schizophreni* AND 'help-seek*' OR 'help seek*' OR 'support seek*' OR 'support-seek*' OR 'service engagement' OR seek* N1 (service OR intervention OR referral). We also hand-searched the reference lists and citations of previous relevant reviews (Doyle et al., 2014; Kreyenbuhl et al., 2009; Smolak et al., 2012; Sood et al., 2022) and all eligible articles.

While service engagement arguably constitutes both a particular form of professional help-seeking and a broader concept (including collaboration and adherence to treatments), we included both in our search following scoping searches which indicated that 'service engagement' is associated with an important body of research within the wider psychosis help-seeking literature.

Inclusion and exclusion criteria

Studies were included if they met the following criteria: (1) quantitative methodology, (2) published in English, (3) included people aged 14 years and above,[1] (4) examined associations between clinical psychosis diagnoses (as defined by DSM or ICD) or psychotic-type experiences, and help-seeking/service engagement, (5) referred to help-seeking as professional and/or non-professional support-seeking, and service engagement as availability for appointments, collaborative responsibility for the management of difficulties, help-seeking, and adherence to treatment (following Tait et al., 2002), (6) measured and/or screened for psychosis/schizophrenia/psychotic-type experience, (7) measured and/or assessed help-seeking/service engagement.

Exclusion criteria were: (1) studies that used qualitative methods only, (2) books, book reviews, book chapters, conference extracts, case reports and systematic reviews, (3) studies that did not examine the relationship between psychosis/psychotic-type experience and help-seeking/service engagement.

Screening and data extraction

The initial search yielded 1572 articles after screening for language, source and participant age. We used Zotero reference manager and established eligibility through (1) title and abstract search and (2) full text article search (see Figure 1). Data were extracted by the first author. Any queries (~10 papers) were discussed within the research team to reach agreement. This included a decision to include three papers with a minority of participants under 14 years (see Demographic characteristics, below).

Quality assessment

We used the Effective Public Health Practice Project tool, guide and dictionary (EPHPP; Thomas et al., 2004). The EPHPP has good content and construct validity (Thomas et al., 2004) and inter-rater reliability (Armijo-Olivo et al., 2012). The tool assesses quantitative studies in six domains: (1) selection bias, (2) study design, (3) confounders, (4) blinding, (5) data collection methods (reliability and validity) and (6) withdrawal and dropouts. Studies are classified as: (1) strong (S; no weak rating), (2) moderate (M; one weak rating) and (3) weak (W; two or more weak ratings).

Quality assessments were completed by the first author and an independent rater with excellent agreement ($k = 0.906$, 95% CI, 0.83–0.97, $p < .001$) (Cohen, 1960; Landis & Koch, 1977).

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[1]This is the age from which UK early intervention for psychosis services accept referrals.

Identification

Records identified through search
(n = 2,155)
(PsycInfo 1,091; PsycArticles 26; Medline 1,009; Ethos 29)

Excluded: books, conference extracts, non-English language studies, and studies with participants 13 years and younger (children)
(n = 1,572)

Screening

Records after duplicates removed
(n = 1,021)

Records screened
(n = 1,021)

Records excluded after title and abstract screen
(n = 922)

Eligibility

Full-text articles assessed for eligibility
(n = 99)

Records excluded after full-text screen
(n = 80)

Not psychosis or non-clinical sample/ no psychosis screen or measure (n = 42)
No help-seeking/service engagement measure (n = 17)
No examination of psychosis/help-seeking (n =11)
Qualitative study (n = 6)
Literature review (n = 3)
Secondary analysis of previously published data (n=1)

