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REVIEW

Defining disengagement from mental health services for individuals experiencing first episode psychosis: a systematic review

Siobhan Reynolds[1,2] · Da Jung Kim[1,2] · Ellie Brown[1,2] · Rachel Tindall[1,2] · Brian O'Donoghue[1,2,3]

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Abstract

Background Individuals affected by psychotic disorders frequently disengage from mental health services, although reports of this rate in the literature have ranged from 6 to 60%. One of the potential explanations for the large variation is that studies have adopted different definitions. Without a universal definition it is challenging to compare rates and factors leading to disengagement across studies. This systematic review aims to identify and compare how disengagement from psychosis services has been defined, measured and operationalised in the literature to date.

Methods A systemic literature search of the PubMed, PsycINFO and CINAHL databases was completed following the PRISMA guidelines for systematic reviews.

Results 1506 Studies were identified, of which 30 were eligible to be included. It was found that disengagement was operationalized as either a categorical or continuous variable across studies, with 18 studies classifying it as a categorical, binary variable. Only four studies applied a time period over which disengagement was said to occur, and only four studies used an instrument to measure or predict disengagement. Few studies considered similar factors in their definition, when this occurred it was because the papers came from the same research group.

Discussion To truly understand the phenomenon of disengagement, studies need to have a comparable outcome variable. The need for consensus on a gold standard definition of disengagement that considers the full breadth of its complexity remains. A potential process for establishing a definition that includes set parameters, agreed upon terminology and time periods of assessment is discussed.

Keywords Disengagement · Systematic review · First episode psychosis · Psychotic disorders · Psychosis

Introduction

It is well recognised that a first episode of psychosis (FEP) requires early intervention and regular follow-up to promote adequate symptom control, relapse prevention, and improved prognosis [1]. Additionally, early and comprehensive treatment can minimise longer-term functional and social impairments that can accompany psychosis [2]. Therefore, a key aspect of the treatment of FEP is engaging individuals early on in their symptom progression to deliver appropriate interventions in a timely manner, reduce the duration of untreated psychosis (DUP) and implement effective long-term treatments [3].

Despite recent advances in treatment delivery and attempts to make services accessible and appropriate for service users, engagement with services can be poor. For example, early intervention (EI) services with a focus on youth engagement [4], those with community based, recovery oriented approaches, multidisciplinary care, and integrated family supports into treatment approach [3] still fail to keep all their services users appropriately engaged with treatment. A 2014 systematic review of disengagement from FEP services found an average dropout rate of 30% across ten studies [5], with other studies reporting data that range from 6 to 60% [6–9].

✉ Brian O'Donoghue
brian.odonoghue@orygen.org.au

[1] Orygen, The National Centre of Excellence in Youth Mental Health, 35 Poplar Road, Parkville, VIC 3052, Australia

[2] Centre for Youth Mental Health, The University of Melbourne, 35 Poplar Road, Parkville, VIC 3052, Australia

[3] Orygen Youth Health, 35 Poplar Road, Parkville, VIC 3052, Australia

Whilst premature termination of treatment is common in many health care settings, disengagement is particularly problematic in people affected by psychotic disorders [10], as it tends to occur when treatment is still recommended, leading to poorer outcomes [11]. For example, treatment disengagement is related to relapse, hospital admissions, worsening psychopathology [12], and increased risks of violence, suicide, homelessness and drug overdose [13]. Overall, disengagement from clinical services and related non-adherence to medication has been associated with low vocational, interpersonal and social function and increases in mortality rates [14].

Engagement is a key component of all mental health services, yet it is unclear how this concept is defined in both research and clinical service provision. It has been suggested by some authors that the varying proportions of disengagement found in the literature may, in part, be explained by the different criteria or definitions of disengagement used [5]. Given this perceived variation in definitions used, the current systematic review aims to identify and compare how disengagement from psychosis services has been defined, measured and operationalised in the literature to date.

