Disengagement From Early Intervention Services for Psychosis: A Systematic Review

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Objective: Therapeutic benefits associated with early services for psychosis are influenced by the degree to which participants engage in treatment. The main objective of this review was to analyze rates of disengagement in early psychosis services and identify predictors of disengagement in these settings.

Methods: A systematic search for studies published in the 1966–2019 period was conducted in PubMed, Google Scholar, EBSCO, Ovid, and Embase. The Observational Cohort and Cross-Sectional Studies scale was used to assess the methodological quality of reports identified in this search. A revised version of the behavioral model of health service use was employed to evaluate and understand predictors of disengagement (categorized as predisposing, enabling, and need factors) identified in the studies with the highest quality.

Results: Twenty studies met the inclusion criteria. Disengagement rates (12% to 53%) and definitions of disengagement varied widely across these studies. Most did not find a compelling association between predisposing factors (e.g., age) and disengagement. Enabling factors, such as lack of family support and living alone, were consistently found to be related to increased disengagement across studies. Finally, need factors, such as lower medication adherence and higher drug misuse, were associated with higher risk for disengagement.

Conclusions: Enabling and need factors seemed to be the most predictive of disengagement from early psychosis services. Substantial between-study variation in identified predictors of disengagement may be addressed by developing and applying a consensus definition of disengagement in future research.

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Results from a series of well-controlled trials have indicated that early intervention services (EIS) for psychosis that are based on evidence-based psychosocial interventions and medications lead to better short-term outcomes in psychotic symptoms, social functioning, quality of life, and treatment satisfaction than does usual care (1, 2). These therapeutic benefits, however, are influenced by the degree to which participants engage in treatment (3). Engagement in mental health care is a complex phenomenon that encompasses not only attending clinical appointments or remaining in treatment for a certain amount of time but also acceptance of a need for help, a therapeutic alliance between providers and clients, and satisfaction with the help received (3). Of note, there is no consensus in the literature about how to conceptually define "engagement" or "disengagement" in EIS.

EIS are known for their focus on promoting engagement by tailoring interventions according to clients' needs and helping participants achieve these goals (1, 4). Many people receiving these services, however, stop treatment before the time judged appropriate by mental health providers. Although programs vary in treatment length, many have a standard service period of approximately 2 years (5). Hence, individuals who leave before this time may not have received the standard dose of treatment, a point we further discuss below.

A literature review by Doyle and colleagues (6) published in *Psychiatric Sciences* covering studies published up to 2012 reported that the proportion of individuals disengaging

HIGHLIGHTS

- A systematic review examined the rates and predictors of disengagement among individuals attending early intervention services for psychosis.

- Enabling factors (e.g., lack of family support) and need factors (e.g., lower medication adherence) were more predictive of disengagement than were predisposing factors (e.g., age).

- Future research requires the development of a consensus definition of disengagement and the application of prospective designs.

from EIS before 2 years varied from 21% to 40% across studies. The authors identified 10 studies that met the criteria for their review, which produced a wide range (>50) of baseline variables that predicted early disengagement from EIS. Several of these reported associations were inconsistent across studies. For instance, some studies reported that clients living without family were more likely to leave services (7), whereas others found the opposite (8). Further research is needed to understand these mixed findings and to increase our understanding of the types of factors that are most important for disengagement from EIS.

Additionally, other factors that may affect disengagement have not been fully explored, such as how different EIS operate, the kinds of services they provide, and the variations in catchment population served by EIS. The use of a conceptual model of service utilization that includes factors at both the individual and the contextual levels, such as the Andersen's behavioral model of health service use (9, 10), could illuminate the matter by categorizing these factors on the basis of their nature and how modifiable they are. This model identifies predisposing, enabling, and need factors involved in individuals' use of health services (9). Predisposing factors include sociodemographic characteristics, such as age, sex, marital status, educational level, race-ethnicity, employment level, and an individual's social networks, such as presence of family and friends. Enabling factors comprise personal, familial, and neighborhood features that must exist for individuals to use health care services. Family support is an example of an enabling factor that may affect disengagement (10). Enabling factors also consider financing (e.g., health insurance) and characteristics of health services—encompassing, for example, the amount, quality, varieties, locations, structures, and distribution of health services facilities and personnel. Finally, need factors include perceived need for health services (i.e., how people view and experience their own general health, functional state, and illness symptoms) and evaluated need (i.e., professional assessments and objective measurements of patients' health status and need for medical care). This model has been widely used (10), and it is particularly useful to identify intervenable factors that facilitate or impede service utilization in various health care settings.

In this review, our goal was to augment and update the previous work by Doyle et al. (6) by expanding the time frame for including reports (up to 2019), conducting a quality appraisal of the studies meeting inclusion criteria, and employing Andersen's model to evaluate and understand predictors of disengagement. Also, to optimize the validity of our review, we included only studies rated as "high quality" on the basis of the Observational Cohort and Cross-Sectional Studies (OCCS) scale to evaluate methodological characteristics in our examination of predictors of disengagement (11).

