

Measuring patient-reported outcomes in psychosis: a conceptual and methodological review

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Abstract

Background: There are calls to use patient-reported outcomes (PROs) routinely across mental health services. However, the use of PROs in patients with psychosis has been questioned.

Aims: To examine the concepts and measures of four widely used PROs, i.e. treatment satisfaction, subjective quality of life, needs for care, and the quality of the therapeutic relationship.

Method: We conducted a literature search of academic databases on concepts, characteristics, and psychometric properties of the four PROs in patients with psychosis.

Results: Although numerous concepts and measures have been published, evidence on the methodological quality of existing PROs is limited. Measures designed to assess distinct PROs show a considerable conceptual, operational, and empirical overlap, whilst some of them also include specific aspects. The impact of symptoms and cognitive deficits appears unlikely of clinical significance.

Conclusions: The popularity of PROs has not been matched with progress in their conceptualisation and measurement. Based on current evidence, some recommendations can be made. Distinct and short measures with clinical relevance and sufficient psychometric properties should be preferred. Future research should optimise the validity and measurement precision of PROs, whilst reducing assessment burden.

Introduction

Since the 1960s, patient-reported outcomes (PROs) have become increasingly popular in the care of patients with psychosis. There is no universally accepted terminology and definition of PROs. In the literature, the terms ‘PROs’, ‘patient-reported outcome measures’ (PROMs), ‘patient-based outcomes’, ‘patient-driven outcomes’, ‘self-rated outcomes’, and ‘subjective evaluation criteria’ have been used interchangeably.¹⁻³ In recent years, the term ‘PRO’ appears most widely used.² The US Food and Drug Administration (FDA)⁴ defined PROs as “...any report of the status of a patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else” (US FDA⁴: p. 2). Treatment satisfaction, subjective quality of life (SQOL), needs, and the quality of the therapeutic relationship can be considered as four historically rooted, commonly used, and important PRO concepts in the care of patients with psychosis.^{2,5,6}

While the list of PROs has increased steadily, their popularity has gained momentum over the past decade, partly through their intuitive appeal for stakeholder groups.³⁻⁵ In the United Kingdom, a recent NHS White Paper³ announced plans for new outcome assessments, in which PROs are to be used to measure the effectiveness of services. Using PROs in the monitoring of outcomes of individual patients and services⁷ can also feed into the patient-clinician communication, reflective practice, quality management and service development.⁸ However, the selection of appropriate concepts and measures remains often difficult. Further, some authors have questioned the use of PROs in patients with psychosis due to conceptual and methodological shortcomings⁹, with some proposing to entirely discard them.¹⁰ Against this background, this review aimed to examine the concepts and measures of four widely used PROs, i.e. treatment satisfaction, SQOL, needs for care, and the quality of the therapeutic relationship, in the evaluation of care for patients with psychosis.

Method

A review of the conceptual and methodological literature on the four PROs in the care of patients with psychosis was conducted. We searched the literature systematically and also followed the recommendations for conceptual and methodological reviews to search widely in disparate sources and allow for overlap in the various stages (literature search, analysis, and writing).^{11,12}

Search strategy and selection criteria

A search of the academic databases EMBASE, MEDLINE and PsycINFO was performed to identify papers that: (1) reported the characteristics and psychometric properties of PRO measures to assess treatment satisfaction, SQOL, needs for care, and the therapeutic relationship in the care of patients with psychosis; (2) provided definitions of concepts intended to be assessed by at least one of the identified measures. The term PRO was used according to the definition by the FDA⁴ mentioned above. The literature search combined three groups of keywords in each database: (1) 'schizophr*', 'psychosis', or 'psychoses'; (2) 'quality of life', 'subjective quality of life', 'treatment satisfaction', 'patient satisfaction', 'need*', 'therapeutic relationship', 'therapeutic alliance', 'helping alliance', or 'working alliance'; and (3) 'psychometric*', 'validity', 'reliability', or 'responsiveness'. Title and abstracts were screened and papers retrieved to assess their relevance. Reference lists of relevant papers were inspected for additional papers. References that cited already identified papers were searched using the 'cited by' option in the electronic database Web of Science. In addition to the search of academic databases, informal networks were used to identify papers.