Methods

Search strategy

An electronic database search of PubMed, Ovid's PsycINFO and CINAHL was conducted on the 30th of September 2018 following the PRISMA guidelines for systematic reviews [15]. Whilst a review protocol was developed prior to the search occurring—as recommended by PRISMA guidelines—in this instance, it was not registered online. Keywords included special characters to capture any orthographic variation and were conjoined via the Boolean operator 'OR'. The complete search strategy was as follows:

1. disengag* OR engag* OR attend* OR adhere* OR 'follow* up' OR default OR dropout OR discontinue*
2. psychos?s OR 'psychotic disorder*' OR schizophrenia OR psychiatric OR patient OR service OR care OR program
3. 1 AND 2

Inclusion criteria

Articles were included for review if they met the following criteria:

(i) Included disengagement or engagement as a study variable. Studies were not restricted to those which provided a definition or criteria for disengagement, as this allowed us to identify studies which examined disengagement, but did not provide any definition for the term.
(ii) Included a cohort of individuals primarily affected by psychotic disorders (over 50% of its sample).
(iii) Published after 1975
(iv) Published in English

Exclusion Criteria:
Articles were excluded if they met the following criteria:

(i) Examined individuals with general psychiatric comorbidities or those attending mental health services rather than focussing on individuals affected by psychosis.
(ii) Dealt with disengagement from inpatient health services rather than out-patient or follow-up psychosis services.
(iii) Focussed on medication non-adherence rather than disengagement with the service in general.
(iv) Used qualitative methodologies

Data extraction and analysis

The titles of papers identified from the search were reviewed by the primary author (SR) for relevance. The abstracts of papers deemed relevant were independently reviewed by the first and second authors (SR and DK) who both then completed subsequent full text analysis utilising the inclusion and exclusion criteria above. Where there were disagreements between eligibility, these was resolved by consulting the last author (BOD). In addition, reference lists of key papers were also reviewed to identify any papers missed from the literature search.

Full text analysis included extracting relevant data from each paper, including; the term and definition used to represent disengagement, whether a tool was used to calculate disengagement or not, the time period over which the study was conducted, and whether disengagement was based on a specific time period of non-attendance. Based on these aspects, the way that disengagement was measured and operationalised as a variable was judged as being either a continuous or categorical variable.

Quality assessment

The quality assessment tool for observational cohort and cross-sectional studies [16] was used to assess the quality of the studies included. This tool was developed by National Heart, Lung, and Blood Institute along with other tools to allow for the assessment of multiple quantitative study designs. The tool facilitates the independent evaluation of 14 components including their stated purpose, setting and

study population, size of cohort, study design and level of evidence, and limitations such as risk of bias, comparability and completeness of data. The tool is designed to help reviewers focus on the key concepts for evaluating the internal validity of a study. They are not intended to create a list that is tallied up to arrive at a summary judgment of quality, rather it encourages critical appraisal of the study before concluding whether the quality of the study is 'good', fair', or 'poor'. In this review, quality assessments were not used to inform our conclusions, as the variable of interest was the definition rather than the outcome. Instead, they were used to encourage critical consideration of the studies and the phenomenon of disengagement, as is considered best practise in PRISMA guidelines.

Results

The initial database search yielded 2227 papers, which were subsequently reduced to 1516 after removing duplicate studies. Following screening, 1293 papers were excluded leaving 223 titles for abstract review. Full text versions were retrieved for 65 papers, and an additional nine were identified from reference lists for full text analysis. From these 74 papers, 30 fulfilled criteria to be included in the systematic review. Figure 1 shows this study selection process. There were 30 studies included in total that addressed the phenomenon of disengagement in early psychosis populations. Within these, there were considerable variation in the number of participants, the length of follow-up period and the rates of disengagement. We also found that the quality of studies varied with 8 rated as strong, 14 as moderate and 8 as weak (Table 1).

