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Social Media and Social Functioning in Psychosis: A Systematic Review

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Abstract

Background

Individuals with psychosis are heavy consumers of social media. It is unknown to what degree measures of social functioning include measures of online social activity.

Objective

To examine the inclusion of social media activity in measures of social functioning in psychosis and ultrahigh risk (UHR) for psychosis.

Methods

Two independent authors conducted a search using the following electronic databases: Epistemonikos, Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects, MEDLINE, Embase, and PsycINFO. The included articles were required to meet all of the following criteria: (1) an empirical study published in the English language in a peer-reviewed journal; (2) the study included a measure of objective or subjective offline (ie, non-Web-mediated contact) and/or online social functioning (ie, Web-mediated contact); (3) the social functioning measure had to be used in samples meeting criteria (ie, Diagnostic and Statistical Manual of Mental Disorders or International Classification of Diseases) for a psychotic disorder or UHR for psychosis; and (4) the study was published between January 2004 and February 2019. Facebook was launched as the first large-scale social media platform in 2004 and, therefore, it is highly improbable that studies conducted prior to 2004 would have included measures of social media activity.

Results

The electronic search resulted in 11,844 distinct articles. Full-text evaluation was conducted on 719 articles, of which 597 articles met inclusion criteria. A total of 58 social functioning measures were identified. With some exceptions, reports on reliability and validity were scarce, and only one measure integrated social media social activity.

Conclusions

The ecological validity of social functioning measures is challenged by the lack of assessment of social media activity, as it fails to reflect an important aspect of the current social reality of persons with psychosis. Measures should be revised to include social media activity and thus avoid the clinical consequences of inadequate assessment of social functioning.

Trial Registration

International Prospective Register of Systematic Reviews (PROSPERO) CRD42017058514; http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017058514

Keywords: psychosis, schizophrenia, social media, social functioning, measures, assessment, systematic review

Introduction

Social functioning impairment is a core dimension of psychotic disorders [1]. Thus, measures of social functioning are crucial for clinical assessment, prognosis, and outcome. Research indicates high engagement with social media platforms and associated social interaction in subjects with psychosis and those at ultrahigh risk (UHR) for psychosis states, including friendship formation and overcoming barriers associated with having severe psychiatric symptoms [2-5]. Social media activity should therefore be included as part of social functioning measures.

In an Australian national survey, more than one-third of adults with psychosis rated social functioning issues as their greatest challenge for the future [6]. Long-term deficits in social functioning have been linked to negative symptoms, such as social withdrawal, apathy, and avolition [7,8], as well as impaired social cognitive capacities, including capacity for mentalization and theory of mind [5,9]. Similar findings have been found for UHR populations; when compared to healthy controls, they show both higher levels of baseline social decline and lower levels of quality of life [10-14]. Conversely, good social functioning has been identified as a robust predictor of recovery [15-18].

Empirical research on social functioning largely originates from standardized questionnaires based on two dimensions [19]. The objective dimension encompasses the ability to meet social roles, such as employability and being a spouse, a family member, or a friend, combined with socioeconomic measures, such as finances and housing [20]. These measures are easily quantifiable and can thus be replicated [20]. The subjective dimension comprises self-reported measures of social roles and measures of satisfaction with family life, recreational activities, and life as a whole [20]. Ratings on both objective and subjective measures are found to correlate with prognosis, course development, and outcome [21].

Since the advent of Facebook in 2004, social media is exponentially more often involved in establishing and maintaining social networks [22-24]. Globally, there are approximately 2.6 billion registered social media profiles and the number is expected to grow by an additional 400 million over the next three years [25]. In 2015, in the United States, more than 75% of people used social media compared to 7% a decade ago, and 92% of adolescents went online daily [26]. Nonetheless, the conceptualization of social media participation as a dimension of social functioning is underdeveloped. At face value, when compared with offline contact, social media platforms represent radically evolving platform structures and a more asynchronistic kind of communication. These are technology-mediated tools that enable individuals to share, exchange, and create ideas, images, and information through online communities and networks [27-29].