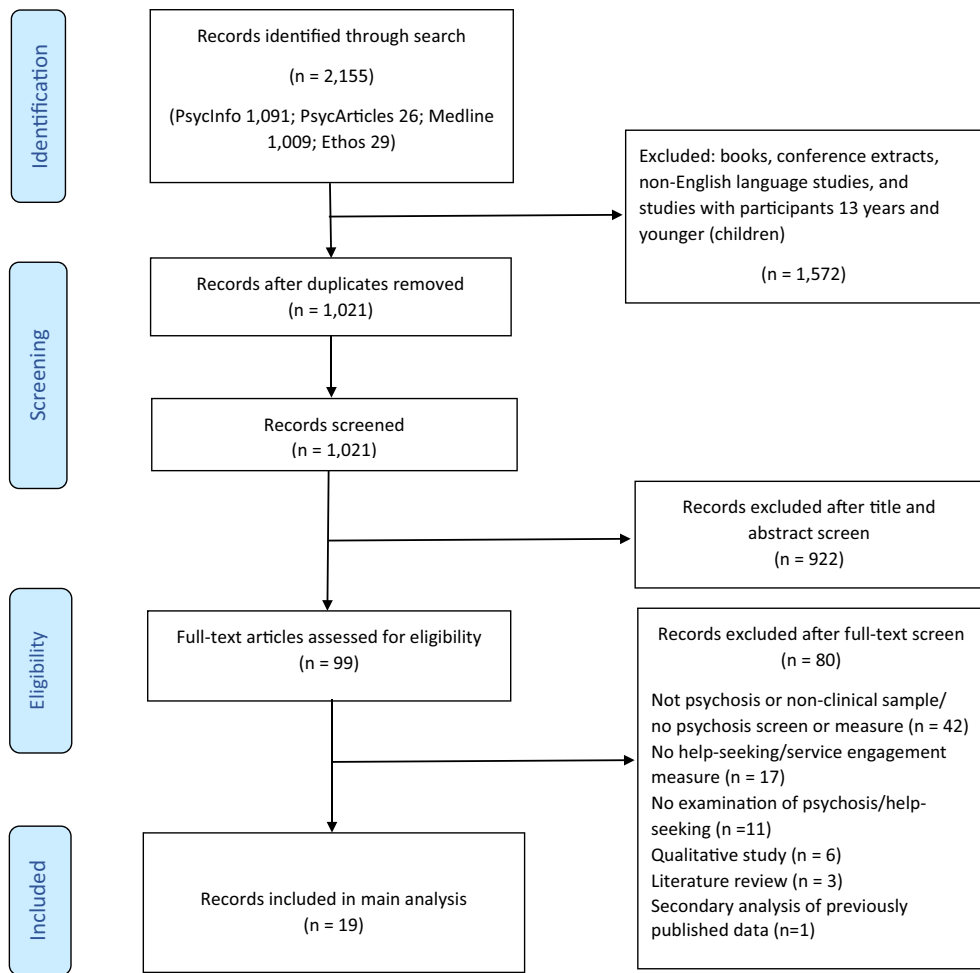**Included**

Records included in main analysis
(n = 19)

FIGURE 1 PRISMA paper selection flow diagram.

RESULTS

Nineteen studies met inclusion criteria (see Table 1). The majority were cross-sectional ($n = 16$) and three were longitudinal in design. Studies were conducted in the United Kingdom ($n = 4$), Switzerland ($n = 4$), Canada ($n = 2$), China ($n = 2$), the United States of America ($n = 1$), Italy ($n = 1$), India ($n = 1$), Norway ($n = 1$), Germany ($n = 1$), Egypt ($n = 1$) and Turkey ($n = 1$). All were published between 2002 and 2022 indicating an increased and international interest in the field over the last two decades. Heterogeneity of help-seeking measures precluded a meta-analysis and so we completed a narrative synthesis.

Demographic characteristics

The 19 studies included 9686 participants, of whom 51% were female ($n = 4945$) and 49% were male ($n = 4741$). Fourteen studies recruited clinical samples ($n = 1979$; 19.4%) and five subclinical samples ($n = 7707$; 75.7%). The most common diagnosis among clinical participants was schizophrenia ($n = 1669$; 84.3%), followed by others including schizoaffective disorder and first episode psychosis. Three studies included participants aged 13 and above (Ibrahim Awaad et al., 2020; Rüsch et al., 2013; Xu et al., 2015)

TABLE 1 Study characteristics.

Authors, date location	Study design	Study population	Sample characteristics	Measures-psychosis	Measures-help-seeking/service engagement	Key findings
Addington et al., 2002 Canada	Cross Sectional	Adults with first episode psychosis who had completed the Calgary Early Psychosis Program (EPP) and 1-year follow-up assessment	Clinical sample (N = 86) Male n = 57 Female n = 29 Mean age = 24	Instrument for Retrospective Assessment of the Onset of Schizophrenia (IRAOS); Positive and Negative Syndrome Scale (PANSS); Scale for the Assessment of Prodromal Symptoms (SOPS); DSM-IV diagnosis	Participants and family members interviewed about symptoms and help sought	38% decided to seek help in the pre-onset period. 75% reported being concerned about their behaviours but not willing to seek help. After onset of psychosis, most frequent sources of help that led to successful treatments were emergency services (52%), family physicians (18%), psychiatrists (18%) psychologists (8%) and family and friends (4%). People who contacted healthcare services were participants' relatives (44%), participants themselves (25%), health care professionals (20%), and friends, teachers, and the police (11%).
Degnan et al., 2022 United Kingdom	Cross Sectional	Black African and Caribbean adults diagnosed with non-affective psychosis, receiving treatment from the UK NHS	Clinical sample (N = 51) Male n = 36 Female n = 15 Mean age = 42.38	PANSS	Service Engagement Scale (SES)	Severity of psychotic symptoms was associated with poorer staff-reported engagement. Network ethnic homophily (more ethnically similar social network) associated with better engagement ($F[1, 44] = 12.95$, $p = .001$, $R^2 = .23$), and racial/ethnic discrimination associated with poorer service engagement ($F[1, 47] = 5.45$, $p = .024$, $R^2 = .10$).

(Continues)

TABLE 1 (Continued)

Authors, date location	Study design	Study population	Sample characteristics	Measures-psychosis	Measures-help-seeking/service engagement	Key findings
Del Vecchio et al., 2015 Italy	Cross Sectional	Adults with first episode non-affective psychosis, recruited via psychiatric outpatient unit	Clinical sample $N = 32$ Male $n = 22$ Female $n = 10$ Mean age = 26	Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I); Brief Psychiatric Rating Scale (BPRS)	Pathways to Care Form (PCF); Family Involvement in Pathways to Care Schedule (FIPS)	Time between onset of psychotic symptoms and initial help-seeking with a health professional was 17.6 (±45.0) weeks. People first approached: psychiatrist (30%); GP (38%), neurologist (21%) and psychologist (11%). 76% of relatives sought medical help. Reasons why family did not seek help included: beliefs that problems were not permanent or associated with stress or substance abuse, stigma, and doubts about effectiveness of psychiatric treatments.
Fridgen et al., 2013 Switzerland	Cross-Sectional	Adults with ARMS (at-risk mental state for psychosis), FE (first episode psychosis), and of no risk for psychosis	Subclinical sample $N = 98$ ARMS: Male $n = 36$ Female $n = 25$ Mean age = 26.8 FE: Male $n = 25$ Female $n = 12$ Mean age = 31	Basel Screening Instrument for Psychosis (BSIP)	Basel Interview for Psychosis (BIP) (developed for study)	Reasons for help-seeking; self-perceived changes in well-being, suicidal attempts, self-harming, and crisis in the family/household. 94.1% of FE participants and 81.4% of the ARMS had sought help at least once before arriving at the clinic. Women sought help more frequently than men (Mann–Whitney U: 609.0; $p \leq .001$). ARMS and FE participants asked for support the most commonly from: family, close friend, GP or psychiatrist.