Data extraction and synthesis

As the conceptual and methodological literature on PROs in the evaluation of treatments for psychosis is vast and disparate, a quantitative synthesis appeared neither appropriate nor feasible. The findings are presented descriptively. While PRO measures can be distinguished according to various characteristics, we focused on the following ones: concept purported to be measured, number and content of domains, estimated completion time, response options,

and type (generic, condition-/disease-specific, treatment-specific, and utility measures).^{4,13}

Numerous psychometric properties for evaluating PROs have been proposed in the literature.¹⁴ We distinguished between reliability (i.e. internal consistency, reliability, scale information), validity (i.e. content validity (including face validity) and construct validity (including structural, convergent, discriminant, cross-cultural, concurrent, and predictive validity)), and responsiveness.¹⁴ Given the lack of consensus on how these psychometric properties are best evaluated and findings synthesised^{4,13}, we used a simple, dichotomous rating of whether or not a psychometric property had been examined for a given instrument.

Results

The results of the search strategy are summarised in Figure 1.

[Insert Figure 1 about here]

The search initially yielded a total of 2181 items (813 duplicates). Titles and abstracts were screened for 1368 references. Based on title and abstract sifts, 1238 references were excluded, as they did not focus on the four PROs or psychosis. The number of potentially relevant references increased from 130 to 224 when additional items were added. Of these, 49 references were excluded for different reasons. Hence, from the 2181 initially identified references, only 175 were included.

Concepts and definitions

Definitions of concepts to be assessed by the identified PRO measures of treatment satisfaction, SQOL, needs for care, and the therapeutic relationship are summarised in Table S1.

[Insert Table S1 about here]

Those measures of treatment satisfaction, for which a definition of the concept to be measured was provided, all purported to assess the multidimensional satisfaction concept of a personal evaluation of health care services and providers by Ware et al.¹⁵ and Ruggeri et al.¹⁶ The identified SQOL measures intended to assess a range of concepts (see Table S1). The only measure of needs that provided a definition of the concept to be measured, the CAN¹⁷, purported to assess a supply and perceived need concept. Pantheoretical¹⁸, Rogerian¹⁹, systemic²⁰, and psychoanalytic^{21,22} concepts were intended to be assessed by the identified measures of the therapeutic relationship. For each of the four PROs, no single, universally accepted definition could be identified. Nevertheless, there are attempts to identify a common conceptual basis. Lauer²³ noted that:

“...there is agreement that quality of life is a multi-dimensional phenomenon and construct, aiming at a holistic or global perspective of individuals in their biopsychosocial nature” (Lauer²³: p. 2).

Similarly, Ware et al.¹⁵ emphasised that treatment satisfaction is most widely measured as a multidomain concept. However, this may imply a risk of providing non-specific or overinclusive definitions. Several PRO concepts other than the one to be measured may meet very broad definitions. E.g. Stevens and Gabbay²⁴ define needs as:

“...the ability to benefit in some way from health care” (Stevens & Gabbay²⁴: p. 21).

Others have found a lack of clarity of the precise nature of some PRO concepts:

“In psychiatry, there is as yet no clearly defined concept of the therapeutic alliance” (Catty²⁵: p. 265).

A tendency was found to use terms from different theoretical backgrounds and traditions with at least slightly different connotations synonymously. For example, the term ‘therapeutic relationship’ has been used interchangeably with the terms ‘therapeutic alliance’, ‘helping alliance’ or ‘working alliance’, each of which has emerged from different lines of research²⁵. Similarly, ‘treatment satisfaction’ has been used synonymously with ‘patient satisfaction’, ‘service satisfaction’, or ‘satisfaction with care’, to name a few^{15,16}. This may lead to a lack of clarity as to precisely which conceptualisation of PROs is being referred to.²⁶

Several definitions of PRO concepts were found to overlap with definitions of other PRO concepts (see Table S1). However, some definitions of PRO concepts did not overlap with definitions of other PRO concepts and contained specific elements. This applied to definitions of SQOL^{27,28}, needs for care²⁹, and the therapeutic relationship.^{18,21,22} Overall, definitions of PRO concepts were found to vary in the extent to which they included overlapping and specific aspects.