Despite having fewer or less-frequent social contacts outside social media, individuals with psychosis or those at UHR for psychosis are heavy consumers of social media when compared to peers of the same age [30-34]. The Internet has become an influential source of mental health information for people with psychosis [28] and, thus, social media and digital devices have been utilized to support mental health care [32-35] and destigmatization campaigns [36]. Particularly for the youngest age group with psychosis and those at UHR for psychosis, there has already been social media-based interventions developed that are targeted on psychological, functional, and social recovery [37,38].

Science and technology studies aim at offering a comprehensive understanding of the interaction between science, technology, and society [39]. According to this framework, technologies may fundamentally alter societal dynamics, influencing communication. Moreover, post-normal science (PNS) is a perspective emphasizing the value of direct stakeholder involvement in practices where facts are uncertain and stakes are high [40], as they arguably are in psychosis. If measures of social functioning in psychosis do not embody the fundamental changes caused by technological innovations and do not consult target groups directly, they run the risk of low ecological validity.

The main objective of this study was to examine whether measures of social functioning in psychosis and UHR for psychosis include the assessment of social behavior on social media. It also compared the validity and reliability of reported measures of social functioning.

Methods

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [41] to ensure comprehensive and transparent reporting of methods and results. The protocol was registered at the International Prospective Register of Systematic Reviews (PROSPERO) in March 2017 (registration number: CRD42017058514).

Search Strategy

Two independent authors (JB and WTVH) conducted a search using the following electronic databases: Epistemonikos, Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects (DARE), MEDLINE, Embase, and PsycINFO. The search terms used were as follows: (“psychosis” or “psychoses” or “psychotic*” or “schizo*”) AND (“social*” or “psychosocial*” or “communit*” or “peer*” or “famil*” or “friend*”). Specific search terms were added to capture social media activity (eg, the Medical Subject Headings [MeSH] term “social media”; see Multimedia Appendix 1 for model search). The search queries were reviewed by an information scientist and were limited to title, abstract, keywords, and subject headings. In addition, a manual literature search was performed using reference lists of reviews and meta-analyses. In cases of doubt, the full-text paper was read to determine eligibility. Papers published between January 2004 and February 2019 were included. The last search was conducted on February 15, 2019.

Eligibility Criteria

The included articles were required to meet all of the following criteria:

1. Empirical study published in the English language in a peer-reviewed journal.
2. The study included a measure of objective or subjective offline (ie, non-Web-mediated contact)

and/or online social functioning (ie, Web-mediated contact).

3. The social functioning measure had to be used in samples meeting criteria (ie, Diagnostic and Statistical Manual of Mental Disorders [DSM] or International Classification of Diseases [ICD]) for a psychotic disorder or UHR for psychosis.
4. The study was published between January 2004 and February 2019. Facebook was launched as the first large-scale social media platform in 2004 and, therefore, it is highly improbable that studies conducted prior to 2004 would have included measures of social media activity.

Exclusion Criteria

Articles were excluded if the only functioning assessed by the measure was one of the following:

1. Premorbid functioning measures.
2. Global functioning measure.
3. Performance-based skills assessment.
4. Studies exclusively dealing with social relationships, including social functioning, between study participants and professionals.

Data Collection

All potential studies were exported into a reference citation manager, EndNote (Clarivate Analytics), before removing duplicates. Two independent reviewers (JB and WTVH) separately performed the screening of titles and abstracts, full-text analysis, and selection of social functioning measures. Disagreements were resolved through discussion until consensus was reached. A third reviewer (SP) was available to resolve disagreements. Finally, the list of included and excluded measures was sent to an independent auditor (HJS) for critical evaluation. The kappa coefficient was used to assess the level of agreement of the two independent reviewers for the selection of included and excluded measures.