TABLE 1 (Continued)

Authors, date location	Study design	Study population	Sample characteristics	Measures-psychosis	Measures-help-seeking/service engagement	Key findings
Hu et al., 2021 China	Cross-Sectional	Children and adults with schizophrenia diagnosis (sub-group of epidemiological survey of mental health conditions)	Clinical sample $N = 367$ Male $n = 180$ Female $n = 187$ Age $> =15$	SCID-I	Questionnaire developed for the study e.g., sources of help, reasons for not seeking help	68.9% of participants sought help and 31.1% did not. Main reasons for not seeking help included: fear of stigmatisation and discrimination (72.9%), lack of mental health knowledge (64.5%), and treatment costs (50.6%). Higher level of education was associated with more positive help-seeking attitudes ($\chi^2 = 6.621, p = .010; \chi^2 = 12.821, p = .005$). Main sources of help were psychiatric services (64.6%) followed by non-medical options (e.g. traditional and/or faith healers; 30.8%).
Ibrahim Awaad et al., 2020 Egypt	Cross-Sectional	Adults with schizophrenia diagnosis recruited via psychiatric inpatient or outpatient unit	Clinical sample $N = 232$ Male $n = 192$ Female $n = 40$ Mean age= 34.08	SCID-I	Questionnaire developed for the study e.g., past help-seeking, frequency of accessing sources of help	58.19% of participants initially contacted psychiatrists and 41,8% of participants initially contacted traditional healers. Reasons for contacting healers included: belief that possessed by Jinn (21.55%), belief in black magic (12.7%), struggling due to envy (8.19%), social acceptability of contacting healers (30.39%), affordability (24.74%), and access (16.49%). Main psychotic symptoms brought to traditional healers were hallucinations (51.55%), delusions (29.9%), and unusual behaviour (9.28%). 60.58% of family members advised patients to seek help from traditional healers.

TABLE 1 (Continued)

Authors, date location	Study design	Study population	Sample characteristics	Measures-psychosis	Measures-help-seeking/service engagement	Key findings
Jilani et al., 2018 India	Cross- Sectional	Children and adults (16–45years) with first episode psychosis recruited via psychiatric outpatient unit	Clinical sample $N=151$ Male $n=122$ Female $n=29$ Mean age $=27.19$	PANNS Diagnosis following International Classification of Diseases, 10 Revision (ICD-10)	Questionnaire developed for the study e.g., reasons for and delay in help-seeking.	Most frequent sources of help included: faith healers (60.3%), local practitioners (20.5%), mental health professionals (13.3%), GP (6.1%). Faith healers were identified as the most popular source of help.
Johansen et al., 2011 Norway	Cross- Sectional	Adults with first-episode schizophrenia spectrum psychosis recruited via psychiatric outpatient unit	Clinical sample $N=148$ Male $n=84$ Female $n=64$ Mean age $=35$	PANSS Diagnosis following DSM-IV	SES	Clinical psychotic symptoms correlated with lower engagement. Positive symptoms predicted lower service engagement and excitative and negative symptoms showed a trend-level contribution.
Judge et al., 2005 USA	Cross- Sectional	Individuals with schizophrenia or schizoaffective disorder diagnosis recruited via psychiatric treatment programme (age range not specified)	Clinical sample $N=20$ Male $n=15$ Female $n=5$ Mean age $=19.8$	Schizophrenia Onset Symptom (SOS) Inventory Diagnosis following DSM-IV	Pathways to Care developed for study e.g., source of help, reasons for seeking/ not seeking help	Participants made less successful help-seeking attempts ($n=4$) than their relatives ($n=16$). Mean time from onset of symptoms to participants recognising changes in presentation was 7.8months (SD $=8.5$). A further 14.4months (SD $=16.9$) to start treatment. Mean DUP was 19.2months (SD $=17.8$). Main help-seeking barriers included: difficulty in recognising active symptoms and seriousness, lack of awareness of where to seek help, financial constraints (insurance or transport).

TABLE 1 (Continued)

Authors, date location	Study design	Study population	Sample characteristics	Measures-psychosis	Measures-help-seeking/service engagement	Key findings
Lecomte et al., 2008 Canada	Cross-Sectional	Adults with early psychosis recruited via early intervention programme	Clinical sample $N = 118$ Male $n = 72$ Female $n = 46$ Mean age = 25	Brief Psychiatric Rating Scale – Expanded version	SES	Men presented with lower service engagement than women (χ^2 (1) $= 3.61, p < .05, N = 112$). Childhood physical abuse predicted poor service engagement ($\beta = 0.34, p < .001$), accounting for 12% of the variance. High neuroticism ($\beta = -0.19, p < .01$) and low agreeableness ($\beta = 0.25, p < .01$) predicted higher service engagement level; accounting for 31% of the variance.
Murphy et al., 2010 United Kingdom	Cross-Sectional	Adults with self-reported psychosis recruited via general population Adult Psychiatric Morbidity Survey (APMS)	Subclinical sample $N = 7266$ Male $n = 3159$ Female $n = 4107$ Mean age = 51.12	Psychosis Screening Questionnaire (PSQ)	Questionnaire developed for the study e.g., engagement with GP and therapy	Women attended GP appointments more frequently than men for emotional ($v^2 = 94.02, df = 1, p < .001$) and physical problems ($v^2 = 23.62, df = 1, p < .00$), and were more willing to seek therapy ($v^2 = 3.83, df = 1, p = .03$). Thought control, paranoia, and strange experiences associated with increased GP attendance. Experiencing two and more symptoms predicted greater help-seeking from GPs, and three or more symptoms predicted greater intention to seek therapy.