This review addressed the following research questions: How has disengagement from EIS been defined and operationalized across studies? What is the quality of the literature on disengagement, and how does this influence our interpretations? What are the predictors of disengagement across high-quality studies? and How can these predictors be conceptualized on the basis of Andersen's model?

METHODS

Search Strategy

We conducted a search of scientific publications in the following databases: PubMed, Google Scholar, EBSCO, Ovid, and Embase. A wide range of keywords in English, Spanish, Portuguese, and French were included. We kept search terms broad to find relevant studies, even when the specific keyword, "disengagement," was not mentioned in the title or abstract. Given the lack of consensus in terminology as noted above, we were interested in any form of disengagement. Accordingly, we included terms such as "disengagement," "engagement," "nonadherence," "dropout," and "discharge" in combination with "psychosis," "early intervention services," "first-episode psychosis," "psychotic disorder," and "schizophrenia." We also manually checked the references of the eligible reports. We searched for articles published from January 1966 to June 2019, including the time frame (2000–2012) previously used by Doyle et al. (6). The terms were also combined for a more precise search and used to identify titles, abstracts, and full texts in the databases noted above.

Articles were included in this review if they reported rates of disengagement (or similar concepts, such as engagement, nonadherence, no therapeutic alliance, and dropout) from EIS; explored predictors of disengagement considered here as predisposing, enabling, and need factors; reported primary data published in peer-reviewed journals; included quantitative or mixed methods; and were written in English, Spanish, Portuguese, or French. We reviewed each report through a sequential process (searching, refining search strategy, examining titles and abstracts, and reviewing full articles). Two reviewers (E.v.d.V., G.M.-A.) independently rated the methodological quality of each report on the OCCS scale. The two reviewers met at the beginning, midpoint, and final stages of the review process to discuss challenges and uncertainties related to study selection. If any disagreements regarding study inclusion arose, the reviewers reached consensus on the final decision.

Three researchers (F.M., E.v.d.V, G.M.-A.) collectively developed a data-charting form and determined which variables needed to be included to answer the research questions. This form was based on the framework set out by Doyle and colleagues (6) and included location of the study, sample and research setting, definition of disengagement, disengagement rates and time, and predictors of disengagement.

Quality Assessment

We used the OCCS scale to evaluate the methodological characteristics of the studies (11). This instrument assesses methodological quality across 14 dimensions (research question, study population, groups recruited from the same

population and uniform eligibility criteria, sample size justification, exposure assessed before outcome measurement, sufficient time frame to observe an effect, different levels of the exposure of interest, exposure measures and assessment, repeated-exposure assessment, outcome measures, blinding of outcome assessors, follow-up rate, and statistical analyses), and has been used in previous systematic reviews of cohort and cross-sectional studies (12, 13). The reviewers of study quality (F.M., E.v.d.V, G.M.-A.) could select "yes," "no," or "cannot determine/not reported/not applicable" in response to each item on the quality assessment tool.

On the basis of the sum of items on the quality assessment tool, each study received a high-, medium-, or low-quality rating. Generally, a study rated as high quality had the least risk of bias, and its results were considered to be valid. A study rated as medium quality was susceptible to some bias deemed not sufficient to invalidate its results, and a low rating indicated significant risk of bias.

After the two independent raters (E.v.d.V. and G.M.-A.) rated each selected paper, a third independent rater (A.R.H.) calculated the kappa interobserver agreement for the National Institutes of Health tool (intraclass correlation=0.7) in Stata 12. All three raters then had a series of meetings to resolve disagreements by rereading the studies and further discussing the studies' methodological features, results, and implications.

RESULTS

A systematic search of the five databases yielded 18,276 hits, and 1,524 additional records were identified through other sources. We reviewed 125 abstracts, of which we excluded 105, yielding 65 full articles for further vetting. Of these 65 articles, 45 were excluded, mainly because they were not conducted in EIS settings or did not report disengagement predictors. The final review included 20 articles that met the selection criteria (7, 8, 14–32) (a flow diagram of the selection process is included in an online supplement to this review).

Table 1 presents descriptive characteristics of the 20 studies. Most articles (N=15) reported results from cohort studies based on clinical and social records at EIS. The remaining reports included two cross-sectional studies, one cluster randomized controlled trial, one case-control study, one cross-sectional cohort study, and a mixed-methods study. Only one study tested the efficacy of the EIS model versus treatment as usual (i.e., the Recovery After an Initial Schizophrenia Episode–Early Treatment Program [RAISE-ETP] study [24]), whereas the others included non-randomized, clinical samples. All articles came from EIS in high-income countries, indicating that this kind of service is scarce in less-resourced settings. Of the 20 studies, 13 (60%) met criteria for high quality (7, 8, 14–16, 18–24, 26), six (35%) for medium quality (17, 25, 27–30), and one (5%) for low quality (31).