Analytic Methods and Data Extraction Procedure

A narrative descriptive synthesis was performed for the included articles. The data extraction procedure was performed in two steps. First, subjective and objective measures of social functioning across different social domains (ie, work, community functioning, socioeconomic status, etc) for both offline and online engagements were identified. Second, the content, quality, and psychometric properties, with a particular focus on whether measures assessed social media activities and interactions, were examined and assessed, including validity and reliability statistics of the measures. Since the selection of screened and included articles was extensive, validation literature was sourced directly from the reviewed articles. In addition, a manual search was performed for each individual measure to identify further validation literature.

Results

Search Results

The electronic search returned 12,437 articles. After duplicates were removed, there were 11,844 articles, of which 671 were reviews or meta-analyses: 178 articles from the Cochrane Database of Systematic Reviews and 493 from Epistemonikos. A hand search of reference lists of reviews and meta-analyses returned a further 82 articles. Full-text evaluation was conducted for 719 articles, of which 597 met the inclusion criteria and were included for the final synthesis. From the 597 articles, 58 measures were identified: 41 (71%) social functioning and 17 (29%) quality-of-life measures that included assessment of social functioning. Interrater reliability (ie, agreement between independent reviewers) for inclusion of measures was high (k=.83). Details of the search results are summarized in Figure 1.

Frequently Used Social Functioning Measures

Details of the included 58 measures of social functioning are summarized in Tables 1 and 2. The three most frequently used measures were the Social Functioning Scale (78 references), the Quality-of-Life Scale (67 references), and the World Health Organization Quality of Life Brief Version (WHOQOL-BREF) (57 references). Several measures (eg, the Social Adjustment Scale II and the Global Functioning-Social Scale) had been used to address social functioning in UHR populations. Although developed for young people, none of these measures were exclusively used in UHR populations.

Structure and Administration of Measures

A total of 35 out of 58 measures (60%) were primarily observer-rated, while 23 (40%) were primarily self-reported. The completion time ranged from 10 minutes (ie, Social Functioning Questionnaire) to 60 minutes (ie, Social Adjustment Scale). Most of the social functioning and quality-of-life measures used a Likert response format (40/58, 69%). Most measures assessed behaviors, not perceived ability, related to physical forms of social functioning, such as face-to-face or telephone contact with friends and family. There was great variability in how comprehensive measures reported on social functioning characteristics, ranging from the First Episode Social Functioning Scale (FESFS) with nine subscales to those who reported a few items (eg, part of a single subscale) of social functioning. Also, quality-of-life measures typically concentrated more on subjective evaluations of general life domains and were thus less focused on social functioning. The FESFS was the only measure to include an assessment of social activity on social medial; this is evaluated in a separate section below.

Psychometric Properties of the Measures

Out of all 58 included measures; 32 (55%) had previously been validated in patients with psychosis, 16 (28%) in a general psychiatric or clinical and community sample, 2 (3%) in a sample of patients with bipolar disorder, 2 (3%) in a sample of patients with depression, 2 (3%) in a sample of patients with somatic illness, 2 (3%) in a nonclinical sample, 1 (2%) in a sample of adolescents of parents with and without major depression, and 1 (2%) did not record any sample information. More data were available for reliability (53/58, 91%) than for validity (47/58, 81%). In general, lack of information prevented a comprehensive evaluation of the psychometric properties of most measure instruments. Theoretical foundation and construct validity was particularly poorly reported. When psychometric properties were reported, measures showed overall good validity and reliability regarding offline social functioning. The Social Functioning Scale, the Groningen Social Disability Schedule, and the Health of the Nation Outcomes Scale are examples of measure instruments with comprehensive reporting of this type of social functioning.