Characteristics of PRO measures

Findings on characteristics and psychometric properties of PRO measures to assess treatment satisfaction, SQOL, needs for care, and the therapeutic relationship are summarised in Tables S2 to S5, respectively.

[Insert Tables S2 to S5 about here]

For several measures, the concept that the measure is intended to assess was not provided. Most measures were generic in nature and used Likert scales. Short versions have been developed for several measures, based on conceptual and practical rather than empirical considerations. A number of measures were found to be long and time consuming to administer. That is, several measures had more than 30 items and a completion time greater than 20 minutes.

Several PRO measures were intended to assess multidomain concepts, with items being grouped within domains, and domains within more general PRO concepts (see Tables S2 to S5). An overlap in the content of domains was observed across measures that are intended to assess different PROs. Specifically, the domains of measures to assess SQOL are very similar and, in part, even identical to domains included in measures of needs. Similarly, this applies to measures of treatment satisfaction and the therapeutic relationship. The content of domains

of treatment satisfaction and needs for care measures, and the content of treatment satisfaction and SQOL measures shows substantial overlap (see Tables S2 to S5).

Psychometric properties of PRO measures

The evaluation of the reviewed measures often included only limited information on psychometric properties in patients with psychosis (see Tables S2 to S5). The methods used to assess structural validity were largely not appropriate for ordinal data, as it is required for the predominantly used Likert scales.³⁰ Only for two measures (i.e. QOLI^{31,32}, EQ-5D^{33,34}) there was evidence on structural validity based on confirmatory factor analysis for ordinal data or item response modelling.^{30,35,36} For most measures, there was no evidence on their measurement precision throughout the full range of scores. Only for the QOLI this psychometric property was examined.³⁶ For some measures, no evidence on their internal consistency, test-retest reliability, scale information as well as content, structural, discriminant, convergent, concurrent, predictive, or cross-cultural validity was found in the included studies.

Empirical overlap of PRO measures

Only a few studies assessed more than one PRO at a time. They consistently suggest low discriminant validity due to an empirical overlap of measures designed to assess different outcomes. PROs were substantially correlated³⁷⁻⁴¹ and a single general factor explained more than half of the variance in SQOL, needs for care, and treatment satisfaction scores.^{2,42,43} The general factor has been interpreted as a general appraisal tendency of patients for positive or negative ratings across measures designed to assess different PRO concepts.⁴² However, this general appraisal tendency left about half of the variance unexplained which is potentially concept-specific. A recent study suggested a bifactor model which confirms the importance of a general appraisal tendency, but also shows the relevance of concept specific aspects. The latter provide distinct information that is independent from both the general appraisal tendency and other concepts.⁴⁴

Association with psychiatric symptoms and cognitive deficits

There was also evidence from several studies that less favourable SQOL is related to higher levels of psychopathology including positive, negative, and depressive symptoms⁴⁵⁻⁵⁶. For the association of psychiatric symptoms and treatment satisfaction, Katsakou et al.⁵⁷ reported an inverse relationship of psychiatric symptoms with levels of treatment satisfaction, which is in line other studies.⁵⁸ There are also a number of studies suggesting that psychotic patients with more severe symptoms have more unmet and total needs for care.⁵⁹⁻⁶¹ However, a more recent pooled analysis of individual patient-level data obtained from 16 studies found that symptom levels are less strongly associated with SQOL in schizophrenia compared to other mental disorders.⁶² A pooled analysis of associations between changes of symptoms and SQOL ratings over time identified an explained variance of only 5.5%.⁶³

With respect to cognitive deficits, evidence on associations with PROs remains inconsistent. Fujii et al.⁶⁴ found that better cognitive performance was associated with lower SQOL ratings in a prospective study of patients with severe and enduring psychosis which is consistent with other studies.^{50,65-70} However, Galletly et al.⁷¹, Ritsner⁷², and Sota⁷³ found the opposite. Deficits in executive functioning, attention, memory and motor skills were associated with lower SQOL. One recent study on bias of PRO ratings by psychiatric symptoms and cognitive deficits at the item level identified no effect of cognitive deficits on the responses to single items and of symptoms on the responses of only two single items. The study concluded that the magnitude of any response bias through symptoms or cognitive deficits, if present, is small and unlikely to be of clinical significance⁷⁴.