Terminology of disengagement

Across studies, numerous terms were used interchangeably to represent disengagement. These included; dropout [10, 17, 18], attendance default [7, 19, 20], lost to follow-up or care [21–24], lack of clinical contact [2, 25–29], and discontinuity of care [30]. The majority of studies employed different definitions for disengagement, bar some exceptions. Two studies from the same research group in Canada used "no clinical contact for at least 3 consecutive months," [29, 31] and two studies from the same research group in Australia used "patients actively refused any contact with the treatment facility or were not traceable" [32, 33]. One definition that was utilised by different research groups was that used by Tehrani et al. from Denmark and Turner et al. from New Zealand; specifically, the "termination of treatment despite therapeutic need" [4, 10]. A description of the various definitions used to describe disengagement are presented in Table 2.

Criteria for disengagement

Time

In order for the term disengagement to apply, there were different criteria utilised for the length of time of service non-attendance. For example, Stowkowy and colleagues [17] stipulated a period of at least 3 months of non-attendance at appointments, and this 3-month time criteria was used in two other Canadian studies by Anderson and Maraj et al. [29, 34]. However, some studies employed shorter periods, e.g., Adelufosi et al. defined disengagement as occurring after an individual failed to attend for 2 consecutive weeks [19], and Cohen defined disengagement as failing to attend treatment during the first 8 consecutive weeks [18]. Comparatively, in most other studies disengagement was considered an absolute concept, with "continuous default" [20], "lost to care" [23] and "no engagement with any level of care [7]" given as definitions without any reference to the duration of the disengagement.

Instruments

Very few studies used an instrument to measure or determine disengagement. The Service Engagement Scale (SES) by Tait was utilised in four studies [8, 11, 14, 35]. However, despite using an instrument to determine disengagement, these specific studies did not provide a definition of disengagement [8, 11, 14, 35]. Other studies utilised scales for disengagement that appear not to be validated, such as Zheng et al. [36] who used the following categories: did not disengage; telephone contact with the patient or a family member or both; telephone contact with a family member only; and no contact). Similarly, Morgan et al. used regular contact, irregular contact, and complete default as scales of engagement with services [7]. Lau also created three different categories of engagement that were based on whether the individual re-engaged or not after their disengagement, and how they re-engaged [37].

Method of operationalisation: categorical vs continuous

There were three methods of classification identified across all the studies identified; two categorical (binary and ordinal) and continuous. Most common (eighteen studies) was categorising disengagement as a binary concept, in other words, disengagement either occurred or did not [2, 4, 10, 17, 19–22, 24–27, 29, 30, 38–41]. Five studies measured disengagement as a categorical variable, but with multiple levels of disengagement, therefore, creating an ordinal scale. Studies used either degree of contact [7, 36, 42] or the cause of disengagement [37, 43] to differentiate each category of disengagement.