Measure Assessing Social Activity on Social Media

The FESFS was developed in 2014 [42] by the authors listing activities based on their experience with people with early psychosis and on reviews of existing measures of social functioning [40]. The FESFS is designed to measure social functioning in young people in the early stages of psychosis and was the only measure instrument identified in this review as addressing social activity on social media. The scale can be administered as observer-rated or self-report, with each item rating behavior—focus on frequency—and perceived individual ability. The FESFS comprises 34 items distributed on nine subscales assessing various domains of social functioning. The item language was intentionally constructed to fit the target group (eg, “hanging out with buddies” and “chatting on the net”). Two items, respectively from the items *Friends and activities* and *Living skills*, address social media activity explicitly: “I am really good in solo activities such as going to the gym, going to the movies, chatting on the net, taking lessons (music, painting, etc)” and “I am comfortable using the phone, Internet, or email to communicate.” The scale is cited five times, of which three of the cited articles include the measure developers as authors.

Scale validation was based on the self-report version. The validation sample included 203 people, with an average age of 24.5 years, diagnosed with a schizophrenia spectrum psychotic disorder, and with an average of 12.7 years of education. The nine factors showed good internal consistency, ranging from .63 to .80. Good convergent and discriminant validity, as well as good sensitivity to change, were also demonstrated. Three subscales had an inverse correlation with negative symptoms.

Discussion

Measures Should Include Contemporary Social Reality

Due to technological innovation and rapid alterations in the norms of social media usage, any instrument designed to measure social functioning, including social media activity, should encapsulate contemporary trends. The main finding of this review was that current measures of social functioning almost exclusively comprise offline social activity, with the sole exception of the FESFS, as discussed in a separate section below. This limitation is likely to reflect the time of development of currently used measures, as most were developed before the launch of the Internet in 1992, and only eight measures were developed or revised after the advent of Facebook in 2006. Many of these scales have good psychometric properties, which may be a good starting point if they were revised to include measures of social media activity. It is notable that the first measures developed were based on chronic inpatients (eg, the Interview Schedule for Social Interaction). However, there is now an emphasis on early intervention to target quality of life and younger early-stage patients, as opposed to chronic inpatients [109], and current measures fail to capture an important aspect of the current social context.

It is worth discussing whether the two most widely used categories of measures—social functioning and quality of life—are expedient. For instance, a number of the measures within these categories address social participation, while others address the more narrowly defined concept of social skills. In practice, then, choosing a measure from either category for evaluative purposes could potentially influence interpretations of findings.

Further, regarding validity, while the original psychometric assessment of some measures show good reliability and validity, they may lack ecological validity. For example, leaving out assessment of social media activity may lead to low scores on social functioning among young people with psychosis and, thus, increase the likelihood of false positives. Moreover, the core negative symptom of social withdrawal [8] may manifest differently in a social media context compared to an offline context. There is also a risk of social media addiction, negative social comparison, cyberbullying, as well as it being used to exclude real-life contacts [27,110], with potential negative consequences on illness course, outcome, and quality of life. Online social functioning measures should aim to be sensitive to these types of matters. Also, they should track symptom levels [2], change in social participation, and support that unfolds online [3]. In this regard, a survey found that adults with schizophrenia were as likely as adults without mental illness to form social relationships online, despite having fewer offline relationships, lower income, and less Internet access [4]. Compensating for symptoms that people with psychosis themselves experience that interfere with socializing in face-to-face encounters [111] may be a fruitful remedy for some of the obstacles associated with the enhanced levels of toxic loneliness and stigma associated with psychosis populations [5]. This type of information would also be important for treatment timing and tailoring.

Social Media Assessment

The FESFS represents an attempt to address contemporary forms of social functioning, including online activity. Additionally, the scale assesses both behavior and ability, which make a more nuanced assessment possible. However, the scale has fundamental limitations. The validation sample has an average age of 24.5 years, which is relatively high when aiming at early psychosis and UHR of psychosis. The subscales related to work and education are not satisfactorily validated, as only a small part of the validation sample was working or studying. Test-retest reliability for the scale has not been conducted and neither factorial structure nor construct validity has been confirmed. In addition, only the self-report version has been validated. Furthermore, the scale has only been cross-validated across context to a very limited extent [112] —as opposed to, for example, the Personal and Social Performance or the Psychosocial Functioning Scale—which implies uncertainty regarding robustness and usability. Further, the authors do not articulate a theoretical foundation for the scale, and scale content is derived from the scale authors' own listing of experience-based domains of social functioning.