(Continues)

TABLE 1 (Continued)

Authors, date location	Study design	Study population	Sample characteristics	Measures-psychosis	Measures-help-seeking/service engagement	Key findings
Platz et al., 2006 Switzerland	Cross-Sectional	Children and adults at-risk for psychosis recruited via psychiatric unit: First Episode (FE), At-Risk (AR), and control group	Subclinical sample $N=104$ Male $n=76$ Female $n=28$ Mean age = 23.2 Age >=14	Scale of Prodromal Symptoms (SOPS); Schizophrenia Prediction Instrument—Adult Version (SPI-A); PANSS	Questionnaire developed for the study e.g., sources of help, number of contacts, symptoms leading to help-seeking attempts	Mean contacts: 2.38 (SD: ±1.42; median: 3; range: 1–8), no between-group differences ($x^2 = 208.375$, $df=2$, $p=.605$). FE contacted mental health professionals more often than other groups ($x^2 = 4.461$, $df=1$, $p=.024$). Main sources of help included: mental health professionals (60.3%), non-mental health professionals (39.7%). 83.7% visited at least once a mental health professional. 89% FE, 65% AR and 8% of control group patients reported positive symptoms at any stage of help-seeking pathway ($x^2 = 35.483$, $df=2$, $p<.001$).
Rüsch et al., 2013 Switzerland	Cross-Sectional	Children and young people at high-risk for psychosis (aged 13–35) recruited via wider research project	Subclinical sample $N=172$ Male $n=101$ Female $n=71$ Mean age = 21.37	PANSS	Two item questionnaire developed for the study: willingness to take psychiatric medication and use psychotherapy	Attitudes towards therapy more positive than for medication ($t=10.03$, $p<.001$). Higher self-labelling and lower stigma stress independently predicted more positive attitudes towards medication. Lower stigma stress, negative psychotic symptoms, female gender, higher age, anxiety disorder diagnosis and higher self-labelling predicted more positive attitudes to therapy ($R^2=0.213$).

TABLE 1 (Continued)

Authors, date location	Study design	Study population	Sample characteristics	Measures-psychosis	Measures-help-seeking/service engagement	Key findings
Schultze-Lutter et al., 2015 Germany	Cross-Sectional	Children and young people with first episode psychosis recruited via wider research project	Clinical sample $N = 126$ Male $n = 74$ Female $n = 52$ Mean age = 30.1	Early Recognition Instrument based on the Instrument for the Retrospective Assessment of the Onset of Schizophrenia (ERIraos)	Pathways to Care	95.2% of participants sought help before first inpatient treatment, and just 23.0% before onset of the first positive symptom ($x^2_{(1)} = 36.698$, $p < .001$). Chosen sources of help included: mental health professionals (54.0%), GPs (16.7%) and semi-professionals (13.5%). Child-onset group (<18 years) reported more self-initiated help-seeking attempts before first positive symptom. Adult-onset group were more likely to seek help after experiencing first psychotic symptom.
Tait et al., 2003 United Kingdom	Longitudinal	Individuals with schizophrenia diagnosis receiving treatment for acute psychosis (age range not specified)	Clinical sample $N = 50$ Male $n = 31$ Female $n = 19$ Mean age = 33.8	PANSS Diagnosis following ICD-10	SES	Higher service engagement in integration (responsive) recovery style group compared with sealing-over (avoidant) recovery style group. Differences between groups for total SES ($F(3,31) = 8.04$, $p < .001$, $n^2 = 0.44$). Positive and negative symptoms scores at 3 months did not correlate with service engagement at 6 months and follow-up.
Tait et al., 2004 United Kingdom	Longitudinal	Individuals with schizophrenia diagnosis receiving treatment for acute psychosis (age range not specified)	Clinical sample $N = 50$ Male $n = 31$ Female $n = 19$ Mean age = 33.8	PANSS Diagnosis following ICD-10	SES	Insecurely attached participants showed lower levels of service engagement ($M = 23.72$, $SD = 10.74$) compared with securely attached participants ($M = 10.07$, $SD = 10.20$): $t = 3.64$, $p < .001$, $n^2 = 0.31$.

(Continues)

TABLE 1 (Continued)

Authors, date location	Study design	Study population	Sample characteristics	Measures-psychosis	Measures-help-seeking/service engagement	Key findings
Tang et al., 2007 China	Cross-Sectional	Children and adults with schizophrenia diagnosis recruited via psychiatric inpatient unit (81.2% of participants aged 15–40)	Clinical sample; ($n = 202$); Male ($n = 98$), Female ($n = 104$); Mean age = 30.9	A questionnaire developed for the purpose of the study to access presenting symptoms, onset and duration. Diagnosis following ICD-10	Questionnaire developed for the study e.g., help-seeking process and treatment facilities used	59.4% of patients sought help from non-psychiatric source, and 40.6% from psychiatric hospital. Non-psychiatric help was obtained from: traditional Chinese medicine (32.7%), general hospitals (31.7%), using breathing exercise, traditional healing methods, praying (25.7%). Reasons for seeking support from non-psychiatric sources: fear of stigmatisation and feeling ashamed (38.3%); difficulties with hospital accessibility (36.7%); fear of electric shock treatment (26.7%); disbelieve in symptoms seriousness (31.7%); no trust in psychiatrists/ their treatment (16.6%); treatment costs (15.8%).
Xu et al., 2015 Switzerland	Longitudinal	Children and young people (aged 13–35) at high risk of psychosis recruited via early intervention programme	Subclinical sample, at baseline ($n = 172$), 1-year follow up ($n = 67$) Male ($n = 38$); Female ($n = 29$); Mean age = 19.96	PANSS	Two item questionnaire developed for the study: willingness to take psychiatric medication and use psychotherapy	After a year, positive attitudes towards psychiatric medication were predicted by fewer negative symptoms and more self-labelling. A higher level of perceived stigma, stigma stress and positive psychotic symptoms resulted in more negative attitudes towards psychotherapy after 1 year. Females presented with more positive attitudes towards psychotherapy after a year than men.