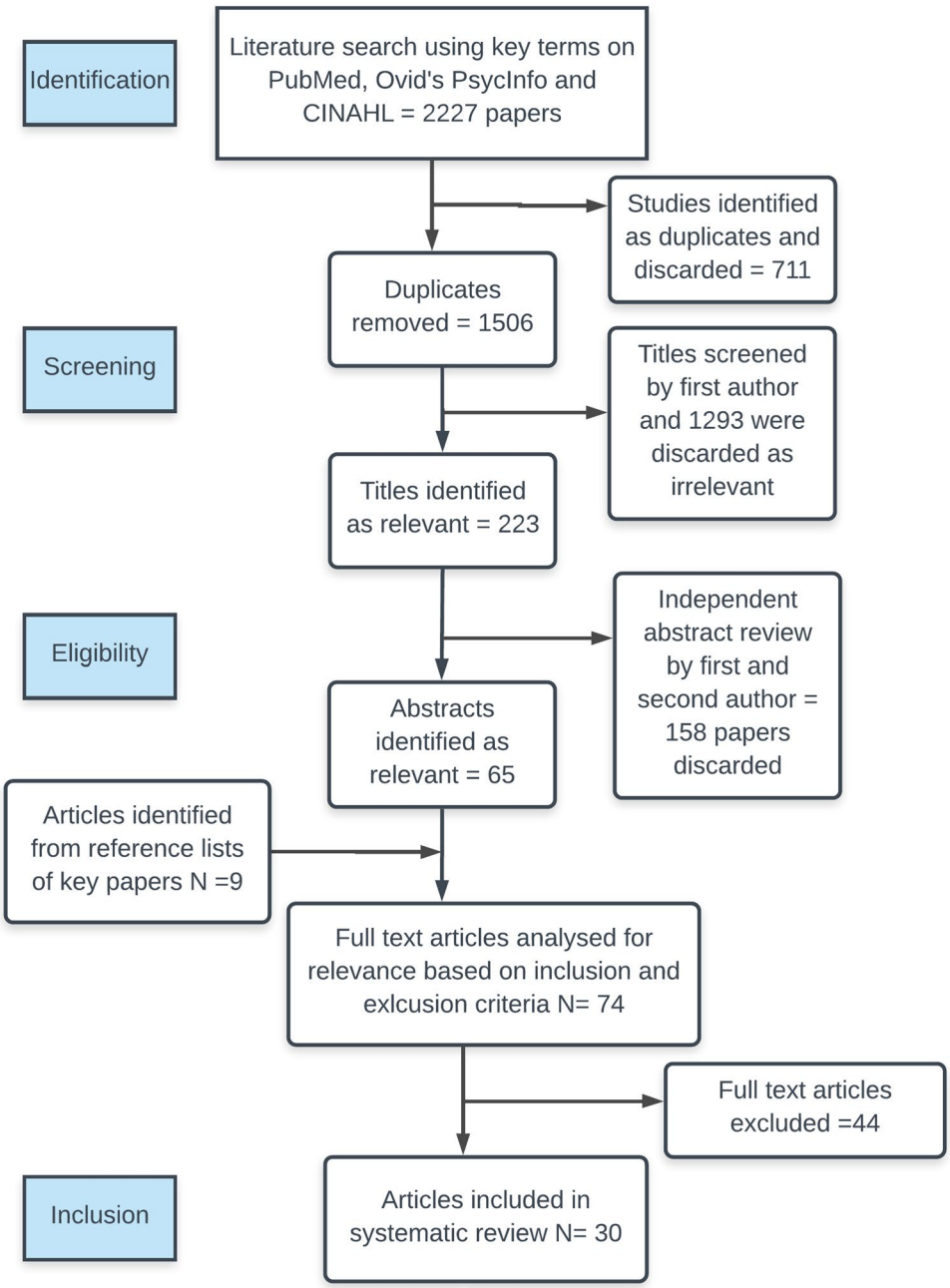

Fig. 1 Process of literature search

Finally, two studies operationalised disengagement as a continuous variable whereby the degree of disengagement was assessed based on the number of missed appointments or time period of no contact. This method was utilised by McCreadie et al. and Anderson et al. [28, 44]. In McCreadie et al's study they compared use and contact with services at the beginning and end of the study year [44]. Similarly, Anderson et al. examined service utilisation, calculating the time to disengagement as the number of months from program entry to the first month of no contact [28]. In the studies which utilised the SES scale, disengagement was also operationalised as a continuous variable [8, 11, 14, 35].

Discussion

Summary of findings

To date there is a sizeable body of literature on the topic of disengagement from psychosis services, in which there is a wide variation in the terminology adopted, and minimal consensus on the definition of disengagement [45]. In our analysis of the studies (Table 2), categorical, binary methods of defining disengagement are used more frequently than a continuous method of operationalising