Science and technology studies is a highly influential theoretical framework analyzing the entanglements of science, technology, and society [39]. A basic premise in *science and technology studies* is that technological innovation affects society and human behavior in fundamental ways. Specific technologies,

such as social media, do not merely add to the possibilities of communication, but changes the nature of communication processes. Consequently, attempts to include technology-mediated communication processes should start from the premise that these probably do not reflect nontechnological communication. Compared with face-to-face contact, social media represents radically evolving platform structures and a more asynchronistic form of communication. However, it is unclear whether social media platforms require extra social flexibility or if they are adaptable to facilitate communication for persons who may have limitations in face-to-face social skills, such as the limitations typically found for individuals with active psychosis. It has been suggested that individuals with mental health problems may use social media to seek support. When compared to face-to-face interaction, social media allows more time for reflection before acting [113].

The FESFS "chatting on the net" item is defined as a solo activity and yet this may not reflect the experience of social media by individuals. Social media includes virtual communities allowing users to create a public profile, interact with real-life and virtual friends, and make new acquaintances. Social media engagements often seem to be a fundamental social activity [114]. Also, the FESFS defines using the Internet or email communication as a living skill. However, it is difficult to equate these technological skills as being representative of social activity or functioning. While the FESFS has been the first measure to attempt to capture social media activity, the measure requires significant further development for validity of measurement of contemporary social media engagements.

Future Research: Need for a Radical Change

The use of social media as a dimension of social functioning in psychosis is a complex issue and the knowledge base is limited. It is possible to explore social media behavior based on the most reliable and valid dimensions of currently available offline social functioning measures, such as the Social Functioning Scale. This scale provided the most comprehensive reporting of traditional psychometric properties for offline social functioning, including construct validity. With this scale, social skills or social behavior were registered as present or absent, thus removing the need for an evaluative decision. This could be a feasible starting point to track online social behavior. Some degree of social skill transfer between online and offline activities seems plausible. Additionally, it might be important to understand the relationship between more traditional measures of social skills and social media usage. In this regard, purely scientist-driven approaches have clear limitations. For example, the likely age gap between researchers and the target group of early psychosis, particularly the UHR segment, risks a lack of understanding of the social context. Therefore, a collaborative approach with the target group as codevelopers of the measure could remedy this shortcoming. The general omission of user involvement, which is highly prioritized and valued in most contemporary health care systems, is a major challenge to the validity of these measures [115]. We therefore propose a theoretical framework in which service users are involved, so as to explore social media as part of social functioning of young people with psychosis.

PNS was developed for interpreting and applying scientific results at the science-policy interface. PNS was tailored for situations where "facts [are] uncertain, values [are] in dispute, stakes [are] high, and decisions [are] urgent" [40]. The research field of social functioning in psychosis includes multiple theoretical perspectives, such as physiological, biological, evolutionary, social, and cultural perspectives. The complex nature of social functioning makes it difficult to indicate causality [1]. There are conflicts of interest causing tension between groups, such as the psychopharmaceutical industry, governments, professional associations, and user organizations [116-118]. The stakes are arguably high as social functioning impairment is regarded as a core symptom of serious mental illness, namely psychosis [119]. The PNS remedy is to communicate uncertainty, assess quality, and justify practice by including extended peer communities. In practical terms, the PNS framework ensures the inclusion of social components perceived as important by the target group. This will presumably lead to inclusion of new facets of social functioning that have been omitted by previous measures, and the risk of implementing outdated or ecologically invalid models is lowered.