TABLE 1 (Continued)

Authors, date location	Study design	Study population	Sample characteristics	Measures-psychosis	Measures-help-seeking/service engagement	Key findings
Yazici et al., 2016 Turkey	Cross-Sectional	Adults with schizophrenia diagnosis recruited via psychiatric inpatient or outpatient unit	Clinical sample $N = 346$ Male $n = 236$ Female $n = 110$ Mean age = 39.52	SCID-I	Questionnaire developed for the study e.g., access to traditional and medical treatments	89.3% of participants sought help from traditional/religious healers. Traditional healers were visited 6.54 ± 7.0 times (range 1–45). Relatives of participants who did not contact traditional healers had a higher level of education than relatives of participants who dis (9.30 ± 4.07 and 5.80 ± 3.71 respectively; $p < .05$).

– these were included as the majority of participants did meet our inclusion criteria ($> = 14$ years), as indicated by reported mean ages of 20–34 years. The remaining 16 studies reported sample ages ranging from 14 to 69 years. Five reported participants' ethnicity; of these, 51% identified as White, 21% Chinese, 11% Hispanic, 10% Black and 6% Asian.

Measures

Psychosis/schizophrenia

Ten different assessments were used across the 19 studies. The Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987) was used in nine studies as a measure of positive (e.g. delusions and hallucinations) and negative (e.g. emotional or social withdrawal) symptoms of schizophrenia and general psychopathology (Addington et al., 2002; Degnan et al., 2022; Jilani et al., 2018; Johansen et al., 2011; Platz et al., 2006; Rüsch et al., 2013; Tait et al., 2003, 2004; Xu et al., 2015). Eleven studies used either the Structured Clinical Interview for DSM-IV Axis I Disorder (SCID-I) or ICD-10 to assess or confirm diagnoses, usually in addition to other measures (Addington et al., 2002; Del Vecchio et al., 2015; Hu et al., 2021; Ibrahim Awaad et al., 2020; Jilani et al., 2018; Johansen et al., 2011; Judge et al., 2005; Tait et al., 2003, 2004; Tang et al., 2007; Yazici et al., 2016). Another seven scales were each used by one or two studies (see Table 1).

Help-seeking

All but one study (Fridgen et al., 2013) that assessed self-reported help-seeking behaviour used non-standardised measures. Eight included a series of questions about sources of help (e.g. family, medical or mental health practitioner, traditional healer), types of treatment (e.g. medication, psychotherapy), reasons for seeking or not seeking help and frequency of contact (Addington et al., 2002; Hu et al., 2021; Ibrahim Awaad et al., 2020; Jilani et al., 2018; Murphy et al., 2010; Platz et al., 2006; Tang et al., 2007; Yazici et al., 2016). Two studies used a two-item scale assessing willingness to accept medication and psychotherapy (Rüsch et al., 2013; Xu et al., 2015). Three studies used a 'Pathways to Care' measure of initial help-seeking for mental health problems and/or reasons for not seeking help (Del Vecchio et al., 2015; Judge et al., 2005; Schultze-Lutter et al., 2015), and one used a linked 'Family Involvement in Pathways to Care Schedule' of family influences in help-seeking (Del Vecchio et al., 2015). Fridgen et al. (2013) used the help-seeking subscale of the Basel Interview for Psychosis (Riecher-Rössler et al., 2015).

Service engagement

All five studies that assessed service engagement used the clinician rated Service Engagement Scale (Tait et al., 2002) indicating consensus in this area (Degnan et al., 2022; Johansen et al., 2011; Lecomte et al., 2008; Tait et al., 2003, 2004).

Quality assessment

Table 2 shows quality assessment ratings for all included studies. All but two were of weak quality. Most were rated as having a moderate selection bias due to recruiting participants opportunistically from hospitals, mental health services, etc. (arguably a high bar for clinical studies).

Most studies were cross-sectional ($n = 16$) and three were longitudinal (Tait et al., 2003, 2004; Xu et al., 2015). As noted above, most ($n = 13$) used unvalidated measures of help-seeking. Just five studies

TABLE 2 Quality assessment ratings.