Methodological Characteristics

Study populations varied notably in terms of their demographic features, with sample sizes ranging between 21 and 786 participants, ages between 14 and 64 years, and the proportion of females between 22% and 53%. All studies featured individuals with first- or second-episode psychosis attending a variety of EIS programs, but the studies slightly differed in inclusion criteria, with one study not reporting any inclusion criteria. Studies were conducted in North America (N=7), Europe (N=4), Asia (N=4), Australia (N=3), and New Zealand (N=2); no studies were from Africa or South America (Table 1). The length of follow-up ranged from 9 to 36 months, and half of the studies (N=10) measured disengagement within 24 months of follow-up. Most studies (N=19) did not report sample size calculations and did not include multiple time-point measurements of independent time-varying predictors.

The EIS disengagement rates reported in each study are shown in Table 1, ranging widely from 12% (14) to 53% (15) within 36 and 24 months of program initiation, respectively. There was no consensus definition of disengagement across studies. Definitions varied broadly from "termination of treatment despite therapeutic need" (16) to no contact with clinical team "after all possible ways to engage had been explored over a 2- to 3-month period" (14). One study defined three different types of disengagement: continuous default from service despite therapeutic need and active tracing by staff (type I), continuous default from service and reengagement through hospitalization (type II), and continuous defaults from outpatient appointments and reengagement through outpatient clinics (type III) (17).

Nonetheless, we could identify some common features across these definitions. First, most studies considered "no contact" with and "active refusal" to clinical team or staff as a key outcome associated with leaving treatment (7, 8, 25). Moreover, several studies operationalized disengagement as dropping out from treatment "despite clinical advice or judgment" (19, 26), which suggests that stopping services against clinicians' recommendations is usually seen as a negative outcome. Treatment disengagement was usually reported or rated only by clinicians, which substantially limits our understanding of why clients may believe that services are no longer required. Second, just two studies stated that disengagement occurs "after all possible ways to engage clients" took place (14, 20). Only one study described exactly what kinds of strategies were used to reengage clients: "these included appointment letters, phone calls, text messages, e-mails, home visits and contact with family, friends and other health, education and social care providers" (14). Third, the highest disengagement rates generally corresponded to definitions of disengagement that included concepts of "dropping out" (7), "treatment retention" (21), "terminated treatment against clinical advice" (26), and "lost to any contact with mental health services" (27).

TABLE 1. Description of 20 studies of predictors of disengagement from early intervention services for psychosis[a]

Study	Setting	Design and sample	Definition of disengagement	Disengagement rate	Follow-up	Predictor and association with disengagement			OCCS scale rating[b]
						Positive	Negative	None	
Kim et al., 2019 (15)	Melbourne; EPPIC	Cohort study; N=707	Actively refused any contact with the treatment facility or were nontraceable	53%	24 months	Not being in employment, education, or training; cannabis use	Family history of psychosis in a second-degree relative	Age, sex, amphetamine abuse	High
Lau et al., 2019 (17)	Hong Kong; EASY	Cohort study; N=277	Type I: continuous default despite therapeutic need and active tracing from staff; type II: continuous default and reengagement through hospitalization; type III: consecutive default from outpatient appointments and reengaged	Varied by definition: type I, 13%; type II, 4.3%; type III, 13.4%	Within the 3-year program	Type I: poor medication adherence; type II: poor medication adherence; type III: history of self-harm or suicide attempts, poor medication adherence, history of substance abuse	Type III: history of substance abuse	Type I: history of substance abuse, history of self-harm or suicide attempts; type II: history of substance abuse; type III: duration of untreated psychosis, forensic history	Medium
Maraj et al., 2019 (26)	Montreal; PEPP	Cohort study; N=394	Considered to have disengaged from the service after 3 consecutive months of no clinical contact	About 20% at 12 months; no differences between groups	24 months	Vocationally inactive on a sustained basis	None	Age, no contact between family and treatment team, substance use disorder, sex, material deprivation, duration of untreated psychosis, racial-ethnic minority status, social deprivation, functionality, symptoms, vocational activity at baseline	High
Hamilton et al., 2018 (21)	Texas; coordinated specialty care service	Mixed-methods research; N=129	Retention operationalized as the likelihood of remaining in the program for ≥9 months	41%	About 18 months	None	Home-based cognitive therapy, male sex	Age, severity of psychosis symptoms, case management, schizophrenia diagnosis	High
Maraj et al., 2018 (18)	Montreal; PEPP	Cohort study; N=297	No clinic or community appointments with the psychiatrist or case manager and not responding to phone calls	24.2%; mean±SD time to disengagement, 13.3±5.7 months	24 months	General: medication nonadherence; among first-generation immigrants: age and medication nonadherence; among second-generation immigrants: material deprivation and medication nonadherence	None	General: immigrant status, age, sex, substance use, educational level, family contact, social deprivation, material deprivation; among first-generation immigrants: sex, substance use, educational level, family contact, social deprivation, material deprivation; among second-generation immigrants: age, sex, substance use, educational level, family contact, social deprivation	High