Future reviews should take social media use or online activity into consideration when also evaluating social functioning measures in general patient populations. When developing and validating social functioning measures, researchers today should include social media activity: content, frequency, quality, and effects, both positive and negative.

Strengths and Limitations

The strengths of the study are evident in the study protocol being publicly available (ie, PROSPERO) before conducting the review, thus ensuring transparency, and the review was conducted according to PRISMA guidelines [41]. In addition, the inclusion of studies was determined by two independent raters and showed high interrater reliability.

The main purpose of this review was to assess to what degree social functioning measures included assessments of any online social activity. Hence, we applied broad inclusion criteria to avoid ignoring any potential measures. A side effect of this strategy was the inclusion of some measures that were not tailored to specifically target social functioning in general or psychosis specifically.

The conclusions drawn in this review may have been influenced by several of the included studies not reporting relevant psychometric properties. Although only one of the identified instruments specifically assessed social media activity, it cannot be ruled out that respondents may answer generic questions about social functioning with social media activity in mind. Another limitation is that each individual study was not assessed for key sources of biases (eg, sample characteristics). However, in line with previous research [20], it seems warranted to conclude that some studies were based on small samples and that most instruments were constructed and tested within Anglo-American cultures. Grey literature was not included. This will typically raise the risk of reporting bias, implying that the included studies represent selective research dissemination [120]. However, it should be emphasized that the aim was to identify instruments with a high level of use within the field and that the search was conducted in several literature databases. The included studies did use samples with somewhat different characteristics (eg, sex, age, and level of symptomatology), which may violate the transitivity assumption and, thus, questions direct comparisons across included studies.

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Abbreviations

DARE	Database of Abstracts of Reviews of Effects
DAS	Disability Assessment Schedule
DAS-II-sv	Disability Assessment Schedule—II: Schizophrenia Version
DSM	Diagnostic and Statistical Manual of Mental Disorders
FESFS	First Episode Social Functioning Scale
ICD	International Classification of Diseases
MeSH	Medical Subject Headings
PNS	post-normal science
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	International Prospective Register of Systematic Reviews
SDSS	Social Disability Screening Schedule
UHR	ultrahigh risk
WHO	World Health Organization
WHO-DAS	World Health Organization Disability Assessment Schedule
WHOQOL-BREF	World Health Organization Quality of Life Brief Version

Multimedia Appendix 1

Model search for replication.

Footnotes

Contributed by

Authors' Contributions: JB conceptualized and performed the current analyses and wrote the first draft. WTVH, HJS, SP had a special role in data collection, extraction, and analysis. SP also had a special role in ensuring that the chosen approach, PRISMA, was performed according to the guidelines. All authors were involved in study design, provided scientific oversight throughout the project, provided detailed comments about the paper across several drafts, and edited the paper.

Conflicts of Interest: None declared.