Study	Selection bias	Study design	Confounders	Blinding	Data collection	Withdrawals and dropouts	Overall rating
Addington et al., 2002; Canada	M	W	W	W	M	M	W
Degnan et al., 2022; United Kingdom	M	W	S	W	S	N/A	W
Del Vecchio et al., 2015; Italy	M	W	W	W	W	N/A	W
Fridgen et al., 2013; Switzerland	W	W	W	W	M	N/A	W
Hu et al., 2021; China	M	W	W	W	W	N/A	W
Ibrahim Awaad et al., 2020; Egypt	M	W	W	W	W	N/A	W
Jilani et al., 2018; India	M	W	W	W	W	N/A	W
Johansen et al., 2011; Norway	M	W	W	W	S	N/A	W
Judge et al., 2005; USA	M	W	W	W	W	N/A	W
Lecomte et al., 2008 Canada	M	W	M	W	S	N/A	W
Murphy et al., 2010; United Kingdom	W	W	W	W	W	N/A	W
Platz et al., 2006; Switzerland	M	W	W	W	W	N/A	W
Rüsch et al., 2013; Switzerland	M	W	M	W	M	N/A	W
Schultze-Lutter et al., 2015; Germany	M	W	W	W	W	N/A	W
Tait et al., 2003; United Kingdom	M	M	M	W	S	S	M
Tait et al., 2004; United Kingdom	M	M	M	W	S	S	M
Tang et al., 2007; China	M	W	W	W	W	N/A	W
Xu et al., 2015; Switzerland	W	M	W	W	M	W	W
Yazici et al., 2016; Turkey	M	W	W	W	W	N/A	W

Abbreviations: M, Moderate; S, Strong; W, Weak.

controlled for confounders, for example, age and gender (Degnan et al., 2022; Lecomte et al., 2008; Rüsch et al., 2013; Tait et al., 2003, 2004).

Synthesis of evidence examining help-seeking in psychosis

Self-reported help-seeking

Fourteen studies investigated when people sought help, from whom, and linked facilitators and barriers (Addington et al., 2002; Del Vecchio et al., 2015; Fridgen et al., 2013; Hu et al., 2021; Ibrahim Awaad et al., 2020; Jilani et al., 2018; Judge et al., 2005; Murphy et al., 2010; Platz et al., 2006; Rüsch et al., 2013; Schultze-Lutter et al., 2015; Tang et al., 2007; Xu et al., 2015; Yazici et al., 2016).

When do people seek help?
Six studies found that people typically do not seek help in the prodromal period but do so following the onset of positive symptoms such as voices (Ibrahim Awaad et al., 2020; Johansen et al., 2011; Judge et al., 2005; Murphy et al., 2010; Platz et al., 2006; Schultze-Lutter et al., 2015). The time between onset of prodromal symptoms to recognising changes in cognition and behaviour is approximately 4.5– 7.8 months (Del Vecchio et al., 2015; Judge et al., 2005), followed by a further 14.4 months before people access appropriate treatment (Judge et al., 2005). One study distinguished childhood- (< 18 years) and adult-onset psychosis (> = 18 years), and found that the former were more likely to recognise prodromal symptoms and seek help over this period, identifying a potentially valuable window of opportunity for early detection and treatment (Schultze-Lutter et al., 2015).

Who do people seek help from?
Eleven studies investigated targets of help-seeking and found that people typically first seek help from psychiatrists and psychiatric hospitals, followed by traditional healers, GPs, other mental health professionals, and lastly family and friends (Addington et al., 2002; Del Vecchio et al., 2015; Fridgen et al., 2013; Hu et al., 2021; Ibrahim Awaad et al., 2020; Jilani et al., 2018; Murphy et al., 2010; Platz et al., 2006; Schultze-Lutter et al., 2015; Tang et al., 2007; Yazici et al., 2016). Preferred sources of support are often culturally determined (see below).

Facilitators and barriers to help-seeking
Six studies explored reasons for seeking/not seeking help. Factors contributing to professional help-seeking include: having more than one positive and/or negative psychotic symptom (Fridgen et al., 2013; Murphy et al., 2010; Rüsch et al., 2013); higher level of education (Hu et al., 2021); and lower stigma stress[2] and stronger self-labelling[3] (Rüsch et al., 2013; Xu et al., 2015). Five studies examined the impact of gender and showed that women are more likely to seek help and do so earlier than men (Fridgen et al., 2013; Lecomte et al., 2008; Murphy et al., 2010; Rüsch et al., 2013; Xu et al., 2015). Factors contributing to non-professional help-seeking include: social acceptability, accessibility and affordability of non-professionals; distrust, shame and stigma associated with psychiatric treatment; positive psychotic symptoms (hallucinations and/or delusions); and a belief that symptoms are not serious (Ibrahim Awaad et al., 2020; Tang et al., 2007). Barriers to help-seeking include: higher levels of perceived stigma and discrimination (Hu et al., 2021; Xu et al., 2015); lack of mental-health literacy and knowledge about services; and financial constraints (including the transport and insurance costs) (Hu et al., 2021; Judge et al., 2005).

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[2]Stigma stress: the impact of a belief that harm related to stigma is greater than resources to deal with the threat.
[3]Self-labelling: awareness of having a mental health problem.

Informant-reported help-seeking (service engagement)

Eight studies examined informant-reported help-seeking in clinical populations. Five explored service engagement as reported by clinicians (Degnan et al., 2022; Johansen et al., 2011; Lecomte et al., 2008; Tait et al., 2003, 2004), and three investigated family members' accounts (Addington et al., 2002; Del Vecchio et al., 2015; Judge et al., 2005).

Clinician-reported help-seeking
Having more severe symptoms (typically assessed using the PANSS) is associated with higher levels of service disengagement (Degnan et al., 2022; Johansen et al., 2011; Lecomte et al., 2008). Lecomte et al. (2008) also found that childhood physical abuse was associated with poorer engagement, while knowledge about rights and certain personality traits (i.e. high neuroticism and low agreeableness) predicted better service engagement. Tait et al. (2003, 2004) examined the impact of attachment style and interpersonal responses to psychosis, and showed that people with an insecure attachment and/or 'sealing over' (avoidant) recovery style were less likely to seek support and more likely to disengage from services, compared with those with a secure attachment style and/or 'integrative' (responsive to and interested in the psychotic experience) recovery style. Interestingly, psychotic symptoms did not predict service engagement at 3- and 6-month follow-up (Tait et al., 2003), suggesting that other factors are more predictive of sustained engagement.