TABLE 1, *continued*

Study	Setting	Design and sample	Definition of disengagement	Disengagement rate	Follow-up	Predictor and association with disengagement			OCCS scale rating[b]
						Positive	Negative	None	
Solmi et al., 2018 (14)	East Anglia, United Kingdom; early intervention in psychosis services	Cohort study; N=786	Considered to have disengaged after all possible ways to engage client had been explored over a 2- to 3-month period	11.7%; median follow-up time of 15 months among those who left the program because of disengagement	Within 36 months	Male sex, age 30–35, duration of untreated psychosis of 5–8 weeks, no first-episode psychosis diagnosis, polysubstance misuse, hallucinations	Unemployment, severe psychomotor symptoms, poverty, first-rank delusions	Marital status, site	High
Rosenheck et al., 2017 (24)	United States; Recovery After an Initial Schizophrenia Episode–Early Treatment Program study	Cluster randomized controlled trial; N=404	Minimal engagement was ≥3 contacts with the supported employment and education specialist over the course of the study	About 32% of NAVIGATE participants had <3 contacts with the supported employment and education specialist during the trial, compared with 76% of those in the control group	24 months	None	Engagement in rehabilitative services	None	High
Casey et al., 2016 (31)	Birmingham and Solihull, United Kingdom; Mental Health NHS Foundation Trust early intervention services	Cohort study; N=103	Results of the Singh O'Brien Level of Engagement Scale, which evaluates longitudinal disengagement, cross-sectional disengagement, and attendance at appointments	NA	24 months	None	Lower education, beliefs about mental illness (caused by social stress and odd thoughts), longer duration of untreated illness	Sex, race-ethnicity, age, socioeconomic status, marital status, biological explanation models, diagnosis, duration of untreated psychosis	Low
Chan et al., 2014 (28)	Hong Kong; EASY	Cohort study; N=700	Continuous default of the EASY service despite therapeutic need and active tracing from staff for psychiatric follow-up	5% at 6 months, 9% at end of first year, and 13% at end of second year	24 months	Negative symptoms at baseline, schizophrenia spectrum disorder (versus other psychosis), medication compliance at baseline, substance abuse within first 6 months of program	None	Age, sex, years of education, age at onset, onset mode, duration of untreated psychosis, positive symptoms, social and occupational functioning, taking second-generation antipsychotic at baseline	Medium
Anderson et al., 2013 (8)	Montreal; PEPP	Cohort study; N=324	No contact for a continuous period of 3 months	28% (N=89) disengaged; median time to dropout, 5 months	24 months	Older age, Black race-ethnicity	Living alone	Sex, material deprivation, social deprivation, substance abuse, symptom severity, police or ambulance contact, total contact	High
Macbeth et al., 2013 (30)	Scotland; early intervention psychosis services	Cross-sectional cohort study; N=64	Engagement measured with the Service Engagement Scale	Service Engagement Scale mean total score, 9.48[c]	More than 12 months	Negative symptoms	None	Sex, academic premorbid adjustment, social premorbid adjustment, positive symptoms, general psychopathology	Medium

continued

TABLE 1, *continued*

Study	Setting	Design and sample	Definition of disengagement	Disengagement rate	Follow-up	Predictor and association with disengagement			OCCS scale rating[b]
						Positive	Negative	None	
Zheng et al., 2013 (23)	Singapore; Early Psychosis Intervention Program	Cohort study; N=839	Telephone contact with a family member only and no contact with client	14%; telephone contact maintained with family only for 55 clients (7%); no contact for 54 clients (7%)	24 months	Ethnicity (Malay group), education	None	Age, male sex, marital status, living alone, employment, duration of untreated psychosis, positive symptoms, negative symptoms, general psychopathology	High
Stowkowy et al., 2012 (7)	Calgary, Canada; Calgary Early Psychosis Treatment Service	Cohort study; N=286	Disengagement defined as program dropout before 30 months; those considered to be patients who dropped out did not return calls, could not be reached, or did not attend appointments for 3 months	31%	Before 30 months	Schizophreniform diagnosis	Family member in program, negative symptoms, general psychopathology	Age, sex, premorbid functioning, duration of untreated psychosis, living alone, marital status, age at onset, functioning, quality of life, cognitive functioning, positive symptoms, drug use	High
Chen et al., 2011 (25)	Hong Kong; EASY	Case-control study; cases, 700 clients who received intervention from EASY between 2001 and 2003; controls, 700 persons who received standard care between 1998 and 2001	Having no psychiatric contact at the end of the study	EASY, 23%; standard care, 30%	24 months	None	Phase-specific early intervention (vs. standard psychiatric care)	None	Medium
Conus et al., 2010 (22)	Melbourne; EPPIC	Cohort study; N=786	Active refusal of any contact with the treatment facility; the date of the last face-to-face contact between the case manager and the patient was considered the disengagement date	23.3%; 11% within the first 6 months, 16% within first 12 months, and 26% within first 18 months	Within 18 months	Forensic history, no education or no employment, living without family, diagnosis of other psychosis (vs. schizophrenia), persistent substance use during treatment, living without family at discharge, severity of illness at discharge	Premorbid functioning (assessed with GAF), duration of prodromes (in months), severity of illness, functioning (GAF) at discharge	Sex, family history of psychosis, past psychiatric history, past substance use, history of sexual abuse, history of physical abuse, suicide attempts, duration of untreated psychosis (in weeks), age at onset, age at baseline, lack of insight, comorbid condition at baseline, including substance abuse	High
Turner et al., 2009 (19)	Christchurch, New Zealand; early intervention for psychosis service and outreach program	Cohort study; N=236	Terminated treatment against clinicians' advice	34%	24 months	Unemployment, substance use at baseline, functioning	None	None	High
Lecomte et al., 2008 (29)	Vancouver, Canada; early psychosis intervention	Cross-sectional study; participants admitted to the service; N=118	Higher scores on the Service Engagement Scale, indicating difficulties in engagement	Almost 50% experienced difficulties engaging with the clinician or case worker	NA	Male sex, forensic history, childhood physical abuse, therapeutic alliance, knowledge regarding consumer rights, low neuroticism, high agreeableness	None	Insight, substance use	Medium