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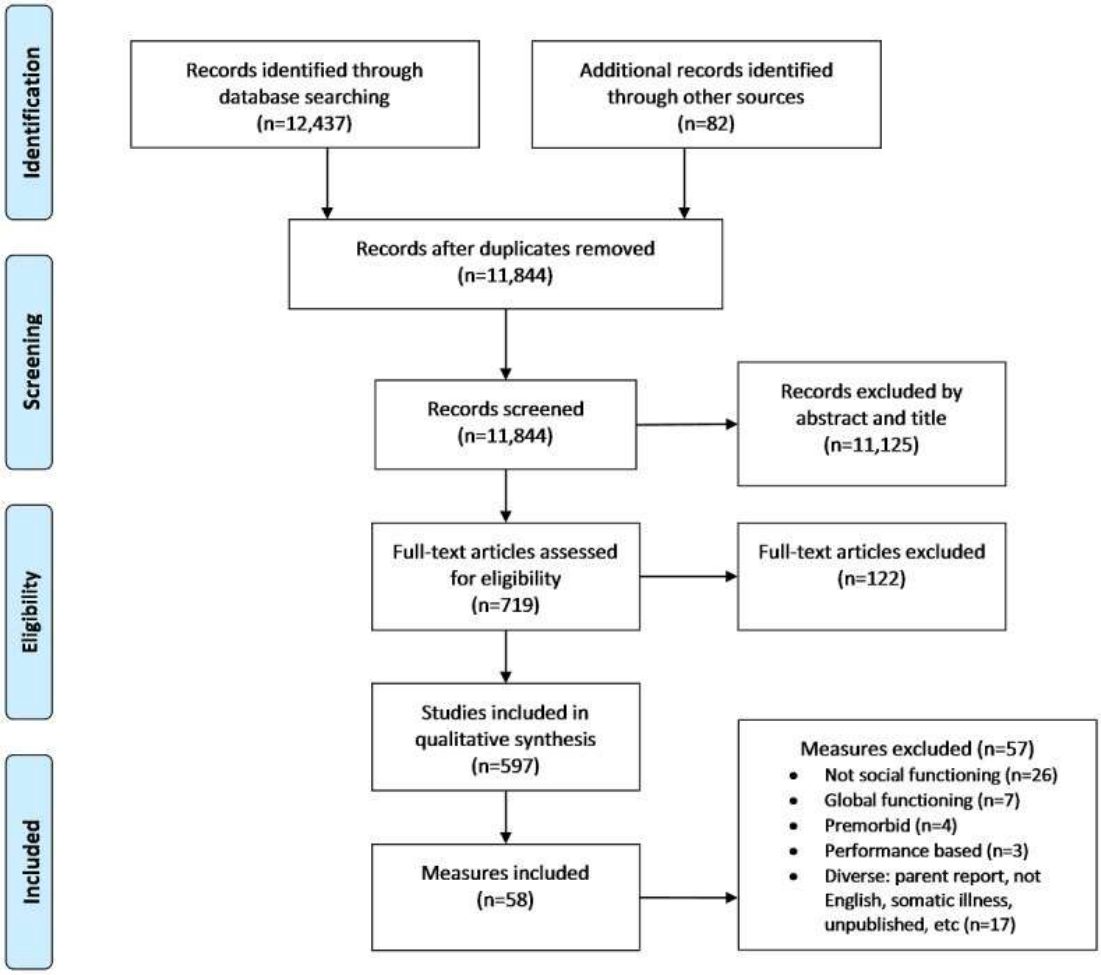
Figures and Tables

Figure 1



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Flow diagram of the reviewing process according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Table 1

Included social functioning measures (N=41).

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[a]Number of citations the scale has gotten throughout the years, which indicates the scale popularity and impact.

[b]Reliability: 1 (perfect reliability), ≥.9 (excellent reliability), ≥.8<.9 (good reliability), ≥.7<.8 (acceptable reliability), ≥.6<.7 (questionable reliability), ≥.5<.6 (poor reliability), <.5 (unacceptable reliability), 0 (no reliability).

[c]WHO: World Health Organization.

[d]DAS: Disability Assessment Schedule.

[e]DAS-II-sv: Disability Assessment Schedule—II: Schizophrenia Version

[f]SDSS: Social Disability Screening Schedule.

[g]WHO-DAS: World Health Organization Disability Assessment Schedule

[h]UHR: ultrahigh risk.

Table 2

Included quality-of-life measures (N=17).

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[a]Number of citations the scale has gotten throughout the years, which indicates the scale popularity and impact.

[b]Reliability: 1 (perfect reliability), ≥.9 (excellent reliability), ≥.8<.9 (good reliability), ≥.7<.8 (acceptable reliability), ≥.6<.7 (questionable reliability), ≥.5<.6 (poor reliability), <.5 (unacceptable reliability), 0 (no reliability).

[c]WHOQOL-BREF: World Health Organization Quality of Life Brief Version.