Table 1 Characteristics of included studies and quality rating

Study	Study population	Setting (type of service	*N*	Follow-up period (months)	Rate of disengagement (%)	Study design	Level of evidence	Overall quality rating
Schottle et al., 2018, Germany	FEP	EI	119	48	8.7	Cohort—P	II	Moderate
Maraj et al, 2017, Canada	FEP	EI	297	24	24.2	Cohort—P	II	Strong
Lau et al, 2017, Hong Kong	FEP	EI	277	36	13.0	Cohort—R	II	Moderate
Lam et al, 2016, UK	VLOP	OP	131	12	54.0	Cohort—R	II	Weak
Spidel et al, 2015, Canada	FEP/FES	OP and IP	117	24	–	Cohort—P	II	Moderate
Chan et al, 2014, Hong Kong	FEP	EI	700	24	13.0	Case control—R	II	Strong
MacBeth et al, 2013, Scotland	FEP	EI	64	12	–	Cohort—P	II	Moderate
Zheng et al, 2013, Singapore	FEP	EI	775	24	14.0	Cohort—R	II	Strong
Anderson et al 2013, Canada	FEP	EI	324	24	28.0	Cohort—R	II	Strong
Adelufosi et al, 2012, Nigeria	FSEP	OP	313	6	20.4	Cohort—P	II	Moderate
Stowkowy et al, 2012, Canada	FEP	EI	286	36	31.0	Cohort—P	II	Strong
Dodgson et al, 2012, UK	FEP	EI	188	60	20.0 (pre EI) 8.0 (EI)	Cohort—R (comparison)	II	Moderate
Conus et al, 2010, Australia	FEP	EI	660	18	23.3	Cohort—R	II	Strong
Lecomte et al, 2008, Canada	FEP	EI	118	24	–	Cohort—P	II	Moderate
Turner et al, 2007, New Zealand	FEP	EI	232	24	24.6	Cohort—R	II	Moderate
Schimmelman et al 2006, Australia	FEP	EI	134	18	50.0	Cohort—R	II	Moderate
Holmes et al, 2005, Australia	FSEP	OP	142	12	29.0—homeless vs 10.0—FSEP	Cohort—R	II	Moderate
Craig et al, 2004, UK	FSEP	EI and CMHT	131	18	14.0—EI services 32.0—CMHT	RCT	I	Strong
Tait et al, 2003, UK	FES	OP and IP	42	6	60.0—low 8.6—no	Cohort—P	II	Weak
Morgan et al, 2003, Ireland	FES	OP	72	90	6.0—no 23.0—irregular	Case control—P	II	Moderate
Reeves et al, 2002, UK	VLOP	OP	54	60	21.0	Cohort—R	II	Weak
Milner et al, 2001, UK	FEP	CMHT	43	24	9.3	Cohort—R	II	Weak
Garety et al, 2001, UK	FSEP	OP	31	12	40.0	Survey	III	Weak
Svedburg et al, 2001, Sweden	FEP	IP and OP	71	60	11.8 "with unmet care needs"	Case control—P	II	Moderate

Table 1 (continued)

Study	Study population	Setting (type of service	*N*	Follow-up period (months)	Rate of disengagement (%)	Study design	Level of evidence	Overall quality rating
Faccincani et al, 2001, Italy	FSEP and non-affective psychosis	OP	35	84	43.0	Cohort—R	II	Weak
Kendrick et al, 2000, UK	Chronic psychosis	OP	102	24	30.0	Cross sectional—R	III	Moderate
McCreadie et al, 1997, UK	Schizophrenia	OP and IP	468	12	11.0—rural, 32.0—urban	Case control—P	II	Strong
Tehrani et al, 1996, Denmark	First admission, 68% FEP	IP	131	12	26.0	Cohort—P	II	Moderate
Cohen et al, 1995, USA	62% FSEP, 48% affective	OP	112	2	43.0	Cohort—R	II	Weak
Johnstone et al, 1984, Scotland	OP Schizophrenia	OP	66	60–108	27.0	Cohort—R	II	Weak

FEP first episode psychosis, *FES* first episode Schizophrenia, *FSEP* first/second episode psychosis, *RCT* randomised controlled trial, *EI* early intervention services- outpatient, *CMHT* community mental health team, *VLOP* very late onset psychosis, level of evidence: I RCT, II case control/cohort, III uncontrolled) *OP* out-patient, *IP* in-patient, *P* prospective, *R* retrospective

disengagement. However, each study used different behaviours and terms to define disengagement.