continued

TABLE 1, *continued*

Study	Setting	Design and sample	Definition of disengagement	Disengagement rate	Follow-up	Predictor and association with disengagement			OCCS scale rating[b]
						Positive	Negative	None	
Turner et al., 2007 (16)	Christchurch, New Zealand; early intervention for psychosis service and outreach program	Cohort study; participants admitted to the service; N=232	Termination of treatment despite therapeutic need	24.6%; those who self-discharged were considered "disengagers" (N=39)	Within 12 months	Duration of untreated psychosis, current substance use	Insight, illness severity, diagnosis of mood disorder	Sex, living with parents, ethnicity (Maori), employment, inpatient admissions, compulsory admissions, police contact, age, interpersonal relations, quality of life, positive symptoms	High
Schimmelmann et al., 2006 (20)	Melbourne; EPPIC	Cohort study; sample drawn from a larger cohort treated at EPPIC between 1998 and 2000; N=134	Actively refused any contact with the treatment facility or was not traceable	23%	Within 18 months	Living without family	Severity of illness	Diagnosis, functioning, substance use	High
Garety and Rigg, 2001 (27)	South London, United Kingdom; South London and Maudsley National Health Service Trust	Cohort study; all presentations of first- and second-episode psychosis in a defined catchment area; N=21	Nonengagement recorded when the person was refusing contact or was lost to any contact with mental health services	40%	12-month assessment	None	None	None	Medium

a EASY, Early Assessment Service for Young People with Psychosis; EPPIC, Early Psychosis Prevention and Intervention Centre; GAF, Global Assessment of Functioning; NA, not applicable; NHS, National Health Service; PEPP, Early Intervention Program for Psychosis.
b The Observational Cohort and Cross-Sectional Studies (OCCS) scale was used to rate the quality of the study.
c Possible total scores range from 1 to 14, with higher scores indicating better engagement with services.

In addition to varying in disengagement definitions, the studies differed in how long participants were followed up. The follow-up assessments ranged from 9 to >36 months after EIS initiation. The lowest rates were associated with definitions considering "all possible ways to engage them had been explored" (14) and "active tracing from staff for psychiatric follow-up" (28). Some studies used scales to measure levels of engagement or disengagement, such as the Service Engagement Scale (29, 30) and the Singh O'Brien Level of Engagement Scale (31). Finally, the sole randomized controlled trial identified in our search reported much lower rates of disengagement among those participating in the experimental EIS condition (32%) than among those receiving usual care (76%) (24).

Predictors of Disengagement
Table 1 also summarizes findings related to predictors of disengagement (14–29). We reorganized these predictors as predisposing, enabling, and need factors on the basis of Andersen's model (Figure 1). For the purpose of organizing significant predictors according to Andersen's model, we selected only studies with a high quality rating (N=13).

Predisposing factors. Almost all studies explored the relationship between general sociodemographic factors, such as age and sex, and disengagement. For instance, in a cohort study (N=324) that included clients of an EIS in Canada, Anderson et al. (8) reported that older age was associated with an increased risk for disengagement. Most studies, however, did not provide compelling evidence for such associations. Regarding the relationship between migrant or minority racial-ethnic status and risk for disengagement, findings were mixed. In a cohort of 775 patients from the Early Psychosis Intervention Program in Singapore, Zheng et al. (23) found that being of Malay descent was associated with leaving services early. In Canada, Black participants had an increased risk for disengagement, compared with White patients (8). Another Canadian study reported that disengagement rates were not noticeably different among first- and second-generation immigrants, compared with Canadians without recent migration history (18). When the sample was stratified by migrant status, the authors found that among first-generation immigrants, medication nonadherence and age were related to disengagement. Among

second-generation immigrants, material deprivation at the neighborhood level and medication nonadherence were associated with disengagement. The authors also found that material deprivation, assessed with a population index that included information on education, employment, and average income, was associated with a higher risk for disengagement.

Two other studies conducted in Canada identified an association between disengagement and unemployment measured at baseline (19, 26), which was also conceptualized as being "vocationally inactive" (26). A recent cohort study, however, has reported the opposite (14). Solmi et al. (14) studied predictors of disengagement among individuals with first-episode psychosis (N=786) in an EIS in East Anglia, United Kingdom. These authors showed that those who were unemployed and symptomatic were at lower risk for disengagement. In contrast, in another study, higher education was consistently related to an increased likelihood of staying in treatment (23). Of note, all studies understood sociodemographic factors from an individual-level perspective. Information regarding contextual factors, such as neighborhood poverty, violence, and marginalization, were generally not reported.