Family-reported help-seeking
Family members often make successful help-seeking attempts on behalf of the person with psychosis – from 44% to 80% of initial help-seeking contacts are made by relatives (Addington et al., 2002; Del Vecchio et al., 2015; Judge et al., 2005). Family members' reasons for not seeking help include beliefs that problems are temporary and due to substance misuse or stress, and stigma associated with mental ill-health and linked services (Del Vecchio et al., 2015).

Cultural aspects of help-seeking in psychosis

Five studies were completed in Asia and Africa (Hu et al., 2021; Ibrahim Awaad et al., 2020; Jilani et al., 2018; Tang et al., 2007; Yazici et al., 2016), and the remaining 15 in North America and Europe. The five studies completed in Asia and Africa showed that approximately half of the participants initially sought help from traditional/faith healers. Social acceptance, affordability and beliefs that problems were related to black magic or Jinn[4] possession were the most common reasons for choosing non-professional sources of help.

Six (less than half) of studies completed in Western-culture countries investigated sources of professional and non-professional help (Addington et al., 2002; Del Vecchio et al., 2015; Fridgen et al., 2013; Murphy et al., 2010; Platz et al., 2006; Schultze-Lutter et al., 2015). Of these, none included traditional healers and just three included religious leaders (e.g. priest or clergy) as sources of non-professional support (Addington et al., 2002; Fridgen et al., 2013; Schultze-Lutter et al., 2015).

DISCUSSION

Help-seeking behaviour in psychosis

This is the first systematic review to synthesise the literature examining professional and non-professional help-seeking in people with clinical and subclinical psychosis. We included studies examining self-, clinician- and family-reported help-seeking, and incorporating (the wider concept of) service engagement (Tait et al., 2002) to ensure comprehensive coverage. The search yielded 19 studies conducted

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[4]Jinns are spirits in Arabian and Muslim cultures who appear in the form of a human or animal and possess a person.

in 11 countries across Europe, North America, Africa and Asia. Importantly, all but two longitudinal studies (Tait et al., 2003, 2004) received weak overall quality assessment ratings, typically due to cross-sectional designs and use of unvalidated measures of help-seeking. We recommend that the findings be interpreted with caution for this reason, while noting the high bar set by the quality assessment tool.

We found that people typically start seeking help after the onset of positive psychotic symptoms, though the prodromal period in childhood-onset psychosis, when people both recognise changes and seek help, may present a window of opportunity for targeted interventions. More commonly, it takes several months (~eight) for people to recognise changes and over another year (~14 months) to access recommended treatments.

There are clear cultural differences in preferred sources of help; professional help (e.g. from mental health services and practitioners) is the most investigated and reported source of support in Western-culture countries, while non-professional help (including traditional/faith healers) is commonly sought in African and Asian countries. This is consistent with a previous review (Smolak et al., 2012) and the wider literature indicating that the people living in collectivistic cultures are less likely to seek professional help for mental health problems compared with individualistic societies (Markus & Kitayama, 1991; Mojaverian et al., 2013).

Facilitators and barriers to help-seeking overlap with those identified in a recent review of access to early intervention services (Tiller et al., 2023), adding further evidence for the role of (not) help-seeking in DUP. Self-reported barriers include knowledge (e.g. mental health literacy), relationships (particularly family support) and stigma (cf. Tiller et al., 2023). Clinicians also highlight early adversity, insecure attachment/avoidant coping, and severity of symptoms as barriers to initial help-seeking and/or ongoing service engagement. The role of attachment aligns with previous reviews which show that people with psychosis who are securely attached are more likely to trust others, seek help and engage with services, compared with people who are insecurely (particularly avoidantly) attached (Berry et al., 2007; Sood et al., 2022). Being female, having a higher level of education, and experiencing multiple psychotic symptoms all facilitate help-seeking. Men are less likely to seek help across mental health conditions, in line with traditional gender-based roles (Seidler et al., 2016; Thompson et al., 2016).

Limitations of the current review

Our review is limited by a focus on quantitative research, and an examination of the qualitative literature is needed to triangulate our findings. In the search, we did not use medical subject headings or search term filters. We did not use backwards and forwards citation tracking, or consult with a librarian or subject expert beyond the current authors (cf. McDonald et al., 2018).

Methodological limitations and gaps in the literature

Study design and use of unvalidated measures limit the field. All but three studies were cross-sectional and relied on retrospective accounts, and 17 were quality-assessed as weak. Two of the three longitudinal studies were assessed as of moderate quality, so we can have confidence in the finding that people with an insecure attachment/avoidant recovery style are less likely to seek help for their psychosis (Tait et al., 2003, 2004).

While there is some consensus on measures of psychosis and good consensus for service-engagement, there is no agreement on reliable help-seeking measures, and this precluded a meta-analysis. Furthermore, measures were not standardised for each of the study populations (cf. Aggarwal et al., 2012; Thakker & Ward, 1998), and help-seeking measures used in European and North American studies did not consistently include traditional/faith healers and religious leaders as potential sources of help, which may have affected results if samples included people from non-Westernised communities (noting that ethnicity

and nationality were not consistently reported). A linked question remains about what constitutes professional sources of help in different cultures. Following Tait et al. (2002), we classed traditional/faith healers as non-professionals, and recognise that others would categorise groups differently.