Conflicts within the literature

Need for care

An issue noted across studies was that rates of disengagement often included individuals who terminated contact with the consent of their clinicians. In one study this also included a cohort of individuals who had moved out of catchment area and would likely be deemed not suitable to remain engaged with the service, or refused services due to lack of therapeutic need [36]. It remains unclear whether this should be considered true disengagement or whether this should be viewed as early discharge, transfer of care or an informed decision to discharge against medical recommendation. One study clearly differentiated between those who disengaged with and without unmet care needs [21], whereas another study considered that individuals were engaged if they had a planned dropout from psychiatric services by discharge to their GP or their care was transferred out of the service area [2]. It is clear that any definition of disengagement should consider whether there is a need for care not being met at the time an individual disengages. In first episode psychosis, relapses are reported to occur for around 40% of individuals and there still remains little consensus on what factors predict their occurrence [46]. Hence it can be argued that individuals who have achieved remission of symptoms following a first episode of psychosis may continue to have a need for care; however, the optimal length of time that an individual should remain engaged with early intervention services is still unclear [47].

The difference between lack of attendance and disengagement

Several definitions of disengagement equated attendance with engagement, with the terms often used interchangeably. However, the frequency or proportion of appointments not kept is theoretically and clinically different from whether an individual has disengaged from services [48]. Individuals may be attending mental health services, but not building a true therapeutic alliance or participating in session content. They may be attending due to pressure from family, or from legal requirements such as community treatment orders. Alternatively, an individual may be therapeutically engaged, but their attendance is limited by work commitments, distance to service, lack of access to transportation or physical illness. Any definition of disengagement should consider differentiating attendance-engagement and session-engagement as important, separate components.

Disengagement with subsequent re-engagement

A further issue exists with how to categorise temporary disengagement, followed by a re-engagement. In a 2017 study from Canada, clients who left the service temporarily, but returned before the 24-month time point were still classified as having disengaged [49]. However, four studies agreed that individuals who return to treatment after initial dropout were considered to have remained in treatment [28, 37, 50, 51]. Another study by Lau et al. measured different levels

Table 2 Comparison of each study's parameters and definition/measures of disengagement

Study	Term used to represent disengagement	Definition of disengagement	Instrument Used	Time period required	Method of disengagement operationalisation
Schottle et al, 2018, Germany	Disengagement	Patient repeatedly refused further treatment despite the need and several attempts at re-engagement. Not due to practical reasons (moving out of catchment area)	–	–	Cat: binary
Maraj et al, 2017, Canada	Disengagement	No clinical contact for ≥ 3 consecutive months (i.e., no clinic or community appointments with the psychiatrist and/or case manager and not responding to phone calls)	–	3 months	Cat: binary
Lau et al., 2017, Hong Kong	Disengagement	Type I disengagement: continuous default from the EI service until the end of the 3 year service despite possible therapeutic need and active tracing from staff. Type II disengagement: continuous default from the EI service and re-engagement through hospitalization. Type III disengagement: those who had ≥ 2 consecutive defaults from OP appointments and re-engaged to the EI service from OP service	–	–	Cat: ordinal
Lam et al., 2016, UK	Lost to FU	Lost to FU or not engaged with specialist services at discharge	–	–	Cat: ordinal
Spidel et al., 2015, Canada	Treatment non-adherence	High scores indicate low engagement	SES Scale [15]	–	Cont: predictive
Chan et al., 2014, Hong Kong	Default	Continuous default from OP appointments till end of the 2-year service, despite therapeutic need and active tracing from staff for FU	–	–	Cat: binary
MacBeth et al., 2013, UK	Poorer engagement	High scores indicate low engagement	SES Scale [15]	–	Cont: predictive
Zheng et al., 2013, Singapore	Disengagement	No contact with patient, or telephone contact with a family member only Scale used: did not disengage; telephone contact with the patient or a family member or both; telephone contact with a family member only; and no contact	Semi-structured, non-validated scale	–	Cat: ordinal
Anderson et al. 2013, Canada	Disengagement	No contact for a continuous period of 3 months prior to completion of the 2-year program	–	3 months	Cont: %
Adelufosi et al., 2012, Nigeria	Defaulters	Patients who failed to keep their clinic appointments on the scheduled date and who did not re-attend within 2 weeks following this date were operationally categorized as "defaulters"	–	2 consecutive weeks	Cat: binary
Stowkowy et al., 2012, Canada	Dropping Out	Dropping out (not returning phone calls, unable to be reached, or not attending appointments for 3 months) before 30 months	–	3 months	Cat: binary
Dodgson et al., 2012, UK	–	Unplanned discharge from service or moved out of area Engaged = planned discharge from service or in contact with service	–	–	Cat: binary