Enabling factors. One of the most robust findings was that lack of family support was associated with increased disengagement rates (7, 20, 22). Nonetheless, a study in Montreal by Anderson et al. (8) reported that individuals living alone had a reduced likelihood of service disengagement, compared with people living with others. Another inconsistent finding was related to participation in rehabilitation services, such as vocational training or person-centered psychotherapy. For instance, results from the NAVIGATE trial (24), which compared EIS and treatment as usual, indicated that engagement in rehabilitative services that were focused on work or school participation was associated with a lower likelihood of successful follow-up in the trial. Those who received the NAVIGATE intervention, however, were more likely to engage with supported employment and supported education interventions and to continue trial participation. No studies reported information on the characteristics of EIS, including distribution of facilities, type of personnel, and professional training. Finally, two studies found that those who did not receive a first-episode psychosis diagnosis (14) and who reported less stigma (24) were at lower risk for disengagement.

Need factors. Several studies showed that individuals reporting medication nonadherence and drug misuse (especially polysubstance misuse) were at greater risk for disengagement from EIS (15–17, 20, 22). For example, Lau et al. (17) reported that a history of substance abuse was related to different types of disengagement. Poor medication adherence, on the other hand, predicted disengagement and reengagement through hospitalization (type II) and reengagement via outpatient services (type III) in the same study (17).

Moreover, in that study, a history of self-harm, suicide attempts, and hospitalizations was also associated with increased disengagement. No consistent evidence was found regarding the role of duration of untreated psychosis in predicting treatment disengagement. One study noted that a certain range of length of untreated psychosis (between 5 and 8 weeks) could predict disengagement (14), but other studies have shown otherwise (22).

Although it is known that the duration of untreated psychosis is associated with increased symptomatology and worsened functioning, its relationship with disengagement remains unclear. Another commonly hypothesized disengagement factor has been symptoms at baseline, but the results are inconclusive. For instance, Solmi et al. (14) reported that individuals having first-rank delusions at baseline were at lower risk for disengagement. In other studies, when only negative symptoms were taken into account, lower symptomatology was associated with decreased disengagement (7, 16, 22). In terms of functioning, five studies used a specific measure or index to assess such an outcome (7, 19, 20, 22, 28). Turner et al. (19) reported that those who were disengaged from EIS were more likely to have higher scores on Health of the Nation Outcome Scales (a scale to measure health and social functioning) and higher scores on the Global Assessment of Functioning at baseline, meaning that those who disengaged had better social functioning and general medical health. These results seem counterintuitive, given the way disengagement has been framed in the literature (e.g., "leaving services despite clinical advice"), but they may suggest that those who feel better and have increased functionality may decide to leave services earlier than expected.
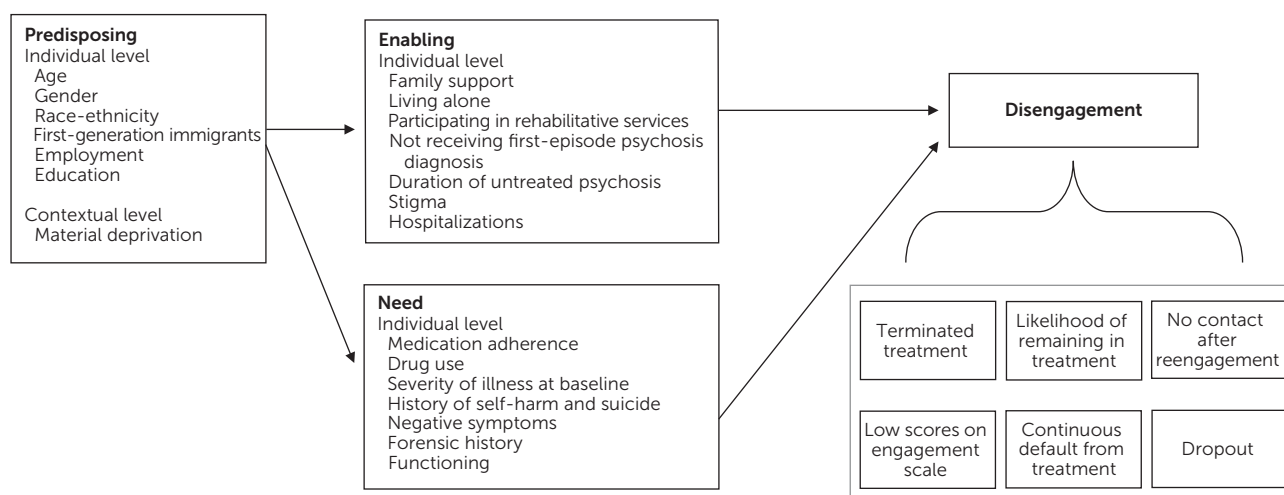
DISCUSSION

This review examined 20 reports on disengagement from early psychosis services.