Discussion

Main findings

The current review examined concepts and measures of four established PROs, i.e. treatment satisfaction, SQOL, needs for care, and the therapeutic relationship in the evaluation of treatments for psychosis. There are at least three important findings. First, despite the increasing popularity of PROs with numerous concepts and measures, evidence on the methodological quality of existing PROs remains limited. Second, there is a considerable conceptual, operational, and empirical overlap across measures designed to assess different PROs, although some concepts and measures also included aspects specific to individual PROs. Last, the influence of, or bias by, cognitive deficits and psychiatric symptoms appears limited and unlikely to be of clinical significance.

Limitations

The review has several limitations. The findings may be biased, as important references on concepts, characteristics and psychometric properties of PRO measures may have been missed. Concepts that may be relevant for one of the four PROs, but were not captured in an existing measure, were not included. The review was selective in examining concepts and measures of only four PROs and only a limited number of psychometric properties.

While Mokkink et al.¹⁴ achieved a degree of consensus on the terminology and definitions of psychometric properties and provided guidance on data synthesis for reviews of the methodological quality of studies investigating psychometric properties of PROs, there is no consensus on how to synthesise findings on psychometric properties per se. The current review classified PROs according to whether or not they assessed specific psychometric properties. Given the absence of a consensus, this did not include ratings of the extent to which these psychometric properties were met. Finally, given the nature of conceptual and methodological reviews^{11,14} there may have been a subjective bias of the authors in the analysis and interpretation of the literature.

Methodological quality of PROs

Over the past decades, numerous concepts and measures of PROs have emerged.⁷⁵⁻⁷⁷ By contrast, our review found only limited evidence on their methodological quality. Several measures were not linked to specific concepts. A number of measures were long and time consuming to administer. This may imply undue assessment burden on patients with psychosis as well as increased assessment costs.

For most measures, there was no evidence on their measurement precision throughout the full range of scores, as has been established by a few studies for observer-rated outcome measures in mental health⁷⁸ and, on a larger scale, for PROs in other medical disorders⁷⁹. The methods used to assess structural validity were largely not appropriate for ordinal data.⁸⁰ Only a few of the reviewed studies conducted analyses based on confirmatory factor analysis for ordinal data⁸⁰ or item response modelling.⁸¹ There are several implications of treating ordinal as continuous data, including attenuated relationships among PRO items in the presence of floor or ceiling effects, presence of pseudofactors, and incorrect parameter estimates.⁸² These may challenge findings on the structural validity of PRO measures. In other words, measures using Likert scales, which have not been examined with psychometric methods appropriate for ordinal data, may be impaired in their ability to summarise patients' item responses into scores that adequately reflect their dimensional structure. This is, however, central for the use of PROs in the evaluation of care as such scores provide the basis on which value is assigned to treatments.

Conceptual, operational, and empirical overlap

The conceptual, operational, and empirical overlap of PROs has several implications for the validity of existing PRO measures. Campbell and Fiske⁸³ in their seminal work on discriminant and convergent validity stated:

"One cannot define without implying distinctions, and the verification of these distinctions is an important part of the validation process" (Campbell & Fiske⁸³: p. 84).