Table 2 (continued)

Study	Term used to represent disengagement	Definition of disengagement	Instrument Used	Time period required	Method of disengagement operationalisation
Conus et al., 2010, Australia	Disengagement	Case notes suggested that patient actively refused any contact with treatment facility or were not traceable. Treatment discontinued in spite of need	–	–	Cat: binary
Lecomte et al., 2008, Canada	Low service engagement	Higher SES scores indicated difficulties in service engagement	SES Scale [15]	–	Cont: predictive
Turner et al., 2007, New Zealand	Disengagement	Termination of treatment despite therapeutic need within 12 months of entry	–	–	Cat: binary
Schimmelman et al. 2006, Australia	Disengagement	Refusal of any contact or nontraceable within 18 months	–	–	Cat: binary
Holmes et al., 2005, Australia	Discontinuity of care	Discontinuity of care at discharge and decreased length of engagement with mental health services	–	–	Cat: binary
Craig et al., 2004, UK	Lost to care	Not in regular contact with the clinical team. Contact was defined as either contact with the index team, contact with any mental health service or contact through psychosocial treatment	–	–	Cat: binary
Tait et al., 2003, UK	Low service engagement	N/A—Higher SES scores indicated difficulties in service engagement	SES Scale [15]	–	Cont: predictive
Morgan et al., 2003, Ireland	Default	Maintaining no engagement with any level of psychiatric care	–	–	Cat: ordinal
Reeves et al., 2002, UK	Lost to FU	Could not to be contacted or had moved away	–	–	Cat: binary
Milner et al., 2001, UK	Disengagement	Failure to engage with psychiatric services, or unplanned disengagement with local services (GP or other psychiatric care)	–	–	Cat: binary
Garety et al., 2001, UK	Non-engagement	'Non-engagement' was recorded when the person was refusing/lost to any contact with mental health services. 'Engagement' referred to contact not to compliance with treatment	–	–	Cat: binary
Svedburg et al., 2001, Sweden	Not in contact	Disappeared or terminates contact at 5 years	–	–	Cat: binary
Faccincani et al., 2001, Italy	Out of contact	Out of contact with any form of psychiatric care at 7 years	–	–	Cat: ordinal
Kendrick et al., 2000, UK	Loss of contact	Still in documented contact with secondary care at 2 years	–	–	Cat: binary
McCreadie et al., 1997, UK	Not in contact	Use of services at 1 year	–	–	Cont: %
Tehrani et al., 1996, Denmark	Dropout	Termination of treatment despite therapeutic need	–	–	Cat: binary
Cohen et al., 1995, USA	Dropout	If during the 8 weeks after the initial appointment, patient did not return to the rehabilitation program	–	8 weeks	Cat: binary
Johnstone et al., 1984, Scotland	Out of contact	Out of contact: No contact with medical or social services 5–9 years after an admission to psychiatric hospital	–	–	Cat: binary

Cat categorical, *Cont* continuous, *OP* out-patient, *IP* in-patient, *FU* follow-up

of disengagement, based on how the individual re-engaged [37]. This highlights that disengagement may not be an absolute occurrence and disengagement should instead be viewed as a 'period of disengagement.' This is important, as each period of disengagement may have different factors contributing to it, and therefore, different approaches may be needed to re-engage the individual. Support for this argument comes from qualitative studies that have considered disengagement from the perspectives of service users and clinicians [52].