Research, public health and clinical practice implications

Research designs require improvement. Specifically, we need longitudinal and experimental studies to test causality, using reliable and culturally sensitive measures, and controlling for potential confounders. Research examining decision making and help-seeking in people with psychosis and an insecure attachment style would be valuable, as this group is particularly vulnerable to failing to seek help, extended DUP, and worse health outcomes (cf. Boonstra et al., 2012).

The field is limited by a lack of validated help-seeking measures and over-reliance on idiosyncratic scales. We summarise the measures identified in the current search and two others used to assess help-seeking in psychosis (see Table 3).[5] Interview schedules can inform clinical assessments (e.g. the help-seeking subscale of the BIP; Riecher-Rössler et al., 2015). Brief self-report measures are needed for research and monitoring of clinical interventions (e.g. the Help Seeking Measure; Sood et al., 2021). Combining self- and informant-reported measures (e.g. the SES; Tait et al., 2002) enables triangulation of data. Studies and measures that seek to identify *sources* of help should include culturally relevant groups including traditional/faith healers and religious leaders.

This review focused on help-seeking and psychosis in clinical and subclinical populations (rather than analogue samples) to inform public health, service level and clinical practice decisions, to facilitate access to recommended treatments. Mental health education in schools could benefit those with childhood-onset psychosis, and should include details about the nature and course of psychosis (including prodromal symptoms), optimism regarding treatment options, and how and where to seek help (cf. Hu et al., 2021; Judge et al., 2005; Schultze-Lutter et al., 2015). Public health campaigns should target men and family members, as men are less likely to seek help, and family support and involvement improves access to effective treatments. Both school and wider public health campaigns should adopt culturally sensitive and normalising methods to tackle the stigma and perceived discrimination which deter many from seeking help (Hu et al., 2021; Xu et al., 2015; Tiller et al., 2023).

Within clinical services, assertive and culturally sensitive engagement efforts should target people with a history of early adversity, poor mental health literacy, limited social support and more severe psychosis. Assessing attachment style would inform individual therapeutic interactions (cf. Partridge et al., 2022; Sood et al., 2022); attachment-congruent support (e.g. ensuring consistency of contact with people who are anxiously attached, and taking a more assertive engagement approach with people who are avoidantly attached) may improve access to recommended treatments, reduce DUP and enhance clinical outcomes.

Summary and conclusion

This is the first systematic review to examine help-seeking behaviour and psychosis. We identified 19 studies which indicate that people with psychosis usually delay help-seeking and do so only after experiencing multiple symptoms. Help-seeking behaviour is affected by age, gender, culture, attachment/recovery style and education. Barriers include perceived stigma and discrimination, poor mental health literacy, and lack of family involvement.

We need reliable and culturally sensitive measures of help-seeking, and longitudinal and experimental studies to test likely mechanisms. Educational campaigns should raise public awareness of psychosis utilising culturally sensitive and normalising narratives, and give clear information about how to access

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[5]Thanks to an anonymous reviewer who suggested we tabulate help-seeking measures used in psychosis research to inform future studies.

TABLE 3 Help-seeking measures.

	Focus of measure	No. items	Commentary
Idiosyncratic measures designed for a specific study/clinical practice	Variable	Variable	Measures fit purpose of study/clinical practice. No reliability/validity information. Variation precludes comparisons across studies. We recommend researchers move to validated measures.
Two item scale (Rüsch et al. (2013))	Willingness to accept medication/psychotherapy	2	Two-item self-report measure. Brevity valuable in research and clinical practice. No reliability/validity information. Language assumes acceptance of mental illness: *"If I become mentally ill, I would be willing to …"*.
Pathways to Care Form (Perkins et al., 1999)	Factors associated with initial help-seeking decisions	–	Unable to access
Family Involvement in Pathways to Care Schedule	Family influences in help-seeking decisions	–	Unable to access
Basel Interview for Psychosis – help-seeking subscale (Riecher-Rössler et al., 2015)	Sources of initial and subsequent help-seeking	3	Interview-based assessment for people at risk of psychosis. Applicable in research and clinical practice. Currently available in German only. Reliability/validity assessed for some subscales (that lend themselves to these analyses) but not help-seeking subscale.
Service Engagement Scale (SES; Tait et al., 2002)	Engagement with mental health services	14	Validated staff-rated measure of engagement with mental health services. Applicable in research and clinical practice. Consistently used measure of service engagement. Language could be updated as arguably assumes clinicians' opinions are necessarily correct.
Help Seeking Measure (HSM; Sood et al., 2021)	Likelihood of help-seeking when upset/distressed	3	Three-item self-report measure. Applicable in research and clinical practice. Internal consistency good to excellent for state ($\alpha = .89/.93$; Sood et al., 2021) and excellent for trait version ($\alpha = .93$; Skrobinska et al., 2024). Requires further validation.
Help Acceptance Measure (HAM; Skrobinska et al., 2024)	Likelihood of help-acceptance when upset/distressed	4	Four-item self-report measure. Applicable in research and clinical practice. Internal consistency good for state ($\alpha = .86/.88$) and trait versions ($\alpha = .88$). Requires further validation.

support. Mental health services should measure attachment/recovery style and help-seeking intentions at early contact, and use this information to target engagement efforts to ensure access to 'full dose' treatments for everyone with psychosis.

AUTHOR CONTRIBUTIONS

CONFLICT OF INTEREST STATEMENT

None.

DATA AVAILABILITY STATEMENT

Not applicable.

ETHICS STATEMENT

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

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