The verification of distinctions appears to be a part of the validation process that has been neglected by most of the research into PROs. New concepts were often proposed without assessing whether they were sufficiently distinct from already existing concepts to warrant them being measured separately. This review suggests that an insufficient distinction of PROs at the conceptual level has led to a considerable overlap in the content of specific domains. This implies that, both at a conceptual and operational level, the requirements for establishing discriminant validity were not sufficiently considered when developing PROs. Empirically, this may limit the ability of established measures to capture variance specific to the given concept. Indeed, this points towards substantial empirical overlap across measures. Whilst such overlap may reflect real associations between different PROs (e.g. one PRO influencing another one), it still impairs the ability of each PRO measure to capture distinct information and, in psychometric terms, their discriminant validity.⁸³ However, some concepts and operationalisations included aspects that were specific to one or more PROs. Recent evidence suggests that PROs may reflect both a general appraisal tendency that uniformly influences all PRO ratings in a positive or negative direction and components that are specific for each PRO. The specific information is independent of the general appraisal tendency. Maximising the specific information may be a challenge for future scale improvements.

Influence of cognitive deficits and psychiatric symptoms

In contrast to concerns of some authors that the validity of existing PRO measures may be impaired due to the influence of psychiatric symptoms and cognitive deficits^{9,10}, findings from our review suggested that the influence of, or bias by, cognitive deficits and psychiatric symptoms is very limited. The identified associations of PROs with symptoms and deficits do not compromise their validity as independent outcome criteria. However, all the evidence is taken from patients who consented to participate in research and were seen as capable to provide reasonable responses. Patients with very high symptom levels may have been excluded from such studies, by clinicians or researchers. There is no evidence on a possible threshold of general or specific symptoms above which PROs may yield less reliable results.

Routine use of PROs

The conceptualisation and measurement of PROs in patients with psychosis is of practical relevance. PROs have an intuitive appeal for various stakeholder groups and there are calls to use them routinely across mental health services.³ Even though evidence on the methodological quality of PROs is, overall, limited, there are at least five recommendations that can be made about the routine use of PROs in the evaluation of treatments for psychosis:

1. It should be carefully considered which concept is relevant for the aim and approach of the given service, and the results using which concept would have implications for service delivery and development.
2. The use of several PRO measures should be either avoided or take measures addressing clearly distinct domains.
3. Measures with evidence for good psychometric properties should be preferred, and the evidence on psychometric properties is limited for most measures. Overall, measures using satisfaction-based concepts (e.g. assessing satisfaction with life domains or with treatment) have been more rigorously studied than others.
4. In the absence of evidence showing that longer measures have superior properties, shorter measures should be prioritised to minimise the burden and costs of measurement. However, longer measures tend to be more reliable, and there can be a trade off between brevity and psychometric qualities.
5. The influence of symptoms and cognitive deficits is unlikely to affect findings in small samples (although even a small explained variance may be relevant for research in very large samples).

Future research

Despite the popularity of PROs for measuring the quality of routine mental health care, there are still a number of conceptual and methodological shortcomings. While according to our main findings this includes considerable conceptual, operational, and empirical overlap across

measures designed to assess different PROs, the influence of cognitive deficits and psychiatric symptoms appears limited. There is a need for more rigorous research for identifying short measures that assess distinct PROs independent from overlap with highest possible precision. New methodologies such as item response modelling, item banking and computerized adaptive testing (CAT) may help move this forward.^{74,79} While there have been only a few studies considering such methods in psychiatry⁷⁸, they have led to progress of measuring PROs in other medical conditions. A prominent example is the Patient-Reported Outcomes Measurement Information System (PROMIS).⁷⁹ CAT iteratively selects the item providing the highest precision for a given patient until a desired level of precision is achieved. This minimises the number of items each patient has to complete⁸⁴ and may be implemented on handheld electronic devices. Ideally, conceptual and methodological work should be linked in future research to advance the measurement of PROs in patients with psychosis, so that concepts can both inform research and be refined based on empirical data.

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Contributors

UR designed the study and had responsibility for the successful completion of the study. Under the supervision of SP, UR conducted the literature search, extracted and synthesised the data. UR and SP provided interpretation of the review findings. UR wrote each draft of the manuscript. SP critically revised each draft. All authors contributed to and have approved the manuscript.

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Figure 1. Quorum diagram.