Time period of disengagement

Some studies applied a time period for disengagement, ranging from 2 weeks to 3 months, after which an individual was classified as having disengaged [15, 28, 33]. However, it is unclear whether these time periods are an arbitrary length of time or chosen to reflect a certain number of missed appointments. If a set period of time of non-attendance is equated with disengagement, that time period should reflect the need for treatment at that time. An individual who is unwell and at risk, who does not attend for 2 weeks is different to someone who does not attend for a period of 2 months, but is towards the end of their treatment, has complete symptom resolution and has returned to employment or education.

Future research

As engagement seems to be a very subjective and personal matter for individuals [52], it highlights the importance of qualitative research in this area. Recently, three qualitative meta-syntheses have summarised service users' and careers' experiences of engaging with early intervention services. All have highlighted the importance of a genuine, two-way relationship. [52–54]. Once achieved, the maintenance of this bond is fundamental to enabling the individual's continued engagement. Integrating what we know about the importance of an individual's experience into routine clinical monitoring and data collected for research studies may be an important step forward. To date, this is rarely done with only one study found to include an individual's reported reasons for their disengagement [19]. In this study the authors reported a disengagement rate of 20.4%, which participants deemed was primarily to be due to "distance of home from hospital and dissatisfaction with out-patient care". It is possible that this is a key limitation of many studies thus far, and that future studies should ideally include a patient feedback system for determining why patients disengaged. We acknowledge however that obtaining feedback from individuals who have completely disengaged from treatment may present logistical challenges.

Recommendations

Clearly, whilst the aforementioned qualitative papers have enhanced understanding of the complexities of disengagement, to date this has not translated to the way in which quantitative studies have measured disengagement. Only when there is a consensus between studies on how to define and measure disengagement will research be comparable, allowing statistically or clinically significant results regarding contributing factors to disengagement to be elucidated. Therefore, we suggest that a gold standard definition and measure of disengagement should be adopted. However, this is likely to be complex to devise and it should incorporate the method of classifying disengagement (i.e., categorical, continuous) and a balance between the attendance and the need for care. Furthermore, other behaviours could be more clearly defined, for example, for those individuals who attend appointment but are only superficially engaged. Finally, it needs to be clinically relevant and easy to use in every day clinical practise.

This next step might involve an international consortium of experts in the field working together to develop a gold standard definition. The use of mixed-methods techniques such as the Delphi method [55] or concept mapping [56] would allow this to be undertaken with relative ease. The consistent implementation of its use internationally may present more of a challenge of course, however, it would have the potential to allow clinicians and services to more accurately monitor and subsequently minimise service disengagement. It would be useful to produce accompanying policy guidance to support the use of the standardised definition which would include further direction around defining terms frequently found in the literature, such as; attending appointments, superficial "engagement", therapeutic engagement, and leaving services permanently vs temporarily.

Limitations

The results of this systematic review must be viewed in light of limitations of the search process. As there are many various terms used to represent disengagement, deciding on the search terms was a rigorous process. However, even with the multitude of variations there may have been some papers missed from the search. Perhaps by extending the search beyond major databases and into grey literature, the literature search may be improved further. A further limitation of this review was that it was not registered online on a database such as PROSPERO prior to its undertaking.

Conclusion

This study is one of the first that focussed on how disengagement has been defined, rather than the individual or disease specific factors that may contribute to it. It highlights the broad terms used to represent disengagement, the variety of definitions used, the differences in the way that disengagement is treated as a variable, and the different scales—or lack thereof—that have been used to measure or predict it.

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Compliance with ethical standards

Conflict of interest The authors acknowledge they have no conflicts of interest.

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