Summary of Findings
A few enabling and need factors were consistently associated with EIS disengagement, including lack of family support, lower medication adherence, and drug misuse. Some studies also found a relationship between illness characteristics at baseline and later disengagement, such as fewer negative symptoms and higher functioning (7, 14, 17, 20). Moreover, several predisposing factors, such as older age, male sex, and belonging to a racial-ethnic minority group, were often reported; however, although some studies found associations of these factors with disengagement from EIS, most did not. In addition, the relationship between some of the factors and disengagement was inconsistent across studies. For instance, depending on the study, both longer and shorter durations of untreated psychosis were associated with an increased likelihood of disengagement. Overall, our findings highlight the heterogeneity of the relationship between measured characteristics and disengagement but provide evidence that

FIGURE 1. Predictors of disengagement from early intervention services for psychosis[a]

Predisposing
Individual level
  Age
  Gender
  Race-ethnicity
  First-generation immigrants
  Employment
  Education

Contextual level
  Material deprivation

Enabling
Individual level
  Family support
  Living alone
  Participating in rehabilitative services
  Not receiving first-episode psychosis
    diagnosis
  Duration of untreated psychosis
  Stigma
  Hospitalizations

Need
Individual level
  Medication adherence
  Drug use
  Severity of illness at baseline
  History of self-harm and suicide
  Negative symptoms
  Forensic history
  Functioning

Disengagement

| Terminated treatment | Likelihood of remaining in treatment | No contact after reengagement |
| Low scores on engagement scale | Continuous default from treatment | Dropout |

[a] Based on Andersen's model of health service use (9).

factors associated with the level of support, adherence to a medication regimen, and comorbid conditions were most predictive of disengagement.

Interpretation of Findings
One reason for the substantial between-study heterogeneity in the identified predictive factors may be variation in the conceptualization and measurement of disengagement. This has been also noted in a recent review of definitions of disengagement, which found that only a few studies used a similar definition (i.e., when reports came from the same research group), but most reports defined disengagement as a dichotomous, binary variable (engaged versus disengaged) (32). In our review, we identified three common features across studies when they referred to disengagement: "no contact" with and "active refusal" to the clinical team or staff, leaving services "despite clinical advice," and failure to reengage clients after several attempts to do so. Although some people may leave treatment prematurely because of negative experiences with the care received or because little in their lives changed as a result of that care, others may stop treatment because they feel better and decide that services are no longer required, even though the clinical team might think otherwise. They may leave for circumstantial reasons, such as accidents or moving away from the area served. These heterogeneous reasons for discharge remain largely unexplored, despite their potential importance for predicting postdischarge outcomes (e.g., relapses) and care transitions. Some reasons for terminating EIS reflect, in fact, disengagement, whereas others may refer to processes to and through care that represent affirmation of care and treatment benefits (e.g., positive discharge).

Previous research has linked family support to engagement in mental health care among individuals with early psychosis. For instance, Lucksted et al. (33) found that family

members played a crucial role in promoting engagement among individuals with early psychosis by reminding them about clinical appointments, encouraging attendance, and providing transportation. However, family involvement does not necessarily imply "family support." In other words, some families could also present barriers to clients' participation in treatment by arguing against providers' recommendations and by interfering in participants' choices (33). EIS staff should listen to family members, provide support and compelling information about psychosis, and help participants form their own opinions and navigate family relationships and boundaries. Dialogic practices could be of use to better understand family dynamics and crises, discuss issues from different perspectives, and implement practical solutions that make sense to the client and family members (34).

Poor medication adherence has also been found to be related to leaving mental health services. Some authors have suggested that this finding is not surprising because it may reflect a participant's general level of treatment adherence (35). Poor medication adherence might also represent low trust in the care that EIS offer or misconceptions about the clinical and therapeutic model used by service providers (35). Results from qualitative research have suggested frictions between the subjective meaning that clients attach to experiences of psychosis and the promotion of medication adherence from a biomedical perspective by some providers, which could lead to medication discontinuation and EIS disengagement (36). Therefore, a broader understanding of the pros and cons of taking medications, from both clients' and providers' perspectives, is needed. Additionally, medication adherence needs to be understood within a framework of shared decision making in which participants and EIS staff must find the balance between "the duty to care" (i.e., remaining engaged with clients no matter what

decisions they make) and "the dignity of risk" (e.g., the right to make choices, to fail, and to learn) (3).

Finally, it has been widely reported that comorbid substance abuse is strongly associated with noninitiation of mental health care and disengagement from mental health services among individuals with psychosis. Substance abuse has several negative effects, such as increased relapses and hospitalization, impaired social and occupational functioning, and transinstitutionalization in jails and other non–mental health settings (3). Employing therapeutic strategies based on integrated dual-diagnosis treatment programs may help EIS staff to address comorbid substance abuse early in the course of treatment (3). These are evidence-based programs that emphasize outreach, comprehensiveness, and person-centered care. Under this model, clinicians use a broad set of techniques, including motivational interviewing and social and community-based interventions. Results from previous studies indicate that these programs improve treatment participation and enhance initial and ongoing engagement among those with dual diagnoses of mental illness and substance abuse (36, 37).

Strengths and Limitations

Given the steep rise of EIS in the past few years, here we had the opportunity to extend a previous review on the topic (6) by including a larger and more diverse set of studies. The use of a quality rating based on the OCCS scale enabled a more objective evaluation of the quality of the evidence and the development of methodological and data analysis recommendations for future research. Finally, our work sheds new light on the association between disengagement and clusters of baseline engagement factors by incorporating predictors of disengagement in a conceptual framework.

Some limitations of this review must also be noted. For instance, given the inconsistent findings across the studies examined, it is challenging to reach generalizable conclusions. At least part of the variance seen in this line of research might be explained by context-specific phenomena (e.g., health services organization). Furthermore, we could not conduct a meta-analysis because of the heterogeneity in research designs and definitions of the outcome. Also, selection bias may have been an issue across studies and may have influenced the performance of predictors.

Future Studies

On the basis of our findings, we propose a series of considerations that future research should take into account. First, given the inconsistency across studies regarding disengagement definitions, we suggest bringing key stakeholders together (e.g., through partnerships and community-partnered engagement with client and family advocacy groups) to reach a consensus, develop common metrics and measures of treatment disengagement, and design strategies to increase engagement when deemed reasonable. This discussion should include providers as well as patients and families, considering that they may have differing opinions and

perspectives regarding participation in treatment and disengagement. For instance, Smith et al. (38) conducted qualitative interviews with 56 participants with psychosis who had disengaged from mental health care and with their service providers. Patients commonly expressed the following reasons for disengagement: services not relevant for their needs, lack of trust toward service providers, and the belief that they were not ill. Providers, in contrast, reported lack of insight, language and cultural barriers, and stigma as the main reasons. Such divergent perceptions support the importance of examining these issues from different perspectives. Furthermore, Cook et al. (39) recently reported that self-directed clients, compared with individuals in usual care, had better outcomes (e.g., recovery, education, and employment) but spent less time on recovery-oriented care, such as psychosocial rehabilitation, skills training, and case management. The motives behind these reduced service utilization trends are not yet well understood (5), and they may challenge what researchers and mental health professionals know about treatment length, participation in treatment, and disengagement.

Participatory methodologies, such as Delphi methods (40) and concept mapping (41), are useful to conduct such group activities. For instance, a group-model-building approach (41), which is a system dynamics–based method that has been used to guide the design, adaptation, and implementation of evidence-based practices in varying health settings, could be employed to engage stakeholders in identifying causal loop diagrams (including variables, relationships, and feedback) that represent the main factors affecting EIS disengagement in order to inform the development of improved engagement strategies. This approach would enable inclusion of a broader set of stakeholders, including individuals with early psychosis and their relatives, who are not usually represented in this kind of exercise and whose input is highly needed (42). Related issues might be also part of the discussion, such as perceived and evaluated need for services, unmet needs, satisfaction with services, optimal service length, reasons for staying in or leaving the program, discharge processes, and continuity of care.

Second, most reports corresponded to cohort studies that collected data retrospectively from clinical registries; just a few studies conducted their own assessments and quality assurance. Although data from medical records can be useful for programmatic planning and treatment supervision, its use for research requires a thorough analysis aimed at identifying and addressing multiple biases, such as confounding, selection bias, and measurement error. To move this line of research forward, future studies should examine causal relationships between potential predictors and disengagement while controlling for biases that may arise in data collection and analysis.

A third consideration is that to estimate causality between predictors and disengagement, prospective studies of how predictors vary over time are needed. Unfortunately, all the studies measured potential predictors of disengagement

only at baseline, despite the fact that some of those factors change over time (e.g., medication adherence, symptoms, and social functioning). These time-varying variables could include confounders of the association between predictors of interest and disengagement, which might have a different impact on the outcome depending on the time point at which they are assessed. A series of statistical methods are now available to deal with time-varying variables, such as propensity scores and inverse probability weighting, that can be of use here (43).

Fourth, the selection of disengagement predictors in the studies reviewed here relied mostly on statistically significant associations between the predictors and the outcome in bivariate analyses. Generally, researchers used criteria for the identification and inclusion of predictors that were not based on predefined hypotheses or theories. Future research, therefore, should use well-defined conceptual frameworks to choose the variables to be analyzed and their relationships with each other and with the outcome.

Finally, we note that only one of the 13 high-quality studies assessed factors at the contextual level (18). It has been reported in other health settings that contextual factors such as poverty, accessibility and barriers to care, and characteristics of clinics and providers play an important role when engaging clients with services. These factors, which are best measured at the contextual level, are mostly unexplored in EIS contexts. Most EIS are built around therapeutic principles, such as person centeredness, shared decision making, and recovery orientation, yet little is known about how much those principles help to maintain engagement among clients.

CONCLUSIONS

We found that EIS participants with a lower level of family support, reduced adherence to medication, and higher substance use were at higher risk for disengagement in EIS settings. We also noted substantial between-study variation in disengagement definitions and predictors of disengagement. Future research could address these conceptual and methodological issues by conducting participatory and longitudinal studies.

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